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The views of carers about support for their family member with an intellectual disability: with a focus on Positive Behavioural Approaches

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Abstract

This qualitative study explored the views of family carers about the support that their adult children with an intellectual disability had received in relation to their behaviour that challenged. There was a particular focus on positive behavioural support (PBS), although some participants spoke more generally in terms of positive approaches. Semi-structured interviews with eight family carers were analysed using inductive thematic analysis. Four key themes were identified. Good support, of which PBS was an example, was seen as both having reduced behaviours that challenged and having a wider positive impact on the quality of life of the individual and their families. Key features highlighted were: technical knowledge and skill; a strong value base of warmth, acceptance, and respect; a collaborative, consistent approach; open communication; and the extension of support to the family carer when needed. It was recognised that there is a need for broad systemic change and for the application of a workforce development model that takes account of the needs of staff, carers, and those working in wider systems that have contact with people with an intellectual disability.

Key words: Adult learning disability services; behaviour change; challenging behaviour; carers

What is known about this topic?

- Positive Behavioural Support (PBS) views families as partners and key decision makers with valuable expertise
- Some research has explored the views of family carers of people with an intellectual disability about the support they receive generally
- There is, to the authors' knowledge, no previous research exploring the views of family carers in relation to their adult family member receiving PBS

What this paper adds

- We found that family carers were generally consistent in what they viewed as the key features of good, positive support
- This included technical knowledge and skill; a strong 'humane' value base; a collaborative, consistent approach; and open communication
- The results can help inform future service provision

Introduction

Behaviours that challenge are thought to be prevalent amongst 10-20% of people with an intellectual disability [ID] (e.g. Cooper et al., 2009). While past approaches to such behaviour have often been primarily reactive, included restrictive elements such as physical restraint, and emphasised medication over psychological and behavioural approaches (for an overview, see McKenzie, 2011), over the past three decades positive, pro-active, and preventative approaches have emerged which acknowledge the functional nature of the behaviour. This has culminated in the adoption and promotion of Positive Behaviour Support (PBS) (Carr, 1997; LaVigna & Willis, 2005) in ID services in the United Kingdom and elsewhere. PBS is a collaborative, individually tailored, multi- component approach which aims to reduce CB by facilitating a functional understanding of the individual's behaviour in the context in which occurs. This is coupled with promoting the adaptive functioning and overall quality of life of the person, and not just controlling behaviour perceived as 'negative'. (Gore et al., 2013; PBS Coalition UK, 2015; Toogood, Boyd, Bell, & Salisbury, 2011).

PBS aims to offer an effective means of managing behaviours that challenge by taking a holistic and ecological approach and looking at the individual, psychological, biological, and environmental factors that interact to produce behaviour (Lucyshyn, Dunlap, & Albin, 2002). PBS is an evidence based approach which is known to be effective in producing positive outcomes (see PBS Coalition UK, 2015 for an overview). It is the recommended approach in the United Kingdom for professionals supporting individuals with an ID who present with behaviour that challenges (Royal College of Psychiatrists, British Psychological Society, & Royal College of Speech & Language Therapists, 2007), as well as for providers and commissioners (Department of Health, 2014; Local Government Association & NHS England, 2014; NHS Protect, 2013).

PBS is defined in terms of its values (Gore et al., 2013), such as self determination, and its core components; understanding the function that the behaviour serves for the individual, and the processes of changing these. The involvement of family carers in understanding and changing behaviour is seen as central because they are likely to be closely involved in supporting the individual, have an intimate knowledge of their needs, and may also be core to how the behaviours have developed and are maintained (Hastings et al., 2013; Hastings & Remington, 1994). In PBS, families are seen as partners and key decision makers with valuable expertise (Brown, Nolan, & Davies, 2001; Murray, 2000).

Despite this, there is very little research which explores the experiences of family carers of PBS. Qualitative research, which explored the views of carers of people with ID who displayed behaviours that challenge about the services and support they had experienced, was synthesised by Griffith and Hastings (2014). Seventeen studies were reviewed which covered a range of support services including, residential school services, primary care, and acute psychiatric services, as well as of PBS. The authors found that many available support services increased, rather than alleviated, the burden of care, due to poor communication between professionals and carers, and a lack of staff expertise. Services that were viewed positively employed professionals with high levels of expertise and understanding of the individual's behaviour and communication, along with a proactive, open, and honest approach. In terms of PBS specifically, Fox, Vaughn, Wyatte, and Dunlap (2002) obtained the views of 20 family carers of young children who were in receipt of PBS. The family members highlighted the difficulties that they had experienced in coming to terms with their children's disability, that this had a pervasive effect on all aspects of family life, and the importance of receiving support from staff who genuinely care.

There is, however, to the authors' knowledge, no research which explores the views of family carers in relation to their adult family member receiving PBS. The present study

aims to address this gap in the literature. Specifically, the study aimed to understand more about how family carers conceptualised PBS and how they had experienced this in relation to their family member.

Methods

Design

The study adopted a contextualist approach which gives weight to individuals' subjective experiences within the social context that shapes how they give meaning to them (Willig, 1999). Inductive thematic analysis was chosen because it is largely non-theoretical and is not underpinned by a particular epistemological stance (Braun & Clarke, 2006). The study received ethical approval from the first author's educational establishment.

Participants

Participants were recruited using purposive sampling via support and advocacy organisations in the North of England which provide support to people with ID. Purposive sampling was chosen because we were interested in particular characteristics of the participants, i.e. their experiences of support that their family member had received. Three interviews and one focus group were conducted, based on the expressed preferences of the participants. Five of the participants (three interviewees and two focus group members) had adult children with ID and behaviour that challenged. The remaining three focus group members had experience of support for a family member with ID which was not specifically named as PBS, but was viewed as 'positive' and contrasted with past experiences of unhelpful, and at times restrictive, care. To reflect this, reference is made both to PBS and 'positive approaches' in the results and discussion. Participant information is summarised in Table 1, though all potentially identifying information has been changed or omitted to protect the anonymity of participants.

[Insert Table 1 here]

Procedure

Information about the study was provided to support groups for people with ID in the North East of England. The organisations then provided information to family carers they thought might be interested in participating and who met the inclusion criteria of having an adult child with ID. As one of the aims of the study was to develop an understanding of how family carers conceptualised PBS, this was not formally defined. Following expressing interest, participants were approached by one of two researchers and a face-to-face interview session or focus group session was arranged.

Participants were interviewed between February and March 2016, either in their own home or an office in one of the provider organisations. Interviews lasted up to 60 minutes and were audio recorded. Before commencing, participants were again given an information sheet describing the research, including how data would be used and withdrawal procedures, along with a consent form, including audio recording consent, which each signed. The interviews and focus group were semi-structured and both were guided by the use of an interview schedule. This was used flexibly as a point of reference for the researchers, who encouraged discussion and two-way dialogue, according to the individual context (Kvale, 1996). The broad topic areas covered in the interviews and focus group included the participants' experience of PBS received by their family member, their views on any positive and unhelpful aspects of PBS, what they felt might improve the outcomes for their family member in the context of PBS, any barriers they felt that existed in relation to implementation of PBS. The interviews and focus group were transcribed by the interviewer.

Analysis strategy

The data set was read right through first, then coding of data extracts took place on a second and third reading using Boyatzis' (1998) definition of codes i.e. 'the most basic segment, or element, of the raw data or information that can be assessed in a meaningful way

regarding the phenomenon' (pp 63). Initial clusters and patterns of meaning were looked for across the data set, supported by a word frequency analysis using Nvivo 10.1.3. Initial themes and a number of initial thematic maps were developed, focusing on semantic meaning. To be considered a theme, codes needed to be prevalent in at least three data items. Coded data extracts were sorted into the themes, their sub-themes, and a 'miscellaneous' category. Primary engagement with the literature took place after fieldwork and initial coding to ensure no bias was introduced, either into the interaction between the interviewer and participant, or the coding, thereby giving primacy to participants' world views (Burnard, 1991). This engagement enabled further refinement, definition, and naming of the themes using Patton's (1990) criteria of external heterogeneity (data should be organised such that there are clear differences between discrete themes) and internal homogeneity (data considered part of one theme should have internal coherence). Once the draft final thematic map had been developed, the entire data set was read again to organise all coded extracts into an internally consistent and coherent account, and ensure nothing key had been missed. The analysis was reviewed by, and discussed with, a second member of the research team to help ensure that it was consistent with the data. The final themes were fed back to the participants. No changes were requested.

Findings

Four main themes and associated subthemes were identified, as outlined in Table 2. Each of these is discussed in more detail below.

[Insert Table 2 here]

The bedrock of support

Underpinning principles and values. All of the participants highlighted that good support required to be underpinned by a set of principles and values – those of respect, dignity, care, engagement, and self-determination; of being treated "...like a human being.

Treat him like he matters and like he has a life" (Gillian). These fundamental values were summarised by Jill: "Well, it's treating people with respect isn't it? And dignity." The parents wanted their adult children to be supported by being listened to and nurtured, having someone to turn to if they had a problem, and kept safe: "They listen to him. Staff engage with him" (Douglas). Promoting a sense of self-determination and control in their child was core to this, from being helped to "do things one step at a time" (Emily), to making decisions about everyday life: "What's been put in place for positive behaviour support...give(s) Michael the idea that he has got a choice, he has got an opinion." (Douglas)

These fundamental values were demonstrated by the ways in which staff interacted with their family member. Participants expressed their appreciation of the friendly and relaxed interactions with their loved ones, which involved mutual laughing and joking, and being included when staff interacted with each other: "He's not treated like something separate. The staff include him as part of the home..." (Emily).

Participants valued staff who were caring, positive, calm, and skilled, and who recognised the skills that their family members had: "Some of the staff, you know, prior to this, didn't even realise how much Michael's capable of doing, like telling the time."(Douglas). Participants were pleased when negative staff left the service: "Some of the ones that have moved em, we weren't particularly sad to see them go 'cos em they were some of the real negative ones..." (Douglas). The impact of this was summed up by Jill: "[If] you're not working in a positive way with people, you're actually fuelling challenging behaviour."

The technicalities. The importance of having staff with a high level of knowledge and competence, in conjunction with a strong value base, was also emphasised by participants. They identified the key technical details of highly tailored and individualised PBS and positive approaches that were important to them. Detailed observations – of

individual behaviours, signs of anxiety, communications, like and dislikes – were emphasised, resulting in an in-depth understanding of their loved one which was translated into concrete care plans and strategies: “During that period they would do visits … they’d taken everything into considerations, then put everything into place then moved them.” (Anna). It was, necessarily, an intense and lengthy period: “The provider he is with now, they’ve settled him down really well over the last 8-9 years” (James). There was also an emphasis on having relevant knowledge of other pertinent conditions that impacted on their child’s behaviour: “The staff there have excellent knowledge of autism so they’re very calm [laughs]” (Anna).

Consistency, in staff and in approach, was stressed by all the participants; making sure “everybody does the same and reacts in the same way” (Emily). High turnover amongst care staff was a concern, particularly given the significant number of people often involved in care. Consistency was also seen to strengthen the relationship with the family: “I knew I didn’t have to re-learn staff behaviours and trust, because it was already there” (Anna). A lack of consistency was felt to be at the root of any failures in support: “The last two or three outbursts that Lewis had, going back a year or three ago… they were all due to staff members not following the agreed procedures about him” (James)

Overall, this theme recognised the aspects of support that the carers identified as being crucial for the staff supporting their family member. This represented competence, knowledge, and skills relating to the more ‘technical’ aspects of PBS and positive approaches, in conjunction with a strong, positive value base that promoted the respect, dignity, and self-determination of the individual. This was summarised by Gillian:

“My understanding of positive behaviour support is that there’s somebody there for him that’s trained. Somebody that’s there who cares about him and… not just the job. Because that’s what’s really important.”

The impact of care

While participants were not directly asked about negative experiences of care before PBS and positive approaches, all were keen to talk about this, both as a contrast and to put their feelings about it in context. This theme explored what poor care felt like for the family carers and the impact of this on their child and themselves. This was contrasted to the ways in which PBS and positive approaches had beneficial consequences beyond the direct impact on behaviours that challenged.

Experiencing poor care. Most of the participants' children had been in a range of community, residential, and hospital-based settings, with the latter being viewed particularly negatively. Gillian felt her son had been treated poorly; being talked down to and disregarded: "Don't talk to him like that... he's 37 years old. Why talk to him like he's a kid?" Emily's son was admitted to a hospital where he was "drugged up" and did not have freedom to choose activities. In the hospital in which Douglas's son was based, activities were cut due to reductions in funding: "He had no, nothing to do, just sit, being contained." The detrimental impact of this care on their loved ones and their behaviour was stark:

"I'd say... 'they're not communicating, ...they're not doing stuff, they're not smiling. Have they had a late night?' And they'd just say yes. Um, but obviously I realise now that they were probably terrified." (Anna).

Gillian's son was placed in a hospital several hundred miles away from her home:

"They took him in there and immediately it was bad... He wasn't the person that I thought he was, you know, that I thought he should be."

Emily thought her son "really hated it there", whilst Douglas's son "was very shy and introverted" after coming out.

Experiencing positive care. In contrast to this, all the participants talked of the beneficial impact of PBS and positive approaches, particularly improvements in behaviour: "He very rarely has episodes of challenging behaviour and it's mainly because we feel he has been supported in the right way delivered in the right way; it works" (Douglas). James's son:

“ ...used to be restrained a lot, but that hasn't happened now, well, in about 5 years...And again, it's all about PBS now really, and it really has worked with him.”

Emily talked of her son being more able to control his own behaviour:

“He knows now to ask us to leave the room if he feels very anxious. Rather than, as he might of done, throw the furniture round before.”

The positive impact of PBS was seen by Amanda as regaining her lost son:

“I see him loads now. He's come back to my life. My son is back here. I've got my son back after 18 years.”

“It's just been a battle”

The recognition that care was provided in a system, and that this system was not always experienced as supportive, to families or staff, is outlined in this theme. Participants described having to fight professionals to obtain the right support for their family member, often feeling that the weight and power of the system was against them.

On different sides. After being involved in the care of their loved ones for many years, all the participants had come to feel most professionals were not on their, or their loved ones', side - “they” were firmly ‘other’ - “They seemed to have views that were totally sort of opposite to what we were” (Douglas); “He [the educational psychologist] was really kind of pulling rank or pulling intelligence over me” (Anna); and “They knew better than we did. That was their attitude. They were trained professionals and we were just the parents.” (James). Christopher agreed that, as a parent, “you're always second class.” Anna considered that the professionals who were involved at the point when she was caring for her three children at home didn’t take account of the realities of everyday life: “It’s all very well for professionals to say one thing and another, but, at the end of the day, they go home and they can kind of switch off.”

For some, being on different sides extended to being engaged in a constant battle; to get their loved one out of hospital, to get what they felt was suitable care for their loved one, to have their views heard and acknowledged. Gillian talked of her son's reluctance to let her complain: "Sometimes [son] would say... 'Mam don't, don't, don't because I'll get the backlash.'" Douglas related over 20 years of arguing with and challenging health and social care bodies. He felt that they tried to "paint the blackest picture" with regards to his son's behaviour in repeated attempts to have him put under section: "It was a bit sort of 'we've got a hidden agenda as to where we want to go with this' and that's, that's the fight we've had."

The power and control of 'the system'. Participants were aware that the support their family member received was delivered in a wider context, in which individuals differed in terms of influence, power and control. All participants described having felt powerless and controlled at times within the support system and spoke in terms of being "restricted," having to "obey," of "directions" being given, of having to "push" for "permission." Amanda described hospital staff wielding power over her and her son directly: "They say more or less... 'well, we've got the upper hand and he will do as he's told.'" Power was reflected most starkly in the descriptions of physical incarceration and restraint to which their loved ones had been subjected: "[the hospital] was nothing more than a prison. You know, like a 30 foot barbed wire fence" (Douglas); and "I think the [locked] doors made him feel like... he was some sort of a prisoner." Jill reflected, "If I was incarcerated somewhere... or restrained, well I'd be challenging."

Participants also talked of the difficulties for staff working within a bigger 'system' that they felt similarly powerless and afraid to challenge: "Staff were put under pressure where they weren't even sure what they could tell me and my wife" (Michael); and "One of them said... 'I've nearly lost my job through arguing with these top people.'" (Gillian). It was seen as important for staff to know that the system would support them in taking

managed risks, “Staff have to be confident that what they’re gonna do, they’re not gonna get criticised for.” and for the system to positively support staff: “It’d be nice for the staff if you gave them some sort of recognition of what’s they’ve done… because they probably feel undervalued” (Douglas).

A positive way of working was viewed as possible, only if it was supported by the overall system, which was extended beyond the formal support systems and family carers to include the wider community: “When people have presence in the community and they can build up community networks, when other people can look out for them and not just their carers - that’s when things will improve.” (Jill)

“He’s my son”

This theme recognised the ongoing involvement of participants in their children’s lives, the emotional impact of having a child with ID, and the importance of feeling that their children were now being supported in a positive and appropriate way. The valuable role of staff in providing emotional support for the parents was also highlighted.

A central role. All the participants continued to have a central role in their adult children’s care. None of the participants had received training in PBS, but many felt they had been ‘doing’ PBS long before professionals, “although we didn’t think of it as PBS with the name… in a way, that’s what we were doing anyway” (James). All wanted to be involved: “We felt that we knew him best, we knew him inside out” (James); and “Some of the things that we suggested to put in place proved to work. Cos, obviously, we know Michael” (Douglas). They appreciated providers working with them now: “They’d [the current provider] taken everything, my views… they’d taken everything into consideration, then put everything into place, then moved them” (Anna). Emily talked of the importance of

“communication between staff and relatives,” and all were appreciative of regular and open contact, and being listened to.

An emotional challenge. Having a child with ID and a range of complex needs gave rise to a range of emotions in the participants. While love and care were displayed by all, the frustration, difficulties, and stress were also very apparent: “I’ve lived with it for nearly 40 years; doesn’t make it, doesn’t make it easier...”(Anna). James talked of the impact of his son’s behaviour on the home: “Around our house there are still scars there, where walls have been punched and doors have been kicked.” Anna had “just cried and cried and cried and cried and cried and cried,” while Gillian talked of the “heartbreak” she felt when her son was unhappy in hospital and “I couldn’t do a thing to help him.” In this context, PBS services had been “brilliant” and enabled Gillian to “relax,” while Anna felt relief in her children’s current care being “absolutely excellent.”

Against this background, most of the participants talked of benefiting from being considered as carers and being supported as such. James felt that “staff who support him and us work together,” while Gillian appreciated that the staff were there for her to talk to as well: “They’re here for me as well. I can open up to them.” Anna was keen on more support being available for parents, including dealing with their own emotions, as well as knowledge, information, and crisis support, with a recognition that parents go through different stages of acceptance. She also felt it vital that support consider the realities of day-to-day life for parents: “I might know what to do [for PBS], I just don’t know how to maintain it when I’m tired, ill, frustrated, or just sick of it.”

Discussion

PBS is underpinned by behavioural principles derived from Skinner’s Theory of Operant Conditioning (1953) and the early recognition that behaviour serves a function for the individual (e.g. Carr & Durand, 1985). While not all participants in the present study used

the specific language of PBS, there was a recognition within a number of themes that, in order for PBS to be effective, staff needed to have both technical knowledge and skills, for example in relation to functional analysis, behaviour analysis, and constructional principles, as well as an appropriate value-base. The key components of PBS - values, theory and evidence base, and process (PBS coalition UK, 2015) - were reflected in the ‘bedrock’ of PBS identified by participants in the present study who had directly experienced it, as well as those who described experiencing positive approaches more generally. Many aspects have also been identified by family carers in previous research, including holistic care tailored to individual needs (Griffith & Hastings, 2014), consistency of approaches, and services being based on a deep understanding of the individual (Inchley-Mort & Hassiotis, 2014). There was also a recognition that support was provided within a wider system and that there was a need for everyone who was involved in the support of an individual to work as a team, communicate effectively, and operate in a consistent way.

While the participants gave current examples of being constructively involved in the positive care of their family members, many also described past punitive and negative approaches and having to fight for appropriate care for their child. The negative impact on the family that was described as resulting from poor quality support - the experience of feeling they had not been listened to and frustration with previous service providers - is, unfortunately, consistent with the findings from other research (Elford, Beail, & Clarke Z. 2010; Griffith & Hastings, 2014; Wodehouse & McGill, 2009).

PBS has developed in a context of changing policy and service provision in relation to the support of people with ID. These changes have often been driven by significant failings in their care (Centre for the Advancement of PBS, 2016). Most recently, abuses of care at Winterbourne View private hospital prompted a series of reports and recommendations that are embodied in ‘Transforming Care’ (Bubb, 2014). This policy has a focus on service

improvement for people with ID and/or Autism who display behaviour that challenges and PBS has been identified as being key to this.

Indeed, participants who had direct experience of PBS largely described it as being both effective and in line with what they wanted from support for their child. Participants expressed their appreciation of being cared for too (Fox et al., 2002). These findings emphasise the need for professionals to develop positive, collaborative relationships and open communication with the family (McConkey, Gent, & Scowcroft, 2011) and provide support that fits with the beliefs, values, and circumstances of the family members (Clegg, Sheard, Cahill, & Osbeck, 2001). While this seems an obvious goal, previous research has suggested that service provision can often exacerbate the stress of families (Griffith & Hastings, 2014).

The participants were also clear that support occurred in a larger context and that systemic change was needed to ensure there was wider support for a positive approach. This highlights the need to develop and deliver a workforce development model (e.g. McNall, 2012) which adopts a systems based approach to consider the wider issues that need to be understood and addressed to enable the workforce to be developed appropriately. Despite early work which has proposed collaborative skill development models for carers (LaVigna, Willis, Shaull, Abedi, & Sweitzer, 1994; Lucyshyn et al., 2002), none of the participants in the present study described having received any specific skills development in relation to PBS.

Limitations

The limitations of the study also need to be considered. While a number of common themes are presented, the participants differed in their experiences, views, circumstances, and specific understanding of PBS. The focus group also included three family carers who had experience of support for an adult family member with ID which was not specifically named as PBS. The views of these parents highlighted that collaborative, competent, value based

care should underpin all types of support and that these factors are not just crucial for providers of PBS. Despite the consistency of views across participants, the sample was relatively small, and the participants cannot be considered to be a homogeneous group with views that are representative of the wider group of family carers. The sample chosen, was however, purposive with the aim of identifying individuals with particular experiences (Palys, 2008), rather than a sample that was representative of all family carers. Likewise, the aim of qualitative research is not to generate results that are generalizable, but rather to explore and interpret individuals' experiences in depth (Leung, 2015).

Conclusion

The research has a number of implications both for the role of families in PBS and in respect of the development of the wider workforce. While the family carers were primarily viewing PBS and positive support from the perspective of what they and their loved one needed from support systems, there was also some acknowledgement of their own role in enhancing such support by contributing their detailed knowledge and experience of their family members. The research emphasises the need for families to be involved in genuine collaborative partnerships as a means of sharing this knowledge.

The focus of the family carers tended to be on contrasting positive approaches with previous support that their loved one had received, rather than highlighting difficulties or limitations of PBS itself. In broad terms 'poor care,' whether labelled as PBS or not, was seen as resulting from staff who did not respect and value the person, an inconsistent approach, not listening to the client or family, and who adopted restrictive and/or punitive approaches. The family carers did not generally discuss the more 'technical' issues related to PBS, such as record keeping, reinforcement and functional analysis of the behaviour in those terms. In addition, many of the participants did not appear to have a clear conceptualisation of exactly what defined PBS. If this is reflective of the wider group of family carers, it may have

implications in terms of their being able to differentiate between services that actually do provide PBS and those that have adopted the term but not the approach. In order to address these potential issues there is a need for a clear acknowledgement that family carers are part of the workforce, albeit unpaid, and should have access, in any robust systems-based workforce development approach, to the same development opportunities as paid staff.

Such an approach also needs to ensure that carers and staff at all levels, who are involved in the support of people with ID, have the required competences and share a positive value base (Department of Health, 2014).

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Table 1

Individual interviews						
Participant	Family member		Gender	Age	Additional diagnosis/information	Living situation
Gillian			Male	37	None	Has lived in several hospitals, experienced two shared, supported living placements, and is receiving PBS in his current one
Anna			Male	-	Autism Spectrum Disorder	Lives in residential care. Receives PBS
			Male	33	Autism Spectrum Disorder	Lives in residential care. Receives PBS
			Female	37	Autism Spectrum Disorder	Lives in residential care. Receives PBS
Douglas			Male	29	Autism Spectrum Disorder	Supported residence in the community. Receives PBS
Focus group						
Emily			Male	-	Epilepsy	Has previously lived in at least two hospitals and is now supported in a community setting
Jill			Male	-	Down Syndrome	Not specified
Susan			Female	25	Rare syndrome (not specified to protect anonymity)	Not specified
Christopher			Male	-	Down Syndrome	Not specified
James			Male	Late 30s	ASD	Supported by a 'specialist' provider

Table 2

Theme	Subtheme
The bedrock of support	Underpinning principles and values The technicalities
The impact of care	Experiencing poor care Experiencing positive care
“It’s just been a battle”	On different sides The power and control of the system
“He’s my son”	A central role An emotional challenge

Table 1: Participant information

Table 2: The four main themes and associated subthemes identified from the data