**“It put control back onto my family situation”: Family experiences of positive behaviour support**

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**Abstract**

***Purpose***

Positive Behaviour Support (PBS) is currently considered best practice for managing challenging behaviour in young people with intellectual and developmental disabilities. A key principle of PBS is that all members of the person’s support network participate in the assessment and intervention. It is therefore important to understand what factors act as facilitators or barriers to family engagement; however, research in this area is limited. The purpose of this paper is to conduct a novel piece of qualitative research analysis into experiences of family members of young people who have received family-based PBS.

***Design***

Eight parents of a young person with an intellectual or developmental disability who had received PBS were interviewed about their experiences and factors they found helpful and hindering in terms of their engagement. Thematic Analysis allowed a detailed and robust interpretation of the qualitative data.

***Findings***

Five superordinate themes were identified, namely, PBS is more than just strategies, Considering the family context, The therapist/family relationship, Acknowledging challenges and the ongoing nature of the problem, and Supporting family member change.

***Limitations***

Although research was rigorously conducted, the small sample size mean findings should be considered preliminary.

***Originality/value***

The literature related to family engagement in PBS is limited and largely based on the opinions of professionals. This study identified factors that parents themselves felt were helpful and hindering in terms of their engagement and offers practical suggestions for services and future research.

**Keywords:** Family carers, Intellectual disability, Autism, Developmental disability, Challenging behaviour, Positive behaviour support

**Type:** Research paper

**Introduction**

Young people with intellectual and developmental disabilities are at increased risk of displaying challenging behaviour, impacting not only on their quality of life but also that of their families (National Institute for Health and Care Excellence [NICE], 2015). Positive Behaviour Support (PBS) is currently considered best practice when managing challenging behaviour (Royal College of Psychiatrists et al., 2007). It uses a combination of behavioural, systemic and environmental approaches to not only manage behaviour but also to improve quality of life (Carr et al., 2002), and crucially reduce the need for restrictive practice.

Rather than being a specific intervention, PBS is a multicomponent framework that involves first conducting an in-depth functional assessment to develop an understanding of why the behaviour occurs. From this, a comprehensive set of strategies is then developed which logically flow from the identified function, into a behaviour support plan, which also takes into account the goals of the client and their family (Gore et al., 2013). The idea is for the interventions to be implemented at all levels and by all those involved in the person’s care (Carr et al., 2002; Dunlap, et al., 2008).

There is a strong evidence base supporting the use of PBS including a large-scale research synthesis by Carr and colleagues (1999) and a systematic review by LaVigna and Willis (2012), both of which found that PBS led to reductions in challenging behaviour. A recent randomised controlled trial also attempted to evaluate the effectiveness of staff training in PBS (Hassiotis et al., 2018). This literature is however limited by being largely conducted in institutional settings or focusing solely on professional intervention (Carr et al., 1999, Harvey et al., 2009).

The limitations identified by Carr et al (1999) and Harvey et al. (2009) are important as research suggests that a significant factor related to the success of PBS is the role of those providing support to the person and their commitment and ability to implement strategies (Hieneman & Dunlap, 2000). More recently there have been increasing efforts to evaluate the effectiveness of PBS in community settings. Reid et al. (2013) and Inchley-Mort et al. (2014) both conducted evaluations of community PBS services and found provisional support for its effectiveness. Hassiotis et al. (2009) conducted an RCT of PBS vs treatment as usual in community settings and found significant reductions in challenging behaviour for those receiving PBS.

Hieneman and Dunlap (2000) interviewed key stakeholders in the PBS process, including service providers, consultants and family members, to determine what factors affect outcomes in community-based PBS. All stakeholders, including family members, were chosen based on having significant knowledge and experience of behaviour support. Of the twelve factors identified, six could be considered to be closely related to support provider participation, including; system responsiveness, capacity of support providers, buy-in with the intervention, integrity of implementation, match with prevailing philosophy, and the contextual fit of the plan within the support network. They suggested that future research should specifically consider the role of support providers in the PBS process. Family members are generally central figures in young people’s support system, and therefore play a pivotal role in implementing PBS interventions. Interestingly, a meta-analysis by Harvey et al. (2009), looking at the effectiveness of behaviour intervention, found no direct benefit from family involvement. They suggested that a possible reason for this finding may be professionals holding a more traditional view of the family member’s role in intervention as being limited to implementing strategies developed by professionals, rather than as a collaborative partner. If this is the case, family members who have not been involved in the assessment process and the development of strategies may not be confident in their ability to implement strategies or may feel that they do not fit within their family context.

It would, therefore, seem important to understand how professionals can better work with families to ensure that interventions meet family needs. However, research in this area has been limited and has focussed on the experiences of professionals in providing recommendations regarding how best to involve families, such as ensuring PBS interventions are tailored to individual family’s needs and priorities (Dunlap et al, 2001; Etheridge, 2011). Additional studies have attempted to interview family members directly, but have been limited due to families involved not receiving PBS based on functional assessment, or including the family in its implementation in the home setting (Berryhill, 2014; Thomas, 2010), or have only focused on behaviour support more generically (Wodehouse & McGill, 2009).

To date, there have only been limited attempts to understand factors which impact on family engagement in PBS from the perspective of family members. The current study, therefore, provides an original investigation of the perspectives of family members of young people with a learning or developmental disability who have received family-based PBS about their experiences. Specifically, it aimed to answer the question; what factors do family members find helpful and hindering in terms of facilitating their engagement in PBS?

**Method**

The study utilised a qualitative methodology in which in-depth semi-structured interviews were analysed using Thematic Analysis (Braun & Clarke, 2006). This approach was chosen in order to allow for a detailed and rigorous analysis of participants’ experiences of PBS.

***Participants***

Participants were family members of young people up to age twenty-one with a learning or neurodevelopmental disability, who had undergone or were undergoing PBS. Participants were required to have already received either an individualised behaviour support plan or been given strategies to implement within the home, be aged over eighteen and able to speak sufficient English to participate in the interview.

Three inner-city National Health Service (NHS) teams providing individualised PBS to young people with intellectual disabilities or autism were involved in recruitment. From these three services, ten family members expressed an interest in participating. All ten met the inclusion criteria, although two participants were ultimately not available within the timeframe of the study. Therefore, eight family members were ultimately recruited from two of the services involved.

Participants included six mothers and two fathers, with two parents completing the interview as a couple. Participant characteristics are shown in table 1.

[Insert Table 1 about here]

***Interviews***

Semi-structured interviews were used to encourage participants to speak openly whilst also acting as a prompt and exploring emerging areas of interest. The interview schedule was developed based on a review of the literature related to PBS and family engagement more generally. Interview questions related to families’ experiences of the PBS process, their thoughts about, level of input into and confidence in implementing the developed strategies, and aspects of the process they felt were helpful or unhelpful for them. The interview schedule was reviewed by two family members of a young person with an intellectual disability who displayed challenging behaviour, one of whom was also a study participant, to ensure that it was clear and addressed all areas they felt were relevant.

Although interviews were guided by the schedule they were also shaped by the interviewer exploring emerging areas of interest. This is consistent with an inductive research approach (Charmaz, 2006).

***Procedure***

This study received ethical approval from both NHS Health Research Authority and University ethics committees.

Clinicians from recruitment sites contacted family members directly and provided them with the study information sheets before obtaining consent to pass on their contact details to the researcher. The researcher then contacted potential participants by phone or email to answer any questions and to organise an interview. Interviews were conducted face-to-face in interview rooms at local services and in parents' homes. Interviews took between sixty to ninety minutes and were audio recorded. All recordings were transcribed verbatim by the first author who also conducted the interviews. All personally identifiable information was removed in order to preserve participant anonymity.

***Analysis***

Although a literature search was conducted in order to develop the interview questions, data was not specifically coded to fit within these questions. Instead, an inductive approach to analysis was used in order to generate themes that spanned across the interviews. It is however recognised that this prior knowledge of the literature and the use of an interview schedule may have influenced the data collected and its analysis.

Interviews were analysed based on the six-stage methodology described in Braun and Clark (2006). This involved first reading each transcript twice then coding for any data which could possibly be considered useful, considering what each piece meant and giving it an initial name. Coded data was then compared and contrasted, and considered in terms of how they clustered together to generate initial themes. Themes were then reviewed, refined and considered as to how they might relate to each other before being further refined, named and given definitions. This was done with the use of NVivo qualitative data analysis software.

***Quality***

Coding was done by the first author. In order to improve validity, the coding for the initial interview was reviewed by the final author and any areas of disagreement discussed and reconciled. Additionally, a doctoral student with no involvement in this study, but familiar with qualitative research methods, reviewed the coding of a different transcript to determine a level of inter-rater agreement. This was determined by counting the number of codes agreed/disagreed with. The percentage agreement was 92.90%. Areas of discrepancy were again discussed until an agreement was reached.

Other methods used to ensure quality (Mays & Pope, 1995) were the inclusion of negative cases, such as participants who had been unable to implement strategies; a detailed description of the methodology; respondent validation, where a participant of this study reviewed the results to ensure they were reflective of their experiences; and researcher reflection and reflexivity through the use of a reflective journal.

As analysis in qualitative research is a subjective process, and as the first author was responsible for all data collection and analysis, details about their background are provided for the purposes of transparency. The researcher is a white Australian woman with no children who completed the research as part of her doctorate in clinical psychology. She has an interest in and previous experience providing PBS.

**Findings**

Thematic analysis yielded five superordinate themes; *1. PBS as a holistic approach; 2. Considering the family context; 3. The therapist/family relationship; 4. Acknowledging challenges and the ongoing nature of the problem and 5. Supporting family member change.* Within these superordinate themes, thirteen subordinate themes were also identified and are described in table 2.

[Insert Table 2 about here]

***The PBS process***

All families were asked about the PBS process they went through and a summary of their experiences follows. It should be noted that this is an amalgamation of their experiences and there was some level of variability. The assessment process included initial meetings between the therapist and parents to gather background information and to develop goals for intervention, observations of the young person and meetings with other professionals involved in their care. Families then described further sessions where the therapist and family member worked together to develop initial strategies, which were trialled by the family in between sessions and adapted as necessary. The therapist then provided a written behaviour support plan incorporating these strategies, which the family implemented and which was also shared with others supporting the young person.

***PBS as a holistic approach***

This theme highlights the idea that PBS is a holistic approach with aims that go beyond simply developing strategies and reducing challenging behaviours. Parents in this study spoke about therapists providing emotional support, linking up and working with other professionals and sourcing and applying for additional support and services. This is consistent with the PBS framework developed by Gore et al. (2013), which has as one of its values “the secondary use of other complementary, evidence-based approaches to facilitate behaviour change at multiple levels of a system (Gore et al., 2013, p. 4).”

*Working with the whole system*

Working with the whole of a young person’s support system and ensuring consistent support is a key component of PBS and was seen as one of the most beneficial aspects by the parents in this study. Two parents who had expressed frustration that prior to PBS the young person’s school did not appear to be addressing their concerns found that by incorporating the school in the PBS process, that the school was more likely to take their concerns seriously and implement changes. This was attributed to a belief that schools were more likely to listen when other professionals are involved.

*“I think it started a discussion in school, I think it opened up the school's eyes, because while the parents can go on about something, it's always better when a professional says ‘Yes, you have to do something’ (p1)."*

In some instances, school involvement was also seen as a way to facilitate implementation of strategies at home by first introducing them at school.

*“that's why it's a brilliant school, sometimes they say well we'll work on this…and then as soon as they have implemented it, I implement it at home (p4).”*

Three participants also identified having the PBS therapist support them in getting additional services or support from other agencies. This facilitated engagement in PBS not just by providing additional resources but also by strengthening the therapeutic relationship.

*“[therapist] helped me out getting me in touch with social services, getting me extra support there, which I wouldn't have been able to do without [them] (p4).”*

*Emotional support*

Parents valued the emotional support they received as part of the PBS process, with some describing the sessions with the PBS therapist as therapeutic in themselves. This is important as some parents also spoke about experiencing psychological difficulties as a result of being a parent of a young person with a disability and challenging behaviour. This included feeling a sense of separation or isolation from their friends and peers, low mood, anxiety, low self-confidence and stress. Addressing these was seen as necessary for the parent’s wellbeing and to ensure they had the resilience to engage in the PBS process.

*“It was about supporting the family and um, you know my health is just as important as [young person]'s because if I'm not in the right frame of mind, um, and in the right head space and have the confidence to tackle some of the things that [service] were asking me to try it would have failed (p4).”*

 *“For me it was very helpful, I think that it's a mixture of practical and psychological help. I think that is where parents I think will find it much more useful (p1).”*

***Considering the family context***

*Matching the intervention to the family resources*

Parents identified a range of different strengths, limitations and resources, which impacted on their ability to participate in PBS. These related to family support, finances, time and employment situations. Some families also specifically mentioned the need to consider that resources were likely to be more limited in a home, rather than school, environment. Considering these different contexts and tailoring interventions was considered important in the success of PBS in the home, with difficulties in implementation being linked to a mismatch between the strategy and the available resources.

*“It’s something that has to fit into the lifestyle of the people (p3).”*

*“We haven’t managed to implement that a lot. Um but it, it's hard because the time is so limited…* [*he/she] would probably need to spend I don't know, hours [strategy], which in reality will not happen, [he/she] has other activities to do during the daytime (p6).”*

*Keeping things simple*

Some families highlighted ease of implementation as a facilitating factor and felt that if strategies were too complex or time-consuming then they were less likely to be implemented.

*“I think the trickier things are to do, or more laborious they are to do, the less likely you are to do them (p3).”*

Families also identified it as being helpful when they were able to see how PBS might make things easier for them in the longer term, even if this initially required more effort, or when therapists helped to simplify or break down the issues they were dealing with so they did not seem so overwhelming.

*“I was just doing it for [him/her], because you do think it is the easiest option sometimes and then the easiest options aren’t making it easier for you long-term (p4)”*

*“It’s helpful, and I mean also to help isolate problems rather than seeing it as a field of carnage (p3).”*

*The family’s priorities and goals*

It was evident that parents all had different priorities in terms of the support they wanted from PBS. For example, some parents identified wanting to be given practical advice and support to use themselves, some wanted a better understanding of the behaviour and for others, the priority was more about bringing others in the support network on board.

*“What works for me is that I have specific targeted help understanding the behaviours and what to do with those behaviours (p1).”*

One family member also suggested that a potential barrier to engaging in PBS might be not wanting to focus on the challenging behaviours themselves and in these instances it may be more beneficial to focus on quality of life goals.

*“Sometimes you just want to be like any other family and enjoy something positive rather than being constantly focussed on the most negative aspects of your life (p6).”*

***The therapist/family relationship***

*Therapist qualities (knowledgeable, sensitive and patient)*

Parents in this study reported feeling that their PBS therapists were skilled and knowledgeable and valued the advice that they were given. There was also a recognition, however, of the need to offer advice in a tentative and non-blaming way.

*“Advice was tentatively, very delicately, because when you are telling somebody ‘you could try this as an alternative to what you have been doing,’ you are really saying ‘actually what you have been doing isn't working’… but without it coming across as some sort of criticism (p3).”*

Other factors which were identified as being important in the therapist were a sense that they were listening and genuinely interested in the young person, honesty, and patience.

*“I think the fact that [therapist] was very patient is a biggie, she listened to me, she, she would go over again and again and again until I got it, which was great (p5).”*

*Working as a team*

Although families in this study had varying levels of understanding related to behaviour support all stated that they were the expert in their child and felt that this was something that was recognised by the therapist. All parents described a collaborative relationship with the therapist where the understanding of why the behaviours occurred and the resulting strategies were gradually developed as the result of a two-way process, with the therapist in a position more like a guide.

*“it was us talking to the psychologist, the psychologist, you know explaining things and us realising that in fact we have the solution... it was kind of gradual and gradually we could see that if we, if we gave in, if we change a little bit then the results actually, [his/her] behaviour started to decrease (p2).”*

*“It was very much that we were doing it together (p5).”*

*Being open-minded and willing to try*

A common characteristic that all parents in this study shared was a sense of being open-minded about the PBS interventions and willing to try, despite all participants also acknowledging some uncertainty as to whether PBS would work.

*“I can't say I was confident they would work, but I didn't lack confidence either, it was a bit of the unknown. So I was just, I was open-minded to it (p5)."*

*“I just thought well I'm just going to give it a go, because [he/she's] my [child] (p4).”*

*“What I was doing wasn't working so I was well and truly open, my mind was open and whatever [therapist] suggested I was like, ‘OK, let's try’ (p1).”*

***Acknowledging challenges and the ongoing nature of the problem***

*Not everything will work*

A common theme that emerged was a recognition that not everything would work and that in the short term behaviours may increase. Acknowledging this was felt to be helpful as it allowed for the therapist and the family to plan for it.

 *“We knew that we were going to go through a rough patch because all of these things were a huge change for [young person] and then it was working out things, well what can we do to soften that (p4).”*

Five participants also spoke about not being able to be completely consistent with implementing strategies. This was due to practical limitations, the mood of the young person, and also that parents are not always going to be perfect. Again what families found helpful was acknowledging this and encouraging the parents “*just to do your best (p8)*” and to plan for challenges.

*It is an ongoing process*

All families in this study described PBS as an ongoing process, with behaviours varying along the way. Many parents spoke of new behaviours emerging and some of the originally referred behaviours reducing as a result of the maturation of the young person.

*“you got always new problems, always you have, because since they are a baby they are developing, changing (p8).”*

For this reason, most parents felt that it was important for there to be ongoing support and five about wanting some form of ongoing support into the future. One parent attributed their ability to implement the strategies to frequent appointments with the therapist; furthermore, two parents described this as something that would help families who were struggling with engagement.

*“I think the motivation of having [therapist] round every week. Because I wanted to give her good news every week, we've tried it (p4).”*

***Supporting family member change***

*Feeling more confident and in control*

Most of the parents in this study described feeling more confident and in control as a result of PBS. This was linked to having a plan in place as well as a greater understanding of the behaviours and how to respond.

*“Actually [therapist] did lot's for me, for my confidence as well (p4).”*

“*And so the biggest thing [therapist] gave me, it put control back on to my family situation, where I actually was back in charge (p4).”*

“*It helped that she said ‘Ok, this is what we do, we have a plan’ (p1).”*

*Becoming more relaxed*

One of the consequences of feeling more confident was that parents were also more relaxed about the young person’s behaviour. There was a recognition that this more relaxed approach then, in turn, enabled parents to be able to think more clearly and respond more appropriately to behaviours.

*“I actually became more relaxed about it because now I understood the behaviour (p1).”*

 *“By me taking a step back and taking a breath I was actually able to recognise ‘hang on, this is one I need to step in and deal with, that one I don't’ (p5).”*

*Better understanding of the behaviour*

Families particularly valued gaining a better understanding of why the young person engaged in the behaviour. For some parents even if they were not always able to know the specific reasons for the behaviour, the knowledge that the behaviour is functional was still helpful.

*“Probably the most important thing…I got into my head the realisation that [young person] is not doing this on purpose, [he/she] actually has no control over this (p5).”*

*“You see [therapist] give us the key, there is, even if you can't know the reason, even the small things, the small thing it is for [him/her] a mountain. So there is a reason (p8).”*

**Discussion**

All of the parents in this study described their experiences with PBS as generally being positive. Despite this, some parents spoke of not being able to implement specific strategies and one of a regression in the young person’s behaviour. All parents were able to speak about some of the challenges they or other families in similar situations may face when engaging in PBS.

Parents valued the collaborative nature of PBS, with strategies that emerged from conversations where the therapist acted more as a guide, being more likely to be remembered and implemented. This two-way process also ensures that the interventions fit the family context, something that was found to be important in this study and is well supported by the literature (Dunlap, et al., 2001; Etheridge, 2011; Hieneman and Dunlap, 2000). Interestingly, although most families reported having received written support plans, only one spoke of this as being a key element, and many could not remember specifically what was included in them. To give families more ownership over the support plan, professionals need to actively involve them in the assessment and formulation of behaviour function, and collaboratively develop strategies. Further research on how this can be achieved would be helpful, particularly in terms of how professional expertise can empower parental creativity.

The therapeutic relationship emerged not only as a key factor directly related to engagement but also indirectly as a means of addressing carer well-being. Many of the parents in this study described finding the PBS sessions therapeutic, with many reporting that they felt respected and listened to. Research suggests that family interventions which incorporate an element of emotional support for the family can result in higher levels of engagement (Ingoldsby, 2011).

A novel finding of this study was that parents were not always confident that the strategies would work, yet were willing to try them. Some families also described initial strategies not working at all or temporarily making behaviours worse. Contrary to this, Hienemann & Dunlap (2000) found that seeing immediate outcomes was important for ensuring implementation fidelity. What appeared important for families in this study was acknowledging and preparing for the possibility of strategies not working, which may have then acted as a protective factor (Allen, & Warzak, 2000).

One theme that emerged from this study was that of “supporting family member change”, which focused more on processes of change rather than specific helpful or hindering factors. The reason for including this theme was the clear link between these changes and parents engagement. For example, parents in this study reported that they felt more relaxed about the young person’s behaviours as a result of PBS, and that this in turn then facilitated their ability to implement strategies. An important implication for clinical practice could, therefore, be thinking about how to support parents with this early in the process. Ideas and techniques taken from third wave interventions such as acceptance and commitment therapy (ACT; Hayes et al., 1999) are one potential method of achieving this and previous research has suggested that these techniques can be beneficial for parents of children with a disability who display challenging behaviour (Thompson-Janes, Brice, McElroy, Abbott, & Ball, 2016).

The small sample size and the fact that participants were all drawn from within one inner-city area means that caution should be used when generalising these results beyond the current sample. The sample was also limited in terms of its cultural diversity with the majority of participants coming from white backgrounds and all having lived in the UK for at least 15 years. Additionally, the requirement that all participants be able to speak English means that the perspectives of non-English speakers are not included. The sample may also not be reflective of all family members of young people with challenging behaviour as participants in this study were all parents and all reported an overall positive experience with PBS. Future research could consider exploring the experiences of families who have not found PBS helpful, the perspectives of different family members, such as siblings, and the young person with an intellectual disability themselves, as well as including participants from a variety of ethnic backgrounds.

It is also possible that some parents may not have felt comfortable sharing more negative experiences. Although the interviewer stressed the independence of the research from the recruiting services, it was the service which acted as an initial link and the research materials highlighted the affiliation of the research to the NHS.

**Conclusion**

Although the results of this study should be considered preliminary, they confirm the importance of services working closely with family members throughout the entirety of the PBS process. Strategies which were developed collaboratively with parents were more likely to be remembered, fit with the family context and priorities and ultimately were more likely to be implemented. It was also important for therapists to acknowledge that strategies may not always be effective or that there may be setbacks and to plan for this early on. Further suggestions for engaging family members in PBS include designing and delivering services that go beyond simply developing behaviour support plans by also incorporating elements that address family members’ emotional well-being, whether this be through support in session or by referral to other services, working with and connecting everyone in the young person’s support system and supporting families to obtain additional support where appropriate.

*Table 1.*

*Participant Characteristics*

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Age | Gender | Ethnicity | Age of child | Diagnosis | Time since PBS |
| 54 | M | British | 7 | Autism | 3 months |
| 44 | F | Serbian | 8 | ID | ongoing |
| 44 | F | British | 9 | ID and Autism | ongoing |
| 43 | F | British | 9 | ID and Autism | 18 months |
| 53 | M | Irish | 11 | ID | 3 months |
| 48 | F | French | 12 | ID | 3 months |
| 52 | F | Asian | 17 | ID and Autism | ongoing |
| 59 | F | PNS | 10 | Autism | 24 months |
| *Note. ID = Intellectual disability; PNS= Prefer not to say*  |

Table 2.

*Superordinate and Subordinate Themes Related to Family Engagement in PBS*

|  |  |  |
| --- | --- | --- |
| Superordinate Theme | Subordinate Theme | No. of Participants who contributed |
| PBS as a holistic approach | Working with the whole systemEmotional support | 87 |
| Considering the family context | Matching the intervention to the family’s resources.Keeping things simpleThe family’s priorities and goals | 654 |
| The therapist/family relationship | Therapist qualitiesWorking as a teamBeing open-minded and willing to try | 686 |
| Acknowledging challenges and the ongoing nature of the process. | Not everything will workIt is an ongoing process | 76 |
| Supporting family member change | Becoming more relaxedFeeling more confident and in controlBetter understanding of behaviour | 748 |

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