

“We Can’t Expect Other People to Understand”: Family Perspectives on Problem Behavior

LISE FOX
BOBBIE J. VAUGHN
University of South Florida

MERILI LLANES WYATTE
Hillsborough County Public Schools

GLEN DUNLAP
University of South Florida

ABSTRACT: *This qualitative investigation was conducted with a culturally diverse group of 20 family members who were involved in a process of family-centered positive behavior support. Data were obtained from open-ended interviews in which participants discussed issues related to their child’s problem behavior and the ways that problem behaviors related to families’ lifestyles. The interview data revealed three major themes that included (a) the difficult process of coming to terms with the child’s disability, (b) the importance of having support from people who demonstrate genuine caring, and (c) the pervasive impact that problem behavior exerts on all aspects of family functioning. The data are discussed in terms of the value of gaining greater insight into the perspectives of families, and the implications for the development of family-centered behavioral support.*

Positive Behavior Support (PBS) has been heralded as a “new applied science” of behavior change that provides comprehensive interventions in natural contexts that are focused on broader lifestyle outcomes (Carr et al., 2002; Horner, 1997). According to some authors, PBS has evolved from its foundations in applied behavior analysis to become a unique endeavor that integrates person-centered values, evidence-based practices, and scientific methodology (Carr, 1997; Horner et al.,

1990; Koegel, Koegel, & Dunlap, 1996). Researchers in PBS have become increasingly interested in developing methods for behavior intervention that are effective, durable and result in lifestyle changes for both the individual with problem behavior and those persons who provide care and support to the individual (Carr et al., 1999).

There is an increasing emphasis within PBS to develop supports and strategies for behavior change that can be applied in community contexts by natural intervention agents (e.g., teach-

ers, family members). Evidence indicates that the application of PBS within multiple environments by multiple intervention agents can result in more powerful and durable behavior change (Carr et al., 1999; Horner & Carr, 1997). A key consideration in these assertions is that the application of PBS in natural environments relies heavily on the development of partnerships with family members or other support agents (Fox, Dunlap, & Buschbacher, 2000; Lucyshyn, Blumberg, & Kayser, 2000; Singer, 2000).

In recent years, a number of authors have emphasized the value of partnerships among families and professionals for designing and implementing PBS interventions (Albin, Lucyshyn, Horner, & Flannery, 1996; Dunlap, Newton, Fox, Benito, & Vaughn, 2001). The logic is that open and respectful communication within the context of a support team can provide the basis for understanding the familial and ecological features that are crucial to the optimal design of a comprehensive intervention (Albin et al., 1996; Vaughn, Dunlap, Fox, Clarke, & Bucy, 1997). Unfortunately, there is limited research that directly addresses issues of family life and family functioning as these considerations relate to the processes of PBS.

In one notable investigation, Turnbull and Ruef (1996, 1997) interviewed 17 families that included a member with mental retardation and problem behavior. The aim of this study was to gain an understanding of family perspectives on the challenges and successful approaches for individuals with problem behavior and their families. The interviews provided important information on how families define problem behavior, their experiences with challenges and successful approaches for dealing with individuals who have problem behavior, and their access to information on successful approaches. The data indicated that families were very concerned about the constancy of demand of their child's problem behavior and that this concern was intensified by others' perceptions of the problem behavior. The families also described the stressors of being "on duty" 24 hours a day in supporting their child with problem behavior. The families identified a need for comprehensive support that included a consideration of home routines, expanding the child's social relationships and community inclusion, and

strategies for reducing stress that may trigger problem behavior.

In another study, Fox, Vaughn, Dunlap, and Bucy (1997) engaged in a parent-professional partnership in the behavioral support of one child with severe disabilities and challenging behavior. The mother of the child participated as a full partner in the design, implementation, and evaluation of the behavior support process. In addition, the mother provided an audiotaped journal that was supplemented by family interviews and analyzed to gain an understanding of the family's experience in the behavior support process. In their qualitative analysis, the researchers found that problem behavior affected the family in dramatic and pervasive ways. The family members described accommodations to the problem behavior (to avoid triggering their child's problem behavior), the social isolation of the family, the construction of family roles in relationship to supporting their child with problem behavior, and the demands involved in caring for their son. The data gathered from the mother's audiotaped journal and family member interviews were synthesized into two major themes. The theme of "you end up jumping through hoops" described the impact of problem behavior on the family, and the theme of "a powerful impact" described the impact of positive behavioral support on the child and his family.

These two studies provided an initial framework for research efforts focused on understanding family perspectives and experiences. The purpose of the current study was to build upon the findings of Turnbull and Ruef (1996, 1997) and Fox et al. (1997) in order to provide a deeper understanding of the experience of families whose children have disabilities and challenging behavior. An additional purpose was to contribute to the existing database by obtaining perspectives from culturally and economically diverse families who have children with problem behavior.

METHODS

PARTICIPANTS

The participants in this study were involved in a federally funded research project that developed,

demonstrated, and evaluated a program for building competent family networks for families of children with developmental disabilities and challenging behavior. The project had a particular emphasis on families from underserved communities. The “Family Network Project” recruited families for the project by distributing brochures to school social workers or teachers. These school personnel provided brochures to families who had expressed concerns about their children’s problem behavior at home. Classroom teachers, school social workers, or research staff made follow-up phone calls, or families called project staff regarding participation in the Family Network Project.

The project provided participating families with in-home support and group instruction on developing and implementing positive behavior support. Each family was asked to attend group meetings that occurred every 2 weeks for six sessions and was assigned a support specialist who provided support to them throughout the project. The support specialists provided families with individualized in-home support on the weeks in between the group sessions. Over the course of the six sessions, the project director (the second author) conducted parent education meetings on functional assessment and support plan development using family-friendly materials. The support specialists assisted their families with application activities during the group meetings and then assisted their assigned family with direct application of the concepts within home routines and environments.

This article focuses on three of the four groups formed during the project with four to five families participating in each group for a total of 15 families. The fourth group, comprised of custodial grandparents, was not included in this analysis because their perspectives were so uniformly different from the perspectives of the three groups presented herein.

The 20 participating family members (of the 15 families) in this three-group sample included biological parents who raised the children or other family members who provided part-time assistance for the parents with caregiving activities. As shown in Table 1, 8 of the 15 families were considered low-income families (based on information provided in a demographic informa-

The project provided participating families with in-home support and group instruction on developing and implementing PBS.

tion form) and lived in inner-city neighborhoods within a large urban area. The backgrounds of the families were diverse and included 3 Caucasian, 3 Hispanic, 1 Ghanaian, 1 Nigerian, 1 West Indian, and 6 African-American families.

All participating children had a developmental disability accompanied by challenging behavior (see Table 1). The ages of the children ranged from 3 to 12 years. The functioning levels ranged from children who needed round-the-clock supports to children who required minimal supervision with getting up in the morning and going to bed at night. One child was diagnosed with Down syndrome, eight with autism, one with multiple sclerosis, and the remaining participants were children with mental retardation with an unknown etiology.

DATA COLLECTION

The support specialist established rapport with each family over a period of 3 months in the context of biweekly group sessions and home visits. Support specialists were project staff members who had substantial experience and training in providing behavior support for children with developmental disabilities. The support specialist for each family or the project director conducted the interviews.

One or two semistructured interviews were conducted with all of the participating family members. Interview guides were developed to ensure that interviews were conducted consistently by the support specialists. The guide for the first interview contained open-ended prompts or questions about (a) the impact on the family of problem behavior, (b) how the family addressed the problem behavior, (c) the family’s sources of support, and (d) the family’s vision for a preferred family lifestyle. Initial interviews were conducted with each family prior to the introduction of any

TABLE 1
Demographic Data of Study Participants and Their Children

<i>Child</i>				<i>Family Participants</i>			
<i>Name^a</i>	<i>Age</i>	<i>Problem Behavior</i>	<i>Disability</i>	<i>Name</i>	<i>Relationship</i>	<i>Ethnicity</i>	<i>SES^b</i>
Matthew	11	Property Destruction, Loud Vocalizations	Asperger's Syndrome	Kathy	Mother	Caucasian	Upper Middle
Michelle	10	Stereotypy, Loud Vocalizations	Asperger's Syndrome, Moderate Mental Retardation	Christy	Mother	Caucasian	Lower Middle
Cesar	12	Stereotypy, Property Destruction	Multiple Disabilities, Profound Mental Retardation	Maria	Mother	Hispanic	Low
Juan	10	Property Destruction, Loud Vocalizations, Aggression	Autism	Luz	Mother	Hispanic	Low
Arturo	10	Aggression, Loud Vocalizations	Mental Retardation	Carmen	Mother	Hispanic	Lower Middle
Ashley	6	Aggression	Autism	Kimberly	Mother	Caucasian	Middle
Reuben	8	Aggression, Property Destruction	Cerebral Palsy, Moderate Mental Retardation	Rashama	Mother	African-American	Below Poverty
Devante	4	Aggression, Loud Vocalizations	Autism	Latasha	Mother	African-American	Low
Tolu	7	Property Destruction, Aggression	Autism	Maya	Mother	Nigerian	Middle
Marthew	8	Refusal to Work	Mental Retardation	Beulah	Mother	African-American	Low
Richard	7	Refusal to Work	Autism	Aviel Cassandra Sharon John	Father Aunt Grandmother Grandfather	African-American	Below Poverty
Raymond	3	Property Destruction, Aggression	Mild Mental Retardation, Language Delay	Christine Nigel	Mother Father	West Indian	Below Poverty

TABLE 1 (Continued)

<i>Child</i>				<i>Family Participants</i>			
<i>Name^a</i>	<i>Age</i>	<i>Problem Behavior</i>	<i>Disability</i>	<i>Name</i>	<i>Relationship</i>	<i>Ethnicity</i>	<i>SES^b</i>
Isaiah	6	Aggression	Autism	Twila	Mother	African-American	Low
Ralph	5	Loud Vocalizations, Aggression	Autism	Ruth	Mother	Ghanaian	Middle
Alex	3	Loud Vocalizations, Property Destruction	Autism	Lenithia Michael	Mother Father	African-American	Lower Middle

^a All names are pseudonyms. ^b Socioeconomic status (SES) was determined by parent self-report.

intervention strategies (within the first 4 weeks of attending group meetings). The second interview was conducted at the end of the parent group series. The guide developed for this latter interview included the same topic areas, but with an additional question concerning changes in the child and family since the beginning of the group.

The interviews were conducted in locations determined by the family member and lasted from 45 to 120 min. Of the 36 interviews conducted, 34 occurred in the family home, 1 in a restaurant, and 1 at a parent's office. All interviews were audiotaped for later transcription and analysis.

DATA ANALYSIS

All interviews were transcribed and coded as the study proceeded. As each interview was coded, the interviews and the codes were entered into QSR NUD*IST 4 (1997), a software program for storing, merging, and analyzing qualitative data, by a data collector experienced in data entry and familiar with NUD*IST. Reports were generated from NUD*IST by parent group according to major coding categories. The database numbered the lines of the interviews and provided a framework for the development of a coding tree and branches of coding categories. The length of the 36 interviews entered into NUD*IST by line, ranged from 103 to 1394 lines, with a total of 17,290 lines.

The first three authors conducted the analysis of the first 15 interviews. The third author coded all of the remaining interviews, while the first and second authors coded 7 of the re-

maining 21 interviews. As displayed in Table 2, coding categories were developed and refined through open coding in the 15 interviews of the first parent group, and axial coding was used across the remaining 21 interviews to organize and merge categories into subcategories creating coherent connections through dimensions of "context," "condition," and "strategies" (Strauss & Corbin, 1990). Axial coding allowed the authors to consider (a) the properties of the categories and how they related to family situations described in the interviews, (b) how events occurred along a continuum, (c) how events for the family changed over time, and (d) what events intervened to inhibit or promote the areas of concern in family life (Strauss & Corbin).

Three major codes emerged during the open coding process and approximately six subcategories during axial coding. Each of the six subcategories branched into more subcategories that further defined the major category and subcategories. The authors discussed and agreed on the subcategories in the seven overlapping interviews. Through the inductive process of open and axial coding, the responses from the families were connected both sequentially and relationally to arrive at three themes, "Something Is Not Right," "A Shoulder to Lean On," and "It's a 24-Hour, 7-Day Involvement" (see Table 2).

CREDIBILITY

Credibility was established through a variety of methods traditional to qualitative methodology

TABLE 2
Coding Categories

<i>Major Categories</i>	<i>Subcategory</i>	<i>Subcategory</i>	<i>Theme</i>
Impact of Problem Behavior	Beginning the Journey	Difficult Beginnings, Putting the Pieces Together	"Something is Not Right"
	Rhythm	Social Isolation, Disruption of Routine, Inclusion, Relentless Demands, Family Roles, Promoting Understanding, Siblings	"It's a 24-Hour, 7-Day Involvement"
	Reflections	What Is Fair? Strengths, Hope, Coping	"It's a 24-Hour, 7-Day Involvement"
	Disability World	They Can't Relate, Stranger in Strange Land	"It's a 24-Hour, 7-Day Involvement"
Behavior	Nothing Seems to Work	Problem Behavior, Discipline, Things We've Tried, Accommodations	"It's a 24 Hour, 7-Day Involvement"
Reaching Out	Support	Family and Friend, Professional, Parent-to-Parent, School Support, Lack of Support	"A Shoulder to Lean On"

(Lincoln & Guba, 1985; Miles & Huberman, 1994). The methods of establishing credibility included (a) length of time in a setting, (b) the use of a standard interview across participants, (c) triangulation through the analysis of data by multiple researchers, and (d) member checks with participating families.

The family support specialists spent a minimum of 3 months with their assigned family; thus the extended period of time and the frequency of contact with the family assisted in establishing rapport and gathering candid family perspectives during the individual interviews.

The second and third authors conducted select interviews throughout the three family groups in addition to participating in the analyses of all interviews. The authors' involvement with the data collection and analysis further strengthened the methodological credibility by their agreement on coding categories, definitions, and theme development.

Member checks or the process of confirming the analysis of data occurred with a subset of

families to gather family perspectives about the findings from their interviews. The member checks were conducted with a subset of six families—one Caucasian, two Hispanic, and three African-American mothers. The family participants were asked to read a draft of the research findings and answer two questions. The questions included: (a) "Does this summary capture your impressions, experiences, perspectives, or viewpoints? If not, how is life different for you?" and (b) "Is there anything that is important to you that relates to family life with a child who has problem behavior that should be included in this manuscript?" The family participants provided their answers in writing and follow-up phone calls were made to expand on the written answers. The family responses were incorporated into the findings of the manuscript.

FINDINGS

The results of the analysis are described in terms of three themes that are quotations from tran-

scripts of the interviews with family participants: (a) “Something Is Not Right”; (b) “A Shoulder to Lean On”; and (c) “It’s a 24-Hour, 7-Day Involvement.” Although each family we interviewed was unique in their construction, lifestyle, and history, the family stories about their experiences converged around these three themes. It is important to share that although three themes emerged from the data and are discussed in the findings, the first two themes were secondary to the most pervasive theme, “It’s a 24-Hour, 7-Day Involvement.” The first two themes that are described in the following section emerged as important topics for the families, while the third theme was truly the landscape or background for all other reflections.

“SOMETHING IS NOT RIGHT”

The families we interviewed described the beginning of their journey with their child with disabilities by relaying stories of the birth and subsequent medical problems or their realization that their child was not developing normally. As we listened to each family’s story, it was evident that the retelling of the birth history or search for diagnosis was the family’s description of beginning the journey with their child. The theme of, “Something Is Not Right,” captures the reflections of the difficult beginnings parents described to us, the process of determining what was “wrong” with their child, and their hopes for their child.

Difficult Beginnings. We asked parents to describe the early years of their child’s life and how the child’s disability was identified. The families of children who had disabilities identified shortly after birth relayed their birth stories or early hospitalization experiences. Their stories documented the beginning of a long cycle of receiving troubling information about their child’s medical and physical status. For example, Maria described her son’s birth and shared that “. . . they said that when they pulled him out they strained his neck, arm . . . they said he had drank the fluid and he had a loss of oxygen.” Carmen shared with us that her child was diagnosed as microcephalic during a sonogram 2 weeks before he was born. She described Arturo as “a real serious baby. He was real tense, his body

was real tense, and so he was in therapy when he was little, massaging him and making special chairs . . . He walked real late . . . He would fall a lot when he started walking. They even made a helmet for him because he was falling constantly.”

Putting the Pieces Together. The families whose children had diagnoses of pervasive developmental disorders told a different story of their children’s early beginnings. They described a process of having a haunting feeling that their child was not developing normally and trying to figure out what was wrong. For example, Lenithia shared, that despite the doctor’s assurances that her child would talk when he was ready, she said that “I had this gut feeling that something was different.”

Many of the families described a process of examining their child’s behavior, comparing their child to typically developing children, and reading books and the Internet in search of diagnostic information or insight about their child’s condition. The families of children with pervasive developmental disorders described their struggle with the disparity between the occasions that their child seemed so intelligent and the child’s lack of speech or social connections. Many of the children were described as being very content, for example saying, “. . . she didn’t need me. She would play contentedly in her crib for a little while until I would go get her. She wouldn’t call for me. So, anyway, I just thought she was very independent.”

Hopes. We encouraged families to describe to us their hopes for their children. These families listed being able to communicate, being toilet-trained, and having friends as important outcomes for their children. The ambitions families had for their children were relatively modest. Sharon stated, “. . . if he would be able to communicate . . . express his pain, his anger, his

It was apparent that the problem behavior of the child shaded all activities and functions of the family system.

hurt, verbally, that is my greatest hope. That is my prayer.”

“A SHOULDER TO LEAN ON”

We asked the families to describe to us who had been helpful to them as they supported their child with disabilities. The theme, “A Shoulder to Lean On,” describes the accounts by these families of their experiences in receiving support. Families described to us the ways in which professionals, family members, community members, and friends provided support or did not provide support to them. Within every family’s story, there was a notable relationship of critical importance in which the family member felt a sense of unconditional acceptance. This was described by one parent as: “It’s kind of nice to know that there is a person . . . when you think you’re just going to lose it . . . you can call them up.”

We asked the families to describe for us who they relied on for social support and who had been helpful in providing information or professional assistance. As the families described the individuals who were most helpful to them in supporting their child with disabilities, we noted that a common element across the identification of professionals who were most helpful was the feeling that the professional provided emotional support or encouragement. For example, Kathy described it in this way, “And there was no time that I didn’t think I could call Dr. Tiehl and just cry, or, you know, bring all the boys in and Dr. Tiehl would just scoop up Matthew for me and walk away for awhile so that I could talk to Matthew’s teacher.” Rashama shared with us, “I really enjoyed one lady, she was a child development specialist, she would come out, like every week and help me with this. Not just the behavior but what to expect from him. She was there since he’s been like a year old. She was, you know, the shoulder to lean on . . .” Latasha was the only parent to identify the family physician as a supportive professional. She described his support in this way, “And every time I talk to him he’ll give me words of encouragement. He’ll say something like, ‘You know you are Devante’s primary caretaker and the best thing you can do for him is to love him.’ I mean, this is regardless of if I bring him in for a scraped knee or ear infection, it’s always something about just loving him and being

there for him and understanding. You know, I want to cry every time I come out of there . . . I do.”

Our conversations with the families about support providers elicited many comments about the Family Network Project and the supports that were being provided through the project. All of the parents reflected on the essential value of parent-to-parent support and how important that was to them. Latasha described the importance of the parent group in this way, “It was like an unspoken support. A support just being around people that go through similar things . . . Just that kind of ‘I understand, we understand’ type of feeling in the air. Just to know that you are not the only person . . . sometimes about to pull your hair out or about to cry at a certain moment because things aren’t going the way you’d like them to.” Maya described the comfortable dynamic of the parent-to-parent support by saying, “We were all sharing our problems. Then we look at it and you kind of see . . . you know, the little bit of laughter in it, even though it’s kind of serious.”

For many of the families, informal support from key family members or spiritual support through prayer were identified as the main source of emotional support. Kimberly described the support she received from her grandmother, “She would tell me about other mothers and children she knew throughout her life who had disabilities . . . and she would really try to encourage me and she would always tell me, ‘She’ll be fine . . . You just keep up what you are doing . . . and make sure you show her everything. Take her out in the world and make her do what the other kids are doing.’” Maya shared that she took great comfort in the prayers of her family members. She explained that prayer provides her family with hope and explains, “All they do is praying. They don’t understand, I mean, the scientific part.” Maya reflected that she and her husband were also deeply spiritual and shared, “All this praying helps, but as you know, we do what we’re supposed to be doin’ for him and then we pray for him too.”

“IT’S A 24-HOUR, 7-DAY INVOLVEMENT”

One of the mothers described the impact of problem behavior on family life by saying, “It’s a 24-hour, 7-day involvement. It’s always Matthew. It

gets kind of hard for me and my kids. Everyday we're affected." The families described the challenges of their daily lives, the roles and relationships of family members, and the lifestyle of the family. As they shared their stories, it was apparent that the problem behavior of the child shaded all activities and functions of the family system. The theme, "It's a 24-hour, 7-day involvement," dominated the stories, comments, and responses generated in the participant interviews. It is a complex theme that summarizes the reflections of the family about how the relentless challenges of problem behavior affect the family system, family roles, and family activities.

The families shared many stories about their child's problem behavior. The problem behavior they described ranged from mild annoyances (e.g., shyness, self-talk) to aggression and property destruction. The families described how they responded to problem behavior using traditional discipline techniques including time-out, ignoring, reprimanding, earning activities, and spanking. They also reflected on their frustration that these techniques did not seem to be effective in changing their child's behavior. Luz shared, "What I mainly do is, I ignore him. Like when he's angry and throwin' furniture . . . or jumping on the bed crying or breaking dishes, I just try to ignore and then I go and try to get his mind somewhere else."

Many of the parents were able to identify why their child engaged in problem behavior although they did not know how to respond to the behavior when it occurred. For example, Sharon described her grandchild as, "He's uncomfortable with the surroundings and that's why he starts to self-talk. So I just try and reassure him that it's going to be okay." Christine stated, "He'll do a lot of things to purposefully get my attention, like break something or turn on the TV, turn off the TV, or start yelling." Luz stated emphatically that Juan's behavior was about attention, "24 hours he wants my attention. And that's the problem. That's why he breaks things, writes on walls, and everything, he just wants my attention."

The parents expressed their dilemma about how to discipline. They were often aware that their child did not understand family rules and social expectations, but were distressed about having a different set of consequences for their child

Problem behavior relentlessly affected family relationships, physical circumstances, social networks, and daily activities.

with disabilities. Many of the families shared with us their belief statements about how they should discipline and then remarked that it didn't seem to work for their child with disabilities. Kimberly described her dilemma as, "I think I should punish her in the same way (i.e., as her sister), because they're doing the same thing. But, then again, I'm torn between, was she just imitating this; I can't punish her for that . . . choosing the discipline is very confusing to me. I don't know what to do, because I know sometimes time-out is a reinforcer, but it's not always."

Many of the families described their discomfort with the child's behavior in public. These feelings of discomfort were intensified by the reactions of others in the community. One parent shared that "people look and talk and stare and whisper." The mother of Michelle, who has Asperger's syndrome, shared, ". . . she'll start acting so weird. And all of a sudden people look at you, I mean, honestly, it would almost be easier if she was physically deformed or had leg braces . . . because they would probably not stop. They would say 'Oh,' and keep going." One of the parents had to restrict her child's access to outdoors because he smeared feces on a neighbor's house and another parent said that she stopped taking her child into the community because he made odd noises and was disruptive.

Family Roles. In the majority of the families we interviewed, the mother was the primary caregiver for the children. Some fathers were described as being willing to help although the mother was ultimately responsible for the day-to-day care. The mothers described themselves as the child's guardian or advocate. Maria poignantly described this role by stating, "I used to say, 'Well, I'm just a parent', and then I realized, wait a minute . . . I am his voice. I speak for him. And I am going to speak out." As we listened to the mothers describe their family life, we began to understand that these mothers viewed themselves

as shielding their child from the outside world. Carmen shared that she told one of her children, "If we don't love him (i.e., the child with disabilities), nobody will. He only has our love, you know, his immediate family, and that's it. We can't expect other people to understand him or to love him, it's like our own little world."

Many of the families were troubled by their desire to be fair to the siblings of their child with challenging behavior. Latasha described the reactions of Devante's older sister as, "She's really starting to get tired of it. She's been really patient, as much as a 6-year-old can, with trying to understand, that O.K., Devante has just ruined the cake by licking all the icing off, she's been really patient. But I think that now she's starting to get irritated by it." All of the families who had multiple children faced dilemmas about how to discipline the child with challenging behavior when the rules and consequences were different for their other children. Rashama worried that her other two children may need support or counseling and reflected, "My other two kids are going through some changes now, that I'm dealing with too, and it's getting harder and harder." When the interviewer suggested to Rashama that there were sources of support including counseling that may be available to her family, Rashama remarked, "You look out the window and you see things that you know is out there, but, you really don't know."

Relentless Demands. The mothers we interviewed poignantly described the difficult pace of their lives and the impact of daily demands. These demands may have been different for Luz who was a single parent living on a very limited income as compared to Kathy who had more resources and worked part time. Despite those differences, the demands were described as constant. For example, Carmen shared with us, "Everything is difficult. And then when you've got other kids and they've got homework and they've got to be at school on time and everything. It's just hard to put everything together . . . because there's so many kids, there's the cooking, there's the cleaning . . ." Carmen also shared, ". . . at that point I was working full time, but I couldn't do it because I had so many appointments with Arturo, so then I cut my hours to part time."

Coping. The demands of family life took a heavy toll on the mothers' sense of emotional stability. Carmen shared, "Sometimes I spend a whole day crying and then for months I don't cry." Lenithia describes daily life as, "It's tough day-to-day, And it's just like . . . my life belongs to them." Luz stated, "And there are times when you're just so emotionally and physically exhausted that you just don't want to do that anymore. You just want to scream." Kathy shared with us the following reflections about when her children were preschoolers and she felt the emotional strain most acutely:

It was nuts. And it was a real strain on the family . . . I can remember just putting them all in their car seats and driving and crying while driving down the street. Just thinking . . . well at least they're all in their car seats, and they can't go anywhere. And maybe someone will fall asleep. And I would just drive. And I can remember seeing my girlfriend and told her, I thought I felt like Jekyll and Hyde . . . and she said, "Kathy you're always so happy and loving." And I'm like, "And I'm dying inside."

Many of the mothers described that their lives were tremendously difficult, but that they had developed ways to cope. Kimberly described her reaction to stress as, "I think I have this turn-off mechanism where I kind of have this tunnel vision or something, and I blank everybody else out . . . I just have to block everybody else out and just say, this is what I've got to do." Carmen described her job as her haven from the challenges at home: "My job was therapeutic for me. If I could get away and forget about my problems and then just go and concentrate on work and whatever problems were at work . . ." Rashama, who does not work outside the home, described her difficulties in meeting the day-to-day challenges in this way, "I anticipate when he comes home (i.e., from school). I get anxiety attacks and everything because I know it's going to start again."

Social Isolation. The difficulties associated with the child's persistent problem behavior and the demands of daily life resulted in the family's social isolation. The majority of the families we interviewed described themselves as having limited activities outside of the home due to the difficulties they encountered with their child who

had problem behavior. Kimberly described the difficulty in this way, “You don’t want to take her to other people’s houses, because you’re kind of scared of, ‘What’s she gonna do?’” Lenithia described her rationale for not taking her son to her friends’ homes in this way, “I have to watch him constantly. And if I have to watch him constantly I’m not really there. You know, I’m there but he still has my attention at all times. And that’s not comfortable.” Luz told us, “I don’t have a personal life, I don’t go out. I don’t do anything. I work. Because I’m always tired and under stress.” Carmen described for us how her family became socially isolated, “It’s just growing up that has separated me with the outside world with Arturo, because you are limited to where you can go with him, because of his behavior problems, which didn’t exist when he was little.” She went on to tell us, “We’ve sort of isolated ourselves from everybody. And we’ve got to do the things that we’ve got to do, we just do it for ourselves.”

Many of the families felt that their experience with disability set them apart from their friends and family. Lenithia shared, “They say that I dwell in it, and I probably do, but . . . I feel that they’re on the outside lookin’ in and I’m in and wish I could be on the outside.” Latasha felt that her friends could not relate to her experience of raising a son with autism. She stated, “My friends have children of their own. And they’re like just getting it about the regular stuff, much less special needs or whatever. It’s not intentional, but they just really don’t understand.” In a discussion with the interviewer about the public’s understanding of disability, Carmen remarked, “We didn’t know about it. It was a world we were thrust into when Arturo was born.”

REACTIONS FROM THE FAMILIES

Once these themes were developed and summarized in writing, we provided the findings section of this article to six representative families to see if our interpretations accurately reflected their individual family’s experience. The families agreed that the article was reflective of their experiences and provided us with additional information on how they were doing and new challenges in their

lives (e.g., accessing after-school care and anxieties about puberty). Kathy shared with us, “I could hear my voice and was even drawn to tears when re-feeling the hopelessness and despair.” Luz also stated that reading the transcript “took her back” and almost had her in tears. Lenithia concurred that the paper reflected her experience and added that she felt professionals should know that while routines are very important to family life, sometimes the relentless demands make them difficult.

DISCUSSION AND IMPLICATIONS

The perspectives of these families offer rich information on the construction of families and the effects of problem behavior on family life. These perspectives are not presented as indicators of family pathology, nor are they meant to be representative of other families in similar circumstances. We have presented these perspectives because we feel that they provide insights regarding the ecology of some families whose lives have been touched by disability and problem behavior.

It is important to be explicit about the limitations of these data. First, this study presented the perspectives of only 20 family members who live in an urban environment in a southeastern city in the United States. The inclusion of more family members from diverse communities may have provided richer data and resulted in additional or different themes. Second, the findings of the study are based on a limited set of interviews conducted over a 6- to 9- month period of time for each family. Data gathered over a more extended timeframe might provide better insight on the rhythms of family life and changing dynamics of family functioning. Finally, the data that were gathered represent those perspectives that families felt free or willing to share. Although the inter-

The challenge described by these families calls for family-centered partnerships in the development and implementation of comprehensive PBS.

viewers who gathered these data had developed significant rapport and trustful relationships with the families, it is likely that families may have been unwilling to share some of their most intimate concerns or challenges.

It is notable that families wanted to describe the early beginnings with their child and most frequently initiated the sharing of this information. It was our impression that the families we interviewed felt a need to describe the onset of their journey and felt that those difficult beginnings were relevant to their present-day circumstances. As families relayed those stories, they were laced with descriptions of family stress due to medical worries or the haunting feeling that something was “not right” with their child. In these conversations with families we developed an appreciation for the chronicity of family worries and challenges.

The families we interviewed had children who were 3 to 12 years old who were enrolled in special education programs. We were surprised that these families responded to questions about who provided support by describing the caring relationships they had with friends or professionals, rather than focusing on who had assisted their child in making gains or achieving outcomes. It was very apparent that these families treasured and felt supported by individuals who had established caring and intimate relationships. In addition, these families all placed tremendous value on the opportunity to connect with other parents who were struggling with similar circumstances.

The families we interviewed described a family life that was deeply and pervasively affected by the child's problem behavior. The entire family system was engaged in multiple accommodations in response to problem behavior. Those accommodations included how family roles were defined, family routines and activities, and the sense of emotional well-being by family members who were in primary care-giving roles. These families were changed as a result of the persistent and overwhelming demands of physically intervening with their child or worrying about their child's problem behavior. As researchers, we found it difficult to construct the prose that would adequately convey the emotional, physical, and structural impact of problem behavior on family

life. Problem behavior relentlessly affected family relationships, physical circumstances, social networks, and daily activities.

IMPLICATIONS FOR PRACTICE

The perspectives shared by these families echo and expand on many of the themes described by Turnbull and Ruef (1996, 1997) and Fox et al. (1997). Research on family perspectives has revealed that families whose children have disabilities and problem behavior are experiencing very difficult challenges with limited support. It is evident from these descriptions that assistance is critically needed. An important question for policymakers and service providers is who can provide these services (Schwartz, 1997; Singer, 1997). The challenges described by these families call for family-centered partnerships in the development and implementation of comprehensive PBS (Lucyshyn, Dunlap, & Albin, 2002). Services that are more traditionally provided, such as parent training or educational planning, may not be adequate in addressing the systemic needs of the family (Paul & Frea, 2002).

These families have illustrated to us that problem behavior has a very broad impact on the family system, routines, and activities. Thus, it is critically important to understand the unique structure of the entire family system as we design comprehensive interventions and supports. This suggests a need for new and broader systems of functional assessment that address needs in both home and school environments, and the incorporation of intervention components that emphasize contextual fit and longitudinal impact (Albin et al., 1996; Dunlap, Fox, Vaughn, Bucy, & Clarke, 1997). These general notions are similar to those expressed by a number of authors. For example, from the perspective of assessment, Harry, Rueda, and Kalyanpur (1999) advised that service providers must engage in ecocultural analysis to gain an understanding of the range and type of activities to which an individual has access, and then develop interventions with an understanding of the unique social, interpersonal, and community influences for each individual. This kind of preintervention analysis is much more extensive than the typical functional behavioral assessment that is commonly prescribed. From the perspec-

tive of intervention, Keogh, Garnier, Bernheimer and Gallimore (2000) note that family accommodations need to be more extensive as the problem behavior often becomes increasingly severe as the child grows older.

Problem behaviors clearly present a substantial and generally deleterious impact on all members of a family system. The longer such behaviors persist, the more pervasive is their influence. The major contribution of the current study is to highlight the extensive and pervasive role that problem behaviors can have on family life. The great challenge that lies ahead is to develop an enhanced understanding of this phenomenon, create valid methods for assessing family functioning in relation to behavioral support, and build effective strategies and resources for linking family-focused assessment to family-centered intervention and support.

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ABOUT THE AUTHORS

LISE FOX (CEC #507), Research Professor, Department of Child and Family Studies; **BOBBIE J. VAUGHN**, Research Assistant Professor, Department of Child and Family Studies, University of South Florida, Tampa. **MERILI LLANES WYATTE**, Classroom Teacher, Hillsborough County Public Schools, Tampa, Florida. **GLEN DUNLAP** (CEC #194), Professor, Department of Child and Family Studies, University of South Florida, Tampa.

Correspondence concerning this article should be addressed to Lise Fox, Department of Child and Family Studies MHC 2113A, Louis de la Parte Florida Mental Health Institute, 13301 N. Bruce B. Downs Blvd., Tampa, FL 33612-3807. E-mail: fox@fmh.usf.edu

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