Giving Voice to Parents of Young Children With Challenging Behavior

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ABSTRACT: This study gave voice to parents raising young children with challenging behavior using a qualitative, phenomenological approach. Seven families raising children between the ages of 25 and 43 months participated in a series of interviews. The children's primary diagnoses varied, but all children exhibited challenging behaviors such as noncompliance, self-injury, tantrums, excessive crying, and property destruction. Results showed that parents' experiences could be grouped into 5 major themes: (a) obtaining accurate and useful information, (b) obtaining services and supports, (c) financial stress, (d) stress among members of the family, and (e) community isolation. Implications for changes to systems of care for young children with challenging behaviors and their families are discussed.

In recent years, there has been increased interest in the science of child development, particularly within the early childhood years (i.e., birth to 5 years) and specifically pertaining to children who exhibit challenging behavior. With greater understanding of brain-behavior relationships and prevention services for young children has come a renewed interest in the developmental significance of early life experiences (National Research Council and Institute of Medicine, 2000). Armed with an increasingly large body of neuroscience research (e.g., O'Connor, Deater-Deckard, Fulker, Rutter, & Plomin, 1998; Plomin, Fulker, Corley, & DeFries, 1997; Rutter et al., 1997), researchers have begun to ask questions about the efficacy of prevention services and supports for young children, particularly those with challenging behavior (i.e., behaviors that interfere with "optimal learning or engagement in prosocial interactions with peers and adults"; Powell, Fixsen, & Dunlap, 2003, p. 2). Despite such an agenda, the voices of parents often remain unheard, regardless of widespread acknowledgment that parents play a critically important role as their child's most important teachers (Lucyshyn, Dunlap, Horner, Albin, & Ben, 2002). Not only are parents their children's most important teachers, they are also experts in their children's lives, with stories to share that can shed light on the
The voices of parents often remain unheard, regardless of widespread acknowledgment that parents play a critically important role as their child's most important teachers.

The current study was designed to give voice to a sample of parents raising young children with challenging behavior. The purpose of this qualitative investigation was to share detailed parent reports of experiences obtaining services and supports for their children within their local system of care. Using an ecological framework, parent reports are presented and discussed in relation to an analysis of community-based services and supports for children and families within the same geographic area (Raffaele Mendez & Hess, 2003).

A SYSTEMIC PERSPECTIVE ON CHALLENGING BEHAVIOR

Several national organizations and consortiums of researchers have jointly assessed the political, social, and economic impacts of child development (e.g., National Research Council and Institute of Medicine, 2000) while others have promoted the use of specific evidence-based practices designed to prevent challenging behavior and promote social-emotional development (e.g., the Center for Evidence-Based Practice: Young Children with Challenging Behavior, http://www.challengingbehavior.org). This body of research endorses several prevention-oriented concepts, such as: (a) human relationships serve as the building blocks of healthy development; (b) children develop along trajectories characterized by continuities, discontinuities, and important transitions; (c) children's growth and development is influenced by the presence of risk and protective factors; and (d) meaningful outcomes may be obtained through implementing evidence-based interventions designed to both teach skills and promote inclusion into a wider range of natural community environments (Bailey et al., 1998; Dunlap & Fox, 1996; National Research Council and Institute of Medicine; Powell et al., 2003; Smith & Fox, 2003). Given the fact that over 200,000 children and families received early intervention services and supports in the United States in 1997 to 1998, each with an average total expenditure of $15,740 per child (Hebbeler, Spiker, Mallik, Scarborough, & Simeonsson, 2003; Levin, Perez, Lam, Chambers, & Hebbeler, 2004; U.S. Department of Education, 2001), documentation of meaningful system-level as well as child- and family-level outcomes has become an issue of national significance and critical need (Bailey, 2000, 2001; Bailey et al., 1998; Carta, 2002; Guralnick, 2000; Turnbull & Turnbull, 2000). This is particularly true with respect to young children with challenging behavior, who often require high levels of service and have inconsistent or poor outcomes.

Unfortunately, there has been an increasing trend in the number of young children with challenging behavior. Estimates may be as high as 12% or 16% of the total population ages birth to 3 years (American Academy of Pediatrics, 2001; Campbell, 1995). In light of sharp increases in federal appropriations for early intervention services from 1987 to 2006, it is notable that services and supports were provided to only 2.41% of the national population of children birth to 3 years in 2006 (Danaher, Goode, & Lazara, 2007). Consequently, federal legislators and policy makers have sought to develop, implement, and evaluate strong prevention programs for young children in order to minimize the prevalence and impact of child psychopathology over time, particularly with respect to challenging behavior.

THE ECOLOGICAL MODEL AND THE SYSTEM OF CARE

One of the most widely accepted frameworks by which to understand early childhood development is Bronfenbrenner's ecological theory (Bronfenbrenner, 1979, 1986, 1999), which considers a child's development within "a complex system of relationships affected by multiple levels of the surrounding environment" (Berk, 2006). Bronfenbrenner's model comprises five different subsystems: (1) the microsystem (i.e., a child's direct interactions with immediate family members and his or her surroundings); (2) the mesosystem
(i.e., a child's connections to individual microsystems such as the home, child care/preschool, hospital, peer group, or local neighborhood); (3) the exosystem (i.e., the social environment indirectly impacting the child's experiences, such as the parent's place of employment); (4) the macrosystem (i.e., a culture's overarching laws, values, and customs); and (5) the chronosystem (i.e., the presence of time relative to the sequence or pattern of events that impact a child's development). Since its original articulation in 1979, Bronfenbrenner's model has received considerable support and endorsement, as the model allows one to identify both the systems that are impacted by changes in familial functioning and also its direction and outcomes.

A second advantage of the ecological model is its focus on prevention and its linkage to systems of care (SOC; Stroul & Friedman, 1986). At the policy level, factors impacting familial functioning can be considered relative to their impact upon a regional system of care for young children and their families. Defined as a comprehensive spectrum of mental health and related services coordinated into a network designed to meet the multiple and changing needs of children and adolescents (Stroul & Friedman), the SOC is an exosystem which plays a significant role in positively influencing the lives of children and families in need of support. The ecological model appears to be a useful tool for evaluating the system-level effectiveness of a local SOC, as it affords the opportunity to assess the patterns of variables that either strengthen or weaken the system over time. Evaluated within an ecological framework, researchers and policy makers are better able to identify specific risk and protective factors that either positively or negatively impact children and families. When used in this fashion, the ecological model not only helps explain the process of development but also contributes to the evaluation of the SOC in which it is applied.

A sizable body of interdisciplinary research has evolved in support of an SOC designed to both improve children's growth and development and to prevent the occurrence of challenging behavior in young children. Despite strong theoretical support for early childhood prevention programs (e.g., Campbell, 1995; Dunlap & Fox, 1996; National Research Council and Institute of Medicine, 2000; Ramey & Ramey, 1998; Sandall & Ostrosky, 1999), demonstrations of accountability are needed. Qualitative studies in early intervention and early childhood special education (EI/ECSE) are presently lacking (Sandall, Smith, McLean, & Ramsey, 2002); quantitative studies may not adequately measure family-related outcomes. Bailey and his colleagues (1998) suggested that professionals pay greater attention to the personal experiences inherent to family assessment.

In one such study, Raffaele Mendez and Hess (2003) sought to estimate the number of children living within a large county in central Florida who were identified with special needs, to identify the challenges faced by their families, and to pinpoint specific gaps within the county's existing service delivery model. They identified several challenges facing the families of the children, ages birth to 3 years: (a) arriving at a proper diagnosis, (b) lack of support from the child's primary care pediatrician, (c) entering and navigating the system of care, (d) balancing work and child care, and (e) obtaining parent support. Likewise, the authors identified a number of service gaps for children birth to 3 years, including (a) a lack of adequate developmental screening and assessment; (b) limited access to information; (c) deficiencies in public school education, care coordination, and child care; (d) limited access to social opportunities; (e) limited access to mental health services; and (f) limited employment opportunities, transition services, and transportation. Though the study addressed the concerns of families with children ages birth to 3 years, detailed narrative reports of parent experiences were not possible, nor did the study focus exclusively upon young children with challenging behavior.

**EXPRESSION OF FAMILY VOICE**

Research that focuses on participants' personal meanings "gives voice to people who have been historically silenced or marginalized" (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005, p. 199). Through the use of qualitative methods such as narratives and life histories, researchers are able to effectively communicate meaningful information that might not be obtainable using more conventional methods. Applied to the context of
EI/ECSE, such methods offer important opportunities for parents of young children with challenging behavior to share their perspectives with a wider audience than they would typically access (Fox, Vaughn, Dunlap, & Bucy, 1997; Maurice, 1993; Pugach, 2001). Fox, Vaughn, Wyatte, and Dunlap (2002) conducted a qualitative study with 20 family members who participated in the development and implementation of positive behavior support (PBS) interventions for 15 children ages 3 to 12 years with challenging behavior (average age, 7 years). Using a semistructured interview format, the team reported three specific themes: (a) the difficulties of coming to terms with a child's disability; (b) the importance of having support from others; and (c) the pervasive impact that challenging behavior exerts on all aspects of family functioning. The authors indicated that the families interviewed "felt a need to describe the onset of their journey and felt that those difficult beginnings were relevant to their present-day circumstances" (p. 448). Likewise, the authors reported that such information had provided them with a greater understanding and appreciation of the magnitude of impact a child's challenging behavior has upon the entire family system. Although further research is needed to increase understanding of the experiences of families with very young children who are experiencing challenging behaviors, these findings illustrate the type of contribution qualitative methods can make toward bringing out family voice.

METHOD

APPROACH

This study used a qualitative approach emphasizing the phenomenological experiences of parents of young children with challenging behavior. Data collection included an a priori written description of the researchers' own experiences relative to the phenomenon, or a "bracketing interview" (Marshall & Rossman, 1989), followed by retrospective in-depth interviews with a small number of selected cases. We collected data through semistructured interviews that involved one primary question followed by probing using open-form questions (Gall, Borg, & Gall, 1996), then systematically analyzed the data (in the form of oral tapes and written transcripts) to identify themes and supporting quotes. The findings are presented as case evidence for the experiences of parents of young children with challenging behavior within the service system rather than as verification of the presence or absence of predefined variables.

PARTICIPANTS

Parents Interviewed. We interviewed 8 parents representing 7 families for this study—6 mothers, 1 father, and 1 grandmother. The majority of participants were the primary maternal caregiver, in one case a mother/father couple was interviewed together. Four parents characterized their race/ethnicity as African American, and 4 described themselves as Caucasian. The average educational attainment of the parent participants was 14 years (range, 12–18 years). Occupations ranged from paraprofessional to professional. Although all parents lived in the same county in central Florida, six different zip codes were represented in the sample of seven families.

Children Discussed. Children discussed in the interviews included 5 boys and 2 girls with an average age of 36 months at the time of the interview (range, 25–43 months). Child concerns were first identified at an average age of 15 months (range, 0–36 months), whereas the average age at which the children were evaluated by a developmental specialist and determined to be eligible for early intervention services was 32 months (range, 20–39 months). Children's diagnoses included both medical (e.g., asthma, bronchitis, otitis media, eczema, ventricular septal defects, gastroesophageal reflux) and developmental diagnoses (e.g., developmental delay, speech delay, developmental language disorder, Williams syndrome, pervasive developmental disorder—not otherwise specified). In addition, each child exhibited a wide array of challenging behaviors including self-injury, noncompliance, tantrums, excessive crying, feeding difficulties, property destruction, biting, screaming, hitting, stuttering, scratching, throwing objects, dropping to the floor, or jumping off high platforms. The 7 children discussed in this study also received a variety of supports
and services, including speech therapy (n = 3; 43%); occupational therapy (n = 1; 14%); physical therapy (n = 1; 14%); early intervention (n = 2; 29%); pharmacotherapy (n = 4; 57%); and a behaviorally oriented parent support group (n = 1; 14%). In addition to these services, 1 child was on a waiting list for an eligibility evaluation for preschool exceptional student education services (n = 1; 14%); 1 awaited an appointment for a speech therapy evaluation (n = 1; 14%); and 1 was on a waiting list for services provided by the Early Intervention Positive Behavior Support (EIPBS) program (n = 1; 14%). Table 1 presents demographic information regarding the children and parents in this study.

PROCEDURE

Step 1: Participant Recruitment and Sampling. We selected participating parents or guardians from three sources: (a) the entire sample of parents or guardians with children either enrolled in the EIPBS program or on a waiting list; (b) parents or guardians of children receiving services and supports provided through Infants and Young Children of West Central Florida, Inc. (IYC); and (c) parents or guardians of children receiving services and supports through the Florida Diagnostic Learning Resources System (FDLRS).

Initial contact for prospective participants was established in writing through a flyer disseminated to all parents or guardians in the EIPBS program, through the IYC's Family Resource Specialists/FLDLS' Parent Liaison Coordinator, or through personal contact by the first author with parents or guardians attending the IYC/FLDLS-sponsored "New Star Training" sessions. Interested parents or guardians voluntarily contacted the first author to further discuss their participation in this study. The first contact provided us with the opportunity to ask questions linked to several screening criteria using a form developed for this study. The form gathered information about parent characteristics and child characteristics (i.e., those shown in Table 1), including current medical/developmental diagnoses and types of challenging behaviors exhibited. Based on this screening process, we chose 8 participants who met our inclusion criteria: having a young child (up to 3 years, 11 months, 30 days) with challenging behavior, defined as behavior that "interferes with or is at risk of interfering with optimal learning or engagement in prosocial interactions with peers and adults" (Powell et al., 2003, p. 2). Additional criteria included ability to speak English well enough to participate in an in-depth interview with a monolingual English-speaking interviewer, no history of contact with the interviewer, and being a resident of the county in which data were collected for at least 12 months. In order to obtain a diversity of voice consistent with residents of the community, we used purposeful sampling to obtain a final sample of participating families varying in racial, ethnic, cultural, and demographic characteristics but sharing the commonality of caring for young children with challenging behavior. All participating parents/guardians were provided with a $50 cash stipend.

Step 2: Bracketing Interview. Before initiating data collection, the first author, who interviewed all parents, conducted a bracketing interview. According to Marshall and Rossman (1989), phenomenological researchers are required to write an a priori description of their own experiences, thereby allowing them to "bracket" their experiences from those of the study's participants. The purpose of this type of self-examination is for the researcher to clarify his own preconceptions relative to the phenomenon, which is also expected to be ongoing throughout the research process.

Step 3: Pilot Study. We conducted a brief pilot study with the first 3 participants using a checklist of topic domains including diagnosis; pregnancy, labor, and neonatal course; stressors associated with obtaining support; early intervention services and supports (including those intended to treat challenging behaviors); and preschool or child care experiences (see Table 2). We conducted a follow-up interview to review the interview transcript with the parent(s) and gather any additional information the parent wanted to include. Although we were careful to avoid rendering opinions on the utility or efficacy of specific behavior intervention strategies used with the children discussed, we did provide participants with resources describing positive behavior intervention strategies for future use and consideration.
### TABLE 1

Demographic Characteristics of Children and Parents in the Study

<table>
<thead>
<tr>
<th>Child</th>
<th>Gender</th>
<th>Age (in months)</th>
<th>Primary Medical Diagnoses</th>
<th>Parent(s) Interviewed</th>
<th>Parent’s Race/Ethnicity</th>
<th>Parent’s Marital Status</th>
<th>Parent’s Highest Level of Education (in years)</th>
<th>Parent’s Occupation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bri</td>
<td>Female</td>
<td>39</td>
<td>Allergies; possible ADHD</td>
<td>Mother</td>
<td>African American</td>
<td>Single</td>
<td>14</td>
<td>Admin. asst.</td>
</tr>
<tr>
<td>Grace</td>
<td>Female</td>
<td>35</td>
<td>Williams syndrome</td>
<td>Mother</td>
<td>Caucasian</td>
<td>Married</td>
<td>12</td>
<td>Admin. asst.</td>
</tr>
<tr>
<td>Darnell</td>
<td>Male</td>
<td>39</td>
<td>Eczema; speech delay</td>
<td>Mother</td>
<td>African American</td>
<td>Married</td>
<td>15</td>
<td>Homemaker</td>
</tr>
<tr>
<td>D.J.</td>
<td>Male</td>
<td>33</td>
<td>Ventricular septal defect</td>
<td>Grandmother</td>
<td>African American</td>
<td>Single</td>
<td>13</td>
<td>Disabled</td>
</tr>
<tr>
<td>Andrew</td>
<td>Male</td>
<td>38</td>
<td>PDD-NOS</td>
<td>Mother</td>
<td>Caucasian</td>
<td>Married&lt;sup&gt;a&lt;/sup&gt;</td>
<td>14</td>
<td>Homemaker</td>
</tr>
<tr>
<td>Lenny</td>
<td>Male</td>
<td>25</td>
<td>Developmental language disorder</td>
<td>Mother and father</td>
<td>Caucasian</td>
<td>Married</td>
<td>18 (mother)</td>
<td>Accountant (mother) Professional speaker (father)</td>
</tr>
<tr>
<td>Tank</td>
<td>Male</td>
<td>43</td>
<td>Asthma; speech delay</td>
<td>Mother</td>
<td>African American</td>
<td>Single</td>
<td>13</td>
<td>Homemaker/child care</td>
</tr>
</tbody>
</table>

<sup>a</sup> This parent was divorced from the child’s father and remarried to another man. All other participants who were married were married to the child’s father.

*Note. All names are pseudonyms. ADHD = attention deficit hyperactivity disorder; PDD-NOS = pervasive development disorder—not otherwise specified.*
TABLE 2

<table>
<thead>
<tr>
<th>Topic Area</th>
<th>Examples of Prompts</th>
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<tbody>
<tr>
<td>Pregnancy, labor, and neonatal course (including NICU)</td>
<td>“Tell me about your pregnancy.”</td>
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<tr>
<td></td>
<td>“Tell me about when you first realized there was something wrong with your child.”</td>
</tr>
<tr>
<td></td>
<td>“Tell me about your experiences with your child’s doctor when you first realized there was something wrong with your child.”</td>
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<tr>
<td></td>
<td>“Tell me about your child’s experiences in child care or preschool.”</td>
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<tr>
<td></td>
<td>“Tell me about your experiences in the Early Intervention/Early Steps Program.”</td>
</tr>
<tr>
<td>Obtaining services for the child</td>
<td>“Tell me about how your child’s difficulties have impacted your career.”</td>
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<tr>
<td></td>
<td>“Tell me how your child’s difficulties have impacted your personal finances.”</td>
</tr>
<tr>
<td>Impact on parents/family</td>
<td>“Tell me about your opportunities to go out into the community.”</td>
</tr>
<tr>
<td></td>
<td>“Tell me about your opportunities to spend time with friends or your neighbors.”</td>
</tr>
<tr>
<td>Access to community</td>
<td>“How have you grown from your experiences raising (child’s name)?”</td>
</tr>
</tbody>
</table>

Note. NICU = neonatal intensive care unit.

Step 4: Interview Data Collection. Prior to engaging in the interview process, interested participants provided written informed consent as well as verbal commitment to participate in two interviews. Participants were informed that data collection would consist of semistructured interviews but were also invited to share any written information (e.g., pertinent reports and medical records) they felt would potentially add to the data collection.

Using the semistructured interview guide developed for this study, the first author met with each parent to administer the interview. The interview guide included a single, open-ended question followed up with additional questions as necessary. The opening question was “Every parent has a story. Please tell me about your story and experiences as a parent of (child’s name).” Parents’ comments guided the direction of the interview. While the interview was being conducted, the interviewer completed the checklist of topic domains to ensure coverage by each participant. We conducted a second follow-up interview with each participant to confirm correctness of transcripts and provide opportunities for additions or revisions to the checklist. All topic areas were covered by pilot study participants; these transcripts were included in the final sample. Each initial interview lasted an average of 67 min, with follow-ups lasting an average of 48 min. The average total length of the two interviews combined was 116 min.

We audiotaped all interviews and transcribed using a procedure called “shadowing” (Newman, 2002): we played back a segment of the audiotaped interview, paused the tape, and then dictated the text verbatim into a computer using voice recognition software. Following transcription of the semistructured interview, the researcher selected up to five segments of each interview transcript to present to the participant at a second meeting.

During the second interview, the participant received the checklist of topic domains completed during the first interview, and any topic that had not been covered was discussed. At this meeting, the participant also revised segments of the transcript from the first interview and responded to questions regarding each segment: (a) “When I asked about [question], you mentioned [read transcript]. Does this sound like what you meant to say?”; (b) “Is there a way that I should modify
the statement to reflect a more accurate portrayal of your experiences?"; and (c) "Are you pleased with/do you agree with this segment?" After reviewing each segment, participants were asked if there were any other questions or if there was anything they forgot to mention during the initial interview.

Saturation. Saturation was considered to be the point at which new themes were no longer reported by parent participants (Denzin & Lincoln, 2000; Strauss & Corbin, 1990). After review of transcripts and supporting quotes for 8 participants, we determined that saturation had been achieved; we agreed that data collection had reached a point where subsequent interviews were estimated to add little additional information to the data that had already been collected.

DATA ANALYSIS

We analyzed unabridged transcripts through a systematic, sequential, and verifiable process (Krueger & Casey, 2000) that ensured systematization by being both documented and clearly stated. Likewise, data analysis was verifiable through a clear "chain of evidence" (Patton, 1990) that connected themes with sections of the original transcripts for each individual participant (Krueger & Casey). For example, all transcripts included the participant's initials, date, and page numbers such that each segment of text could be verified. We kept two copies of each transcript, one intact and a second for organizing into thematic categories by color coding with markers that identified the transcript of origin. Multiple color-coded vertical lines drawn down the left margin of the paper allowed us to cut individual segments of text from its original transcript when creating thematic categories.

We created thematic categories attaching individual segments of text cut from transcripts to flipchart paper. Each sheet of flipchart paper represented one of five primary themes (discussed in the Results). After organizing transcript segments into their respective themes, we wrote descriptive summaries of the participants' reports. We summarized and described the findings of each participant interview in a way that retained each parent's voice and avoided making value-laden judgments or elaboration by the authors. After describing each individual transcript, we summarized the data across participants.

RESULTS

Five primary themes emerged from the data: (a) obtaining accurate and useful information, (b) obtaining services and supports, (c) financial stress, (d) stress among members of the family, and (e) community isolation.

OBTAINING USEFUL AND ACCURATE INFORMATION

Multiple parent respondents shared experiences regarding obtaining information from pediatricians and other sources relative to both diagnoses and supports for their child. Several parents considered information provided by pediatricians to be inadequate, although a few felt the information had been helpful. Some negative experiences were related to the lack of responsiveness or knowledge of pediatricians about concerns voiced by parents. Lack of responsiveness appeared to be due to the pediatrician's assessment of the child's behavior as within the normal range of functioning for the age. For example, one pediatrician interpreted the behaviors of concern with giftedness rather than emotional or behavioral challenges, assuring the grandmother "Don't worry about it. If he's aggressive, it's just that he's very intelligent." Pediatricians were also described as unwilling to refer very young children for testing because of the possibility that the child would improve as he matured. One mother explained:

"Every time it got worse, we'd take him in to the pediatricians and complain to them about the new symptoms, remind them about the old symptoms, tell them, "Look, what can it hurt to just have him tested?" Their thoughts were, "There's no point to having him tested. He's too young. He's still developing. Wait until he's done developing and then we'll see if there's a problem."

Parents interpreted the reluctance of pediatricians to make diagnoses or refer for testing as an unwillingness to accept the parents' assessment of the situation, combined with lack of information about serious challenges that can manifest them-
selves in very young children. Andrew’s mother described her frustration with this type of experience:

We started talking to his pediatrician when the head banging got worse, and they kept telling us that it’s not abnormal for a child to bang their head pretty hard to put themselves to sleep. So, they didn’t have any concerns for him; they thought that he’d outgrow it. We told the pediatrician, “This is ridiculous. He’s banging his head at night so severe, he has night terrors, he’s losing speech, he’s getting violent when I can’t understand him. I’m getting stressed not being able to understand him. I’m getting stressed not knowing how to deal with his violent temper tantrums. Please help me.” Once again, it was, “He’s getting close to 2, the terrible 2s, he’ll outgrow this.” They gave me a pamphlet on temper tantrums and how to handle them, and their idea of handling them was to pretend that they’re not happening, just ignore them.

Several parents expressed concern about their pediatrician’s lack of knowledge about specific types of disorders, leading them to seek out information on their own and resulting in a feeling that they were better informed than the pediatrician. One mother recounted:

We have had to educate everyone that we come into contact with, our pediatrician included. . . . For a parent, especially a first-time parent, that’s incredibly frustrating, because you’re so scared, and you want to talk to somebody who knows what the hell they’re talking about. When they’re telling you, “Well, I’ve never heard of that,” you’re thinking, “How are you going to help me if you don’t even know what my daughter has?” I mean, I know more than they know.

Several parents reported using the Internet as a primary source of information to support their child. Although the degree of Internet usage varied across participants for reasons such as access to Web-linked computer systems, an individual’s ability to effectively research a topic of interest, and access to research databases (e.g., PsycInfo, the Educational Research and Information Clearinghouse), parents also differed relative to the degree with which they researched information on their own (e.g., from obtaining simple descriptions to investigating medication side effects to reviewing research). Grace’s mother sought information on the Internet after receiving inadequate information from her pediatrician.

We asked her for information . . . she only copied like half of an article on something, and sent it with no cover letter. All of the information we found out, we found on our own, because we’re smart enough—and sat there for hours on end on the Internet finding it ourselves.

In addition, interpretation of the usefulness or validity of information obtained from the Internet varied across participants. Some parents found the information to be extreme, whereas others felt it provided useful information. Grace’s mother was cautious about what she found: “A lot of what’s on the Internet is pretty extreme, because it’s the people that are going through those extremes that are so determined to help other people who are going through the same thing.” In contrast, Andrew’s mother appeared to depend much more on what she could find on the Internet because of general lack of information about her child’s condition:

It’s all I do all day. I’m on the Internet 24/7. The fact of the matter is that I know in my lifetime, nor my son’s lifetime, will there ever be a cure for it. But if I can find natural ways of making him at least live happy, then that’s what I’ll do, and the only way you can do it is to try to find what are all of the causes that they’re looking at.

A few parents in this study described positive experiences with pediatricians, including pediatricians’ demonstration of concern through listening to parents and willingness to collaborate with the parents on diagnosing and deciding on steps of action. For example, Tank’s mother expressed appreciation for her pediatrician’s responsiveness to her phone calls when she needed advice for handling difficult situations: “My pediatrician was very good. He’s very, very good with Tank . . . if I call, he calls back. If I call during the night at 2 or 3 o’clock in the morning, he calls back. . . . He’s really good.” Bri’s mother expressed satisfaction with her pediatrician’s willingness to pursue a diagnosis while not unnecessarily labeling the child:

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When she saw Bri, she thought that she had allergies. She pointed out the darkened circles around her eyes. I have been satisfied with her, but we are still questioning what's happening. [The doctor] is very supportive and is concerned with labels. She told me to be very cautious about accepting any labels until they showed me evidence. [The doctor] said that she herself was labeled as a child [and] that we need to rule out everything first.

Such reports are indicative of a partnership relationship between the parent and pediatrician in contrast to noninformative and frustrating interactions reported by most participants in this study.

**Obtaining Services and Supports**

Although parents provided a variety of responses in relation to this theme, each shared the experience of having difficulty obtaining services for their child. The frequency, intensity, duration, and type of service varied widely across children. Consequently, the degree to which parents reported positive and negative experiences varied as well. The types of difficulties reported by parents varied from logistical issues such as not being able to schedule appointments easily to broader concerns such as frustration with professionals' training and experience (e.g., not understanding the optimal treatments for a particular disorder) and the need to continually research and fight for their child to obtain appropriate services. As an example of a parent's frustration with a medical doctor's understanding of her child's illness, Darnell's mother noted,

I did not think she was really knowledgeable about eczema. What she advised me to use I found later was causing him to have bacterial infections from the wound. She was telling me to keep him heavily oiled with Vaseline and . . . such. However, I found that because of him scratching profusely and breaking skin, that was not allowing the wounds to breathe. It actually kept him infected.

Parents also spoke of difficulties finding child care providers who could manage their children's issues. For example, D.J.'s grandmother described one experience:

We put him in child care and we noticed that he was going through changes in child care with behavior. He wanted to direct the class. She wanted them to write; he wanted to read. She wanted them to play with toys, he wanted to watch a movie, and he would disrupt the class because he wanted to do what he did, so he wanted to change the schedules at school. So we had threats of him being put out of school. No fighting, no hitting, no kicking. Just not being able to manage him with the other 8 or 10 children in the class, so we had another challenge. He was going to be put out of school.

Care coordination also was stressful for parents. Several parents spoke of having to fight to obtain appropriate services. Grace's mother reflected on her struggles with having a service coordinator accept her input in service decisions:

You know, looking back, I probably should have gotten a new service coordinator, but I didn't. I managed to get everything we needed, but I had to fight for every freaking bit of it. So early intervention made my life more difficult because instead of giving me the services that my daughter needed, every conversation with them was stressful. I had to do major research and major documentation to justify any decision.

Andrew's mother also noted how difficult it was for her to get educators in Florida to implement the provisions of her son's individualized education program (IEP) from another state.

What we're working on is forcing the State of Florida to honor the IEP that he already has in existence. The school is willing to give him the speech therapy and the occupational therapy there, but they're not willing to only let him go to school for 2½ hours per day. They want him going from open to close, 5 days a week. It's been deemed through his IEP that not only can he handle [only] 2½ hours of that type of training, but he can only handle it 4 days a week. In Minnesota, they take a past opinion of the child and what they know about the child into heavy consideration, especially when they're scheduling the classes, whereas Florida is going to say, "We know what's best, and we want him to go 5 days a week, 6 hours a day." That's the beginning and end of it.
Five parents described positive experiences with the professionals who provided support to their children. For example, 1 parent noted satisfaction with the developmental assessment completed by the early intervention program. Another parent spoke of wanting her child to work with a specific teacher who had provided excellent education to a sibling of the child with special needs. Parents also were highly appreciative of providers who were perceived to have gone above and beyond the routine level of service. Bri’s mother described her experience:

I was just excited that she would take the time on a Saturday to come out and spend time with us. I had met with her before, but this time, she gave up her own personal time at home and even offered to go to the mall with me. That says a lot about that she’s definitely willing to help and that these people do exist, to try, try to help you get there.

Similarly, Grace’s mother expressed appreciation for the creative approach of one provider:

We got hooked up with [the provider] through [the hospital]. [The provider] is a miracle for us. She was the first person who was able to sit and talk with me and give me ideas about how to help get her to eat and different things I could do, and told me different things she should be doing, how to make her do it, you know? She’s very clever and easy to talk to, and very creative. She had a lot of different methods that she tried with Grace. She started out doing signing with Grace, and that has been incredibly effective in helping her learn how to communicate.

**FINANCIAL STRESS**

Although parents varied relative to their type of employment and socioeconomic level, each acknowledged a degree of financial strain resulting from their child’s challenging behavior. Financial stressors appeared to fit into two primary categories: (a) expenses directly related to the child’s needs (e.g., cost of medications, health insurance, gas, child care, food), and (b) the difficulty of advancing in a career while raising a child with challenging behavior. As an example of the costs associated directly with the child’s needs, Andrew’s mother noted:

His last surgery was two weeks ago. He had adenoids and his tonsils removed. That was a $7000 surgery that insurance paid 85% of, so we were stuck with a $1000 bill. Over the last year, medical bills that we have accumulated that health insurance is not responsible for comes to a total of $3000. That’s after insurance’s part. That doesn’t include all of the prescriptions, monthly prescriptions. His monthly prescriptions total about $65 a month. Out-of-pocket expense. Special dietary needs are about $100 a week.

Other families with insurance described having to put the co-pays for frequent office visits on their credit cards. As Grace’s mother described it, “We have insurance, but it’s a $25 co-pay every time you walk through somebody’s door, and so we’re on the ‘Visa health plan,’ along with our insurance, going quickly into debt.” Parents also described the challenge of having expensive therapies recommended for their children that insurance did not cover. For example, Andrew’s mother noted the challenge of paying for applied behavioral analysis (ABA) therapy:

Andrew’s going to need 30 to 40 hours a week of ABA therapy at approximately $70 an hour. That does not include getting him enrolled in speech and occupational therapy. Health insurance usually pays full for those, so there is not out-of-pocket with those two therapies. My health insurance pays for all of that for him. I’m very blessed, but the ABA therapy is the most important therapy. It is the one that he gets the most of, and health insurance doesn’t want to pay for that.

Similarly, parents such as Bri’s mother described the difficulty of finding and affording nearby child care that provided adequate attention and an appropriate environment for the child:

If you can afford good child care, that’s good. Before I had a child, I never thought about the cost. It’s expensive. Her child care is way across town, so I’m running over there every day, so the gas is outrageous. So I’m trying to work between the hours, and thank God that my cousin owns the child care.

A second source of financial stress voiced by the parents in this study concerned the difficulty of advancing in a career while raising a child with
challenging behaviors. Bri’s mother described her situation:

It’s been a problem. I’ve been trying to get promoted, but I have to take time off from work because of my daughter. Absenteeism for your daughter limits promotions, but you have to know where your priorities are. I’m being penalized for it; I’m not paid for being out for my daughter’s sick time. I don’t get personal days; vacation days are the only option. Sometimes she’s at the doctor 2 or 5 times a week, and I have to change my schedule at work to accommodate the appointments.

One parent (Grace’s mother) balanced work and caring for her child by having her child attend a preschool at her work.

The preschool is actually where I work. They are run independently, but I am able to peek out my door and hear her hollering, and if they’re having issues, they can bring her to me. It works out really well because, with my history, trust is very difficult. It took me that whole year to get me to let my mother-in-law keep her all day long, let alone put her in preschool. So the fact that it’s on the facility where I work is good, because that way she is able to be independent without me having a panic attack every time I pull away.

**STRESS AMONG MEMBERS OF THE FAMILY**

Data obtained across participant interviews indicated that young children with challenging behavior may have a negative impact upon relationships among both immediate and extended family members. For example, Darnell’s mother indicated that:

[H]is condition affected everybody. When he's . . . waking up in the middle of the night . . . and crying at the top of his lungs . . . my other children would wake up . . . We had to move Darnell out of their bedroom because it was affecting everyone.

Stress over disagreements about how to handle behaviors reportedly created discord across generations. One parent described the impact of her child’s behavior on her relationship with her parents:

When we first came down here, we had to live with my parents for a short period, and then we ended up coming here. My son created too many problems. He was up all night. My stepfather works construction . . . He tries to go to bed early and my son’s up all night, making loud noises. It’s very difficult to get him to sleep without him crying, so my father’s up all night. My parents are considering a divorce right now because of everything. It’s caused a lot of tension. My father and I no longer speak.

Another parent described the impact her child’s behavior had on the family’s ability to visit relatives who lived within a few hours’ driving distance. She reported that in the past she had visited her family every 4 to 6 weeks, but since problems had arisen with the child, “We don’t go. I think we’ve been down once, no, twice in the last 2 years. Very short visits.”

**COMMUNITY ISOLATION**

All parents noted some type of community isolation, although parents differed in the ways and degree to which such isolation occurred. Isolation was due to the amount of time needed to care for the child, stigma associated with challenging behavior, fear for the safety of the child, and reactions of the general public when a child acted out coupled with the embarrassment that parents felt. One parent described a stressful visit to a friend’s house that reduced her willingness to attempt such outings:

We had an episode where we went to a friend’s house . . . and we haven’t seen them since. I was so mortified . . . We’re still twitching . . . It was just that other kids have temper tantrums or what not, but they tend to calm down quicker or it’s just not as disruptive, and because his are so violent and so much longer, it made everybody twitch.

Another parent talked about limitations placed on family activities such as going to restaurants and movies:

Definitely inhibits our ability to go out into the community . . . Our restaurant[s are fast food only] . . . any place where we can pay first and then leave. Any place that has a quick exit . . . Lenny is unpredictable and
he's destructive not only to our own family unit, but to people around him. Things like movies . . . we cannot normally take him.

Most parents also expressed concern for the reactions and judgments of others about their children's behavior in public places. One parent explained:

They see this child, and they see a spoiled rotten, undisciplined kid. They don't see a child who has a problem. . . . You go in public and your child pitches a fit, and all you hear is, "Thank God my children don't behave that way." "Oh, that child just needs a . . . good spanking. Take him out to the shed," you know? That's all you hear.

Some parents also described adaptive strategies that enabled them to get into the community, such as spouses taking turns caring for the child. As one parent reported:

My husband is phenomenal. He is one of those rare men who will wash dishes, vacuum, and clean house and [do] laundry. . . . There's a lot of times on the weekend when he will keep [our daughter], and my friend . . . and I will go . . . shopping or just putter around for several hours.

Similarly, a couple characterized themselves as a "tag team," enabling each other to get out into the community while one parent stayed home with the child. Another parent assumed the role of advocate, and recognized that that role helped reduce community isolation by providing a connection to other families in similar situations.

**DISCUSSION**

Development and implementation of successful, sustainable programs require involvement of all pertinent stakeholders (Rogers, 2000). A missing voice in understanding children with challenging behaviors and the experiences of their families is that of the families most directly involved (Brantlinger et al., 2005). This study enabled parents of young children with challenging behavior to describe their experiences. A set of common themes emerged from these descriptions. Overall, these results provide evidence of the considerable difficulties that parents experience in raising a young child with challenging behaviors. Although the families in this study came from different demographic backgrounds and had children with varying diagnoses, the types of problems that they experienced were quite similar. As described in the Results section, although parents noted both positive and negative experiences, negative experiences predominated in the interviews.

**Families with a greater number of risk factors consistently reported greater difficulties accessing and/or dissatisfaction with their community's system of care.**

Five central themes emerged from the parents' descriptions of their experiences obtaining services and supports for their children with challenging behavior within a single local SOC: (a) obtaining useful and accurate information about their child (including diagnoses or problem identification), (b) obtaining supports and services, (c) financial stress relating to addressing their child's challenging behavior and to their own careers, (d) stress among family members (both immediate and extended family), and (e) community isolation. Similar findings have been reported elsewhere (e.g., Fox et al., 2002), but this study extends the findings downward to families with children with challenging behaviors under 3 years of age. The findings reported in this study also corroborate the importance of essential prevention-oriented concepts reported by experts in the field, particularly the notion that a child's growth and development is influenced by risk and protective factors (Bailey et al., 1998; Dunlap & Fox, 1996; National Research Council and Institute of Medicine, 2000; Powell et al., 2003; Smith & Fox, 2003). Families with a greater number of risk factors consistently reported greater difficulties accessing and/or dissatisfaction with their community's system of care. Within the same local SOC, the findings obtained in this study corroborate those reported by Raffaele Mendez and Hess (2003), most notably confirming the limited service provision in the community for young children with challenging behavior and their families.
Many of the service gaps identified by Raffaele Mendez and Hess (2003) were also reported by parents in the current study, including lack of adequate developmental screening and assessment, limited access to information, deficiencies in public school education, care coordination, child care, access to social opportunities, and lack of accessible services. Although the local SOC is actively engaged in improving quality of service delivery, the findings of the current study illustrate the meaning and impact of each central theme upon family functioning.

Given the experiences reported by parents in this study, it seems clear that there is a need for medical professionals who serve as a gateway to further services for children with challenging behaviors (e.g., physicians, physician’s assistants, nurse practitioners, and nurses) to receive comprehensive training on behavioral, educational, and psychological aspects of pediatric health conditions (Power, Heathfield, McGoe, & Blum, 1999). Training for these professionals and the implementation of more comprehensive multidisciplinary practice at the gateway are needed, such as including mental health professionals with a thorough understanding of behavioral, psychological, and subsequent educational concomitants of these conditions. The accessibility of Web-based information (upon which parents in this study frequently relied) certainly raises questions about the accuracy and trustworthiness of such information. Service delivery systems need to consider how to help families make decisions about the veracity of Web sources, given parents’ resourcefulness in attaining the information. Additionally, local SOCs might capitalize on this set of assets, developing communication systems on the Web that create easy access to accurate and timely information for clients in the region or by creating a comprehensive community resource directory for families and providers (Raffaele Mendez & Hess, 2003).

Some parents reported very positive experiences with professionals who went the “extra mile” (e.g., meeting on Saturdays, in the evening, and in the home), as well as professionals who sat, listened, and talked, and provided child-specific ideas and suggestions. Such a finding again implicates the need for comprehensive, multidisciplinary (mental and physical health) practice at various levels of service delivery. Another positive articulated by one parent related to broader social supports within a system of care. For example, the constant need to fight to get services (articulated by all participants) led in at least one case to a parent assuming a strong advocacy role for her child and for others. Again, SOCs can help mobilize and focus advocacy strengths that arise from interactions between parents and professional service providers, and the ecological model can serve as a useful framework for assessing changes and improvements in a family’s access to community services and supports over time.

The presence of a child with challenging behaviors (a set of conditions inherently involving degrees of risk) is likely to result in additional risk factors impacting the family, influencing the family’s ability to manage the challenging behaviors, and possibly leading to a further escalation of challenging behaviors.

It is important to place these results within the context of a consideration of risk and protective factors (Bailey et al., 1998; Dunlap & Fox, 1996; National Research Council and Institute of Medicine, 2000; Powell et al., 2003; Smith & Fox, 2003). It is apparent that the presence of a child with challenging behaviors (a set of conditions inherently involving degrees of risk) is likely to result in additional risk factors impacting the family, influencing the family’s ability to manage the challenging behaviors, and possibly leading to a further escalation of challenging behaviors. It is important that practitioners conduct comprehensive individual family assessments to determine the full range of supports and coordinated services needed to address the needs of the child with challenging behaviors. Such a comprehensive assessment must examine both needs and resource/support assets. Research is needed to identify the full range of components needed in such a comprehensive assessment of a given family’s unique risk and protective factors, and to identify the decision-making bases for identifying needed supports.
This study illustrates the value of phenomenological interviews to such a research effort and to assessment and decision making. An additional benefit of the phenomenological interview appears to be the family's experience of being listened to and being given voice, a finding also reported by Fox et al. (2002). More recently, Cihonski (2005) reported potential therapeutic effects of phenomenological interviews with adolescent participants in a qualitative study, and participants in the current study reported similar benefits of their participation. Together, these studies suggest that opportunities for families to describe their experiences may have value as a therapeutic intervention. Further research in this area is recommended.

It is also important to note that this study was limited to parents from a single county. Similarly, the sample size of this study was too small to meaningfully compare families of different demographic characteristics. No parents of Hispanic background were included in this sample, in spite of numerous attempts to include Latino families. Although it is clear that their exclusion limits the generalizability of the current study, some research (e.g., Bailey, Skinner, Rodriguez, Gut, & Correa, 1999) suggests that additional attention must be paid to better understand variables associated with family's awareness, use, and satisfaction with services and supports for young children. In light of this limitation, the follow-up interviews conducted with each family provided an additional opportunity for caregiver input, thereby enhancing the data's trustworthiness.

Another limitation pertains to the socioeconomic variability among parent participants. Only 1 of the 7 families reported having a very low income, despite efforts to include families with varying socioeconomic backgrounds. Although additional research and a broader range of voices is needed in future research efforts with parents in different communities, the themes emerging from this study may provide a useful framework for understanding and evaluating the quality of services and supports for families of young children with challenging behavior.

In addition, this research might be further expanded to consider issues expressed by parents at varying points in a child's development, both cross-sectionally and longitudinally. Research is needed in communities where parents are highly involved in SOCs. Finally, issues pertinent to single and two-parent families needed to be examined more fully in future research.

The results of the current study support the need for the inclusion of parent voice in designing interventions for young children with challenging behavior. Assessed within an ecological framework, phenomenological interview data offer a useful means by which to evaluate local systems of care and to enhance the quality of family-centered service delivery. Future research efforts are encouraged to enhance the means by which parent voice can be used to illustrate the practical utility of community-based services and supports and their role within their respective systems of care.

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