EXPERIENCES OF MOTHERS WHOSE YOUNG CHILDREN

ENGAGE IN CHALLENGING BEHAVIORS

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Dedication

This dissertation is dedicated to my mother Amy Devers. From her I learned that when families have 'less than desirable' beginnings, they can rise above those early experiences through a conscious commitment to mend the past, live in the present, and move forward into the future. Amy also showed me that I had value as a parent and as an educator—she took my advice and my words seriously about how to 'parent' her grandson, my nephew. Her belief in me helped me to have confidence that my experiences, skills, and abilities, indeed have value to others. Amy passed away in April 1999. Our shared beliefs help me to continue to feel connected to her, because I know she's in my cheering section on "the other side."

Abstract

The purpose of this hermeneutic phenomenological research study was to understand the experiences of mothers whose young children engage in challenging behaviors. Challenging behaviors are commonly thought of by professionals as a child's personal conduct that results in injury to self or others, and/or causes damage to the physical environment, and/or interferes with the acquisition of new skills, and/or socially isolates the child (Doss & Reichle, 1991). Challenging behaviors are considered to be appropriate up until about the age of 3, unless the frequency, intensity, and duration of the behavior exceeds what is developmentally appropriate for a younger child (Needlman et al., 1991; Rapp & Hutchinson, 1987). Many studies cite a correlation between the early onset of challenging behaviors, later deviancy, and criminal behavior, and several studies have documented an increase in the prevalence of challenging behaviors in young children. Given the documented correlation between challenging behaviors and later deviant behaviors, the increasing reported prevalence of these behaviors in U.S. samples, the frequently cited etiology of the behaviors as maternal and parenting issues, and the involvement of parents in parent education as an intervention strategy, it seems appropriate to have a better understanding of parents' experiences of parenting their young children who engage in challenging behaviors. In this phenomenological study, 10 mothers were interviewed about their experiences of parenting their young children who first engaged in challenging behaviors between the age of 2 and 5 years. Some of the eight themes found revealed that parents are tireless advocates for their children but don't always know what to do, parents want their concerns to be heard by medical and education professionals, parents don't cause their children's challenging behaviors,

parents feel isolated, and all parents of young children who engage in challenging behaviors may not have similar experiences. These findings are discussed in relationship to other research on young children who engage in challenging behaviors, and mothers' experiences of parenting them. Based on the consistencies and discrepancies between the existing literature and the mothers' reports in the present study, recommendations include the need for more research to better understand this population of parents, and more training for the professionals who work with them and their children.

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CHAPTER 1 – BACKGROUND

There is a substantial difference between parents indicating on a questionnaire that a child frequently has temper tantrums at the grocery store and parents' descriptions of what they experience when a child has temper tantrums at the grocery store. Even if parents feel confident that they are responding appropriately by carrying the child out of the store in the middle of the tantrum, they are pretty sure that everybody within a 50-foot radius hears their child. Whether or not the parents make eye contact with others, they sense that others may be making judgments about them, their child, and their parenting skills. One of the parents in Turnbull and Reuf's 1996 study described it like this:

> One time I took George to the supermarket, and he kind of jumped up and down and rocked and hummed. He was laughing a lot, and a woman gave me a look. She wouldn't dare say anything, but she gave me a look almost to say, "Why would you bring a boy like that in here?" She didn't have to say anything. Her look told it all. (p.283)

Such stories are poignant, as they reflect the feelings of the parent at the time of the incident, rather than just describe the incident. Several parents in the present study described similar experiences.

Additionally, in Chapter 2, I describe my experiences as the parent of a child with challenging behaviors, and as a teacher of children with challenging behaviors. Reflection on these experiences as a parent, and as a teacher, prompted me to look for research about the experiences of parents whose preschool children engage in challenging behaviors.

What are Challenging Behaviors?

Doss & Reichle (1991) define challenging behavior as "behavior emitted by a learner that results in self-injury, or injury to others, causes damage to the physical environment, interferes with the acquisition of new skill and/or socially isolates the learner." (See Appendix A.) Interest in temper tantrums, problem behaviors, and challenging behaviors is not a new area of study. Early in 1972, Richman, Stevenson and Graham (1975) conducted an epidemiological study of 705 3-year-old children living in a London borough, one of the first research studies examining the behavior and emotional problems in the preschool child. Until that time, only populations of adolescent and school-age children had been examined for psychiatric disorder. They found that approximately 7% of the 3-year-olds in their study had moderate to severe behavior problems and 15% had mild behavior problems. This finding was similar to the findings in older age groups (Graham & Rutter, 1973).

Needlman et al. (1991) reported that as early as 1930, parents were surveyed to identify numerous factors associated with the increased number of temper tantrums. Sixty years later, Walker (1998) found that the incidence of these behaviors was continuing to increase. Similarly, Kelleher, McInerny, Gardner, Child, and Wasserman (2000, p.1315) examined the changes in patterns of referrals for pediatric visits from 1976 to 1996, with clinician-identified "psychosocial problems" in children aged 4 to 15 increasing from 6.8% in 1976 to 18.76 % in 1996.

What Research Says About Challenging Behaviors

When I first examined the research literature regarding the population of preschool children with behavior problems (Goldsmith, 1991), the existing literature

verified that this population of young children did indeed exist and was increasing (Beare & Lynch, 1986; Jenkins et al., 1982; Funk & Ruppert, 1984; Hunt et al., 1990; Thompson, 1985). The limited research findings usually reported intervention strategies, or hypothesized the etiology of the behaviors. While researchers at that time often focused on maternal depression and irritability as a "cause" of the behaviors, they also acknowledged the important role parents play in getting help for their children (Needlman et al., 1991). Referencing the work of Friedlander, Weiss, and Taylor (1986) and Shepherd, Oppenheim, and Mitchell (1966), Stallard (1993) states that "Indeed, it is often the parents' perception of the behaviour which is of most importance and will to a large extent determine and shape the nature of the parent-child interaction" (p.414) According to Stallard (1993), "for the clinician, parental perception is an important determinant of the appropriate course of action, and could result in more flexible preventative work by identifying and responding to parental concerns at an early stage" (p.414). While the studies noted above clearly included parents and reported their perceptions, there was no reference to the *parents' experience* of parenting their child with challenging behaviors. In addition, because none of the studies were qualitative, there was no opportunity for parents to tell their individual stories so that their voices could be heard.

As I now review the current research regarding problem behaviors in preschool children, there are more studies than when I first examined this literature (Goldsmith, 1991). While it is documented that there is an increased number of children with challenging behaviors since my earlier exploration of this literature (Walker, 1998), it is not clear if there really are more children with challenging behaviors, or if we are better

at diagnosing behaviors, or a little bit of both. But, more children with challenging behaviors means more referrals, more behavioral programs, more specialized teaching staff, more inclusive programming, and more special education training for regular education teachers. It also means many parents are struggling to effectively parent their children with challenging behaviors.

<div align="center">Research Question</div>

The central research question of this hermeneutic phenomenological study is: What are the experiences of mothers whose young children engage in challenging behaviors? There is ample data based on parents' ability and willingness to provide accurate information about their child's development and behavior via checklists and surveys. There is a paucity of information, however, specific to the personal experiences of parents whose young children engage in challenging behaviors.

In most cases, when young children are not in child care and early education programs, they spend much of their time with their parents, meaning that parents have the potential to be the primary interventionists regarding children's challenging behaviors. Parents must cope with a wide variety of challenging behaviors both at home and in public. But, they are expected to consistently implement intervention strategies that are designed by others who do not live with the child and the child's challenging behavior on a daily basis (special education teams, special education teachers, occupational therapists, physical therapists, psychologists, mental health professionals). Given that parents can be crucial to the success of the intervention and the child's ultimate ability to interact prosocially with peers and the environment, knowledge of parents' daily experiences may

help professionals to be more sensitive to the experience of the adults who have the most potential to influence positive outcomes in their children.

<center>Why Look At Challenging Behaviors?</center>

Three Ways to Think About Challenging Behavior

There are at least three researched ways to think about challenging behaviors. The first two ways focus on who is affected by the child's challenging behavior and the third way suggests that challenging behaviors serve a purpose.

Adults are challenged. This focuses on how adults are affected by the challenging behavior. In a personal communication on May 10, 2001, Dr. J. Reichle at the University of Minnesota said, "We call them challenging behaviors (which encompasses terms such as problem behavior, behavior disorders, and aberrant behavior) because adults are challenged about how to intervene and guide these behaviors." Kaiser and Raminsky (2003) present a similar definition of challenging behavior (below), and like Reichle, agree that "perhaps more to the point, challenging behavior is challenging for *us*, the people around him [the child], his family and teachers (p.10)."

Children are challenged. This focuses on how children are challenged by their own behavior." Similar to Doss and Reichle (1991), Kaiser and Raminsky (2003) define challenging behavior as any behavior that:

- Interferes with children's learning, development, and success at play

- Is harmful to the child, other children, or adults

- Puts a child at high risk for later social problems or school failure (Chandler & Dahlquist, 1997; Klass, Guskin, & Thomas, 1995; Ritchie & Pohl, 1995)

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They suggest that while the behavior is challenging for adults, challenging behavior is also challenging for the child:

> It puts him in danger by preventing him from learning what he needs to know to succeed in school and get along well with his peers. It is also challenging for him because he probably doesn't have much control over it. Even if he does know what to do instead—and chances are he doesn't—his ability to regulate his feelings and actions just isn't up to the job yet. Improving matters will be an enormous challenge for him. (p.9)

This suggests that early onset of challenging behaviors occurs at a stage of development in which the young child may be unaware of his or her behavior and does not yet have the skills or ability to manage his or her behavior.

Challenging behaviors serve a purpose. Reichle and Johnston (1993) and others (Carr & Durand, 1985a; Doss & Reichle, 1991; O'Neill, Horner, Albin, Storey, & Sprague, 1990) have demonstrated that a significant proportion of challenging behavior may be emitted to convey social intent: gain attention from adults or children, gain objects or privileges, avoid/escape attention from adults or children, avoid and/or escape tasks and/or events or personal discomfort. Therefore, the behaviors serve a purpose, although the adults may not see the behaviors as communicative attempts to seek something or escape from something. If adults only perceive the child's behaviors as bad and in need of punishment, the opportunity for the child to learn new and appropriate communication strategies can be missed. If adults perceive that the child's behaviors are unsuccessful attempts to communicate an intent, then the door is open to determining the goal of the specific behaviors and to teach new communication strategies that will help the child to be more successful.

Significance of Looking at Children with Challenging Behaviors

There are three areas of research to consider when deciding whether or not it is important to view challenging behaviors as an important topic of study: prevalence, adult-child relationship, and the relationship of early onset of challenging behavior to future problem behavior.

Prevalence of challenging behaviors. Doss and Reichle (1991) presented an all-encompassing definition of challenging behaviors that includes the definition provided by the *Diagnostic and Statistical Manual of Mental Disorders* (1994): a cluster of behaviors that falls into three subclasses—attention deficit hyperactivity disorder, conduct disorder, and oppositional defiant disorder. Some children experience difficulty moving from the oppositional behaviors characteristic of toddler children (16 months to 32 months) to the more mature social interactions of older preschool (48 months to 71 months) and early elementary aged children. We know that for some children, behavior problems characteristic of early childhood do not diminish with maturity, and ultimately translate into later deviancy. How often does this happen?

While the focus of this study was to understand the experiences of mothers whose young children engage in challenging behaviors, it is worth mentioning that the incidence and prevalence of challenging behaviors is significant and has captured the interest of researchers worldwide since 1980 (Bird et al., 1988; Caspi et al., 1995; Fergusson, Horwood, & Lawton, 1990; Lavigne et al., 1995; McGuire & Richman, 1986; Mulatu, 1995; Stallard, 1993; Weiss, Sigman, Weiss, & Mosk, 1993). Of the 10,748 children who participated in these studies, Caspi et al. (1995) conducted a 12-year longitudinal study of 800 children who entered the study at 3 years of age. Among both

boys and girls, "lack of control at ages 3 and 5 was positively correlated with teacher and parent reports of inattention, hyperactivity, and anti-social behavior at ages 9 and 11. These behaviors continued through adolescence." It is knowledge of this relationship between early onset of challenging behaviors and later anti-social behavior that often motivates parents and teachers to address the behaviors while children are young.

Adult-child relationship. When adults respond to children's challenging behaviors by requesting **or** expecting a certain behavior to change, and the child produces the desired behavior change, the relationship between the adult's response and child's behavior change is considered to be positive, or effective. An example of this would be the situation in which a child engages in a temper tantrum during drop-off at childcare because the parent has agreed to read one story but the child is demanding that two stories be read. The parent might say, "We agreed that I would read one story. As soon as you stop crying, I will read the one story. If you continue to cry and scream, I will not be able to read any story." If the child stops crying and sits to have the story read, then the relationship between the parent's response and the child's behavior change is considered to be positive. This is a common parenting strategy, and one that often works with children who do not engage in challenging behaviors.

Parenting guides are full of strategies (redirections, reminders, punishment, and time-outs) that work with typical children. The problem is that when parenting children who engage in challenging behaviors, these types of strategies may not work, and parents are baffled about what to do. Subsequently, parents often continue to try the same types of strategies that are successful with typical children because that is all that they know. When this happens, the behavior of concern is actually escalated rather than eliminated,

and the relationship between the strategy and the behavioral outcome is seen as ineffective.

In the example above, the request for more than one book may be the child's attempt to have "just a little bit more time with Mom or Dad." Or maybe the book requested for the second reading is the one book that makes the child feel secure before the parent departs. But the child doesn't know how to communicate that. When parents do not see their child's behaviors as communicative attempts to seek something (a reassuring story) or escape something (the parents' departure), they often get frustrated with themselves and their child. If parents only perceive their child's behaviors as bad, and in need of punishment, the opportunity for learning new and appropriate communication strategies can be missed.

Relationship to future problem behavior. There is ample evidence to suggest that challenging behavior during the preschool and early elementary years is predictive of future problem behavior (Achenbach & Edelbrock, 1981; Campbell, 1990, 1995; Coie, 1994; Constantino et al., 1993; Fergusson & Horwood, 1996; Fergusson, Lynsky, & Horwood, 1996; Lerner, Inui, Trupin, & Douglas, 1985; McGee, Silva, & Williams, 1984; McGuire & Earls, 1991; Moffitt, 1993; Patterson, Capaldi, & Bank , 1991; Patterson, DeBaryshe, & Ramsey, 1989; Patterson, Reid, & Dishion, 1992; Reid & Patterson, 1991; Richman, Stevenson, & Graham, 1982; Robins, 1991; Spivak, Marcus, & Swift, 1986; Schroeder, Mulick, & Rojahn, 1980). If we believe that the behavior serves a need, we have to find other ways for children to meet those needs. Otherwise, children may continue to use those behaviors, regardless of the consequences. According to Reichle (2001), this suggests that early prevention and intervention efforts are very

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important. He continues, however, "that it may be that the strategies that work with challenging behavior also are good ones to use with typically developing children. Typically developing children may learn in spite of our less than optimal practice."

<div align="center">Parents of Children Who Engage in Challenging Behaviors</div>

Parents are Key Providers of Information

As early as 1977, Minde and Minde found stability in parental report of behavior problems over a 9 month period. How is this behavior reported? Pediatricians often ask parents "Do you have any concerns about your child's development?" during a routine visit or well-child check. Or, parents may approach their physician with a concern about their child's behavior.

Stallard (1993) reported that parents are extremely important in the process of identifying the needs of their children: "indeed, it is often the parents' perception of the behaviour which is of most importance and will to a large extent determine and shape the nature of the parent-child interaction." (p.414). Glascoe et al. (1991) reported that "parents are known to provide accurate descriptions of current behavior, and parent report measures are the most frequently employed assessment technique in evaluating young children" (p.9).

Parents provide their perceptions about their children's behaviors in many ways. Suarez and Baker (1997) used semi-structured parent interviews that assessed parents' perception of global support regarding their child's behaviors. Turnbull and Reuf (1996) collected data about family's perspectives on problem behavior through phone interviews. During the process of assessment and/or intervention, parents are often asked by health care and educational professionals to provide information about their child.

Parents share this information during face-to-face interviews that use standardized

questionnaires (Jenkins et al., 1982), or through open-ended anecdotal discussions, or

completion of standardized assessment tools (Achenbach, 1992). These research studies

have indicated that parents are indeed rich resources of information about their children.

According to Powell, Fixsen, and Dunlap's (2003) Overview of Prevalence

Research,

> for samples of young children identified through healthcare visits,
> estimates of psychosocial problem rates are between 10% and 21%,
> while rates for externalizing problems are between 7% and 17%.
> Within kindergarten and preschool populations, rates of 8% to 25% for
> externalizing behavior problems have been found. (p. 22)

If 7% to 25% of children aged 5 and under have challenging behaviors, then 7%

to 25% of that parent population has to make decisions about how to interact with and

experience their children's behaviors. The studies referenced above (Minde & Minde,

1977; Stallard, 1993; Glascoe et al., 1991, Suarez & Baker, 1997; Turnbull & Reuf, 1996;

Jenkins et al., 1982; Achenbach, 1992) identify parents as key providers of information

about their child's challenging behavior. This is good because it honors parents' role as

the person(s) who know the child best. Parent-generated information reflects knowledge

of the child across more domains and for longer periods of time than educator's

experiences with the child. But the down side of some of this research (Jenkins et al.,

1982; Achenbach, 1992) is the method that is used: most data is collected through

standardized checklists or questionnaires, meaning that only certain questions are asked,

and only certain answers can be given. There is no format for parents to talk about their

experiences or answer questions that aren't asked. While the parent is able to provide

information about their child, and/or give self-perceived information about their

parenting skills, the studies do not indicate that parents had the opportunity to talk about their experiences. Only three studies were identified that were conducted differently.

First, Fox, Vaugh, Wyatte, and Dunlap (2002) conducted a study titled "We Can't Expect Other People to Understand: Family Perspectives on Problem Behavior," in which they interviewed a culturally diverse group of 20 family members who were involved a process of family-centered positive behavior support (PBS). The interview data revealed three major themes: "the difficult process of coming to terms with the child's disability, the importance of having support from people who demonstrate genuine caring, and the pervasive impact that problem behavior exerts on all aspects of family functioning (p. 437)." The authors described that the perspectives shared by these families "echo and expand on many of the themes described by Turnbull and Ruef (1996), and Fox, Vaughn, Dunlap, and Bucy (1997).

Upon finding the 2002 study by Fox et al., I contacted Dr. Lise Fox at the University of South Florida, and asked where I might find more qualitative studies about parents' experiences of parenting children who engage in challenging behaviors. In reply, she wrote (personal communication, April 26, 2004):

> I wish I could be a help to you … but I don't know of additional qualitative studies in this area. Ann Turnbull has done some similar work. I applaud you for your interest in this topic. There is very little on this and I think a qualitative study would be a very important addition to the literature.

Second, in one notable investigation, Turnbull and Ruef (1996) conducted phone interviews with 17 families in which one child in each family had mental retardation and problem behavior:

The interview was focused on: (a) the families' definition of problem behavior, (b) current challenges they face, and (c) successful approaches for helping individuals with problem behavior and their families, as well as suggestions from families about what kinds of information they believe would help them in addressing challenges. (p.280)

The dominant theme that emerged from this study was families' sense of responsibility in keeping the child with the problem behavior "afloat." They frequently reported feeling that they were "going it alone," because of the extensive advocacy required to obtain even mediocre services. Examples of the feelings these families experienced included "fear that their child would do something so awful that s/he would be locked up (p.283)," "frustration that neither they nor the service providers had an adequate understanding of the nature of the problem behavior, and/or the specific antecedents that triggered it (p.284)," and the exhaustion of being 'on duty' 24 hours a day.

The third study was conducted at Temple University in 1988 by Robert Naseef, building on his own experience of parenting a child with autism. Naseef interviewed 31 members of seven families in which one child in each family was either blind, deaf, autistic, emotionally disturbed, physically handicapped, or learning disabled. His four basic interview questions focused on "what helps families of exceptional children to cope successfully?" and in summary, yielded these implications for practitioners:

1. Parents found that parents of other handicapped children were extremely helpful, in addition to spousal support, but it took time to develop successful coping behaviors. (pp. 254–255)

2. Parents' most helpful experiences came from professionals who went the extra mile," and parents of other children with disabilities. It is noteworthy that these families had more helpful than unhelpful experiences. (p.256)

3. The most trying or difficult experiences with relatives, friends, and professionals seemed to occur during the time surrounding the initial diagnoses when there was a high likelihood that friends, relatives, and even professionals had some level of denial about the situation. (p. 258)

4. Families reported a positive outcome in that having a handicapped child actually brought the family closer together, even though the presence of the disability created a certain level of stress for each family member. (p.259)

Grief and Loss

When parents of newly born or newly adopted children gaze at the small person now permanently in their care, there is almost always an unspoken wish which says, "I hope the baby is okay." "Okay" often means that there are no identifiable disabilities or birth defects. But the wish also holds the parent's dream for their child's future. When the dream does not happen, parents often mentally re-draw the picture that they have of their child, and contemplate what the new picture means. They often reflect on what their experience of being a parent has been so far, and redefine what they think it might mean for the future.

In his 1998 book, *Loss of Dreams,* Ted Bowman says that while grief is a part of life, it is not something that we readily embrace, especially when the loss is intangible. Therese Rando (1993) suggests that there are two kinds of losses, the physical loss of something tangible, and the psychosocial loss of something intangible, such as having a

dream shattered (p.20). Mitchell and Anderson (1983) further describe this kind of loss as

an "intrapsychic loss that is likened to the experience of losing an emotionally important

image of oneself, losing the possibilities of 'what might have been,' abandonment of

plans for a particular future, and the dying of a dream" (p.40).

    Welcome to Holland. When children are born with a disability, or develop a

disability after birth, parents' dreams of what 'might have been' change. Emily Perl

Kingsley (1997) describes this in her well known article, *Welcome to Holland.*

> I am often asked to describe the experience of raising a child with a
> disability. To try to help people who have not shared that unique
> experience to understand it, to imagine how it would feel. It's like
> this…
>
> When you're going to have a baby, it's like planning a fabulous
> vacation trip—to Italy. You buy a bunch of guide books and make
> wonderful plans. The Coliseum. The Michelangelo David. The
> gondolas in Venice. You may learn some handy phrases in Italian.
> It's all very exciting.
>
> After months of eager anticipation, the day finally arrives. You pack
> your bags and off you go. Several hours later, the plane lands. The
> stewardess comes in and says, "Welcome to Holland."
>
> "Holland?!?" you say. "What do you mean Holland?? I signed up for
> Italy! I'm supposed to be in Italy! I'm supposed to be in Italy. All
> my life I've dreamed of going to Italy."
>
> But there's been a change in the flight plan. They've landed in
> Holland, and there you must stay.
>
> The important thing is that they haven't taken you to a horrible,
> disgusting, filthy place, full of pestilence, famine and disease. It's just
> a different place.
>
> So you must go out and buy new guide books. And you must learn a
> whole new language. And you will meet a whole new group of people
> you would never have met. It's just a different place.
>
> It's slower paced and less flashy than Italy. But after you've been
> there for awhile and you catch your breath, you look around and you

begin to notice that Holland has windmills…and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy. And they're all bragging about what a wonderful time they had there. And for the rest of your life you may say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away because the loss of that dream is a very, very significant loss.…

But if you spend your life mourning the fact that you didn't go to Italy, you will never be free to enjoy the very special, the very lovely things … about Holland.

Special children, challenged parents. Robert Naseef's son, Tariq, was a healthy child at birth and throughout infancy. Upon entering toddlerhood, Tariq did many things typical of toddlers. He walked, indicated preferences and dislikes, and had a small but useful vocabulary. At 18 months, Tariq stopped talking and stopped playing with the toys he had received for his birthday. Instead, for days and weeks on end, he played only with a transparent rattle with brightly colored beads inside, and became extremely agitated if it was removed from his grasp. Upon reflecting about Tariq, Naseef (2001) wrote,

All parents have a dream for their children—an image of who their child will be and what he or she may accomplish in life. When a child is impaired by a physical, sensory, or mental handicap, that dream is shattered and lost, and parents are faced with having to accept a child who will never be able to live up to their expectations. (p. 1)

For the parents of the children who do not successfully make the transition from the temper tantrums of toddlerhood to the more sophisticated coping skills of preschoolers, their experience may be much like that of Emily Kingsley or Robert Naseef

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described above. Parents didn't plan on this and their lives suddenly became very

complicated:

- they received more notes from their child's teacher

- there were more meetings with their child's teacher

- they had to authorize 'professionals' to come and look at their child in a

   group setting, then have meetings with the 'professionals' to share the

   information

- they had to make decisions about the best placement for their child

- they had to try new strategies at home

- they had to keep track of notebooks that went between home and school every

   day in which they and the child's teacher wrote information about their child

- they had to negotiate their work schedules in order to attend specialist's

   appointments with their child

Drawing upon his own experiences as the parent of a child with autism, in 1988

Robert Naseef completed his dissertation on the topic, "What Helps Families of

Exceptional Children to Cope Successfully?" because he saw the need to "tell his story."

Naseef knew that he sometimes had intentionally rejected the recommendations made to

him on his child's behalf, because to do so would mean that he had accepted the

unacceptable, that his child was autistic (p.2). But he also saw that some families were

experiencing success. These families knew that they were experiencing success, and they

felt good about their success. Naseef wanted to know the factors that contributed to that

success. He ultimately wrote the book, *Special Children, Challenged Parents* (2002),

which focused on the struggles and rewards of raising a child with a disability.

In his process of accepting Tariq's autism, Naseef carefully describes the

sequences of dreams that he had, in which Tariq was 'normal.' Upon waking, he would

find himself exhausted from the work he did in his dream to "make Tariq normal." Then

he would awaken, only to remember the extent of Tariq's disability. The dreams

repeated over 3 to 4 years, until he could finally accept the reality of what he must deal

with and how he could accept it.

<div align="center">Overview</div>

It is possible that some researchers and scholars may ask the question, "why is

there a need to look at challenging behaviors in young children and the experiences of

their mothers?" In response, the following ideas must be considered:

- Challenging behaviors are defined as personal behaviors by a child that injure

  themselves, other children or adults, or the environment, and negatively

  impact a child's ability to acquire growth and development in all areas,

  especially social-emotional development (Doss & Reichle, 1991; Kaiser &

  Rasminsky, 2003).

- Challenging behaviors are age appropriate up until about the age of 3, unless

  the frequency, intensity, and duration of the behavior exceeds what is

  developmentally appropriate for a younger child (Needlman et al., 1991; Rapp

  & Hutchinson, 1987). This study focuses on mothers' experiences of

  parenting children whose behaviors go beyond what is considered

  developmentally expected temper tantrums.

- Many studies cite a correlation between the early onset of challenging behaviors and later deviancy, criminal behavior, etc. (Campbell & Ewing, 1990; Chandler & Dahlquist, 1997; Klass, Guskin, & Thomas, 1995; Ritchie & Pohl, 1995; Vitaro, DeCivita, & Pagani, 1995; Webster-Stratton & Herbert, 1994).

- Several studies have documented an increase in the prevalence of challenging behaviors in young children (Kelleher et al., 2000; Walker, 1998).

- Many studies look at several variables when considering the source of children's pathology: maternal depression, parenting behaviors, etc. (Bahtia et al., 1990; Shonkoff & Marshall, 2000).

- A common intervention strategy is parent training, parent education (Fox, Vaughn, Dunlap, & Bucy, 1997).

Given the documented correlation between early onset of challenging behaviors and later deviant behaviors, the increasing reported prevalence of these behaviors in U.S. samples, the frequently cited etiology of the behaviors as maternal/parenting issues, and the involvement of parents in parent education as an intervention strategy, *shouldn't we gain a better understanding of the experience of parents whose young children engage in challenging behaviors?* This study is intended to address this need for understanding.

CHAPTER 2 – METHODOLOGY

The methodology used for this qualitative research study is hermeneutic

phenomenology, the human science which studies persons and searches to understand the

fullness of their lived experience within the context of a particular lived experience (van

Manen, 1998). Through interviews, the researcher focuses on participants' everyday life

experiences, trying fully to understand an experience from the participant's point of view.

From the interviews, the everyday life experience is expressed in the form of a written

text. The understanding of the participants' lived experience comes through the

researcher's interpretation of that text. This study focused on the everyday life

experiences of mothers whose young children engaged in challenging behaviors. My

goal was to understand that experience from their point of view. "It [phenomenology] is

the study of the lifeworld—the world as we immediately experience it pre-reflectively,

rather than as we conceptualize, categorize, or reflect on it" (van Manen, p.9).

Historical Overview

Hermeneutics, according to the Fourth Edition of the American Heritage

Dictionary of the English Language (2002) is "the theory and methodology of

interpretation, especially of scriptural text" (p.821). Phenomenology is defined as:

1. A philosophy or method of inquiry based on the premise that reality consists of

   objects and events as they are perceived or understood in human consciousness

   and not of anything independent of human consciousness.

2. A movement based on this, originated about 1905 by Edmund Husserl.

   (American Heritage Dictionary of the English Language, p.1318)

Simply put, hermeneutic phenomenology is the methodology of interpreting objects and

events as they are perceived or understood only in the human consciousness, not of

anything independent [outside] of the human consciousness. According to Max van

Manen (1998), hermeneutic phenomenology tries to be attentive to both terms of its

methodology:

> It is a *descriptive* (phenomenological) methodology because it wants
> to be attentive to how things appear, it wants to let things speak for
> themselves; it is an *interpretive* methodology because it claims that
> there are no such things as uninterpreted phenomena. The implied
> contradiction may be resolved if one acknowledges that the
> (phenomenological) "facts" of lived experience are always
> meaningfully (hermeneutically) experienced. Moreover, even the
> "facts" of lived experience need to be captured in language (the human
> science text) and this inevitably is an interpretive process. (pp.180–
> 181)

Phenomenology evolved during the German Romanticism of the 1800s in response to

two dynamics occurring at this time: the drive to reformulate ideas about science, and the

question of how to study cultural science. All research methodologies are identified by

their ontology (the examination of reality), epistemology (what is truth), and purpose (to

explain, to understand, or to effect change). It is these specific characteristics that set

hermeneutic phenomenology apart from other methodologies:

1. Ontology: the researcher is connected to the "who" and "what" that is being

   researched—the researcher and subject are closely involved with each other.

2. Epistemology: what is true is what the researcher and the subject agree to be true.

   Knowledge is dependent upon what is happening to the subject, and what is

   happening between the researcher and subject(s) at the given time of the

   interaction, and cannot be generalized to other populations.

3. Purpose: to have a deep and sympathetic understanding of the life world and to communicate that understanding to others.

Six Definitions of Hermeneutics

While Edmund Husserl is considered the father of hermeneutic phenomenology, several others have made significant contributions towards the evolution of this research discipline. In his book *Hermeneutics*, Palmer (1969) presents a chronology of six modern definitions of hermeneutics which outlines this evolution, beginning with J.C. Dannhauer.

Hermeneutics as theory of biblical exegesis. It is likely that the most widespread understanding of the word "hermeneutics" is still in reference to the principles of biblical interpretation (Palmer, 1969, p.34). Palmer (1969) references Dannhauer's 1654 book *Hermeneutica sacra sive methodus exponendarum sacrarum* as most likely the earliest recorded occurrence of the word as a book title. Palmer (1969) suggests that "this reflected the beginning of the distinction between actual commentary (exegesis) and the rules, methods, or theory governing it (hermeneutics)" (p. 34).

Hermeneutics as philological methodology. Philology, also known as historical linguistics, is the "study of linguistic change over time in language or in a particular language or language family, sometimes including the reconstruction of unattested forms of earlier stages of a language" (American Heritage Dictionary, p. 833). In 1761, Johann August Enersti authored a hermeneutical manual which "asserted that the verbal sense of Scripture must be determined in the same way in which we ascertain that [verbal sense] of other books." Benedict de Spinoza further suggested that "the norm of biblical exegesis can only be the light of reason [that is] common to all." Ernesti and Spinoza,

therefore, highlighted the importance of using language that communicates the "light of reason to all" when communicating the meaning of scripture.

Language continues to be an integral part of this methodology because the "facts" of lived experience must be captured in language (van Manen, 1998). This includes the language that is spoken by the researcher and the subject, and the language that is heard and authentically interpreted and written by the researcher. Along the same line of thinking regarding the use of ordinary language to communicate meaning, Marjory Brown's (1989) eighth criteria for establishing the quality of good qualitative research parallels this concept:

> The interpretation makes clear the meaning of the text (within cultural tradition) important for the conduct of life. This is done in part through the language used by the researcher who reflects mastery of *ordinary language* usage. Obscure language is avoided since the purpose of interpreting a text is to make sense out of an object of study that is difficult to understand. (p. 283)

It is reasonable to consider that the ideas introduced over 200 years ago have provided the structures for the evolution of the practices that make hermeneutic phenomenology what it is today.

Hermeneutics as the science of linguistic understanding. Fr. D. E. Schleiermacher, properly regarded as the father of modern hermeneutics as a general study, was the first to re-conceive hermeneutics as a science, or art, of understanding. His contribution marks a turning point in the history of hermeneutics. In the early 1800s, Schleiermacher moved from the idea of hermeneutics as the philological process of interpreting Scripture "in the light of reason common to all," to the idea of a "general hermeneutics, whose principles can serve as the foundation for all kinds of text

interpretation" (Palmer, 1969, p. 40). This was the beginning of defining hermeneutics as a discipline of its own.

Hermeneutics as the methodological foundation for the geisteswissenschaften. As one of the great philosophical thinkers of the late 19th century, Wilhelm Dilthey moved beyond Schleiermacher's "general hermeneutics" to the view of hermeneutics as "the core discipline which could serve as the foundation for all the *geisteswissenschaften* (i.e., all disciplines focused on understanding man's art, actions, and writings)" (Palmer, 1969, p.41). Dilthey's contribution was the idea that in order to interpret a great expression of any aspect of human life, one must possess an act of historical understanding [of the great expression]. van Manen's (1998) presentation of Dilthey is that

> The emphasis for Dilthey (1985) was not the fundamental thought of the other person but the world itself, the "lived experience," which is expressed by the author's text. Dilthey's hermeneutic formula is *lived experience*: the starting point and focus of human science; *expression*: the text or artifact as objectification of lived experience; and *understanding*: not a cognitive act but the moment when "life understands itself." (p.180)

Dilthey's intent was to develop within hermeneutics a sound methodological basis for the human sciences. He proposed that one can "grasp the fullness of lived experience by reconstructing or reproducing the meanings of life's expressions found in the products of human effort, work and creativity" (van Manen, p. 181).

Hermeneutics as the phenomenology of Dasein and of existential understanding. In 1927, Martin Heidegger wrote *Being and Time*, a phenomenological study of man's everyday being in the world in which he indicated that "understanding" and "interpretation" are foundational modes of man's being. Rather than perceiving

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hermeneutic understanding as re-experiencing another's experience, Heidegger proposed

that hermeneutic understanding is manifested in the individual's power to "grasp one's

own being in the world in certain ways" (van Manen, 1998). Interpretation of text comes

from/through understanding the possibilities of being that are revealed by the text. Some

have described Heidegger's work as interpretive phenomenology which presented yet

another turning point in the definition and development of both the word and the field.

"At one stroke, hermeneutics is connected with the ontological dimensions of

understanding (and all that this implies) and at the same time is identified with

Heidegger's special kind of phenomenology (van Manen, p.42)."

Building on Heidegger's work, Hans-Georg Gadamer (Palmer, 1969) asserts that

"Being that can be understood is language. Hermeneutics is an encounter with Being

through language. Ultimately, Gadamer asserts the linguistic character of human reality

itself, and hermeneutics is plunged into the fully philosophical questions of the

relationship of language to being, understanding, history, existence, and reality" (Palmer,

pp.42–43). Individuals cannot separate themselves from the meaning of the text when

interpreting the text.

Hermeneutics as a system of interpretation: recovery of meaning versus

Iconoclasm. Paul Ricoeur suggests that there are two very different syndromes of

hermeneutics in modern times. Regarding the interpretation of symbols (such as a

dream), Ricoeur presents the idea that interpretation of symbols can serve the purpose of

recovering hidden meaning, or interpretation of symbols can serve the purpose to

demystify illusions. Because the two approaches are antithetical to each other, Ricoeur

asserts "that there can be no universal canons for exegesis but only separate and opposing

theories concerning the rules of interpretation. The demythologizers treat the symbol or text as a window to a sacred reality; the demystifiers treat the same symbols (say, the biblical texts) as a false reality that must be shattered". (Palmer, 1969, p.44)

Huessrl

Edmund Huessrl is considered the father of hermeneutic phenomenology, as he was the first to integrate the two methodologies (hermeneutics and phenomenology) into one discipline, hermeneutic phenomenology, which included the concept of "lifeworld," the world of lived experience. In his last, and largely posthumously published text *The Crisis of European Sciences and Transcendental Phenomenology* (1970a), he differentiated between our theoretical attitude to life, and our natural pre-theoretical attitude to life. Huessrl said that it is the latter from which all theorizing is derived, and on which all theorizing is based. This is a cornerstone of hermeneutic phenomenology— that experience must come first, and from our initial experiences (prior to our reflecting upon them) we determine our theoretical attitude to life.

Giorgi

Moving away from the logical empiricism of the 19th and 20th centuries in the West, the major contributors to phenomenology (Husserl, Heidegger, Sartre, Merleau-Ponty, Ricoeur, and Levinas) all agreed that the focus of [phenomenology] philosophy has to be "consciousness, human existence, or the very nature of being itself. In other words, this philosophy introduces a shift of focus away from the thing and nature toward human beings and their worlds (Giorgi, 2005)."

> This shift in the movement of philosophy was aided by Husserl
> himself when he designated consciousness as the point of departure
> [from other disciplines] for phenomenology. He reasoned that

anything that had to be dealt with in the world had to come through consciousness. Without consciousness, there is nothing to be said or done. Consequently, Husserl set out to understand consciousness in all of its manifestations. He recognized it to be a medium between human beings and the world and the directed character of consciousness Husserl called, following his teacher, Brentano, *intentionality*. By intentionality Husserl meant that every act of consciousness takes an object that transcends the act. (p. 76)

Giorgi (2005) elaborated on this way of thinking by describing an unremarkable, everyday occurrence in which one observes and perceives an object.

While one perceives a table, the whole table is never given in a single perception, but only a profile of the table is given which is dependent upon the perspective of the perceiver. We perceive the whole table from the top, or the side, or from underneath, but never the table as such. One must adopt a succession of perspectives in order to get a better sense of the whole table. But when we reflect on our own conscious processes, they are given to us only in one way. They are not given in profiles. I cannot change my perspective when I repeat my reflection. One can perhaps reflect numerous times on the same part of the conscious stream and see new details or observe something different, but the part of the stream under observation comes back in the same way. (p. 76)

When I first reflected on one part of the text, I had an initial response, or perspective, to what I was reading. In reading and re-reading that part of the text, I began to "see" the experience with "new eyes," changing my ultimate interpretation of the text. But I could not change my initial reflection. I could only continue to "see" new details which altered my final interpretation of the text. At this point, attentiveness to my foreknowledge, pre-understandings, and assumptions was essential. Without this attentiveness, there was the possibility that my re-readings would serve only to reinforce my assumptions, rather than allow me to "see" a new perspective in order to get a better sense of the whole.

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Foreknowledge, Pre-understandings and Assumptions

According to Dilthey, one cannot conduct interpretive research without having

presuppositions about the object of the study, because interpretive research is about

"lived experience" and lived experience is contextual.

> There is really no true starting point for understanding, since every
> part presupposes the others. This means that there can be no
> "presuppositionless" understanding. Every act of understanding is in a
> given context or horizon; even in the sciences one explains only "in
> terms of" a frame of reference. Understanding in the human studies
> takes as its context "lived experience," and understanding that has no
> relationship to lived experience is not appropriate to the human studies
> *(Geisteswissenschaften)*. An interpretive approach which ignores the
> historicality of lived experience and applies atemporal categories to
> historical objects can only with irony claim to be "objective," for it has
> from the outset distorted the phenomenon. (Palmer, 1969, pp. 120–
> 121)

Therefore, I could not enter this hermeneutic phenomenological research study without

presuppositions, because I have to have some level of understanding of the topic to even

begin my engagement with the topic. The presuppositions reflect what I already suppose

about the topic based on my previous experience with the topic.

Kvale (1996) suggests that presuppositions also play a role in the interpretation of

the text.

> A sixth principle is that an interpretation of a text is not
> presuppositionless. The interpreter cannot "jump outside" the tradition
> of understanding he or she lives in. The interpreter of a text may,
> however, attempt to make these presuppositions explicit, and try to
> become conscious of how certain formulations of questions to a text
> already determine which forms of answers are possible. (Kvale, p.49)

van Manen (1998) posits that, "pre-understandings, suppositions, and assumptions

are the experiences that "predispose us to interpret the nature of the phenomenon before

we have even come to grips with the significance of the phenomenological question"

(p.46). Foreknowledge is the knowledge that we have about a phenomenon prior to

beginning our research and Gadamer (1997) asserts that foreknowledge is the means by

which we orient ourselves to a topic. Prior to this study, I was oriented to mothers'

experience of parenting their young children who engage in challenging behaviors

through knowledge gained from my personal experience and knowledge gained from the

research of others.

Foreknowledge

   Knowledge gained from my personal experience. My foreknowledge about

mothers' experience of parenting their young children who engage in challenging

behaviors was formed in part by my own experiences as a parent and as a teacher. From

these experiences I have come to believe that parents are the first 'teachers' of their

children. At the time, I didn't know it, but every time I responded to my children's cries

by feeding, diapering, or comforting them, I was teaching them that they had the ability

to communicate with the world. Today, I see young children enter child care and

preschool already armed with a wide repertoire of skills and knowledge that they have

learned from their parents: what to expect when they cry or fuss, peek-a-boo games, baby

sign language, bed time rituals, how to hold eating utensils, etc. Given this, I also believe

that children do not develop in a vacuum, but rather are part of systems that include their

family, educational, and medical components

   From my experience as a parent and a teacher, I believe that interacting with

children who engage in challenging behaviors is frustrating for both parents and teachers

of the child. I also believe that often times, adults misinterpret a child's challenging

behavior as an intentional ploy to hurt another child or inappropriately gain possession of

an item, rather than interpreting the child's behavior as an attempt to communicate a need or desire. I had the opportunity to understand this through observation of a child in my class who frequently lashed out at other children in anger. One day, I turned around just as another child was invading his space, and when the other child did not respond to his appropriate verbal request to move away, he hit the child. While the physical response was not an acceptable behavior, I could see that he was frustrated not only with the other child, but also with the lack of response from the other child to his verbal request. He was "using his words," as the teachers told him to, but he wasn't successful.

Knowledge gained from the research of others. Through looking for research about mothers' experience of parenting their young children who engage in challenging behaviors, I learned more scientific information about children with challenging behaviors (definitions, intensity/frequency/duration, correlation to later deviancy, and increase in prevalence). While I found a plethora of research material about intervening with parents, instructing parents, guiding parents in support groups, I found very limited research about parents' experiences of parenting their children with challenging behaviors. And of that research, only a few articles focused specifically on mothers' experiences. From reading this research, I have come to believe two things:

1. Early challenging behaviors are correlated to later deviancy.
2. Working with both parents and children can have a positive impact for children's future behaviors.

With this foreknowledge, I became highly motivated to know more about mothers' experiences of parenting their young children who engage in challenging behaviors.

> A phenomenological question must not only be made clear, understood, but also "lived" by the researcher. A phenomenological researcher cannot just write down his or her question at the beginning of the study. There it is! Question mark at the end! No, in his or her phenomenological description, the researcher/writer must "pull" the reader into the question in such a way that the reader cannot help but wonder about the nature of the phenomenon in the way that the human scientist does. (van Manen, 1998, p.44)

Using personal experience as a starting point. The works of Dutch educational researcher Max van Manen and others provided the framework for describing how I approached the choice of the dissertation topic, data collection, and interpretation of the texts provided by the mothers in my study. In his book, *Researching Lived Experience* (1998), van Manen does more than merely suggest using personal experience as a starting point for beginning a hermeneutical phenomenological study. He indicates that the phenomenon under investigation must be a lived experience of the researcher. Later in his book, van Manen (1998) describes the value of the researcher's lived experience when examining the similarly lived experience of another.

> It is to the extent that *my* experiences could be *our* experiences that the phenomenologist wants to be reflectively aware of certain experiential meanings. To be aware of the structure of one's own experience of a phenomenon may provide the researcher with clues for orienting oneself to the phenomenon and thus to all the other stages of phenomenological research. (van Manen, p.57)

In the fifth of his six Hermeneutical Canons of Interpretation, Steiner Kvale (1996) emphasizes the importance of researcher's familiarity with the phenomena in conducting the interview and also in how the resultant text is interpreted:

> A fifth canon of the hermeneutical explication of a text concerns *knowledge about the theme* of the text. Conducting a qualitative research interview requires an extensive knowledge of the theme so

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that the interviewer may be sensitive to the nuances of meaning
expressed and the different contexts into which the meanings may
enter. (p.49)

Like van Manen, Kvale insists that personal experience with the phenomenon under

investigation is essential to the credibility of a hermeneutical phenomenological study.

In describing data collection and fieldwork strategies, Patton (2002) also refers to

personal experience as an integral component in conducting hermeneutic

phenomenological research:

The researcher has direct contact with and gets close to the people,
situation, and phenomenon under study; the researcher's personal
experiences and insights are an important part of the inquiry and
critical to understanding the phenomenon. (Patton, p. 40)

Indeed, it was personal experience that guided my decision to ask mothers what their

experience of parenting their child with challenging behaviors was like.

In Brown's chapter (1989), *What Are the Qualities of Good Research*?" she

analyzes eight qualities of good research as they apply to empirical/analytic inquiry,

interpretive (hermeneutic) research, and critical science research. Specific to

hermeneutic research, she references the importance of the researcher's familiarity with

the topics which are the subject of the text.

While the researcher may choose to familiarize him or herself with a
particular topic in order to interpret certain texts (as is often necessary
in history and in the study of another culture), he or she can make no
sense of a text in which the subject matter is unfamiliar. Since
meaning is interpreted within the cultural tradition and is interwoven
with social practices and institutions, interpretation must reflect
familiarity with those relevant to the text. (Brown, p.282)

Because qualitative studies about parent's experiences were difficult to find, I was

excited to read one phenomenological study entitled "Giving Voice to Parents of Young

Children with Challenging Behavior" (Worcester, 2005). Upon closer examination, the

author disclosed that while he had much experience working with parents of children with challenging behaviors, he was not a parent. While he could pull from his professional experiences with the families, the depth of personal experience was missing. His motive was sincere, in that he wanted to better understand the parents' experiences, and to be a better practitioner. His information was interesting, but it didn't feel personal. While he could talk about his experiences with parents of children with challenging behaviors, the experience of being a parent was unfamiliar to him.

In contrast, I can recount what it was like to parent a child with challenging behaviors (frustrating, time-consuming, and anxiety-producing). But what was the *meaning* of those experiences? What was the essence of my experience?

In examining other phenomenological and hermeneutic phenomenological studies, I found situations of researchers' motivations similar to mine. Researchers were searching to better understand the meaning of their own lived experiences through discovering the meaning of others' similarly lived experiences (Chen, 2003; Footrakoon, 1999; Goranson, 2001; Jerphak, 2006; Macklin, 1994; McClelland, 1995; Smith, 2003). While not a hermeneutical phenomenological study, Naseef's research (1988) included phenomenological parent interviews in conjunction with assessments of family systems to better understand the meaning of his own lived experience of parenting a child with autism. Herein lies a problem, however, which van Manen (1998) articulates well:

> The problem of phenomenology inquiry is not always that we know too little but that we know too much. Or, more accurately, the problem is that our "common sense" pre-understandings, our suppositions, assumptions, and the existing bodies of scientific knowledge, predispose us to interpret the nature of the phenomenon before we have even come to grips with the significance of the phenomenological question. Another way of stating this predicament

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is that scientific knowledge as well as everyday knowledge believes
that it has already had much to say about a phenomenon, such as what
the phenomenon of parenting is, or what parents do or should do,
before it has actually come to an understanding of what it means to be
a parent in the first place. (van Manen, p.47)

This implies that the very circumstance that is associated with conducting quality

hermeneutic phenomenological study is also the circumstance that can impede

researcher's ability to really listen and hear what their participants have to say.

Bracketing. Husserl was the first social scientist to use the terminology of

'bracketing,' which van Manen (1998) defines as the "act of suspending one's beliefs in

the reality of the natural world in order to study essential structures of the world" (p.

175). In order to understand a given phenomenon, we must suspend what we already

know and believe about the phenomenon, lest our pre-understandings influence our

ability to understand the nature of the phenomenon before we really understand what the

phenomenon is about. Suspending one's beliefs is not the same as forgetting the beliefs.

van Manen says that

if we simply try to forget or ignore what we already "know," we may
find that the presuppositions persistently creep back into our
reflections. It is better to make explicit our understandings, beliefs,
biases, assumptions, presupposition, and theories. We try to come to
terms with our assumptions, not in order to forget them again, but
rather to hold them deliberately at bay and even to turn this knowledge
against itself, as it were, thereby exposing its shallow or concealing
character. (van Manen, p.47)

In order to authentically interview subjects and interpret the resulting text, the researcher

must acknowledge his or her foreknowledge, assumptions, and prejudices about the text

topic, lest that knowledge and information unknowingly intrude upon the researcher's

ability to become one with the text (Gadamer, 1997). The goal here is to "let members'

meanings come through and not substitute sociological or popular interpretations. The operating principle is to allow people to tell their own stories, with theory taking a back seat, at least initially" (Gubrium & Holstein, 1997, p.34).

I entered the interview process believing in my ability to "bracket," or easily put these things aside. I underestimated the power of the interview—the powerful connection I felt with these mothers. I underestimated the power of my desire to "help." My greatest challenge appeared when I began to work with the texts. How did I handle the foreknowledge, assumptions, and prejudices? Unfortunately, not very well in my initial writings. In the beginning, I was continually challenged to really "listen" to what mothers said, and "hear" what they were really saying. It was difficult not to take mother's words and fit them into my own frame of reference. I was interpreting their words in terms of what I thought, and what I thought I knew. Because my thoughts and opinions were grounded in my professional and personal experiences, I thought this made sense. I was an "expert." Obviously, this approach does not embrace the concept of understanding the essence of mother's lived experiences, which is what hermeneutic phenomenology is about. Learning to separate my own agenda from the mother's actual experiences continued to be a huge challenge for me throughout the entire writing process.

Explicating My Connection to the Phenomenon

My professional experience as a teacher. Hearing the mothers talk about their frustrating experiences of interacting with teachers was a humbling experience for me. Those teachers had all the answers, but never considered that the mothers had insights

into their child's behaviors. I was embarrassed to admit to myself that I had unknowingly been that kind of teacher.

During my first year of teaching in a preschool classroom in 1987, I informed one family of my concern about their child's behaviors that had become problematic in the classroom (in 1987, any behaviors that caused disruption in the classroom were called problem behaviors). As a recent college graduate, I was licensed by the Minnesota Department of Education to teach young children. In addition to the experience of parenting my own three children, I had many years of volunteer work with children of many ages. I considered myself to be an experienced educator. But the child's parents were suspicious of my reports, and I was surprised that their response was to reject my message of concern. The parents queried me: Did I really know their child? Did I want the best for their child? Did I want to find ways to help their child succeed? Did I have their child's best interest at heart? Or was I more concerned about the rest of the children in the classroom? Did my intervention suggestions/strategies really represent the opinion of the local school district Early Childhood Special Education (ECSE) experts with whom I was consulting? Through much self-reflection (and self-doubt about myself as a teacher), I asked myself: Was I motivated to adapt my curriculum to meet the needs of their child, or was I only willing to continue teaching in the way that was most familiar and comfortable to me? Was I too concerned about the additional workload that such adaptations might mean for me? As a new teacher it was difficult to identify the fine line between my lack of experience and the child's increasing incidences of problem behaviors in the classroom. Did my inexperience cause the child's behavior, or did the child's behavior cause my fragile sense of authority to be less effective in the classroom?

We struggled through the rest of the year, and in May that child completed my "Year Before Kindergarten" class. I was challenged by a child's behavior in my classroom, I implemented many intervention strategies unsuccessfully, and I tried to get the parents to see things "my way." I felt like I was a failure, both with the child and with the child's parents. I had lost confidence in myself as an educator of both children and their parents.

The following September, their child entered kindergarten and a younger sibling was enrolled in our preschool program. The mother stopped me in the hall one day to tell me how surprised they were when their kindergarten child was diagnosed with a learning disability. While I felt somewhat validated about my initial perceptions that their child's behavior needed some type of support, I felt that I had not been heard by the parent. And I still had an overall sense of failure: I could have done better.

Within that early childhood program, I began to hear more teacher conversation about a perceived increase in the number of children with problem behaviors. In response, I did not ask myself or others if there was an actual increase in the numbers of children and problem behaviors. I sought out information to support my belief and perceived experience that there actually was an increase in the numbers of children with problem behaviors. This search for information led me to enroll in the Early Childhood Special Education licensure program at the University of Minnesota. Through completion of the licensure program I was afforded the opportunity to gain more information about, and more experience with, behaviorally challenged children. It was at this time that I became acquainted with the work of Doss and Reichle (1991) who *included* problem behaviors within their definition of a greater category of behaviors

called *challenging behaviors*. I sensed that while the behavior of children had not changed, the terminology for studying the behaviors *had* changed.

Since that first year of teaching, I have interacted with many teachers and parents about children's problem behaviors. I have continued to be, in many cases, the first professional person to suggest to parents that there are concerns about their child's behavior. Upon hearing this information for the first time, parents most often express surprise, then disbelief, before moving through the other stages of acceptance. From Bowman's work (1998), I began to understand that identification of children with challenging behaviors was not a contest of who was right and who was wrong. My job was to provide the best possible curriculum for each individual child in my care, and to sensitively keep parents informed about their child's participation in the classroom. If parents were unable to hear my concerns, I had to accept that they had the right to disagree with me—without my judging them.

My personal experience as a parent—being on the other side of the table. In 1996, my then 18-year-old son was diagnosed with ADHD—attention deficit hyperactivity disorder. Prior to this diagnosis, I had spent many sessions during the previous 12 years sitting at the conference table across from his classroom teachers and school counselors, listening to their ongoing litany about his academic flaws and behavioral laziness. At one point, I even commented, "Gee, usually I'm on the other side of the table, talking with parents about THEIR children's behaviors. This feels so strange." Not only did the teacher's allegations suggest his lack of competency as a student, I felt that their comments reflected negatively on my ability as a parent. During these sessions, I was repeatedly informed about how my son was not performing well, not

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living up to his abilities. While his attention deficit behavior did not result in injury to himself or others and did not cause damage to the physical environment, it definitely was a challenging behavior in that it interfered with his ability to acquire new academic skills. Although his behaviors did not socially isolate him from his peers, the behaviors did isolate him from the good graces of his teachers. His behavior kept him out of the gifted programs that could have given him the challenges he needed. The teachers told me that he was extremely bright and would definitely benefit from participation in the after-school gifted program. But because he couldn't/wouldn't complete his regular work in a timely manner, they were unwilling to recommend him to the program. Some teachers suggested that I as his parent should be doing something radically different "to make him perform." More often, teachers seemed to throw their hands up in despair or disgust. They were tired of wasting their time with my child. They wanted to interact with hard-working students who seemed deserving of their time. I was the parent receiving negative information about my son's behavior. It felt very different, being on this side of the table

I was frantically trying to parent a child I didn't understand—busy going to school conferences and implementing behavioral interventions at home in hopes that he "would get better." I lived in dread of school conferences: anticipation of yet another evening of bad conferences—another year of bad conferences; being told that my child wasn't worth their time. I could only see myself as a failure because I didn't know what to change or how to make things better. Being a teacher, I thought I should have known better and been able to figure it out. I was afraid: If I didn't figure it out, what did the future hold for my son? Would he make it out of high school? Could he go to college?

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Could he be successful in life? We lived in a rather small church/school community and I was embarrassed because "other" people "knew" about me, about us. I imagined that they thought my son simply <u>wouldn't</u> perform, and that I was incapable of being a more successful parent. When I saw his teachers at the store, at church, in the parking lots, I didn't want to make eye contact with them because I was ashamed and embarrassed of what I thought they were thinking about me and about my son.

The thread of continuity. The thread of continuity between my professional experience and my personal experiences is the parent perspective: the perspective that I did not ask about, nor did I ask others about. Parenting my son was very challenging, and I truly had no idea what to do. As a mother, I knew no one was asking me what it was like to parent my son and to hear about his behavior. I then began to realize that as a teacher, I seldom asked parents what it was like for them to be receiving negative reports about their child's problem behaviors.   I had lost confidence in myself not only as a parent, but also as a teacher.

A humbling experience. One particular parent-teacher situation captured my attention in a very humbling way. The teaching staff and I were very concerned about the overall development of a young child from another culture. We had had numerous meetings with the child's parents in which they dismissed our concerns with comments such as, "I was like that as a child [would bite other children]—my child is like me— maybe it's hereditary," "We thought our child was just a 'late bloomer,'" "We've seen other children hit and bite—it's not just our child doing those things." By the time that they finally acquiesced to our repeated requests for a formal evaluation by the school district, the relationship between the parents and the teaching staff was in a rapid state of

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deterioration. In one of the final meetings which only the father attended, he told us a story. As he fought to hold back his tears, he explained that in his culture, he could not give permission for his child to receive ECSE services without getting permission from his parents who lived overseas. What would he tell his parents? They would ask what was "wrong" with their grandchild if Special Education services were needed. What would he say? While we had professionally used the words "developmental" rather than "right" or "bad," he could only hear that something was wrong with his child. And he was right, because we did think something was wrong. Something developmental, but wrong, nonetheless. In some ways, we had been dishonest. My heart broke as we all wiped our tears. And I silently thought, "How could I have been so insensitive as to not ask even one question about their experiences as parents?" At the time, I was in the midst of writing my doctoral research question about parents and challenging behaviors. My coursework was done; I had a lot of formal education and professional experience under my belt. I was moving along! And yet I, who wanted to hear about and understand parent's experiences with their child's challenging behaviors, had just been insensitive, and too ignorant to fully comprehend what I had done. I had missed the essence of this father's lived experience—that he lived with the agony of being asked to acknowledge that something was "wrong" with his son in order to get the help he needed, versus living with the agony of doing nothing to help his son. Something had to change.

Essence

According to van Manen (1998), the construct of essence is essential to hermeneutical phenomenology. What are essences? Essences are the particulars, or qualities, that make something what it is, or what it would not be without the essence.

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For the mothers who participated in this study, the particulars that made their daily lived

experiences what they were are reflected in their themes of not knowing what to do about

their child's behavior, feeling frustrated with the amount of negative information they

received about their child's behavior, thinking that others blamed them for their child's

behavior, and feeling frustrated with the process of getting help for their child.   These

experiences were at the core of mothers' daily lives. They are truly essences, because

they are not dependent upon categories to define and/or describe them. If you take away

the categories of gender, ethnicity, race, family composition, birth/adoptive family, and

socio-economics, the essences remained the same. But if you take away the essences of

uncertainty, frustration, and guilt, the mothers' experiences are not truly reflected.

Assumptions

Hermeneutic phenomenology is the most appropriate methodology for this study.

> Because human participants can relate intentionally to objects of the
> world, consciousness manifests relationships to things and others that
> are other than cause-effect relationships. Consequently, the concepts
> and practices of the natural sciences are not the best model for the
> human sciences to follow. Husserl in his philosophy introduced a
> method for a more adequate approach to the achievements of
> consciousness and when properly modified the phenomenological
> method can serve as the basis for the human sciences. (Giorgi, 2005,
> p.75)

Anzul, Evans, King and Tellier-Robinson (2001) report that in general, the

experimental paradigm has dominated education research, with a preponderance of

studies being conducted in controlled settings that bear little resemblance to the

complexities and continually changing nature of "real life."   In these experimental

studies, children have been asked to perform tasks unfamiliar to them, such as putting

their hand inside of a covered box and identifying an object inside of the box. While the

object chosen for identification is presumed to be known to most children, the outcome of the experiment could be inaccurate if the child does not have prior experience with the concept of putting their hand inside of a covered container, or does not have prior knowledge of the particular item. The outcomes of such research paradigms only focus on isolated variables, usually highly discrete behaviors or skills, and the extent to which students can or cannot perform them. According to Trent, Artiles, and Engler (1998),

> Education models are guided by research that focuses on deficits of students who, in an artificial setting, fail to meet predetermined standards for an isolated skill or characteristic. This deficit perspective has historically been prominent in special education programs. (p.235)

Reflecting the work of Evans (1998), Anzul et al. (2001) suggests that

> Qualitative research characteristically yields multifaceted findings, and these are often beyond the original focus of a study. Participants may reveal unexpected abilities, strengths, and coping strategies when their performances are viewed in natural settings and authentic situations. In addition, they may reveal unanticipated points of view when they are encouraged to talk about their experiences in unstructured and open-ended conversations. (p. 236)

I looked for the methodology that had the potential to give me the greatest insights into the daily lived experiences of mothers whose young children engaged in challenging behaviors.

Earlier in this paper I cite numerous studies which report that challenging behaviors do indeed exist, that the incidence of challenging behaviors is increasing, that parents provide the most information regarding children's challenging behaviors, that parents' behaviors are sometimes considered as antecedents to their child's behaviors, and that parents' participation is essential to the success of their child's getting support. I also reference that there is much written about what parents should and should not do,

and that parents' perceptions about their parenting experiences have been gathered through completion of questionnaires or structured interviews. I suggest that if professionals truly believe that parents are such an integral part of a child's getting educational support and ultimate success, then we need to understand what it is really like for them to parent their children with challenging behaviors. We need to understand the *essence* of their parenting experience: what is their experience like and what does it mean? Because hermeneutic phenomenology is concerned with interpreting objects and events as they are perceived or understood only in the human consciousness, and not with anything outside of human consciousness, then I assume that hermeneutic phenomenology is the most appropriate methodology to study the lived experiences of mothers who parent their young children who engage in challenging behaviors.

   Parents have little or no opportunity to tell others about their experiences. Although parents communicate with educators and physicians about their child's behavior, there is a lack of opportunity for parents to simply talk about their experiences of parenting their child with challenging behaviors. Of the studies referenced above, none afforded parents the opportunity to speak their own words about their own experience.

   Parents will want to share their experiences. I assumed that parents would be eager to talk about their experiences. This assumption was based in my own experience of *now* being ready to talk, several years *after* the school meetings had occurred and my son had graduated from high school and ultimately college. It is also based in the ongoing relationships that I have maintained with some of the parents I met with initially when their children were preschoolers. From my own professional work, I knew that there were children with challenging behaviors and adults who were parenting them, so I

assumed that there was a need for this research study and that parents would be eager to participate.

<div align="center">Research Procedures</div>

Recruitment

Initially, 400 flyers (see Appendix B) were distributed to four full-day child care centers in Minneapolis, St. Paul, and surrounding suburbs. Because only four mothers responded to these flyers, I did two things to make participation more easily attainable.

First, I opened up the criteria for inclusion to include (Appendix C):

- children who were 2 through 5 years of age when the behaviors were first identified (instead of children who were currently 2 through 5 years of age).

- children who were involved in at least one of the following behaviors (child caused injury to self or others, child caused damage to the physical environment, child's behavior interfered with the acquisition of new skills, and/socially isolated the child) at least two to five times a week during a 2-week period, sequential or non-sequential (instead of having been involved in the behaviors five to eight times a week during a 2-week period within the last 4 years).

Examples of behaviors included but were not limited to biting, hitting, and breaking classroom materials.

Second, upon the advice of a colleague who works with young children with challenging behaviors, I was encouraged to request permission to recruit for participation through the occupational therapy clinics where children receive occupational therapy

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services. There are two reasons why recruiting through occupational therapy (OT) clinics was crucial to the success of my study.

First, there are many children who engage in challenging behaviors at OT clinics. Occupational therapy intervention is very instrumental in helping young children gain control of their body movements. For example, rather than being unaware of their strength when touching another child, they learn ways to gauge their own touching of other people as using a gentle touch rather than giving a hard squeeze.

Second, the parents at the OT clinics were interested in talking about the experiences of being the parent of a child who engages in challenging behaviors. They had reached a level of acceptance about their child's challenging behavior, in contrast to parents who are just beginning to receive negative information about their child, and reluctant to believe it.

Recruiting through OT clinics quickly generated another seven potential participants, of which five met the inclusion criteria. The tenth parent was a professional colleague who requested that I contact her for participation once the study was approved.

Participants

Participants in this study were 10 mothers of a young child who was 2 through 5 years of age when the challenging behaviors were first identified. For the purpose of this study, challenging behaviors were defined as "behaviors that result in injury/damage to self, injury to others or the environment, or interfere with the acquisition of new skills or socially isolate the child."

Mothers and their children represented a diverse cross-section of family life. Some mothers worked, one mother had never worked since the arrival of her first child,

and some mothers had put their careers temporarily on hold to stay home with their child.

All children had some sort of same-aged peer group experience, as some children had

been in full-day child care since infancy, and some children attended part time nursery

school or ECFE classes. Three of the children were female, while the other 7 were male.

Within the female group, of the two who were primarily aggressive towards their

mothers, one also destroyed materials in the home environment. One female was

aggressive towards peers. Within the male group, all presented aggression towards peers,

and one was also aggressive towards his mother. Of the 10 mothers, 3 were single. Of

the 10 children, 4 were adopted (3 international and 1 domestic) and 6 lived with their

birth mothers. The ethnically diverse children represented 4 international cultures. All

children were either first-born or first-adopted. At the time of the interview, 5 children

were the older of two children in the family, and 5 were only children, but all children

had been the only child at the onset of the challenging behaviors.

Data Collection

Using a script (see Appendixes D and E), mothers were screened through a

telephone pre-screening interview that lasted approximately 15 minutes. Of the 12

mothers screened, 2 mothers' children did not meet the criteria, so the mothers were

disqualified from participating.

If qualified for participation, mothers were asked to agree to a 75- to 90-minute

audiotaped interview. The interview site was arranged for the mothers' convenience.

Five of the interviews took place in local restaurants and coffee shops, two took place in

my office, I met two mothers in their homes, and one mother came to my home.

An interview script (see Appendix F) was used for each interview. Every

participant received a $15 Target gift card, with the understanding that a $10 Target gift

card would be given in appreciation of their time, if they chose to discontinue

participation after starting the interview. All mothers completed the full interview and

received the $15 card.

Data Analysis

According to van Manen (1998), "the lifeworld, the world of lived experience, is

both the source and the object of phenomenological research" (p.53). The researcher

must orient oneself in a strong way to the question of the meaning of the phenomenon

being studied, in this case, the experiences of mothers whose young children engage in

challenging behaviors. The meaning of the experience of being the mother of a young

child who engage in challenging behaviors must be found in the *lived experience* of being

the mother of a young child who engages in challenging behaviors. Through interviews,

I obtained mothers' descriptions of their lived experience and that became the data from

which the meanings of their experiences became visible to me. I relied on Giorgi's six

steps of analyzing text data, as referenced in Polkinghorne (1989).

Reading to get a sense of the whole.   "The researcher reads completely through

the protocol to get the 'sense of the whole' " (Polkinghorne, 1989, p. 53). The first four

interviews were transcribed by an independent transcriptionist, and I transcribed the

remaining six interviews. In each case, I first read through the text without making any

notes. This first reading gave me a 'sense of the whole,' a basic idea of what each

mother's experience was about: the age and behavior of her child, and general orientation

to how she responded to the behaviors. Upon completion of this first reading, I then

reread the text slowly, this time making notes regarding similarity to other texts, mothers'

repetition of their own statements within the text, possible themes, comments that were

novel but not thematic, and statements that I needed more information about. Often, this

meant re-listening to the tape for clarification, and sometimes it meant looking for

additional information about the statement within the text.

     Dividing the transcript into meaning units. According to Giorgi, meaning units

are essential components of an experience as they "retain their identity as contextual parts

of the subject's specific experience." At this stage, I read the texts again, looking at all of

the notes and grouping expressions that I thought had some similarity. The codes were

developed according to Giorgi's stance that meaning units become apparent each time

that a transition in meaning is perceived, which could be a change in subject matter or a

change in activities described.

> The researcher reads through the protocol again and divides the
> transcript into units (blocks) that seem to express a self-contained
> meaning from a psychological perspective. This is accomplished by
> recording each time a transition in meaning is perceived—for example
> a change in subject matter or a change in activities being described.
> This is not an automatic or technical process; it requires the
> researcher's judgment. (Polkinghorne, 1989, p. 53)

Another way to consider this is to perceive that the change in subject matter or activities

being described represents the ending of one meaning unit and the beginning of another

meaning unit. The change in subject matter is the transition from one meaning unit to

another. For example, in rereading the text, I noticed how one parent was describing her

enjoyment of the experience of bringing her newly adopted 3-year-old child home.

Suddenly, she switched to describing the behaviors that her child began exhibiting, not

understanding where the behaviors were coming from, and not knowing what to do about

them. I interpreted this change in subject matter as defining the ending of one meaning unit (bringing child home) and the beginning of another meaning unit (not knowing what to do about child's behavior) and noted it. I had not anticipated this response, and in rereading the texts, began to notice many mothers' comments about not knowing what to do about their child's behavior. These comments were grouped together and coded, "Didn't know what to do." Specific to this mother, the meaning unit reflected an essential component of her own behavior, as it influenced the choices that she made for her child. At first she could only find reasons to justify her child's behavior, but eventually she was able to better understand her child's behavior and get help for him. Ultimately, this individual meaning unit was subdivided into additional meaning units, as mothers had different interpretations of the significance of not knowing what do to about their child's behavior. This switch in the subject matter or change in the activities being described occurred many times throughout the texts, and I noted and coded each of them accordingly. I next photocopied all of the coded texts which was approximately 150 pages, then literally cut apart all of the coded texts and lay them out on the dining room table to "see" what I was working with.

Describing the meaning unit. With the 150 pages of cut-up coded text laid out on the table, I could literally "see" the amount of text that I was working with. I was challenged to transform the data from the mother's words to my own words with respect and authenticity.

> After having delineated the natural meaning units, the researcher tries
> to state, as simply as possible in his or her own language, the meaning
> that dominates the natural unit. This is a concise description of the
> meaning unit and is the first transformation of the data from the
> subject's words to the researcher's words. (Polkinghorne, 1989, p. 54)

This is where I first became aware of how my assumptions and presuppositions made this transformation process difficult. I thought that I had done an acceptable job of bracketing my opinions and foreknowledge. But because of how I "saw" the material on the table, I quickly became aware that I had not done an adequate job of bracketing. It was evident that I had assigned categories, rather than let the text "speak" to me. The physical "view" of the data let me "see" that some things that I initially thought had significance, really were not significant. For example, through lack of adequately bracketing, I thought that there would be a category about who first told mothers about their child's behavior. While there *were* quotes to support this, the quotes were not as powerful as mother's statements about *how they felt* when they received the information.

My next step was to organize all of the interview quotations in each of the coded categories onto individual pieces of paper, which allowed me again to "see" that some things belonged, and some didn't. For the things that belonged, I then created a new document entitled Themes, into which I electronically cut and pasted the relevant quotes from the interview text into each of the beginning theme categories.

Interrogating each meaning unit. The question of the study is put to each unit and its accompanying first transformation.

> The next step is to interrogate each meaning unit and its theme in
> terms of the specific topic of the study. The researcher works with the
> meaning units (Step 2) and their first transformations (Step 3).
> (Polkinghorne, 1989, p. 54)

At this point, I had an organization of mother's quotations that loosely fit into rough themes. In order to create introductory and closing statements around these themes, I returned to the original texts with the codes and listened to the tapes as I re-read the texts.

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This time, I was more attentive to pauses in the conversations, sighs, voice modulations of intensity or frailty, and crying. As I listened to each of these tapes while simultaneously re-reading the texts, the tapes jogged my visual memory of mothers' facial expressions and body positioning such as leaning across the table to talk to me or gesturing with their arms and hands. This additional information became the descriptive part of introducing and summarizing each mother's quote.

The next relevant step in this process was to test each research statement, theme, sub-theme and supportive quotes by making them into a sentence that reflected the central research question, "What are the Experiences of Mothers Whose Young Children Engage in Challenging Behaviors?" If the research statement, theme, sub-theme and the quote in the sentence did not reflect the central research question about mothers' experiences, then it did not belong there.

To do this, I wrote a sentence that included the research statement, the theme and sub-theme statements, and the supporting mother's quotation. For example, I wrote out "The experiences of some mothers whose young children engaged in challenging behaviors (research statement) was that they didn't know what was going on (theme statement) and thus felt poorly about themselves (sub-theme statement), as indicated by one mother who was a professional educator and wondered, "if I can handle autistic children, why can't I handle my own child?" (mother's quote about her thoughts about her own experience). I tested another quotation for this theme and sub-theme in the same way: "The experiences of some mothers whose young children engaged in challenging behaviors (research statement) was that they didn't know what was going on (theme statement) and thus felt poorly about themselves (sub-theme statement), as indicated by

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another mother who was professional educator and wondered to herself, "how can my kid be like he is when I know all this information?" (mother's quote about her thoughts about her own experience). I repeated this process for all eight themes, all 25 sub-themes, and all of the quotations used in the body of the text analysis.

Prior to examining the data this way, I sometimes had sub-themes that did not relate to the main theme, quotations that did not fit with either the theme or the sub-theme, and quotations that did not reflect the lived experience of a mother in my study. An example of how I identified something that didn't belong was within the theme of isolation, or not belonging. One mother described how the neighbors ignored her, and would not let their children play with her daughter. In creating the sentence, I wrote "For one mother, the experience of parenting young children who engage in challenging behaviors (research statement) was isolation (theme statement), because the neighbors ignored her and excluded her child (sub-theme statement), and were so mean "that they made another child in the carpool who had challenging behavior actually get out of the car so that his pregnant mom had to walk to school with him" (mother's quote about the experience). My memory of this part of the interview is that the mother in my study was horrified at the insensitivity which her neighbors displayed towards the pregnant mom because, "people help each other out, that's what they do." But the story about the carpool mom was not the lived experience of the mother in my study. Even though it had meaning to her, it was the lived experience of another parent, not her, so it did not belong in the theme.

Establishing essential meanings. Polkinghorne's description of Giorgi's fifth step in analyzing hermeneutic phenomenological data is that the researcher creates a

statement that ties the meaning units together in a way that "includes the concreteness

and the specifics of the situation in which the subject's learning took place."

> Once the meaning units have been transformed into psychological
> language, the researcher works to synthesize and tie them together into
> a descriptive statement of essential, non-redundant psychological
> meanings. The transformed meaning units are related to each other
> and to the sense of the whole protocol. (Polkinghorne, 1989, p.54)

Specific to the example given earlier in which I indicated that "the experiences of some

mothers whose young children engaged in challenging behaviors was that they didn't

know what was going on, and thus felt poorly about themselves," I created the following

statement as the introductory paragraph for the sub-theme *I Was Stunned by My Inability*

to Manage My Child's Behavior that tied the meaning units of this sub-theme together:

> All new parents quickly find out just how huge and important the
> parenting role is, even those new parents who have prior experience
> with young children. In contrast to parents who didn't know what to
> expect, four parents reported being knowledgeable about young
> children, as they were recently or currently employed as educators of
> young children, or interventionists who worked with young children.
> For these parents, the unsettling experience of not knowing what to do
> was compounded by the fact that they had expectations of themselves:
> they should be able to manage their child's challenging behavior. But
> all were surprised and dismayed at their inability to be successful in
> dealing with their own child's challenging behaviors.

Within this sub-theme, I incorporated the stories told to me by the four mothers who were

experienced educators of young children. An example of a more precise statement that

included 'the concreteness and the specific of the situation in which the subject's learning

took place,' is the following statement in which I outlined one mother's experience

before presenting her actual words:

> Ellen's description of her surprise at being caught off guard by her
> daughter's challenging behavior began as a simple accounting of
> events, but evolved into self-recrimination. Being knowledgeable

about typical behaviors and challenging behaviors prior to the birth of her daughter did not prepare Ellen and her family for the tasks at hand. Ellen described in earnest how they 'just dealt' with what they were given to deal with and accepted that as their 'norm.' They did not understand that 'norm' had a different meaning until after their second daughter was born—a daughter without challenging behaviors. However, with the growing awareness that her daughter's behavior was becoming increasingly challenging, surpassing even <u>her</u> vast knowledge and wealth of experience, Ellen described in dismay the desperation of 'not knowing what to do.'

These examples reflect the specifics of the situation in which the mothers' experiences took place.

Developing a description at the general level from the protocol. Giorgi's sixth step indicates that:

Only after completing the situated descriptions does the researcher develop a description at the general level from the protocol. The construction of the general structural description leaves out the particulars of the specific situation reported in the protocol. Instead, it centers on those aspects of the experience included in the protocol that are transsituational or descriptive of learning in general. (Polkinghorne, 1989, p. 55)

In answering the central research question, "What Are The Experiences of Mothers Whose Young Children Engage in Challenging Behaviors?" an example of this general description is the introductory paragraph for the first theme "I Was Puzzled and Dismayed By My Child's Behavior and Didn't Understand its Cause or Know What to do About It:

The children of the 10 mothers who were interviewed were all first-born, or first-adopted children. The significance is that as first time mothers, they easily described where they saw themselves on the continuum of being knowledgeable about child development and parenting: either they were well informed about typical development but not as much about parenting, or they knew little about either. This lack of information and experience often left them unsure about

themselves as parents, and more importantly, unsure of what they
should do about their child's behavior.

In steps 5 and 6, Giorgi is suggesting that the researcher move from a specific description to a general description. I interpreted this to mean that the researcher must first be intimately familiar with the text before being able to write more generalized statements about the text. However, in the presentation of the transformed text, the researcher must first present the generalized descriptions before moving to the descriptions that include the "concreteness and the specifics of the situation in which the subject's learning took place. This is reflective of the researcher's continual movement between the "parts" and the "whole" of the text.

Follow-up Communication With Mothers

Polkinghorne (1989) indicates that the main issue of the validity of phenomenological research concerns the question, "Does the general structural description provide an accurate portrait of the common features and structural connections that are manifest in the examples collected?" (p.57). He included five "doubts" to be addressed when considering this concern, of which two are:

- Is the transcription accurate, and does it convey the meaning of the oral presentation in the interview?

- In the analysis of the transcriptions, were there conclusions other than those offered by the researcher that could have been derived?

  (Polkinghorne, p.57)

To determine the validity of my transcriptions and conclusions, I created the following letter and attachment to be given to the mothers in the present study (see Appendixes G and H).

The following contacts were made with 9 of the 10 mothers in the present study.

1. Two mothers were contacted via office mail, because of close proximity

2. One mother was contacted via e-mail (she had previously contacted me through e-mail when she moved out of the country)

3. Six mothers received phone messages from me. For two of the mothers, I left the message with the adult who answered the phone. For the remaining mothers, I left a voice mail message. Three of the mothers who received my voice mail agreed to receive the letter electronically.

I was unable to contact one mother, as her phone number was no longer in service, and her last name was not listed in the phone directory. Five of the mothers have responded and indicated that there is no need for revision of the themes.

CHAPTER 3 – FINDINGS

Parents Want to be Heard

While participation in the study was open to both mothers and fathers, only

mothers responded. The 10 mothers chose to participate in this research study because

they wanted to be heard. They came to the interview with the anticipation that someone

would listen to them, and also that someone would understand them.

One mother rushed through the restaurant entrance late one Halloween morning.

Even in the midst of the Halloween excitement and preparations for her two young

children, she had still agreed to meet at this time that was extremely busy for her. She

smiled softly and laughed as she explained her motivation for coming out on such a busy

day: "Like I told my husband—somebody wants to hear. I'll go!" Similarly, another

mother entered the main dining room of a local restaurant long after the supper hour was

finished. Having just come from an evening school event with her son, she was tired, and

not feeling good about how she had responded to the tantrum her son had just had. But

she too was eager to participate. Why? "My son goes to occupational therapy and I saw

the flyer there, and thought, somebody's interested in hearing my story, because most of

the time nobody wants to hear your story." Thus the stories began.

Theme #1: I Was Puzzled and Dismayed By My Child's Behavior and Didn't

Understand its Cause or Know What to do About It

In *The Six Stages of Parenthood*, Ellen Galinsky (1981) describes how "the

relationship between the parent and child is interactive: What the child does affects what

the parent does, which in turn affects what the child does (p.68)." She further describes

three factors that impact this relationship. First,

> The child's mode of communication is critically important. A child
> who howls constantly, no matter what is wrong, will be much harder to
> decipher. Success in responding to the baby's cues does not
> necessarily come quickly or easily. Two other factors are important.
> One is a knowledge of the tricks of the trade: what else to do when the
> first thing one tries doesn't work. The second is a knowledge of child
> development and an understanding of what kinds of behavior to expect
> and what these kinds of behavior signify. (Galinsky, pp 69–70)

The children of the 10 mothers who were interviewed were all first-born, or first-

adopted children. As first time mothers, they easily described where they saw themselves

on the continuum of being knowledgeable about child development and parenting: either

they were well informed about typical development but not as much about parenting, or

they knew little about either. This lack of information and experience often left them

unsure about themselves as parents, and more importantly, unsure of what they should do

about their child's behavior.

Early on, I Thought I Had Reasonable Explanations For My Child's Behavior

The first child of one mother joined their family when he was 3 years old. Both

she and her husband had done much research on adoption, specifically about adoptees

from their son's country. Her face appeared thoughtful, as she described their experience

of being first-time parents to their first child.

> Because we had waited for a child for quite some time, we were just
> there trying to love him, trying to be a family. We were aware that
> there were risks: potentially health, behavioral, and emotional [risks],
> but we kind of put that stuff aside for a while. Because we were aware
> there were risks, we didn't try to compensate, but we let some things
> [in a louder voice] <u>go</u> for a while.

> When we started going out [of our home], I tried to find a preschool
> program (new mom with 3-year-old child, don't know what to do,
> where to go—somebody gives me an idea and I do it). I would leave

him [at preschool], and he would be tearing apart the classroom, throwing chairs. [He] started stripping down all his clothes one day, and I was shocked. I thought, "Oh, he's still transitioning—he can't understand, it's too much stimulation". And I could always come up with a reason for the behaviors—a fairly justifiable reason, but [long pause, then softly] it would break my heart.

Her last comment acknowledged that while her thoughts at the time were very sincere (because she wanted to give her child every chance possible to successfully adapt to his new environment), it was still heartbreaking for her to see her child do those behaviors and not understand why the behaviors were happening.

This mother continued to describe how easy it was to justify the situations in which her son's behaviors were out of control. With a matter-of-fact quality, her voice modulated between soft and firm as she emphasized certain words:

I brought him to this little community program—it's 2 days a week. And I felt comfortable telling my mom's friend [who was the program director] about his background, thinking at least if she knew something … [it would] help [her] to understand it [his behavior]. And I think she probably looked more forgiving and patient with him, because of the relationship ties [with my mother]. But I think she was <u>flabbergasted</u> because she'd come out with, "He was <u>fine</u>, and then all of a sudden he just started throwing <u>chairs</u>, he was throwing <u>books</u>, he <u>attacked</u> a child.

With resignation in her voice, her eyes were wide, as she leaned across the table towards me and described how she responded to the program director: "I have <u>no</u> idea what to tell you. I mean he's not throwing chairs at home [with laughter], but we didn't have any little kid chairs for him to throw. I figured it was different behaviors due to the different environment."

Another mother talked about the point in time during which she first became aware of her son's challenging behaviors and how it seemed easy to identify why the

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behaviors had occurred initially. But when that initial reason was no longer plausible, she

postulated another idea about why her son behaved the way he did.   In thinking about

the onset of challenging behaviors, she recalled that [the behaviors started] "basically

from the time he started entering daycare."

> It was right next door, a very convenient place to go, and a very good
> facility. There was a reason for that [behavior], and the reason for his
> behavior there was that he wasn't communicative at that point [he
> spoke and understood another language, not English]. He was 2½ and
> he had been living in another country.

> I was worried of course, but I knew very well that he was going
> through a stage. And he seemed to come out of it okay, and I still got
> aggressive behavior reports even after he started communicating more.
> I guess I still wasn't too worried about it. I've gone from a little more
> worried to a little less worried, back and forth on it. But it's been on
> and off, so I guess it's still consistent because he's almost 5 now and
> he hasn't really changed.

Considering the continuation of the challenging behavior, she later wondered if "that

bully behavior that my son is giving other kids is because he's being bullied a little by his

nephew. I think he is, so I don't know, he's like experimenting with the roles of being a

bully (giggle). I don't know." But interlaced throughout her ideas about the reasons that

the behavior might be occurring was her experience of feeling worried about her son's

behavior. Sometimes more worried, sometimes less worried, but consistently worried,

nonetheless.

Another mother was also very aware of her son's behaviors, especially when she

went back to work part-time. She and her husband worked opposite schedules so that

their son only went to a home daycare 2 days a week. Similar to parts of the perception

of the mother above [she indicated that she knew very well her son was going through a

stage], this mother thought much of her son's behavior was developmental in nature—

that children aged 2½ years old did those kinds of behaviors.

> But there [at day care], he was … having the incidences with other children where he would be kind of aggressive towards them like throwing a toy at them, or hitting them with the toy. And again, initially, (even though it was embarrassing and I didn't really know how to handle it) I thought, well, he's 2½; I'm kind of leaving that up to you [the daycare provider]. So I'd have a conversation with her at the end of the day. So those kinds of things started happening. But they were pretty minimal, and I kind of racked them up to him being 2½.

Within her experience of feeling embarrassed about the behaviors, she still felt some

confidence in thinking that his challenging behaviors were developmental in nature

because, "well, he's 2½." However, that confidence was shattered when he turned 3. At

that time she switched daycares, and "then we really started having problems."

One mother easily recalled and described the experience of becoming aware of

her daughter's behavior.

> She was younger and she started at [an early childhood program at a local college] and there's a lot of aggression, and the wooden toys, whacking them [the other children]. She's very aggressive, she's pushing them [the other children] over the sidewalk, and they're hitting their heads. And these were just little people, and it was pretty bad. And I just thought that she had a strong personality, and you try to think the best of your child. You don't really think of anything else at that point. Or that she's just precocious, naughty, that maybe she needs to be disciplined more. That was the first route that we went, so we started taking away things at that point. And then the teachers started to see that the situation wasn't getting any better, no matter what they did, no matter what I did, she was still doing it [the aggressive behavior].

Similar to the mother in the previous description, she also had experienced the point at

which she began to see that her daughter's behaviors were not going to be ameliorated by

simply increasing the consequences for the behaviors.

> And the aggressions kept going, and kept going. But it would go in
> cycles, and the one thing that I've noticed—it's like growth spurts or
> something. Because now she's just coming out of one of her bad
> phases, and I'm not kidding, she's grown an inch. That whole joint
> thing that we do in OT [occupational therapy]—I don't know if there's
> anything to that. But there is a seasonal thing definitely. I see that
> when the seasons change. It [the behavior] gets really bad.

Continuing to observe her daughter closely gave her a very small cue about two possible sources of the behaviors—seasonal change and growth spurts. She only described the seasonal change as related to her daughter's behavior, not necessarily causal. Most importantly, it gave her an opportunity to be on the alert for challenging behaviors when the seasons change so that she could be proactive rather than reactive about interactions with her daughter during those times. This mother had noticed that when her daughter had gone through a period of challenging behaviors, there was almost a growth spurt after the bout of challenging behaviors ended. Like her awareness of the season changes, she only saw the growth spurts as related to her daughter's behavior, not necessarily causal, and used the awareness to be more proactive than reactive about interactions with her daughter during those times.

My Child's Bright—Maybe That's Why She's So Challenging

Parents expressed awareness (and seemed to find comfort in knowing and/or believing) that their child was "bright." "Bright" was the word they used to describe how their children accessed information, taught themselves to read at an early age, were intuitive about social appropriateness at an early age, had immediate cognitive recall, or had very active minds. They didn't brag about their children, or suggest that their children were gifted. They just recognized that their child had very observable strengths in certain areas, and sometimes wondered if there was a relationship between their child's

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cognitive skills and their child's challenging behaviors. For example, one mother

described her daughter's skills by saying, "We know she's very bright. . . . It's not that

she's reading or anything—it's the way she takes in information."

One mother described the inconsistency between how her son had acquired verbal

skills at a very early age, but had always lagged behind in social skills (e.g. his aggressive

behavior reported earlier), and how she experienced that as perplexing to her.

> He started saying words, and then started saying sentences, and then
> he was off. But social skills were always so much further behind.
> He's very large—he almost comes up to my shoulder [indicating with
> her hand how tall her son was]. When he was tested at the
> neuropsyche clinic, he tested at age 8 [he's now 5] for his verbal skills,
> so when he talks he can sound very mature, and he can talk very
> formally, sometimes, to people on the phone. He kind of catches them
> off guard. I don't know that he necessarily understands what he's
> doing. He's very good at his verbal skills, and he's been like that since
> he started talking. So he's tall and he speaks very well, [and] people
> have also assumed that he's older.

> It's perplexing. He's very smart. He taught himself how to read last
> summer. He has always been very good at building things,
> engineering things, and he can concentrate for a very long time. He
> can play by himself. And he's very imaginative. I've encouraged that,
> but he's developed it on his own. He has a memory that is just
> amazing. And he's really good at music. I don't think he's like a
> genius, or gifted per se, but you can just see. Not like a savant, not off
> the scale. But he is really smart. He's very eager to learn, and he's a
> very happy kid. So on the one sense it kind of balances out, but then
> when you have to live with someone like that on a daily basis, the
> struggles are so stressful.

> And also it's hard—when you look at another family, you can look at
> it and see, "oh that's what's happening," or you can see that
> relationship and that role. And I'm always thinking, "What's
> happening in our family—what's really twisted and unhealthy that's
> going on?" You just can't be with someone like that [my son] and not
> feel like something is happening that's unhealthy to a certain degree.

She saw her son's verbal and cognitive precocity as strengths that offset his less

developed social skills, but she experienced the dissonance between the two behaviors as

extremely stressful when dealing with them on a daily basis. While she often wondered

what was happening in their family, her underlying experience was fear. She felt afraid

that something really "twisted and unhealthy" might be going on.

Another mother described her daughter's "brightness" in terms of the possible

relationship between how her daughter takes in so much information and how she

handles that information. Since the early age of 1 year (she's now 5 years old), her

daughter would be aware of all of the sensory information in her environment, such as

sights, noises, and smells. She thought that her daughter seemed to know that it was

important to keep her responses to all of that information internal when in public, but

understood that once she was in her own home, it was safe to let loose.

> My thought is that she's a very sensitive child. She is very aware of
> her surroundings—keenly. Sensitive emotionally but also physically
> sensitive to her surroundings. My daughter was way too socially clued
> in. This was a 1-year-old that I could take to the grocery store and she
> knew it's not appropriate to throw a fit. An autistic child would have
> absolutely no concern or awareness of a setting like that. Her
> language skills were so advanced and her social emotional maturity
> was such that I knew she wasn't autistic. That's part of her problem—
> she's almost too clued into people. It's weird how she can be
> independent of peer pressure and yet be so keenly aware of what's
> going on. She's like an old soul. She watches with this detached
> objectivity. It sounds like I'm making her out to be some kind of child
> prodigy and I don't necessarily think that she is.
>
> She is so sensitive to her environment that maybe that's part of what
> makes her so bright. She's taking in stimulus all the time and
> sometimes it overwhelms her little system and she just can't handle it.
> On the way here today, I said, "Oh, it's such a gloomy day.
>
> I really could use some sunshine." She said, "Yes, Mom. But a
> cloudy day makes it better to watch the sunrise." I said, "Why do you
> think that?" She said, "Well, if it's dark and you look out at the
> horizon, you can see the sun more easily." I thought, okay. First of
> all, how do you the know word horizon and second of all, you've

> obviously put some thought into this. Here I am saying, oh, it's
> another gloomy day. She's making it into this discussion.

In trying to understand her daughter's behavior, this mother described her emotion of

feeling amazed by her daughter's ability to use language and communicate in such a

profound and abstract manner. She has come to believe that her daughter is very bright

and "knows" it would be inappropriate to act out in certain settings so she holds those

responses inside of her. She thinks that because her daughter is absorbing so much

sensory input, "when she comes home, she just loses it because she knows she can."

However, in describing her understanding of her daughter's behavior, this mother's

experience was that of feeling concern that others might misinterpret how she "knew" her

daughter—that she was thinking that her daughter was a child prodigy

Two other mothers considered that there might be a relationship between their

child's challenging behaviors and their "brightness." One mother pondered the thought,

"She's really bright—maybe that's why she's so challenging." She then began to explain

how she observed her daughter's experiences with music as an example of her daughter's

'brightness.' Her voice grew very soft and rhythmic as she described how her daughter

responds to music.

> We listen to some songs. Music calms her down. She likes music.
> We'll listen to a song, and she'll know the whole song, and she can
> repeat it back to me. And she's [even] got a hearing loss in her right
> ear. We'll be listening to Radio Disney and they'll have a new song
> on, and I'll turn off the radio and as we walk in here, she'll start
> singing the song.

Another mother had a similar perception about her child's 'brightness,' and its

relationship to her son's challenging behaviors: "His mind is very active and he makes

trouble when he's bored."

Because I Didn't Know What to Expect, I Wasn't Sure There Was a Problem

> "I think when you have a kid with challenging behaviors, you get so
> used to it that the way you look at it gets skewed. Your bar of what's
> normal keeps going more and more over [the top]. You still think
> you're in the normal range, and you're not." A mother in this study

For some parents, the experience of not knowing what to do about their child's

challenging behavior was related specifically to the fact that their child was a first-born.

While they were very aware of their child's behavior, they had no idea what the behavior

meant. Lacking familiarity with typically developing children with whom they could

compare their child's behaviors, they had no awareness of the difference between typical

and atypical development and behavior.

When no children of the same age were available for comparison of behaviors,

one parent compared her child's behavior to other family members who had behaviors

similar to her child's. She made assumptions that such behaviors were inherited

characteristics, and not necessarily problematic. In an explanatory voice, one mother

carefully described how she created such a comparison in an attempt to make sense of her

son's behavior.

> He was my first child. I never really had anything to compare him to.
> I have people in my family that are very strong personalities, so I just
> thought, he's just kind of out there [like them].

While acknowledging that the behaviors did indeed exist, she paused before concluding,

"I still didn't really think that something was wrong, but I didn't know what to do."

Another mother described a similar perception about her first child. Because he

was born 2 months premature, he was hospitalized for 5½ weeks, and was smaller than

his peers in height and weight at the age of 1. When asked if there were ever any

surfaces about his level of development, she replied,

> Did I know there were development issues? Even still now, no, not
> really. I just figured he doesn't like to jump, so he doesn't jump. I
> didn't realize that a 3-year-old should be able to balance on one foot at
> a command for the count of 10.

> After we did the evaluation for physical therapy, the physical therapy
> teacher was asking me questions, and asking my son to do different
> things: Can you stand on your right foot? He looked at her like, what?
> I asked her, "Should a kid at the age of 3 do that?" She replied, "They
> should be able to do that."

Knowledge of large motor development was crucial to understanding her son, as

his lack of these skills was one of the factors that exacerbated the onset of his challenging

behaviors. Once she became aware of what her son was capable of, and what he needed

help with, she was able to provide more support for him at home.

As one mother struggled to understand what was going on with her child, at one

point she thought the problem was because she didn't understand kids. In a high-pitched

voiced, she mimicked how people's voices chattered on and on, when they told her how

happy she should be.

> I think I probably had post-adoption depression, because I was
> crying—I couldn't believe how I had changed my beautiful life. I
> thought "what <u>have</u> I done?" And everyone is saying, "Oh, you should
> be so happy, he's so darling, he's beautiful." Physically he <u>is</u> a
> beautiful child, and I thought, "You have NO-O-O-O-O idea."

> So I cried a lot, and the crying subsided, but the crying would start up
> again when one of these intense behavioral situations occurred.
> Because I didn't know what to say, because I don't understand
> education either. I mean, I'm a software engineer. And I thought, "I
> don't get it, I don't get kids."

Her experience was one of self-questioning. She and her husband had waited for their

child for several years, but once the extreme behaviors began, she questioned if she had

made the right decision to leave her satisfying career to be a stay-at-home mom. When she experienced the dissonance between people's admiration of her beautiful child and her self-perceived lack of understanding her child, she again questioned herself as a mother and decided that she just didn't "get it."

I Was Stunned by My Inability to Manage My Child's Behavior

All new parents quickly find out just how huge and important the parenting role is, even those new parents who have prior experience with young children. In contrast to parents who didn't know what to expect, four parents reported being knowledgeable about young children, as they were recently or currently employed as educators of young children, or interventionists who worked with young children. For these parents, the unsettling experience of not knowing what to do was compounded by the fact that they had expectations of themselves: they should be able to manage their child's challenging behavior. But all were surprised and dismayed at their inability to be successful in dealing with their own child's challenging behaviors.

One mother entered parenting thinking she would be a really good mom, and expressed surprise that her years of teaching experience were of little help in parenting her own child with challenging behaviors.

> He joined our family at 5½ months (he was our first). I have 22 years of teaching experience, a master's degree in early childhood, and I thought I was going to be the best mom there could be. Now [holding her thumb and forefinger millimeters apart] I feel like I'm about this big. And I think that's significant, that I came to this thinking I would be a really good mom. That my life experiences, my experiences with children, and my experience working with other parents would serve me well. And I'm a really good teacher, and I'm really good with difficult children. In fact, I oftentimes get those, most challenged children in my classroom, 'cause I'm good with them. Somehow none of that information has served me very well.

Her physical expression was one of fatigue as she told me this. She expressed sadness, lamenting that her life experiences, and her experiences with other parents and their children, were of little use with her own child.

Another mother's description of her surprise at being caught off guard by her daughter's challenging behavior began as a simple accounting of events, but evolved into self-recrimination. Being knowledgeable about typical behaviors and challenging behaviors prior to the birth of her daughter did not prepare this mother and her family for the tasks at hand. She described in earnest how they 'just dealt' with what they were given to deal with and accepted that as their 'norm.' They did not understand that 'norm' had a different meaning until after their second daughter was born—a daughter without challenging behaviors. However, with the growing awareness that her daughter's behavior was becoming increasingly challenging, surpassing even <u>her</u> vast knowledge and wealth of experience, she described in dismay the desperation of 'not knowing what to do.'

> Because of my field, I knew about the whole notion of challenging
> behaviors and managing behaviors before she was born . . . there were
> a couple of days where I picked her up and physically carried her out
> to the front yard to put her shoes on because I didn't want her
> screaming and waking up her sister.

When asked, "As a parent, how did that feel?' she replied,

> Infuriating and horrible. I felt guilty. I felt like if I can handle autistic
> children, why can't I handle my own child? I just felt wrong. I felt
> like this isn't the way it's supposed to be. I went to a presentation by a
> well known parent educator. She had put her home phone number on
> the handout which I'm sure she regretted afterward. One day I put my
> daughter on the bus and it was such a negative experience, I called her
> [the parent educator] at home. I talked to her for an hour. I said, I just
> don't know what to do. I can't keep having my daughter's perspective
> because she is so unreasonable sometimes. Even though I try all the

> little tricks, nothing works. She still ends up kicking and screaming
> and then I lose my temper. I know she's going to wake up the baby
> and ruin my afternoon. The parent educator was really great. The fact
> [that] she took my call. She heard my message on the answering
> machine and then she picked up. She knew I was desperate.

She described her experience as feeling shocked at her lack of success with her own child, and feeling horrible and guilty about her interactions with her child. But from that experience of feeling so negative about herself, she chose an action—that of seeking help from the parent educator.

One mother who is a seasoned teacher wondered out loud "How can my kid be like he is, when I know all this information?" Also, she thought that others were probably aware of the discrepancy between her ability to manage the children in her classroom, and her inability to be successful with her own child.

> Well, I'm sure they probably said what the hell is going on in her
> house and how can she be a preschool teacher and be so good with
> kids and look what's going on with her son. I think that was probably
> the hardest thing for me. And the parents whose kids were getting
> hurt. They knew who I was, because they knew he was my son, and
> here I am a preschool teacher in their center. And caring for kids.
> How can my kid be like he is when I know all this information?

Similar to the other professional mothers in the study, she had the expectation that she could easily transfer her classroom knowledge and skills about teaching young children into parenting skills that would guide her in parenting her son. While the skill set is similar, the realization that parenting a child at home is different than teaching young children in the classroom came as a huge surprise—and a personal let down.

Another mother also works with children and was equally dismayed at her inability to manage her daughter's behavior at home. While exhibiting socially appropriate behavior in public and in the presence of other people, at home her 4½ year

old daughter would frequently hit and kick her and have intense temper tantrums during which she would break her own toys. When asked if her daughter's teachers had suggestions for how to manage her daughter's behaviors at home, she responded, "It's all the stuff that I've already tried. Which is part of the problem. I know it [this stuff]." With her breathing punctuated by quick gasps for air, she described the disappointment and frustration of not being able to figure out what to do about her daughter's challenging behaviors.

> There's no pattern to it. It happens in the morning, it happens at night.
> It happens on the weekends. It happens when she's tired, when she's
> not tired. I can't figure out what sets it off. But now that I've gotten
> really mean with her, that there's no second chances, no nothing, it's
> better. But I can't be like this forever . . . [according to her teacher at
> child care] she's very calm, very controlled. My daughter says she's
> not sad and not mad. She won't tell me why she's doing it or why
> she's feeling that way. [If I knew why], we could do something. I
> guess she's young and she can't tell me. And I can't figure out why
> she's doing it, so I don't know what to do.

This mother's statement of "I can't be like this forever," carried an undertone of fear which focused on the source of her daughter's behavior, how much longer would the behavior continue, and how long could she continue to be so rigid. She summed the totality of her frustrations when she said, "If you could figure out a precursor to it, you could stop it before it actually starts. I can't figure it out.*"*

I Felt Embarrassed

As one mother began reconstructing the process by which she became more aware of the intensity of her son's behaviors, her shoulders dropped slightly as she sighed, then paused briefly, before explaining how at the time she wasn't convinced that something

was really wrong, but she didn't know what else to do. With a note of resignation in her

voice she continued:

> … and also I was embarrassed. And so, I sort of felt at a loss, because
> what I was doing wasn't working. He was still doing those things, and
> I didn't know why, because they would just come out of nowhere. It
> wasn't like they were fighting over a toy, or he was really excited.
> Occasionally that would happen, but a lot of times, too, he would just
> be sitting next to someone, and he would do something.

When dealing with their young children who engage in challenging behaviors, parents are

often encouraged to try and figure out their child's motivation for doing the behavior. If

parents can see what happened just before the behavior occurred, maybe the source of the

behavior can be identified, and parents can deal with their child's behavior differently.

For example, if their child predictably hits other children when they get too close to him

or her, parents might conclude that their child is afraid that his or her materials might get

touched or knocked over, or that their child is concerned that a special object (doll,

blanket, toy) might be taken by another child if the other child gets too close. In such a

situation, parents might make sure that they or another adult is in close proximity to their

child during times that the children are grouped closely together, such as when waiting

for a turn to use a specific toy or sitting on the couch to watch a movie. In this mother's

situation, there did not appear to be an event before her son's behavior occurred. This

left her feeling that there was very little that she or other adults could do to keep the

behaviors from occurring.

Summary

Eight of the 10 mothers interviewed expressed concern about their child's

behavior, and expressed self-doubt about their ability to work successfully with their

child's behavior. Some of their concerns about behaviors were expressed as, "I could

always come up with a reason for the behaviors . . . but it broke my heart," "I've gone

from a little more worried to a little less worried," "the struggles are so stressful." Some

of the mothers' self doubts were expressed as, "I felt guilty … if I can handle autistic

children why can't I handle my own child," "I came into this thinking I would be a really

good Mom … I'm really good with difficult children … none of that information has

served me well," "how can my kid be like he is when I know all this information," "I

don't get it—I don't get kids." Mothers were concerned about their child's behaviors, but

doubted themselves before they doubted their children. They seemed to move along a

continuum in which they first doubted themselves, then justified their child's behaviors,

and ultimately were able to recognize and accept that their child was different from other

children. Once they were able to accept this, they were able to search for and access

resources that would enable their child to get the help that was needed.

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Theme #2: It is Painful, and Often Demoralizing, to Receive So Much

Negative Information About Your Child

</div>

"By gum, if he makes it through a day, through a class, without doing
something wrong, I'd sure like to hear about it." a mother in this study

Becoming informed and staying informed about their child's behavior was a

difficult experience for parents. As described in the first theme, early in the process,

parents did not understand their child's behavior. They often rationalized, or justified the

behavior in their attempt to "account" for it, or make sense of it. Receiving information

at this stage was extremely difficult, because as one mother described, "It's too new—

they're not ready to hear it yet. I'm just [now] starting to find the answers and know what to do."

But even after mothers became more comfortable with the idea that their child did indeed engage in challenging behaviors, staying informed about specific incidents and situations continued to be painful, and often demoralizing. Why? As the next section indicates, the information they received was almost always about how their child performed poorly. Comments about their child's successes were few and far between.

Sometimes Teachers Gave Me Notes or Talked to Me Privately About My Child's Behavior

During an extended visit in another country, one mother's son was temporarily enrolled in a local preschool. When she began receiving reports about his challenging behaviors (she did not describe the behaviors that were reported to her) she talked with her son about all the fun things that they would be doing during their stay that summer, and told him that they couldn't return to Minnesota until the date on their plane tickets. Because he didn't pursue the issue with her any more, she thought things were okay at school. But at school, he was often non-compliant, saying to his teachers, "I don't like it here, I don't want to be here anymore, I want to go back to Minnesota." When asked if the teachers gave her feedback on his behavior, this mother thoughtfully murmured "H-m-m-m," then paused a long time before talking. The tension was evident in her face as she described how her anxiety built when the teacher's reports escalated from routine daily observations to being told, "Look, this is really getting out of hand."

> Yeah, um, they did. I think they [the teachers] really wanted it to work
> in the beginning, so they weren't telling me everything that was
> happening. They wanted to give me positive reports, you know, and

they'd always say, "wel-l-l-l, "This happened, but otherwise he liked
this, and he did good in that." They tried to keep it very positive, and
then one of the teachers who had studied a little bit more of early
childhood stuff, and [had] a little bit more English, just sat down with
me and said, "Look, this is really getting out of hand."

When asked, "What was that like to hear?" she quickly replied, "OH, that was shocking!"

She experienced much anxiety, and ultimately, fear, in regards to her son's behaviors at

school. She tried to calm his anxiety about living in a place where he didn't want to be

by focusing on all of the fun they would have, and when she heard no more, she assumed

that all was well. But with the advent of more frequent school reports about his behavior,

her anxiety about his behaviors turned to fear that the teachers might tell others about her

son's behaviors and that she would be viewed as not being a good mom.

At one point in time, one mother noticed that she was experiencing increasing

difficulty managing her son's behavior while riding in the car. She had no idea what had

changed, or what was going on. Coincidentally, soon after she began to notice these

challenging behaviors at home, the school contacted her about her son's behavior

problems at school.

We take my Dad to [a place] up the street. It [the route] would have to
be the same way [every time]. If I went straight instead of turning, my
son would just get all blown out. Just obnoxious. Screaming. [She
demonstrated with her own hands] He does his fists and then shakes.
That got to be hard [for me to deal with]. I didn't know what was
going on. That's when I got a call from school. They were having
trouble. The school first brought it to my attention where he was
having trouble transitioning where he could go from reading to math.
He would refuse. Then [he would] throw his notebook down, and then
he would grab at kids at their arm. At that point, he was grabbing
[other kids] at the neck when he would get upset.

While acknowledging that her son's behavior was problematic, she was unsure what to

do. She agreed, however, with their request to do an Attention Deficit Hyperactivity

Disorder (ADHD) checklist, even though she didn't think that ADHD was the source of the behavior.

> Their first thing [that happened is that] they would call me and say, "We want to do an ADHD quick checklist." I said, okay, but I don't think he is [ADHD] because my child's learning. He went into Kindergarten only knowing how to count to 3, and at this point he was already counting by 5s, 10s, 20s, and knew every kid in the class. I knew there wasn't any attention [problem]. Something was going on. A couple times I was there [at his school] I was seeing that. He had a teammate at doing something [repetitive board patterns] and she wasn't doing it his way. He was doing it right because they were doing patterns on a board and when they would get to the end, he knew you were still supposed to do the pattern. But she wanted to start over. I saw it [the behavior of hurting other children] there. But he couldn't express that [he knew he was doing it right].

This mother was in a very perplexing situation. She knew that something was not right, because she had visited her son's class while he was there, and had observed the behaviors of concern. She also could see why her son responded the way he did, and knew that his behavior was not appropriate. She agreed to the school's request to do the ADHD checklist, even though she felt confident that ADHD was not the source of her son's behaviors. Her experience was that of supporting the school's request, but feeling that the school was not willing to listen to her—to hear how she thought about her child's behavior. But neither could she identify the source of the behavior, or what should be done about the behavior.

Another mother reported that after choosing to leave one in-home program where she had received some feedback about her son's challenging behavior, she had enrolled him in another in-home program that was more structured. While her son's behaviors in the first setting had been mildly aggressive, the behaviors escalated in the next setting, and she began to get frequent feedback about her son's behavior.

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Then when he was 3, I switched daycares, and then we really started
having problems. … The woman who was running it talked to me a
couple of times about how he wouldn't sit still during circle time, how
he would fidget a lot. So we talked about strategies about how to deal
with that. And then there was an incident where he kind of attacked
one of the other kids. He scratched them a couple of times pretty
badly. And that parent kind of freaked out.

And then his energy level, and not being able to focus for even a short
period of time, was frustrating for them. So I asked them to persevere,
because at the time they had wanted us to consider leaving. My second
child had just been born, and we had also just bought this house, and
we were in lots of transitions. So I asked if he could stay (and he was
still only going 2 days a week), and he stayed until March of that year.

This mother had worked with her son's teacher about strategies to help him sit

appropriately at group time, but that still didn't address his aggressive behaviors towards

other children. Even though she knew the program director was asking them to leave the

program because of her son's aggressive behaviors towards other children, she asked if

they could stay just a little bit longer—until the transitions in their life settled down. She

experienced being heard by the program director, and her son was allowed to remain in

that program for a short while longer. But because of their life situation (new house, new

baby), the only solution she could see after his leaving the program was to keep him

home with her. With a look of defeat on her face, she said, "and then I just took him out.

At that point I was just staying home, and so then he just stayed home with me."

Another mother described the frustrating experience of not being heard by her

son's teacher. On repeated occasions, she asked for communication about her son's

behavior at school.   The teacher only passed on negative phone messages and made no

apparent attempt to see any positive behavior that her son might present.

I've been going to my son's classroom on Tuesday afternoons to help,
and I see how negative a teacher can be. I've never gotten a

> communication about something he's done good. But I get all these e-mails and these phone calls about things that aren't cool, the problems he's causing, but I don't get communications [about his good behaviors] and I think that's a good reminder for me as an educator how important that is. Because, by gum, if he makes it through a day, through a class, without doing something wrong, I'd sure like to hear about it.

This mother was consistently proactive in her attempts to have productive communication with her son's teacher. From her vantage point as an educator, she asked if the teacher would be willing to send home a daily report about her son's behaviors.

> I asked her [the teacher] if she would be willing to send home a daily report. And it was all negative. So, I'm thinking, he's there for what, 5½ hours, and I can't believe he did everything bad. So I'm thinking, could I make some little report sheet where she has to mark that he did things some of the time, or most of the time. Like, did he keep his hands to himself some of the time, or most of the time? Even if he brings home "some of the time," great!

Again, this mother did not feel that her son's teacher was willing to "really" hear what she was asking for. While her intent had been to establish a positive communication experience with her son's teacher, the teacher turned the daily report system into an informative, but negative, experience.

When one mother's son was about 18 months old, he received physical therapy and occupational therapy services through their school district's early intervention program. Having met the goals that were set for him, the family moved on. Then their son started having issues at daycare where he was hitting and biting other children. During a 2-month time period, his parents were receiving notes weekly, and sometimes daily, about their son's behaviors. She experienced feeling defensive many days that she picked her son up from child care because she interpreted the notes to mean that her while son had a problem at child care, it was up to her to fix it the problem.

So any time that there was a biting incident, we would get a report to
us about that. The teachers were saying basically that your child has a
problem and we had to fix it.

When asked how that felt, she paused briefly before continuing.

It was hard. I think I told you before he's our only child, and being a
first time parent, you read about biting. The way it was approached to
me, I got very defensive. I hated to pick him up every day because I
would get a note about what happened.

This mother's experience is not unique among parents of children who engage in

challenging behaviors. It is very possible for the pick-up experience from child care to be

a fun experience. Parents are happy to see their child whom they have been away from

all day. Children are happy to see their parents and excited to show them a special toy

they played with that day or a special project they made. Or maybe there is a note from

the teacher describing something fun or interesting about their child that day. When

parents have had negative pick-up experiences and begin to have anxiety about picking

up their child from childcare, the joy that could be shared between parent and child is

diminished, and possibly even destroyed.

Another mother reflected on the ways she had been informed about her son's

challenging behaviors at two different childcare centers, and how she felt about it.

At [the childcare center], they've just given me the oral reports, which
is a lot nicer. At the other one, they were like, "I have to have you
sign this," for every little thing. It just seems so institutionalized—it
didn't seem as caring to me.

Similar to other parent's experiences, she knew that she needed to be informed about her

son's behavior. It seemed easier, however, to receive the information if the teachers

showed even a little bit of empathy or caring about her and her child.

I Felt Angry When Teachers Described My Child's Behavior in Front of Other Parents

Another mother told of similar pick-up experiences with her son. She also

elaborated upon the experience by describing the angst she felt every time she left him.

Her distress was compounded by the insensitivity she experienced when picking him up

from preschool.

> We did Early Childhood [Family Education or ECFE] that whole year,
> and that was good. That's where we needed to be—I felt way more
> supported. He would have behaviors there, and throw the ECFE
> teachers, but the Special Ed. staff was there and I didn't worry so
> much because I knew that there were people who were more capable
> of handling him, than like in our initial experience, with the
> community program. And if he lost it, they could pick up the pieces.
> And I worried the entire time he was there because you just don't
> know what he might be doing—hurting himself, or somebody else, or
> destructing the property. And then you go to pick him up, and they
> say, "Blah, blah, blah, he pulled somebody's hair while we were doing
> art, he hit somebody while he was doing art." His fine motor skills
> were delayed, and art was frustrating, and I don't know if they picked
> up on it or not (ECFE). I said, "Can't we just skip art, can we just keep
> him out of that environment?" But they kind of wanted to keep him
> with the group, and try things. And I think they were trying standard
> fare, and then the OT would get more involved, and they started
> pulling him out for more special ed., and they always made sure that
> he had an adult in the regular ECFE room.

Her experience was that of not being heard by the ECFE staff in her son's program. She

knew her son's limits, and thought that it was more important to have him be successful

in the total school experience, rather than continually put him in specific situations where

she was pretty sure that would be unsuccessful.

> The year that he was 4, he actually went to a preschool at church. And
> I did that because that's what everybody was doing. It was time to get
> out of ECFE, and I did it. I talked to the director, and I said here's
> some background, here's some behavior issues. It was falling apart
> right from the get go. I mean, he was whipping [throwing chairs]. It
> wasn't so much hyperactivity—he could sit during circle time, but he
> might hit somebody.

When asked how she got that information from the teachers, her voice took on a harsh

tone of indignant sarcasm as she said, "Notes—or right in my face when I picked him up.

Right in front of other parents. It was very nice."

A different mother also recalled an insensitive interaction when her son was asked

to leave his daycare. At the time of the interview, approximately 2 years had elapsed

since the incident, but it was still a very unpleasant experience in her memory.

> There was a point [at which] he was asked to leave his daycare, and he
> was about 3½ then, and he was still biting. It was just amazing. I can
> talk about it, I mean I didn't like it then, I don't like it now. But it was
> [pause] part of it was how it was done.

> I told you he was born in [another country]. So he's [of another race].
> This was a small family daycare and there were five or six kids. I felt
> like we were on good terms with the daycare provider and the other
> parents. He was biting kids and I knew nobody liked it, but people
> seemed to kind of accept it, and all of a sudden one day, well, let me
> back up. I'd go [to pick him up], and it was in the season where
> parents were standing outside, the weather was nice, and the kids
> would be in the back yard, and the parents would come,

> and everybody would kind of gather there. I'd show up to pick him
> up, and the daycare provider would say, "Well [my son] bit so and so
> today." In front of all these people, and this happened like day after
> day after day.

> Eventually one day, she said, "Can you stay for a little bit?" And I
> said "Sure," and she said, "I'm going to have to ask you to leave. The
> other parents aren't comfortable because he's biting." And I said,
> "Well, has anybody been really hurt?" I felt like I'd really been
> stabbed in the back by some of these parents, and it turned out that at
> least one of them was concerned that he was carrying a communicable
> disease because he'd been born in [another country].

> I was just floored. I talked with my pediatrician about it, and she said,
> "He's been tested twice, here and in [the other country]. He's
> negative. He's more at risk, and the other kids are more at risk than he
> is, because they've probably never been tested." So I told her [the
> daycare provider] that, "So if he bites somebody and draws blood, he's
> at risk."

> There was another mom that went to bat for me, and they backed off
> and said we could stay. I was teaching. They said we could stay until
> the end of the school year. But, [holding her thumb and first finger
> millimeters apart] I felt like I was this big.

She summarized her feelings about these experiences by simply saying, "You know, it

was terribly humiliating to me—terribly embarrassing. And I kept thinking, I've done

everything the pediatrician's recommended. I've done everything the daycare provider

has recommended, and I don't know what else to do."

I Felt Disheartened When I Thought Teachers Were Unfair, and Even Unprofessional

For one mother, her son definitely had engaged in challenging behaviors such as

biting or hitting other children, and while she did not like the way information was

presented to her, she never denied the existence of the behaviors. There were other times,

however, that she received verbal reports of something he supposedly had done, but she

later found that the report wasn't accurate. While she had self-described her reactions to

the other notes as defensive, there was a tone of outrage in her demeanor as she described

a situation in which her son was accused of intentionally hurting another child, when in

fact, it had been an accident

> I think it's crazy where I was told of a case where my son supposedly
> pushed someone, but another teacher saw it. What really happened
> was one of the little kids who was just learning to walk pulled herself
> up on the back of his shirt. He turned around to see what was going on.
> As a result of him turning around, the little one just coming up [his
> shirt] was knocked over and she started to cry. [It was reported that
> the teacher said to my son] "Why did you push that kid down? Don't
> push people." He was just turning around to see what was going on
> and bumped the little unstable one over.

> One teacher scolded him and then he got upset. The other teacher saw
> from across the room what really happened. So he got scolded, he got
> upset, for something that he didn't understand what he did.

When asked if she thought she was always getting the full picture, she replied that maybe

only parts of his challenging behaviors were being seen.

> I think that what was happening is little bits would be seen, the bad
> part, so he was labeled as the bad child, the trouble maker. Again,
> from looking on the Internet [at an article titled] "Is your child labeled
> the bad child? Could other things be going on?" I thought, I wonder if
> other things are really going on. If you give him a book and ask him
> to sit down and read a book, he's happy as can be. But if somebody
> comes over and tries to take that book from him, he's going to get
> mad. And I don't blame him.

Similar to other mothers' experiences, she was willing to accept the negative reports

about her child's behavior. But she expected that the teachers would treat her child

fairly, and only report the accuracy of real occurrences, not assumptions of what

somebody thought might have happened.

Another mother knew that her child was being aggressive with other children, as

she had seen it herself when she visited his classroom. She also had a good

understanding of what her child understood and did not understand. When she was

informed that her child would be punished in a way that she was certain he did not

understand, she called the school to try and advocate for her son.

> He got more physical [when he couldn't express his frustration]. He
> wouldn't use his words. He'd use more actions. It upset me, because
> one time, he hit a kid [early in the week], and then they called me and
> they [the school] said, "We just want to let you know that if he hits
> again [this week], he's not going to go on the field trip next week." I
> got a note [later that week] saying that he [had] hit a kid on
> Wednesday, and the field trip was the next Monday. I called and said,
> "This is really unfair. My son doesn't even know what tomorrow is,
> let alone next week. I think you're punishing him wrong." That was
> bad all that year. They just wanted to punish the behavior, not see
> what was going on.

This mother again experienced not being heard by the staff at her son's school. While she was motivated to find out what was really "going on" for her son, she thought the school was only willing to look at one piece of the total picture—punishing him. At this point, she called her advocate at the Association for Retarded Citizens (ARC), asking for help in advocating for her son.

While parents didn't enjoy the process of becoming informed about their child's challenging behaviors, they also knew that they had to be informed. On occasion, parents were open to giving their child's teacher the benefit of the doubt, because they thought it was possible that the teacher was doing the best that she or he could do. In some situations, however, parents clearly had expectations when they knew that their child's teachers were trained as professional educators in formal educational settings. They expected them to act professionally, which did not happen to one mother.

> I would get it [the information] in daily notes, sometimes in person. Usually, I think people were pretty up front with me about how it was going. But then, I did have, I think I had the most unpleasant experience when I moved into a new office at work. There were some files that hadn't been cleaned out, and one happened to be on my son. And I was like, oh, cool. A file on my son. And I opened it up, and in red letters on a piece of paper really big was "Another day from hell with [my son]." And that really made me angry as a teacher. That someone would write it, and put it in the file. That would be one you would write and shred [as a teacher], and just say, "Whew, I'm done with that." And as a parent, it really broke my heart. Probably [because] the person who wrote it (because I knew their hand writing) really made me lose trust. That was an interesting feeling as a parent. To have someone that you held pretty close, and to find that [the file], and to know that they wrote that. So that was a really icky time.

This mother experienced a roller coaster of feelings regarding this particular note. At first, she described the excitement about finding a file about her child, and assumed that reading the information would be a pleasant experience. Her glee quickly changed to

anger when she realized that the person who wrote the note was a trusted colleague who had written such a note in anger and left it for others to find. Like the other mothers, she was not in denial about her son's behavior—she knew the situation was really bad. But she felt betrayed and disrespected when she discovered that a trusted colleague would say such things about her son behind her back.

When talking about the teacher's feedback that she had received about her son, another mother easily focused on recent situations with her son as a preschooler in which she had been asked to leave a program. When asked if that was the first time she had been asked to leave a program, she paused. After a few moments of thoughtful reflection, she recalled an experience when her son was only 6 months old.

> Um-m-m. When he came [to us through adoption], like I said, he was 6 months old. We attempted to take him to an ECFE class which was for kids between 6 to 12 months. We were in this room with all kinds of toys, and they put out a mat, you know a big gym mat, and the parents and children are supposed to sit on the mat. The parent and the child [sit], and listen to stories, and [he's between] 6 to 12 months old. He was crawling, he was exploring. I mean he's always been driven to explore, for lack of a better word. And she would put out this bin of toys. The baby toys were in the middle, and the babies were just supposed to stay in this confined area. Well, in the meantime behind us, there are all these climbing toys, toddler toys, and he was a little more interested in them. So he would leave the mat, and go back to those toys. And she would tell me to go get him. I felt like every week we were scolded, that we were supposed to stay on the mats. And he wanted to take off. And it was pretty obvious that unless I just held him and he cried, he wasn't going to stay there [on the mat]. I mean he wouldn't just sit there, just sit there and play like the other kids did. And I didn't know why. I still don't know why. And eventually she asked me to leave the class because she said, "I don't have time in between my other classes to go clean all those other toys."

When asked if the ECFE teacher provided her with any other resources to explore her son's behavior, she replied, "No, we were just a problem. We switched to a different activity in a different district and had a marvelous positive experience." She continued.

> But this [the first ECFE educator] was also the woman who opened the
> first day of class with having parents talk about their labor and
> delivery stories, when it was very obvious that not everybody had that
> … So, after about 4 weeks of that, I thought, I don't need this.

This mother's experience was that of having the needs of both herself and son disregarded. She endured this experience for a short time before deciding that "after about 4 weeks of that, I thought, I don't need this." Of the 10 mothers interviewed, her son was the youngest of all the children who were asked to leave a program. And in ECFE, the child is not the only one asked to leave—the parent is excluded also.

Summary

As stated earlier, while parents need to be informed about their child's behavior, early in the process, it is very difficult for them to hear the information. While some of the mother's comments in this theme did reflect their unwillingness to hear the information about their child's behavior early on, more often the comments were about the manner in which the information was presented to them.   Mothers felt disrespected when teachers or caregivers spoke to them in voices that were loud enough for other parents in the same area to hear all the details of their child's unsuccessful day. While they were able to understand the problems that their child's behavior was causing in the classroom, mothers experienced times when the teachers made assumptions about their child's behavior which were not true. They felt angry about this. Teachers did not seem willing to work with the parents to create communication systems so that parents and

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teachers could share daily information. It also seemed that teachers only shared negative

information about their child. It just seemed that teachers were unwilling to look for the

"good" in their child, and about this, mothers felt much sadness.

Theme #3: I Sense That Others Think I'm to Blame for My Child's Behaviors

"People think it's my fault and that if I say anything I'm just making
excuses. That is my impression—most people think that if a child is
acting out in public, that you're too lenient—and you have no
consequences, or no follow-through." a mother in this study

A frequent occurrence reported by parents of young children who engage in

challenging behaviors is the experience of feeling criticized by others. While these

experiences are not limited solely to situations involving their children's behavior, the

times that parents reported feeling criticized the most often paralleled the times that their

children publicly presented behaviors considered socially undesirable or unacceptable.

What were these experiences like for the parents? Parents described what it felt like

when people told them directly to their faces that their children's behavior was their fault,

while other times they presumed that people were thinking that it was their fault. Parents

worried about what other people thought of them, realized that there were times when

they as a parent could have handled things in a better way, and in the end, wondered if

their child's behavior really was their fault.

Some People Tell Me to My Face That it's All My Fault

One mother recalled being told directly to her face by others that she was not

doing a good job as a parent. An experienced teacher of many years, and skilled at

working with challenging children, she was told directly by others that she wasn't doing a

good job:

And I've had people tell me that I shouldn't have adopted if I couldn't figure out a way to handle my kids. And I've had people say it directly to me—if you would only do this then you wouldn't have this problem … be more consistent, be stricter, be harsher in my discipline, do what you say and say what you mean. My response to all of them is, 'walk a mile in my shoes and then be critical of me'. Or sometimes people say to me, 'well, if you just give him consequences at home. . . . You become really cynical, [like] 'why didn't I think of that?'

Not only did this mother receive such information from friends and family, she also recalled one conversation with her pediatrician in which he said, "Well, you just have to tell him what the limits are and enforce those limits." Highly offended, she thought, "Like, hello, I've been doing that for 6½ years, you know, and I'm good at this."

In reflecting about her experience of being told that it was all her fault, she recounted a conversation with the psychologist in which the psychologist helped her talk about how she didn't feel like a very good Mom.

Psych: It's pretty apparent to me that you don't feel like you're a very good mom.

Mother: I don't.

Psych: Why do you think that is?

Mother: Like could I just go down the list of all the people who have told me I'm not doing a good job? … I could just give you a list of all the people that have told me I'm a really bad mom.

Psych: It sounds like you've kind of been bashed.

Mother: That's how I feel. I feel like I have just been bashed. By a lot of professionals, which is almost harder.

I think, okay, if I'm really such a bad mom, if I'm so inconsistent and if I'm really missing the boat, why is my younger son [who does not engage in challenging behaviors] the way he is?

This mother felt confident that she was doing the same thing with both children. She didn't understand why "Other people don't get it, that if I was really so lenient, then why

wouldn't they both be like my older son is?"   Her experience, once again, was that others

didn't hear her frustration of knowing that she was already doing all of the things that

were being suggested to her, but none of them were working with her son who engages in

challenging behaviors.

Regarding others' judgments of her parenting skills, another mother summed it up

simply when she said, "People have told me throughout it doesn't seem like I have good

authoritative [skills]; I don't have good control over him. They say I don't discipline

him."

When I Sense That Others Think My Child's Behaviors are My Fault, I Worry About

What They Think About Me as a Parent

One mother described a public incident with her son that involved ending one

activity and getting ready to go home, when she felt vulnerable to the scrutiny of others.

> For example, tonight we were at an event at school, and it went until
> 8:00. We were there at 6:30. At 7:30, I said, "In 15 minutes, it will be
> time for us to go. We've got 15 minutes left for you to choose."
> About 7:30, people had been there for about an hour, lots of families
> started leaving. And I watched family after family say to their kid
> ['it's time to go']. It's just so interesting, because I said, "In 15
> minutes we need to go—how do you want to spend your last 15
> minutes?"

> Other families just say, "Come on John, come on Mary, it's time to
> go." And up they went and off they went. With no problem. And yet
> at 15 minutes, and 10 minutes, and at 2 minutes [I give the warning].
> And he has a temper tantrum, starts crying, screaming, "I don't wanna
> go, it's too soon." You know, he and I have talked about this, and I
> said, "Have I ever changed my mind? When I say it's time to go and
> you have a fit, have I ever changed my mind? No. So, why'd you do
> this?" He doesn't know. But he's screaming and crying, and [he
> thinks] it's too sad, and it's whatever. And I'm totally humiliated in
> front of all these people. Everybody's looking at you, and they're
> thinking, like, you know. In situations where we don't know people,

I've heard people say, like to who they're with, "Boy, some people just can't discipline their kids."

She felt humiliated and was painfully aware of the difference between how other children easily complied with a single request to leave, and how her son emotionally responded to her well thought out preparatory cues to get ready to leave. His tearful outbursts and ultimate tantrum brought the kind of attention she had come to dread: the unspoken message that says she doesn't know how to discipline her child.

Another mother described how she and her husband have made changes that don't require so much of their energy when dealing with their daughter

She doesn't really take our energy any more, like she used to take it. Now it's just so calm . . . we give her two choices, telling her what she has to do [ex: You can put your toys in the basket or you can put them in the bucket]. She still throws her fits, she throws [herself] down on the floor, throws things, stomps, screams, you know. But it's just—it doesn't faze you. It's when other people are around it. Like "oh my gosh, you deal with THAT? She [for that reason] doesn't go to stores.

But she still feels vulnerable to the looks of others when her daughter acts out in public.

With much frustration, another mother talked about the difference between what she thought parenting would be like, what it's actually been like for her, and how that impacts how she sees (and questions) herself as the parent of a child who engages in challenging behaviors. Her voice got very quiet, as she cupped her hands around her mouth to mimic the unspoken whisper that asked the question "what do you do when she's like THAT?"

For some reason, I thought it would be easier. You know, you always have that idea that parenting is going to be easy. Because everybody tells you that you can do it, and if it's not working out, it's your fault. It's always like it's the parent's fault. Sometimes it's just the child having issues.

When asked if she had received that kind of information, that if something's wrong with the child, it's about her, she replied, "Yeah."

> It hasn't come out [verbatim], but people are like, "what do you do when she's like <u>that</u>?" Look at me. I think I'm a pretty good parent here.

This mother continued describing her response to what she thought others were thinking about her as a parent. She had begun the interview by describing the difference between her 4-year-old daughter's behaviors at home and her behaviors at school. At school, her daughter was "the perfect child," but as soon as they walked out the door, she began the challenging behaviors: "I don't want to do that [go to the car], I don't have to do that [go to the car]." Once her daughter was inside the car, her protests continued, escalating into throwing things inside the car, and kicking the back of the driver's seat during the ride home. One time she ran down the street. When describing these situations, this mother was surprised at her unexpected emotion, and told most of this story through tears, stopping briefly to catch her breath between situations.

> In stores, she screams. She's really smart. She screams, "I hate you 'cause you don't love me anymore. I hate you because you take things from me and you're mean to me." And then people look at you. She goes, "I hate you because you try to hurt me," which I never do. (It's pretty funny because this is just because I'll say, "you can't have that toy.") If I heard that from another person, I'd think they're abusing their child. So I've just taken her out of stores. I never did this when she was 2. It's only been since this summer [she's 4] that I've had to physically carry her out of stores and physically put her in her car seat because she's screaming and yelling. She's not little.

This mother's typical response in such a situation was to wait for the screaming to subside. As she described how that worked, she said, "Then I stand outside the car a lot and she screams in her car seat. I'm thinking, "What are these people thinking?"

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When asked what she thought the teachers thought about her as a parent, one

mother shrugged and rolled her eyes upward as she quickly answered,

> Well, I'm sure they probably said what the hell is going on in her
> house. How can she be a preschool teacher and be so good with [other
> people's] kids, and look what's going on with her son. I think that was
> probably the hardest thing for me. And the parents whose kids were
> getting hurt. They knew who I was because they knew he was my son.
> Here I am a preschool teacher in their center, and caring for kids.

As a professional educator, she was well informed about the issues around child

maltreatment, and the responsibility that professionals have when they have concern

about a child's well-being. She described in detail one situation with her child that was

particularly worrisome.

> I think my scariest moment as a teacher was when I literally had to
> haul him [then 4 years old] out of work in the arm hold. His legs are
> flailing and he's trying to hit me. I put him in the car in his seat and
> closed the door. I'm sure I slammed the door actually and then stood
> back, saying [to him] "When you're calm, we'll leave." And so I
> turned like this [she rotated her body 45 degrees] and I see a parent
> going [looking at me questioningly]. And I'm going, what did I just
> do? What did I look like? And I went over and I talked to her and I
> said, "Oh, I suppose you're wondering what I'm doing?" She goes,
> "Yeah, because my son does that to me. I just don't know what to do.
> So how is it working?" So it was like instead of being judged, (like,
> oh my God, I can't believe you're doing that), it was like, hey, how do
> you make it work?

She was glad that her experience was helpful to another parent. But it still was unnerving

as she "realized a parent was watching me, because of my professional job [as a licensed

teacher]. Did I [she asked herself] do anything inappropriate right now that I could be

called on?"

Another mother was well aware of her daughter's behaviors, and had concerns about how the people at her daughter's school might treat her daughter. When asked if she had ever felt that the teachers didn't like her child, she replied,

> Well, that's why I volunteer, and that's why I'm always hanging around the school. I'm trying to be the nicest person I possibly can, because I feel that if I put on the positive front that I'm really working, then they'll be nice to my daughter. That I'm not this monster—they probably have visions like, "Well, no wonder [my daughter is the way she is]".

Her fear about how the teachers at school might treat her daughter prompted her to volunteer at school. Her experience was that of hoping to be understood—that if teachers had a positive experience with her as a volunteer, they might think that she had the ability to be an effective mother, that she was probably trying hard at home with her daughter, and thus be nice to her daughter.

As one mother began reconstructing the process by which she became more aware of the intensity of her son's behaviors, her shoulders dropped slightly as she sighed, then briefly paused, before explaining how at the time she wasn't convinced that something was really wrong, but she didn't know what else to do. With a note of resignation in her voice she continued:

> I think people didn't think I did enough, that I didn't react enough. Like when something would happen, I wouldn't make a big scene about it. Because a lot of the time (I didn't want him to hurt other children, ever), I would do something. But I just got the feeling that it wasn't enough to appease the other parents. I think that a lot of time, they [other parents] wanted me to make a bigger deal out of it.

The problem was that she didn't know how to make a 'bigger deal' out of it. She knew that what she was doing wasn't working. With a hint of exasperation, she said, "I didn't know what to do. And also, I was embarrassed."

The way that one mother described the following situation, it seemed as though

she was caught between a rock and a hard place. She felt like she couldn't win.

> I send him to OT [occupational therapy] for his sensory [needs].
> Cutting his fingernails and getting his hair cut are the biggest chores of
> the world. They're [those chores] very bad. He's been in [OT] over a
> year and I'm not any closer to being able to cut his fingernails or his
> hair. His last hair cut, my brother in law did with his clippers. But
> he's [my son] very strong, so it's a very hard chore to get done. My
> brother-in-law took him out in the back yard and [just like that] he was
> done. He [my son] had not one episode. It was more a tickle thing
> [the way my brother-in-law used the clippers]. I watched and it was
> great to see. But the fingernails, I have to sit on him. I've gotten notes
> from school. He's got marks on his wrists. Can you explain these?
> Yeah. I tried to cut his fingernails. Then I get notes from a different
> school saying his fingernails are long. Can you please cut them? I
> can't win.

It was evident that this mother knew her son well. Because of his sensory needs, she

knew that clipping his fingernails would be upsetting to him. So, in choosing not to upset

her son, she delayed cutting his nails. But this put him in the situation of having nails so

long that he scratched himself, leaving marks that the teachers noticed. She was then

asked to do something about the nails. But when she attempted to cut his nails, he

struggled so much that he had marks on his wrists, and teachers asked for an explanation

about the marks. From her perspective, the people at her son's school were not interested

in understanding how difficult it was for her to manage this aspect of her son's personal

hygiene. It seemed like there was no way for her to win.

Sometimes I Need Help—I Think There are Better Ways I Can Interact with My Child.

Not one mother presented herself as perfect, or as having all the answers. While

mothers talked about the successes that they eventually had when dealing with their

child's behaviors, they also acknowledged that there were times that they felt that they

could have done better. Some mothers talked about the reality of repeating certain interactions with their child that they knew were previously unsuccessful. Other mothers talked about feeling uncomfortable with some of the choices that they had made. Most often, mothers described choosing those interactions because they were tired, frustrated, or just didn't know what else to do.

When talking about her goal of seeking professional help for her and her son, one mother clearly wanted new and better ideas about how to interact successfully with her son.

> It's definitely one more thing that I want to do—[get more help with] problem solving. I think consistency is one, and from more people than just me. I bribe him too much. I need someone to help observe. My sister-in-law does that with me. She's very smart, provides objective voice, devil's advocate, whatever. Sometimes she provides more feedback than other times. I think sometimes she gives up, [I think she's probably] saying "There she goes again, driving her kid." I'll just say quickly sometimes, you get in the habit of saying stuff when you're tired, instead of doing something different. I just do the same old thing, like "You're not going to get this, if you don't do that."

Her continued dialogue indicated some ambivalence about the concept of what works and what doesn't work. In one breath, she expressed comfort with the idea of saying the words to her son, "You're not going to get <u>this</u>, if you don't do <u>that</u>. Because that's usually what works, and I just want to do what works." Soon after, however, she indicated that she thought those words were indicative of bribing, and it seemed as though she wasn't comfortable bribing him. Because her goal in seeking professional help was to get new and better ideas about how to have more frequent successful interactions with her son, she was ready to move beyond using bribery as a way to set limits with her son.

Another mother voiced a similar desire to do things differently when dealing with her son, because the traditional forms of discipline were not working.

> We've really felt like we're at a loss of what to do any more as far as handling tantrums and anger. Because the traditional forms of discipline, of handling the situations, they never have worked, and they really don't work now. Instead of finding new ways, we're just becoming increasingly frustrated because time outs don't work. What I end up doing is making threats that probably 75% of the time I don't follow through on, and that's just ridiculous. I just do it, and as it's coming out of my mouth ("you <u>know</u> you're not going to do that!"), I just feel like I have to say <u>something</u>, I have to do <u>something</u>. So finally, I just said we're going to go to the next step, and actually we've been on the waiting list at the Autism Center. But they have this waiting list, and we just can't wait [so that's why I've arranged for this person to come].

At the time of the interview, she had just arranged for a professional to come to their house and start working with her and her husband, just to have some strategies at home.

> One mother verbally created a scenario in which it became clear that in times of stress, her behavior was different than how she typically interacted with her son.

> There were nights that I was completely overwhelmed and if my husband wasn't there, I don't know what I would have done. I would have picked up the phone and said, "Mom, I need your help now."

When I asked, "tell me about overwhelmed," she paused, and then continued.

> Just where he [my son] keeps telling me, "I can't, I can't." [And I say] "Yes you can, you can." [And he keeps saying] "I can't, I can't." Or I'm tired. [I ask myself] How much longer do I keep going? So I just do it [for him]. That's being overwhelmed.

It was obvious that this was not a typical interaction that she would have with her son, as she had plenty of examples in which she was successful in encouraging him to attempt tasks that he successfully completed. This situation exemplified her meaning underlying a statement she made later: "Not always can a parent do everything."

One mother described in great detail, the work of Howie Glasser, author of

Transforming the Difficult Child, (also known as The Nurtured Heart Approach). She

indicated that Glasser's approach "has made more impact than anything else we have

done."

> He [Glasser] starts out by saying, "We're our kid's best toy, and our
> kids know how to push our buttons to get reactions out of us." And
> difficult kids like intensity of reaction. And so, they do expect to push
> our buttons and get these reactions. Like, is that true or <u>what</u>!
> Obviously he [my son] gets a reaction from me. And it [Glasser's
> approach] really works. And I blew it tonight. It's like he had this big
> melt down, and so I'm walking him out to the car, saying everything I
> shouldn't say. But I'm human. And I think, well, he got my buttons.

Her use of the words, "but I'm human," so clearly describe the humbling experience of

dealing with her son's challenging behaviors—the frustrating and unbalanced walk

through the emotional minefield of having the knowledge of what to do, but not always

remembering or being able to use that knowledge.

Hannah wanted her son to have a bilingual, bicultural experience so that when he

spent time with his non-English-speaking grandparents he could communicate with them.

On an extended trip to the grandparent's country, she enrolled him in a local preschool,

hoping for him to have a cultural "immersion" experience. As his challenging behaviors

escalated in the classroom, one of the teachers finally spoke to her.

> She ended up telling me that she really thought that he was acting out
> because he was insecure because he had been going through so many
> transitions and because of the culture shock [of the new school in a
> different country]. She [the teacher] said that she had seen him go
> under a table, or hide in the school at one point. And she thought that
> that might be something about him, that in this new environment he
> was really not adjusted to it, and he wasn't ready for that change.
> Then I thought, "Wow, I really made a mistake." He had been in that
> environment for already a month, and I'd been involved in things
> where I couldn't really change daycare, and I didn't have anybody else

[for childcare]. So, I tried to make adjustments for the rest of the time.
I mean, I felt guilty.

Her intentions had been to help her son have the language skills to communicate

successfully with his grandparents. But through her experience of feeling guilty, she

concluded, "I felt like I was doing a good thing. It didn't go very well."

I'm Beginning to Question Myself—IS It My Fault?

As they reflected on their experiences, some mothers' parents wondered if their

child's behavior *was* a result of something they were doing wrong. As the struggle of

their dilemma became more clear, their self-talk became louder as they began to

understand what was happening, but had no idea how and why the behaviors were

occurring. Ultimately, the question arose: IS it my fault? This question was verbalized as

"have I been a bad parent?', "what am I doing wrong?', and "maybe I'm just not giving

him enough attention."

With much emotion and tears in her eyes, one mother recalled how her son's

behaviors just kept going "up and up." While she was well aware of the challenges of her

son's behaviors, she didn't have self-doubt about her parenting skills until one daycare

provider announced that her son could not return to the daycare. She really questioned

herself as a good parent when the daycare provider handed her son to her, saying she

couldn't take it anymore.

> It just kept going up and up [his behavior]. I remember in home care,
> coming to pick him up, and this woman handing him to me and saying,
> I can't take it any more. I said, "What do you mean you can't take it
> any more?" "All he does is cry [the woman said]." As a mom, I was
> angry at her that she didn't give me more information. Then I was
> feeling bad for myself. Have I been a bad parent? Has he not been in
> good care and I haven't realized this? Then feeling sad for my son.

> Have your needs been getting met? These are crucial formative
> months. What has been going on in your life?

This mother knew early on that her son was different from other children. While she had figured out strategies for successfully interacting with him at home, she first seemed surprised, then angry, that others would find his behaviors difficult to deal with. But from the surprise and anger, she quickly moved to questioning herself as a parent.

One mother's child had received Early Childhood Special Education (ECSE) services for motor delay when the child was about 18 months old. Having attained the motor goals that the occupational therapist and physical therapist set for the child, the family moved on. When their child was about 2½ to 3 years old, they began getting reports about biting and hitting issues at daycare. Her eyes filled with tears as she recalled the February–March time frame when she first started getting reports about her child's challenging behavior at day care. Visibly swallowing before speaking, she said,

> That was the February–March time frame and it was for a couple
> weeks in a row, probably once a week. The teachers were saying
> basically that your child has a problem and we had to fix it. I took it
> personally that I must be doing something wrong. Why is my child
> doing this if no other child does it? What am I doing wrong or what
> should I be doing, or what shouldn't I be doing?

As stated earlier, mothers often questioned their parenting abilities as the source of the problems that their child was experiencing, rather than concluding that their child needed help.

Another mother appeared thoughtful as she talked about the school her child attended when visiting in another country, and how the staff at the school had managed her child's behavior in the classroom. Thinking about that experience, and reflecting on

recent reports about her child's classroom behavior, she also considered how she and her

child interacted at home.

> They just gave my child a job, they let my child pass out bowls and
> pass out the spoons. Normally they need to pass off these jobs to other
> kids because everybody wants to do it. But they ended up letting my
> child do it all the time. Because the only way to keep my child out of
> trouble is [to make sure] if my child is occupied.

> Yesterday my child was chasing the other children too much and my
> child wouldn't leave them alone, and they were really tired of it, and
> my child just wouldn't let up. My child was still chasing them, and
> my child just wouldn't let up …and the teacher just sat with my child
> in the sandbox and played with the sand, and as long as my child was
> directed and occupied [the behavior is okay]. . That's what I've heard
> all along.

> I think my child just wants attention and tries every way to get it. It's
> one of the things that I say to my child when he pulls on my ear, or
> when my child yells in my ear. "That's not the way you get attention
> you know." But then, again, I think how <u>is</u> my child going to get
> attention in a nice way, because maybe that <u>is</u> the only time I give my
> child attention.

When reflecting on the reports she had received about her child's behaviors, and

contemplating my child's need for attention, this mother considered the possibility that

maybe her interactions with her child caused him to act out. She wondered if she was

doing something wrong, and concluded, "maybe my child wants it [attention] that bad,

and I'm just not giving enough."

One mother had expressed many emotions during much of the interview, but her

voice took on a note of confidence as she described the experience of realizing that her

daughter's behaviors were not her [the mother's] fault.

> Once I realized it wasn't me, [but that] it was her behavior [that was
> the problem], I realized I hadn't changed anything [that would make
> her act that way].

In response to the question, "how did you realize it wasn't you?" she continued,

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All of a sudden I went, hey, I'm not the bad parent. I have to figure out why my child's acting this way. I didn't consciously make her do that [behavior]. Sometimes I'm like, did I make her do that? No. It's in the back of my head. I was thinking, this is really challenging. Then maybe it's just a phase. But it's not me, thank God. Then I could sit down and be more rational. Before that, I was all sucked up into it. She's just doing it to get mad at me. It was like, no. I had to go back to a teacher mode. I had to become a teacher with my own child. If it's not what I'm doing, why is she doing that? Maybe if I change something I'm doing, I can change her. It's not me that's making her do it. I don't know if that answers it, but it made me feel better once I realized it wasn't <u>my</u> fault that she's acting that way.

In her discussion with herself, this mother came "full circle." She realized that while her consistent responses to her daughter's behavior were developmentally appropriate, they always evoked the same negative behavior from her daughter. While she realized that she needed to find out the reason her daughter behaved the way she did, she also realized that by changing her feedback to her daughter, her daughter might respond differently.

Summary

Two things were evident in all of the interviews: mothers wanted life with their child to be less stressful and they were willing to do whatever it took to achieve that. This included questioning their own behaviors, and ultimately changing their own parenting practices. While they first seemed to go through a period in which they questioned their own ability to parent their child, they ultimately arrived at similar conclusions that both their child's individual uniqueness and their current parenting strategies most likely contributed to the situation.

Theme #4: I feel Isolated From Most People But am Grateful

for the Few Who Understand and Support Me

"It's just so critical not to feel isolated, or alone, and I do. It's very isolating. People don't want to be your friend. And it's really hard to

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accept that. It really is. Having kids changes your social network to begin with. But then to have this kind of situation on top of it narrows it even more. It's just very tough. He doesn't really have any friends. It's so hard to keep friends, and I'm sure I'd be the same way [if I was another child's parent]". A mother in this study

I Keep to Myself

One mother and her family experienced this isolation as coming from within themselves, but not lasting very long.   When asked what that was like, in a matter-of-fact voice, she replied

> For a while, we kept it to ourselves because we felt he's bad, or this isn't normal. The more we talked to people, we talked to these friends that have kids or those friends that have kids, and it came out that it [hitting, biting] does happen. It's not an uncommon occurrence.

Her experience was that of having other parents hear her concerns about her child's behavior. Through talking with other parents, she felt reassured that even though the behaviors that her son was doing at child care were not acceptable, the behaviors were not uncommon. Talking with others about their son's challenging behaviors at daycare provided her with real information about real kids—these things do happen. And as she said at the end, "there's ways and things to do to get through it."

While the family above initially kept to themselves and gradually opened up to others later, in another mother's family, the experience of isolation was reversed. She described how she had initially been very open in the beginning, but later began to withdraw to protect herself.

> Friends? They cannot understand. I don't know if people want to hear it any more. College friends—I don't go into too many details. I do that to protect myself. Well, okay, in the beginning, all your friends want to hear everything. … And then you feel yourself pulling away because people don't understand it. Their kids are enrolled in everything. They're in soccer, they're in dance, and my kid can't

handle it. He can't handle taking directions from other people, let
alone being with too many other kids. And so then you find yourself
pulling away.

Her face looked sad as she told this story. The people who had been her friends and

support system in the beginning were no longer able to be that for her. She described the

situation as "people don't understand," but the experience was more likely that of her not

feeling "heard" by her friends.

In the case of one mother in this study, a parent made comments to this mother

about her daughter's behavior. That mother that she and her daughter would not visit at

that friend's house any more.

We used to go to a friend's house once a week. She [my daughter]
was out of control over there. We don't visit her [at her house]
anymore. Plus, the [other] mom said [about my daughter], "she's kind
of a little high strung lately," which I thought was a nice way of
putting it. I said, "How about if we just meet at the park from now
on?"

While the information about her daughter was not complimentary, this mother

appreciated the other parent's honesty. Knowing how that parent felt about her

daughter's behavior, she was then able to make an alternate plan about how the children

could still play together.

Others Exclude Us

Activities in American culture that involve young children and/or their families in

interaction with other children and families are varied and many: birthday parties, play

dates, and church Sunday School, to name a few. For children who engage in

challenging behaviors, participation in these activities has outcomes that are different

than for other children. The child with challenging behaviors is often expelled or

excluded from the activity. Through tears, one mother described how her son was not

invited to birthday parties:

> He never got invited to birthday parties, play dates. It was sad,
> because it was like nobody likes my kid. Everybody's saying, oh,
> you've got such a fun kid. [I think to myself] then why don't you want
> him around?

While she had always arranged parties to celebrate her son's birthday, he was not invited

to the birthday parties of other children.

Another mother and her daughter experienced a more blatant form of isolation. In

her neighborhood, the neighbors forbade their children to play with her daughter. When

asked if there were people who were especially not supportive of you, she answered very

quickly.

> The neighbors—people with other kids. The little girls—the little girls
> and their mothers. They don't want anything to do with me. They
> don't just say it—they don't allow it.

This particular situation of exclusion was very different from situations reported by other

mothers. From this mother's report, there seemed to be a parent-child dialogue or

discussion in which mothers and daughters together decided to exclude her daughter.

Although the details how this exclusion occurred, the reality for this mother and her

daughter was that the neighborhood others shunned her, and the neighborhood children

were not allowed play with her daughter. The reality for this mother and her daughter was

that the neighborhood mothers shunned her, and the neighborhood children were not

allowed to play with her daughter.

This same mother also had occasional situations in which adults initially appeared to be supportive of her. But after the parents and their children had visited her house, and their children experienced injuries from her child, she never heard from them again.

> Only a couple of parents that I found in play groups—like they come over to your house. It just seems like it's never worked out. There have always been injuries … from my child, and I never hear from them again. The only support that I get would be from the parents of the kids who are kinda naughty. But, then, it's just not a good situation. The parents [of those children] aren't very good at taking care of the kids. There's a lot of spanking.

From these two descriptive scenarios, it seemed evident that this mother was persistent, but her second strategy didn't seem to be very good either. When it was obvious that one set of playmates was not going to work out for her and her daughter, she approached another group of parents and children, inviting them into her home environment. She just was not going to give up on her child, or herself.

While children of some of the mothers interviewed never got invited to play, other children did get invited to play, but for one time only. This was the case for one mother's son, as they often were never invited back.

> I used to schedule play dates for him. I don't do that very much any more. Because other people just don't—they don't understand. They're so judgmental, like, it's back to I'm a bad mom. As a matter of fact, we've been invited to a lot of places ONE time, and then that's it. Or we made play dates with certain kids, and things didn't go well, and I was so embarrassed I didn't invite them back.

This mother's demeanor again took on a look of sadness and frustration as she talked more about how she no longer arranged play experiences for her son. While at one time those play experiences had been pleasurable for her to set up, she now felt judged by other parents when they observed her son's behavior, or things didn't go well at her own

home. Her experience of feeling embarrassed and thinking that she was judged by other

parents was just too much to bear, and she chose not to schedule play dates.

Another mother attempted to have her son participate in a variety of activities,

including the Sunday school at her church. Similar to the exclusion she had already

experienced in other organized settings such as family home day care and drop-in child

care, she was told not to bring him back.

> In some more formal settings like Sunday school, he just didn't fit into
> that. They were pretty clear: we can't handle your kid. So in some of
> the more formal situations like that (that you would want your child in,
> and expect people to be excited about), they were pretty clear that this
> wasn't going to work. [They said] "Don't bring him back next
> Sunday."

At this point in the interview, it seemed as though this mother was aware that her child's

uniqueness made it difficult for other adults to work with him. This was stated more as a

matter of fact, rather than being stated with a lot of sadness about her child not fitting in

with other children.

Greeting children and their parents upon arrival at child care is a typical routine

performed by teachers. This greeting tells children and parents that they are welcome

and that the daily experience of being in daycare has begun. One mother described an

on-going situation at her son's child care in which the teacher would not look up from the

breakfast table to visually or verbally acknowledge their arrival. While she initially

described it as "silly," she still experienced it as an exclusionary behavior towards her

and her son by one specific teacher.

> [It was] just silly little things . . . the teacher not looking up to
> acknowledge that you just walked in the classroom. When you're [the
> teacher] sitting there with the doorway right here, all the other kids are
> sitting around, and the doorway opens up. They're [the teachers]

staring straight down [at the table in front of them] while the other kids eat breakfast. … It happened a few times.

We stayed at the same center, and we're still there because it was primarily just one of the teachers who was doing it. There's multiple teachers in the classroom. The other two teachers were more— sympathetic isn't the right word—but they were more understanding about it's nothing we're doing as parents. It's just something we need to work through. The one teacher was just making us feel that there's something we're doing or not doing.

While this mother described this situation as "silly," it was obvious that the practice of one teacher ignoring the arrival of her and her child was painful. She experienced the lack of recognition as the teacher's planned ignoring of their arrival. Not acknowledging one's presence is a way to subtly send one of several messages. She felt that through the teacher's ignoring their arrival, she was saying that the problem with her son was due to something she was doing—or not doing.

A Few People Understand and Support Us

"It makes a huge difference to know you're not alone. A HUGE difference." a mother in this study

Parents indicated that there were more people who did not understand them and excluded them than people who understood and included them. While the supportive people were few in number, their support to parents was immeasurable. Parents who experienced similar issues with their children were described as one source of support.

In the same breath that one mother described how she found herself pulling away, she also described the solace in finding a friend with a parenting situation similar to hers.

I do have a friend who adopted from [the same part of the world] at the same time, but she's, well, 'these are kids.' I know she means well, but she's more of a type B personality and lets things roll. Now that they're getting into school, there are probably more issues. So she approaches [it] differently, but she's always listened, and we've always shared. We do have friends who have adopted from [the same

part of the world] with children with more severe issues. We can commiserate.

In contrast to all of the times that she had felt not heard by others, she was describing the experience of being heard. There was much comfort in being with another mother who was willing to listen to her, to understand, to commiserate.

Similarly, another mother indicated how their social world had changed, and how isolating that was. But she also focused on the importance of friends who accepted her and her children.

> I think that another thing that you might find—it's pretty isolating. Our social world has gotten pretty small. There are a few families that we will do things with, because I know, at least I hope, they're good enough friends, and they're tolerant enough that if he does something, they're going to still accept us. And most of those families are families with kids, with children who are challenging.

Both of these mothers described the experience of being accepted by others. Their interactions with other parents of children with challenging behaviors were essential to their sense of confidence and well-being.

One mother easily compared the difference between the "warm fuzzy notes" she received from the small in-home daycare her son attended, and the negative written feedback that she got about her son's behavior when he attended a larger group childcare setting.

> Luckily, I just happened to find someone who had background in early childhood. Her son had attention deficit, but she didn't want to medicate, so she chose to quit her job to be home with him. She was a preschool teacher. She was going to take a couple kids in so she could earn some money. I just happened to see her ad at the right time and get him in. It was great. It was probably the first time that I really felt as a parent I was starting to get those warm fuzzies. Look what [her child] made today. Gosh, [her child] had a little trouble at lunch, but boy, once we did this, or he had a break in the room, he came out to

play really good with Legos. I just saw the successes building and building and building. And for the first time, I heard him say, "B. is my friend. I have a friend." We're talking 4½ years old and finally he's saying, I have a friend.

One mother found much support for herself and her son from her son's advocate at the Association for Retarded citizens (ARC), one of two advocacy groups in the Twin Cities that are available to support parents and guide them through the maze of special education services. Parents can call when they need help or support. While she had known about her ARC advocate for some time, she became fully aware of how much this person could help herself and her son when there was an attempt to exclude him from a school activity.

> My advocate from ARC is wonderful. I don't always know what I'm supposed to call them for. I'm having trouble this year. It's great to have somebody that you can call and say, are they allowed to do this? When am I supposed to do this? One of the things [that happened] this year was he was in this star base [class]. They were going to a national army base or air force base and doing their classroom actually there. The very first day my son was acting up. I guess he was getting out of line. He was pounding on a glass table and it really sounded awful. I called her [the ARC advocate] and said, "They don't want him to go. He is so excited. He's talked about this up until now. He came home today and talked about it. It will break my heart to tell him he can't go." She's like, "They can't. I can't believe they can't accommodate him there when he's having a moment. Take him to a bathroom or to another room." Then I ended up calling [the person], she is in charge of the autism for all of [the district's] public schools. I called her and told her what was going on. She goes, "Let me call." She didn't tell me what she was going to say. She called me back and said, "They really can't do that [exclude him]. They have to call an Individual Education Plan [IEP] meeting if they want to exclude him from something." It's nice to have that [the school district's support], too. She [school district's autism representative] was there. She can tell me the legal part . . . I never even thought to use her but my ARC advocate suggested it.

Clearly, she had the experience of being heard by her advocate from ARC.

Some mothers reported parent-teacher relationships as ones that kept them feeling supported. One mother felt very supported by her child's teachers. When asked if there was anybody that she felt comfortable talking to because she knew they would not judge her, she easily and quickly replied:

> Oh, yeah. I feel very supported. It's not like her teachers are just her teachers. They're also my friends. They don't judge me because most of them are parents. Especially one teacher, because she has a child with similar issues. She's a good source. She's like, "I've been through that." Sometimes it's nice to hear, "This is what I did." I just need . . . how can I do that? Give me an idea of how I can handle this behavior. Give me some practical applications how I can use this. That's the best thing. I know the research behind it. When she's screaming, I need something to do.

She felt supported because her daughter's teachers listened to her without judging her.

When asked about support, another mother also quickly described [through tears] the teaching staff at her son's child care center:

> Definitely, one of my biggest supports came from the center, a teacher I work with or actually a supervisor that I think had a challenging child herself, so she shared that information with me. But just the knowing that I could go in and just be open. I could say, "I really don't like my kid." It's okay to say that. [And to feel their response as] "You're right. That's really crappy behavior you're having to deal with," and not feeling like . . . Someone would say something like, "What do you mean? You don't like your kid?" No [right now, I don't]. Spend a day with him. Come and walk in my shoes.

Why was the experience with her co-workers so important to her? "Just to be able to say it and really be heard helped. But also [I felt support] I think because they [the teachers] knew my son from when he was born and some of the struggles I had."

Early in the interview, one mother had talked about the support from her family. Now, her face got serious as she described how that had changed. The first time that her own mother indicated she couldn't handle their son, the mother in this study was

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devastated because she thought that her son's behaviors had improved. But she 'picked

up the pieces' and described how she had a plan for moving forward.

> My family's been supportive. But that's all getting pretty taxed.
> There's more babies in our family now. My one sister, he feels so safe
> with her, but now she's got two little kids of her own, so she's kind of
> out of the picture for child care. My other sister, she's a single parent,
> and I just can't ask her. And my mom and dad are really good, but the
> last time they watched him, I hadn't prepared him [my son] enough.
> We weren't home; he thought we were gonna be there and then leave,
> but we weren't there. My parents were to get him off the bus. He was
> confused. He thought I was still gonna be there. It was a Friday, [the
> end of a] long week. He lost it, kicked my dad in the ribs … scared
> my parents. And they're in their 60s.
>
> My mom said, "I've got to be honest with you. I don't think anybody
> can handle him." And I'm thinking, 95% of the time life is way better,
> so I'm crushed. But I also think it's time for us to move on. So I
> actually have an interview for somebody from [a local college].
> There's a job posting out there. He doesn't require a Personal Care
> Attendant [PCA], but I thought about interviewing PCAs for just
> sitting [child care].

This mother had felt supported by her family in the beginning, but that was changing. In

the above situation in which her parents had last watched her son, she felt responsible for

the outcome because she thought she hadn't prepared her son adequately for the change

in the routine. She felt confident that her son could be successfully watched by her

parents if she provided him with enough preparation, but her parents either could not or

would not hear that. This situation prompted her to look for alternate in-home child care.

She said, "I tried it before, and I wasn't comfortable, but I'm ready to let go. I'm ready

to give it a try—our marriage needs it. I kind of forget where there's any fun."

One mother had previously described the year in which she started getting reports

about her son's behavior. While it seemed that it was only one teacher who acted in a

judgmental way, this mother felt that she was indeed being judged as a parent. She

started to feel better about herself as a parent when she started talking with other parents about what was happening in her son's classroom.

> I had words with the director. [I said] I think things [needs] are being met. But I don't think things are fair. I tried not to point fingers. She acknowledged to me that she can't really say [anything] about her employees, but she kind of acknowledged to me that she could understand what I was saying.

> It made me feel a little bit better that maybe it wasn't just me. Then we've had a few conversations with some friends of the parents of the kids in the classes. We were talking about day care. In some very general terms, I threw something out [and found out] that they had the same feelings about the same person [in the classroom who was telling them] about how their son was the worst one in the classroom. So between the four of us parents, we had our own support among ourselves about our active boys and how they were being judged as being bad because they weren't conforming to all the rules all the time. At first, I was all defensive about it and thought I was the worst mother in the world. But in talking to other people, their boy in the same class who was doing similar things was also getting into trouble.

It appeared that her courage to speak with the director about her concerns about how her son was being treated had an impact on the director, and on the organization of the program. She reported, "Maybe it's just the classroom environment. Shortly after my son moved up, they reorganized the whole toddler room. Maybe our case wasn't the only case." This response led her to experience feeing that she had really been heard by the director.

In another mother's family, her own mother was one huge support system. Her mother has a standing 'date' with her son every Saturday morning. This worked very well for everybody, especially the mother in this study, because it gave her a little break from her son.

> Well, my mom's very supportive, and she wants to know—actually when my son was first diagnosed, she wanted to know as much as she

could. I think she's kind of made a connection with him, because he struggles with things, and she struggles with things. So she's very supportive, but she struggles with anxiety, so it doesn't take much for her to be at the top. My son goes to her place every Saturday morning for usually about 3 hours. And they have a little routine that they do. Since my husband started working at his job about a year ago, (he works Saturdays), it just gives me a little break. So they [my son and my mother] have a whole little thing that they do, and it's very expected that he go there. So it's like every Saturday he calls her, and they plan out what they're going to do.

Summary

Early into the interview process one mother had commented, "One thing I think you'll find is, it's very isolating." While this wasn't an experience that all of the 10 mothers experienced, for the ones who did experience some level of isolation, it was very sad. And while the mothers felt sad about their own isolation from other adults, their greatest sadness was about others not wanting to accept their children: not being invited to birthday parties, not being invited to play dates. These mothers were courageous. They were diligent in searching out other environments in which both they and their children could be accepted.

Theme #5: I am Extremely Challenged by My Child's Behavior in Public Places

"You feel like you can never bring your child back there." a mother in this study

Sometimes I Feel Angry, or Embarrassed and Humiliated by My Child's Behavior

Most mothers in the present study indicated how they really 'knew' their child, and this particular mother was no exception. This knowledge about her child guided her in communicating with adults who were new to her child's behavior. While her voice was slow and labored as she described a specific incident in which her son spit in another

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person's face, she had the ability to find some humor in how she had to remedy the

situation.

> I tried to leave him at the Y this summer, and I thought it was going to be cool, because he'd been doing really well in his other program. I tried to leave, and I pushed it too far, and oh my gosh, one of the people grabbed him from behind, and another caregiver is looking on, and he's trying to break away, and he [pause] spit [pause] in the person's face, and the onlooker goes, "Oh my god," and you're [pause] just [pause] melting, you feel <u>so</u> humiliated, and then he grabbed the woman who was holding him, and grabbed her necklace, her 14 karat necklace and broke it. And I'm just falling [apart], because I thought we were okay. I thought we were okay—[very long pause] and we weren't. [after another long pause, some laughter] And you're apologizing profusely, taking her necklace, spending gobs of money to have it repaired, so you're not only definitely humiliated, you're putting money into fixing broken items. And then you feel like you can never bring your child back there.

This mother recalled another story about her child's behavior in public in which she was

embarrassed. This was similar to the other situations in which she thought it would be

okay to leave him, because he had been doing so well. She was more composed during

this story, and merely rolled her eyes as she described another spitting situation.

> He's been away from me a lot. He did a little drama class the other two mornings. When [did] he start losing it [at the drama class]? Exactly the same time [he started losing it at other places]. At 5 weeks. And he started not wanting to go. I couldn't leave him. He would cling to me. And the teacher (of the drama class) said, 'it's okay, you're safe here, you can stay with me,' and I explained a little bit, only a little bit, because he was being successful. And she was an elementary ed teacher. So I didn't really want to get into it with her. Well, at the end, he started losing it, it wasn't in front of the other kids, and that was good—he saved his face that way. But he started spitting at her, (ugh, which I hate), and saying 'I'm gonna kill you,' and you just wanna take your head and bury it in the sand. Like, I <u>know</u> why he's doing it, but the receiving end of the person doesn't, and it's a little bit terrifying, I think.

The significance of this particular story is that while she continually experienced her

son's behaviors as very challenging when in public settings, she also had the experience

of beginning to notice that there seemed to be a time frame within which her son could

manage his own behavior. When he exceeded that time frame, he began to act out.

Because she experienced the awareness of noticing this pattern, she decided not to pull

him out of the class. Rather than continuing to force him to go alone, or to pull him out

of the class, she decided instead to support him at that crucial time (5 weeks) by going

with him, and ultimately helping him to have a successful experience.

One mother well remembered feeling angry when she was paged to come get her

son out of the drop-in child care at a local health club. Having decided that working out

was one way to relieve the stress that she experienced through parenting a child with

challenging behaviors, she quickly found out that his challenging behaviors in public

actually caused her more to experience more stress.

> I think there was a tough one [situation] when I joined a health club
> that had rink din place to drop your kids off while you worked out.
> My son had a PCA [Personal Care Attendant]. That's how hard his
> behavior was—the State of Minnesota deemed that I could get some
> support [the PCA would take care of her son for a limited time] while I
> had some time to myself. For some reason I wanted to go work out
> and the PCA wasn't [available]. It came to the point where I needed to
> have him there—I needed him to be in the care. I remember saying
> [saying to the workers], "I really need to work out and it looks like you
> just have two other kids so please make work [with my child]." It's
> like begging—it's not a choice.

What happened?

> I usually got a call over the intercom, "[Mother's name], please come
> to the child care." Then I would slink through swearing in my head,
> "all I want is a half hour to myself." That was tough. I think I
> probably took him three times and just said [to myself], "nope, I guess
> I won't be working out," because it was too stressful.

From this mother's perspective as an early childhood educator, the child care people didn't have many children to watch and should have been able to accommodate her son. But just as her son's behavior had escalated, her tolerance for his behavior had escalated and it didn't seem 'that bad.' Because of her skill and expertise, the drop-in child care setting looked 'do-able.' But to the unskilled staff, it looked impossible.

I Have Learned That Certain Things Trigger My Child's Behavior, and I Avoid Them

Several mothers commented that they had come to understand that some activities were difficult for their children to manage, so their experience was that of avoiding certain activities. However, for some mothers, their children's response to the environmental setting was not consistent, meaning that sometimes their behavior was okay and sometimes it wasn't. This unpredictability left the mothers wondering, "should we or shouldn't we go to the park?" At the time of the interview, one mother's children had 2 more days of school before they would be at home for 3 weeks due to school conferences and holidays. In discussing how she and her sons would spend that time, we talked about whether or not she would take both boys out in public. She described her ability to deal with his behaviors in terms of how "brave" she was feeling, in the event that she would have to deal with a meltdown. She continued to describe how her son's response to structured environments was unpredictable. Sometimes he might be okay, other times he might not be okay.

> I used to do things like sign them up for classes, structured things. I don't do that. The thing is, he might be fine, or he might just have a melt down, and then it's too embarrassing …

But she never knew which behavior he would present. So, she decided it was easier not to put him in those situations.

When asked if there were any places and things that she felt she couldn't do with her son, another mother talked about the tantrums that her son used to have that caused her to leave wherever she and her son were. She then paused momentarily before describing the things that they still today cannot do.

> There would be tantrums where I would have to leave. As he's gotten older, we've had to be a little trickier about things that we do, like crowds, or going places that have big crowds. It's the chaos, and all the noise, and all the sensory stuff.
>
> And depending upon where he is, he can handle it for a little bit. And then I can see the signs of when, "okay we need to exit now." I want him to be as normal in life as he can. You know, he's a fairly normal kid. But there are things that we really do avoid.

Like many of the other mothers, she had learned how to "read" her child's behavior, and make decisions based on what she saw. Parents of children who engage in challenging behaviors have the experience of walking a very fine line between making choices that best benefit their child (by not upsetting their child, which ultimately makes their parenting experience more enjoyable), but still wanting their child to have typical "kid" experiences like going to the zoo or going to movies.

One mother's demeanor matched the experiences she was describing to me about how she and her husband no longer let their daughter take all of their energy. There was no tension in her body or her voice as she verbally created the scenario about her daughter's behaviors in public—and why her daughter doesn't go to stores.

> You just feel it—she's different, definitely. And we just have to take our energy, and we don't—she doesn't really take our energy any more like she used to take it. Now it's just so calm. We just give her two choices about what she has to do. She still throws her fits, she throws [her body] down on the floor, throws things, stomps, screams. But it's just—it doesn't faze you. It's when other people are around it.

Like "Oh my <u>Gosh</u>! You deal with <u>that?</u> " [For that reason] she doesn't go to stores.

She continued the story about how her daughter's behaviors in public have affected the choices that they make, and don't make, for family outings.

First, family function. My dad had a Halloween party, and it was late at night and we weren't going to eat until 8, and his house is always hot. Never once has it been a good situation. This was the first time that she's been okay. . . . So, we don't usually do the family thing.

We can't do anything at night. I figure we'll go to theater, it's just always been our thing, and we go and she knows the protocols. I can't give her any sugar, I can't just let her run the place, or she'd be out on the stage or something. I let the leash out a couple of times. . . . "Can I go play with Suzie?" I said "I'm sorry you can't, and the Mom said, "Oh, she'll be fine." The next thing I know, she's hanging off the balcony with the other kids, and the mom's just . . . [looking at me as if to say], "If she hurts my child, I'm gonna kill you".

For another mother, while some of her responses had been told through tears, there was a definite confidence in her voice when she talked about the choices that she had made with her daughter. Though the choices were made as a result of some unpleasant situations, she felt good about the decisions she had made.

People don't know your child. We go to Target and these parents are letting their kids run around. She would like to do that. I think I scared her because I said, once, you like to run from me so you're always [going to be] in the shopping cart. It's not a choice. That's why we never go to the mall anymore because she likes to run. You can't contain them in a mall. I said, "You run from me. It's not safe." I said, "I don't know who's around the corner. You need to stay by me." She said, "Why?" I said, "Because there are people that could hurt you." So now she's a little scared when we go to stores because there are people that want to hurt her. I'm okay with that. Now she gets it. There are people that want to hurt you. Now she'll see somebody in the store and say, "Does that man want to hurt me?" I'm like, "I don't know if that man wants to hurt you."

With the same self-assurance that her choices for her daughter were appropriate, this mother also described how she and her daughter don't go to restaurants either.

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We haven't been out to a restaurant since June. She would be in a restaurant and start screaming and yelling. I have the theory that if I'm in a restaurant, I don't want anybody else around having to listen to my child scream. That's rude. It's disrespectful to all those people. If she's going to yell and scream and throw food on the floor, we'll leave. So we don't go to restaurants any more. She likes going out to restaurants. She does [understand we don't go to restaurants because of her behavior]. She wanted to go out to eat. She didn't want to go to Perkin's. I said, "We can't go. You get out of control in restaurants. You scream and yell. You won't sit still. You throw things around." [My daughter said] "But I like to go there." "We're not going there." I said, "I can't trust you to behave in a restaurant. Until I can, we won't go there."

Things That Many Families Do Regularly are Very Unpleasant With My Child

While some mothers had made clear choices about activities that they would and would not do with their child, other mothers persevered with their child's behavior and public outings. Albeit unpleasant, they kept trying.

When asked if there were activities that she and her family felt that they could not do because of her son's behavior, one mother grimaced as she described the unpleasantness of restaurant eating and social get-togethers with friends.

Restaurant eating was not pleasant. Grocery shopping was hell. I remember my sister came up for Easter so we went to the church Easter egg hunt and she was like, Oh, my God! Because he was like a terror. Grabbing eggs. It wasn't like the cute, oh, look what we found. I would say there's a lot of things we didn't do as a family.

When asked if there were more examples, she continued.

Anything that would be related to social get-togethers with friends. I remember being at a neighbor's house . . . they were having a get-together and there were kids there. This was when he was a toddler. We're all sitting around on the deck. Everybody is moving their chairs to keep him away from the steps because he's being so insistent on trying to go down. There were toys to play with [but he wasn't interested in those]. The other two kids that were on the deck were content. [All of a sudden] he just zoomed backwards and the one guy just caught him right before he dropped off the deck [sigh].

As much as she liked to have social interactions with other families, keeping her son safe

was very stressful. Other families' homes just weren't set up to accommodate her son's

activity level.

When asked if her daughter's behavior had any impact on where she could go

and what she could do, another mother's confidence showed again as she very firmly

stated, "Yes, it is."

> If we want to go to the grocery store, I make sure she's in a good
> mood because if she's not, I won't go . . . you can tell if she's already
> on edge a little bit. Over the weekend, she wanted to go to Target and I
> said, "How are you feeling today?" [My daughter said] "I'm a little
> tired and a little cranky." I said, "You know, we're not going to
> Target." She has to be really happy to go to Target.

When asked how her daughter accepted that decision, she said her daughter was upset.

> I said, "We're not going to go because you already said you're cranky.
> If you're cranky, you get angry." Then she went into her room and she
> said, "You're mean to me. You don't love me (which I can take)."
> That's typical. At least she's not hitting me. I'd rather her to say you
> don't love me because I know it's just her anger coming out. So she
> wanted to go to Target last night. I said, no, we're not going to Target.
> You've had a long day. We need to go when you've had a lot of sleep.
> She goes, "Because then I get cranky". I think she's catching on but
> for some reason, I thought it would be easier.

In this situation, this mother experienced being heard, and understood by her daughter.

Another mother lamented the freedom that she used to have around activities such

as shopping.

> It's still hard not to do some of the things I was able to do before, with
> his behavior. It's hard to just want to go shopping. But it really
> helped to sit down and follow some of the suggestions [I was given].
> Write out what we're going to do. That's really helped. One time we
> went shopping and I did my shopping list. The last thing on the list
> was to go to the toy department. It really made a difference. To give
> him a pen and let him cross off something as we did it. (As soon as we
> get all this done, then we get to go to yours). It did work. He didn't
> run off. My heart just pounds when he's not right next to me in the

store. I know he would scream if somebody grabbed him. That thought of him not being right there is, oh, I hate it.

Her enjoyment of shopping changed when her son's challenging behaviors emerged, because she couldn't trust him not to run off.   While she hasn't given up shopping with her son, she has found some successful strategies to make the experience less stressful for her. Even with her new strategies, the experience still has an element of fear involved.

Summary

While no parent is enamored with the idea of publicly dealing with a child who has tantrums, runs away, or insists on climbing all over the items in a friend's home, for families of children without challenging behaviors, it is an occasional occurrence that can be tolerated. For the families of children with challenging behaviors, it is more likely to be a predictable occurrence for which a plan is needed.

One mother arranged for a check-in system with her daughter to determine if going shopping or dining out would be a good idea. It seemed that her daughter was beginning to understand that there was a relationship between her own behavior, and the activities that her mother was willing to involve her in. Another mother also had a strategy for helping her son to remain engaged and interested in the shopping experience so that he was less likely to run away during their outings. Specific to the toddler age of her son at the time of the experiences she recounted, a different mother did not report having any strategies in place.

Theme #6: I Struggle and Work Very Hard but Still Find It Difficult

to Get Help for My Child

All parents of children with any measure of disability work hard to coordinate the

appointments necessary for the intervention and success of their child: pediatricians,

developmental pediatricians, therapists, intervention teams, etc. For parents of children

with easily diagnosable disabilities, many service systems are already in place. Parents

of children who engage in challenging behaviors have a slightly different experience

because many of the behaviors that the children first present are within developmental

norms. This means that parents are often left to figure things out for themselves. While

some professionals are quick to work with a family, others take a "wait and see" attitude,

during which time the child's behavior is escalating out of control. Several mothers in

the study talked about attending workshops, reading books, and conducting their own

online searches in the attempt to understand what was happening with their child.

A Few Doctors Were Helpful

At one point, one mother was receiving numerous reports about her son's biting

and hitting incidences at day care. She was not getting help from her son's teachers

about possible intervention strategies, so she went online to find out about such behaviors

in young children. From her own research, she decided to contact her pediatrician, who

was very helpful.

> He was having [incidents] where he was starting to act out. I think we
> got two notes in a month. One of the big things that really stood out to
> me was lack of verbal skills and frustration. I called his pediatrician.
> [I said] I'd like to talk to you and see if you can help me with this. She
> looked at him and tried to talk to him. She said, I think I need to refer
> you to occupational therapy and do a speech therapy evaluation. Ever
> since we started that, it's been 8 weeks now, (we're only doing

physical therapy right now), it seems to make a world of difference in his attitude and the things that are going on. It was primarily [like I found on] the internet, saying [the behavior was due to] frustration. She [the pediatrician] thought that because he wasn't physically at the 3-year-old level with his large and fine motor development, and his verbal skills were average, his only way out was to bite or hit.

Because she was not feeling supported by her son's teachers, this mother conducted her own research about the behaviors that were being reported to her. She used the information to guide her in approaching her pediatrician, both in asking questions and also in sustaining a conversation about her son's development and behaviors.

Another mother also was fortunate to have a physician who was quick to see the reality of her son's behaviors, and make the appropriate referral. While she was concerned that her son hadn't exhibited enough of his challenging behaviors during the office visit, the pediatrician was quick to see all that he needed to see in order to help herself and her son.

Luckily, I had a really proactive doctor, and he said, "I know a behavioral pediatrician. Let's get him in to see him right away." I went and saw the behavioral pediatrician. His father and I went and it was about an hour visit. I felt like my son wasn't doing much [of his challenging behaviors] at all. Because we [teachers] often say kids behave differently in other settings, I'm giving all this information. For some reason, his father had taken him out of the office. I said to him [the pediatrician], "He didn't really do much for you. He goes, "Oh, he did plenty." That made me think he's really worse than I thought because I thought this was a good day. I think when you have a kid with challenging behaviors, you get so used to it. That the way you look at it gets skewed. Your bar of what's normal keeps going more and more over.

This mother experienced her son's physician listening to her, truly hearing her concerns. The behavioral pediatrician also "tuned in" to her son's behaviors, all of which gave her the experience of being heard. While she was grateful for being taken seriously, she

summed up her experience as a parent when she said, "You still think you're in the normal range, and you're not."

Before leaving the country to bring their son home, one mother contacted a physician whose specialization was working with internationally adopted children. She was fortunate that her pediatrician never told her just to wait, that everything would be okay. But she also indicated that she would not have accepted that answer.

> I found a pediatrician before I [left], and they [the clinic] knew we were adopting. She had done a ton of international adoptees, but she's very interested. She is phenomenal. She has entertained all my questions. I set up a meeting with her last year (1 year ago yesterday) and he [my son] was falling apart at school. I sent her a two-page letter saying here's everything we need to talk about. And she sat there for 1 hour, she listened to my ideas, she gave me people to contact, she calls me back, she's never shirked me, like I'm a psycho mom who thinks her kid has all these issues.

I Feel Angry and Frustrated When Doctors Misunderstand Me, or Don't Seem to Take My Concerns Seriously

One mother described how she had always known that her son was extremely active, but was unsure what that level of activity meant. While she observed how other young children acted in public, and knew that her son acted different, she didn't understand why, and relied on her pediatrician's perception that he would 'settle down.'

> As an infant, he was challenging, but I didn't think it was 'abnormal'. I mean he never sat for long; [he] crawled within 2 weeks of us having him in our family. I'd go other places, and I'd see moms put a blanket down, put their baby there with some toys, and that child would sit and play. That never happened.

> Or, I'd go to a restaurant, and you'd see a mom there with her child (it's typically a mom), and the child would be sitting there and entertaining themselves with toys, and he [my son] wouldn't sit on a chair, he wouldn't sit on a blanket. I'd take him to a Bible study at church and all these other kids would be sitting at their parent's feet,

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and he'd be running around, and so, I was surprised. But our pediatrician would keep saying, "He's active, he's physical, he's developing all these motor skills, and he'll settle down." That never really happened.

[Finally] I found someone who was willing to have a dialogue with me, and who seemed to listen to what I'd say, because when I would go to my pediatrician and say, "You know, I'm really concerned about the behaviors escalating," she said, "Well you just have to tell him [my son] what the limits are and enforce those limits." Like, hello-o-o, I've been doing that for 6½ years, you know, and I'm good at this.

When one mother's first doctor finally referred her to a pediatrician, the initial results of switching doctors were dramatic, as her son's feeding issues were addressed immediately. However, the longer she stayed with the new pediatrician, the more she learned that there were more battles to fight.

The doctor finally referred me to a pediatrician (I was going to a GP). I brought him in to the pediatrician, and he was like, "This kid is malnutritioned." Within a month, he [my son] had a feeding tube. From there, I got referred to a feeding clinic because he wouldn't eat any more by his mouth once [he] got the feeding tube. They recommended early childhood [early intervention services through Early Childhood Special Education]. . . . We went for his 1-year checkup. He [the pediatrician] was happy with his weight gain, but I wasn't [happy] with his development. He recommended the pediatrician we still see now. He's an excellent pediatrician, but has no bedside manner. He still uses the word retarded. With every stab he gets me with, he comes back with an excellent comment for me. He's very well known [locally], so I guess I'm lucky to have him.

When asked if she felt support by her doctor, she quickly said, "no."

He immediately wanted to go with the medication, too. At that point, he had already called my son retarded. I still have to fight that. My son can read. He's mainstreamed. I tell him [the pediatrician], "My son is the best speller in the classroom. They had a society last year where they had to have a business and sell something. His [business] was to sell correctly spelled words to kids.

When I asked for a referral for a geneticist thing, I wanted to see what was going on. My son wasn't that old, and I could have wanted another child even though I had done so much fighting [already]. And

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he was kind of, "Why? I think he's just got a very sophisticated syndrome and there's probably not a name for it." I'm like, "I'd kind of like to know in case I want to have another child—if this is possible." [He said] "Well, yeah. I understand that." So then he referred me. When my son started eating orally again, I wanted a referral for a throat specialist. Once he started eating again, food was coming out of his nose, so I didn't know if something was wrong with his palette. He [the pediatrician] was like, "Well, I think it's just a coordination problem, but yeah, if you want to see somebody [I'll make the referral]."

The pediatrician did not seem to share this mother's concerns about her son's development, and even went so far as to identify him as retarded. While he complied with her request for a referral for genetic counseling, her experiences were that he did not seem to hear what she was concerned about and felt that he did not share her concerns.

Similar to the mother above, another mother experienced much of her interaction with the medical community as a fight. She was very frustrated when her opinions and suggestions were not taken seriously—when she was made to feel that she had no credibility.

I feel that everything is a fight, everything is a battle. You just have to keep fighting the system. I said to the psychologist, and also to the play therapist there (who's a psychologist) over a year ago, "Do you think he could be on the autism spectrum? I've been doing some reading, and it seems like Asperger's to me." No, they just didn't see that. It's an attachment disorder, it's the adoption. And I said, okay, they're the psychologists. I'm just a first grade teacher. So then they recommended that we do a neuropsyche assessment, so we came to the U to a neurologist who's very highly recommended.

I said, "Will you be checking for ASD [Autism Spectrum Disorder]?" He said, "Well, I know what I'm looking for." I said, "I'm just wondering if this is one of the things you might be looking for." He said, "Of course". And I thought, okay, you're the neuropsychologist, you do the assessment. So then they did the assessment. They presented the results to us, and as they're giving the report to us, the neuropsychologist said, "I've been consulting with your psychologist,

and she's wondering if maybe the stresses in the marriage are affecting
your child."

She was disappointed, and highly offended that her concerns did not seem to be taken

seriously. Not only that, the neuropsychologist was suggesting that her marriage was the

source of her child's behavior! She continued,

> "I said to him, 'You try living with a kid like this, and tell me your
> marriage isn't stressed. We had a fine marriage until he came along.'
> You know, like okay, now go after our marriage. And so his
> conclusion was that he [my son] was not on the autism spectrum."

> One mother described the consultation with her daughter's pediatrician when she

was concerned about her daughter's tantrums.

> I talked to her doctor when she was about 1 year old. I said, "She
> throws tantrums and sometimes she bangs her head on the floor or on
> the wall when she's mad." I said, "She doesn't like mixed textures.
> She's having a really hard time transitioning to soft foods." Her
> doctor said, "Does she seem to be forming attachments properly?" I
> looked at her and I said, "What do you mean?" She said, "Well, does
> she make eye contact? Does she snuggle up for story activities?" I
> said, "She is not autistic. I know beyond the shadow of a doubt. I've
> seen enough of them [to know that my daughter's not autistic]."

Being well versed in child development, and knowledgeable about autism, she felt certain

that her daughter was not autistic, but wasn't sure what the tantrums did indicate. She

was quite surprised, and even offended at the direction the conversation took.

It's Up to Us to Pick the Right Environment for Our Child

Clearly, parents agonized over the choices that they were faced with regarding

picking the right environment for their child. Parents realized that environment was more

than just a physical space that their child occupied during their time away from home. It

also had to do with adults' opinions and attitudes about their child.

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At the time of the interview, one mother was in the position of making a choice about her son's school, and she was quite conflicted about the things that she had to consider.

> I don't want to hear that they want to work with him, and then hear the one speech teacher saying, "but he does this." She's the same one that every time my son has an incident, it's with her. He was suspended for hitting her because she gave him [one] piece of felt and he wanted a different piece. Did she pick her battle? Yes. She wanted to win. She couldn't say, "Okay, what piece do you want?" No. She gave him that piece [that she wanted him to have] and that's the piece he had to have.

She wanted to know that the teachers really liked her son, and she felt no assurance about that.

> I'm not seeing that this year. I'm so torn at where to bring him because I was very impressed with [School A]. Everybody's facial expressions. When I walked in, it felt so warm. The school itself felt warm. But the bus ride is half his problem. And then [at School B], 3 blocks down, I didn't get as warm a feeling in there. I don't want it to be the autism [that is] the main concern. I still want him to learn. I don't want him just to learn life skills. I want him to continue to learn.

This mother clearly has expectations that her child will be offered the opportunity to learn more than life skills. She also has the expectation that once the teaching staff says, "This is where he belongs," that they will remain sincere and not give contradictory remarks that suggest that they don't want to work with him.

While the challenging behaviors had begun to be present at the first daycare, one mother chose to switch daycares when her son was 3 years old, and as she reported, "then we really started having problems." Later, she had to make choices again, but this time, the choices focused on whether or not to use medication in hopes of helping him have a better school experience. She described the difficulty of deciding whether or not to have

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her son start taking medications, but focused on what really motivated her to take a

chance with medication.

> What's really motivated me most is I just want to do whatever I can to help my son, because, for however I feel, taking care of myself is helping him. When we tried Ritalin, it was so hard for us. We had to go through all these stages—we looked on the Internet. And then we just decided we're just gonna try it, and if it doesn't work, then we'll just take him off. And it just made a total turnaround at school for him. I decided it might make it easier for the people at school to deal with him. But to see him come through the door, and tell me that he had a great day, and not go to school screaming and crying every day that he's not gonna go, and to see his self esteem skyrocket. Then I thought, to me, it's worth it.

She had so much energy and excitement in her voice when she told this part of the story.

Initially, the decision had been a difficult one to make. But with the goal of making the

best possible choice for her son as the driving force, the decision became easier to make.

Another mother talked about the frustration of seeing that her child not be

successful in the center-based program he was in, and further needing to determine the

best place for her son to be in child care. While she knew that the center he was in was of

very high quality, the program clearly was not working for her son.

> I think being a teacher has made me be able to look at him more objectively, to separate [things] out. If I hadn't been a teacher, then I probably would have fallen into [what] I often see parents [fall into]. With my son, I think the center wasn't the place for him. When I put him in the smaller setting, the home care, he did so much better.

When asked how she made the decision to pull him out of the center, she indicated:

> Luckily, where he was is very supportive, and we really did exhaust everything. It became clear it wasn't the setting for him. I was able to make a smoother transition from the center to home care. Luckily, I just happened to find someone who had background in early childhood. Her son had attention deficit, but she didn't want to medicate so she chose to quit her job to be home with him. She was a preschool teacher. She was going to take a couple of kids in so that

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she could earn some money. I just happened to see her ad at the right time, and get him in, and it was great.

She was aware of the pitfalls that parents of challenging children sometimes are subject to. In her classroom, she had observed parents make excuses for their child, or blame the teaching staff in her area for the child's behavior by saying to the teacher, "Well, I don't see it as being a problem, if you could just work harder, if you could just have more control of your room, maybe you're not meeting my kid's needs." This mother knew that she wanted to be different than those parents.

In the process of figuring out the best placement for her son, one mother described how at one point, she had her son enrolled in two programs at the same time.

He was my everything, I didn't go back to work, he became my little project. So I selected that program [run by my mom's friend], and she said, "you might want to get him into ECFE [Early Childhood Family Education] to have him evaluated." So I thought, "Okay." I had already called about speech evaluation, and they said give him a couple of months. Blah, blah, blah. I did get him into early childhood for a couple a days. So he was going to preschool a couple days a week, and Early Childhood a couple days a week, and I know in hindsight that was too much too fast. But I didn't know [that then]. I was reading so much, and I thought this kid needs to be exposed, and he needs to be evaluated. And so, I was smart enough to get him evaluated, and by January (so now he's home about 7 months), he was receiving speech and OT services through Early Childhood. We got him on an IFSP [Individual Family Service Plan], and he started to do that [work on the IFSP goals and objectives]. I pulled him out of the Community Ed. Program that fall, and I thought, 'this is so much.'

When she realized that two programs were too much for her son, she made yet another decision, which she thought was for the better.

I Make Personal Sacrifices to be Sure That My Child Gets What S/he Needs

"What's motivated me most is I just want to do whatever I can to help him." a mother in this study

It was very clear that parents had the best interests of their child at heart. Even with all of the challenges that their child's behavior presented to them (public displays of inappropriate behavior, isolation, limited family activities, etc.), parents were very motivated to do whatever was needed in order for their child to get services and educational opportunities.

At the time of the interview, one mother's son had just started a new program, with which she was very pleased. Even though it created a transportation challenge for her, she was motivated to continue his enrollment in the new program.

> For the very first time, he was really anxious to go to school. He didn't want to be late even though we had to get up early and do the morning rush routine. I think maybe the newness will rub off a little bit, but there's a definite difference [in that program]: neat toys, a lot of attention directed at him, and it's purposeful attention. They're thinking specifically about certain things they're going to teach them [all the children] that day.

> It's been really rough on me, because I'm a single mom, and I'm taking full time credits. So I have to rush him back [to the other daycare] on a bus, and then come back again [to campus for classes], so it's like four bus trips a day for me. But I want to continue because I really believe that it's really a good thing for him, and he won't be getting into trouble.

One mother's son has regularly scheduled appointments every week, and both she and her husband work full time. She was very clear, however, about what their priorities are.

> We have appointments to go to, but again, I think for my husband and I, our son is our priority. His appointments are at 10:00 a.m. every Wednesday. I miss work in the morning. I've explained to my employer that this is what's going on, and this is what I need to do.

> We [my husband and I] both have the attitude of this is number one for
> us, and we need to make sure this gets taken care of. It's not that work
> is more important. Right now, our son is the most important priority
> to work through this.

When asked about her ability to take time off from work, another mother also explained

how she had the support of her employer.

> I am [able to take time off from work] because I have been with both
> of my employers since I've been in the field. But my main employer,
> I've been with her since [the early 1980s], so we've been together for a
> long time. She's familiar with my son's disability, and she's been
> there since I've had him. I don't just say I need it [time off]. I kind of
> look for permission, and she's very good about it. It helps that [she
> has a family member] with disabilities, so she's familiar with it.

Summary

Each mother wanted to make the best possible choice for her child. They self-

described their experiences as "I'm so torn at where to bring him . . . I want him to

continue to learn," "I just want to do whatever I can to help my son," " . . . made me be

able to look at him more objectively," and "I was smart enough to get him evaluated."

The three mothers who had experienced an intense decision-making process seemed to

have a level of self-appreciation for how they had struggled, and finally arrived at a

decision they were comfortable with. The fourth mother was still in the midst of the

decision-making process, clear about what she wanted for her son, but not sure how to

best achieve it. In each situation the mothers were aware that the final decision for their

child was dependent upon on their knowledge of their child and the particular situation,

and how they communicated that knowledge to the appropriate people.

It was very obvious that mothers were very committed to doing whatever was

necessary in order that their child could possibly have access to the resources that were

needed. It was very obvious that their work was labor intensive and often coming at their

own expense—but mothers did not complain.

Theme #7: I'm Not Sure About Having My Child "Labeled"—

Sometimes Labels are Helpful, but Sometimes They're Not

"You're making him into something that maybe he's not—you don't
know." a mother in this study

As indicated throughout the interviews, parents wanted to do whatever it took to

make the very best choice that would help their child the most. For many parents,

making the decision to have their child evaluated was one of the most important

situations they found themselves in. Why? Making the decision to participate in the

evaluation process meant acknowledging that their child needed help in some area of

development. This process had an element of fear, because as one mother stated,

"You're making him into something that maybe he's not—you don't know." Another

parent commented, "You always want to think the best of your child." But in most

situations, having their child's skills evaluated by a professional was the key that helped

their child receive some kind of intervention services.

Labels Can Make a Difference

One mother, whose son was 14 years old at the time of the interview, described

how she was challenged by others when she actively sought help for her him when he

was 4 years old.   Even though people did not like her son's behavior, they were leery of

him being labeled.

It was really interesting because my mom was always saying, "I just
can't believe his behavior. I've never seen a kid like that." But then
as I proceeded, and we started to get a diagnosis, then people went,
"Oh, really? I don't think you want to label him." I said, "I don't care

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what label is on him. I just want him to get help because I want him to succeed." The more I started to look at his behavior, I started thinking about what kind of impact it was going to have on him in school. I know his dad had an extremely tough time in school. Back then, they didn't really give any support. You were just labeled good or bad, and you're a problem. I know what path that has led him down in his life. I was damned if my son was going to go down that path. His father has disagreed with me on things like the medicine, but I really think my son is where he is today because the medicine helped him get enough self control to do social skills and to keep himself from making choices like doing drugs and stealing cars at this time.

Another mother had already described her frustration with the psychologist, the play therapist, and the neuropsychologist, as they were unwilling to give her son a label. At one point, as indicated earlier, it was even suggested that the stresses of her marriage were the source of her son's challenging behaviors. She further described her search for the label that would help her son get services.

> We're going to O.T., and all of a sudden one day she says to me, "I just have something to talk to you about. I'm wondering if there is the possibility if he's on the autism spectrum." I said, "Really" [with a firmness in her voice]. She said, "Well, I've been thinking about this, and here's a book I'd like you to read—Tony Atwood's book [about Asperger's syndrome]." I took it home, and I came back [to O.T.] and I said, "This is it, this is him."

> So, I went back to the two psychologists and said, "This is him, this is it." And they said "No," and they went back for some testing, and they just didn't see it. So, I thought well, okay. They called the neuropsychologist, and no, they didn't see it. So basically, I spent my summer researching this, learning all I could. I went to three or four conferences put on by the Autism Society. To this day, I have not found anything to rule it out. And, the more I learn, the more I read, the more I think this is it. Then we switched to another O.T., and I said to her [the new O.T.] one day (because O.T. was new to me, this whole sensory integration thing), "Have you worked with many kids who have Asperger's syndrome?" She said, "Oh, yeah." I said, "What do you think about my son?" "Oh, No." she said. And then he [my son] started working with a new speech therapist, so I said to her, What do you think about the possibility of my son having Asperger's syndrome. And she said, "Well, I didn't want to bring it up so early in

our relationship." And I said, "Oh, so you would think that that might be the cause?" and she said, "Oh yeah."

When asked if this was a situation where the label would help, she replied,

> It would help get him some services. So I called [a local agency], and we're on a waiting list to get an assessment. In the meantime, I called [doctor], the psychologist at [another agency], and said, "I'm confused, I don't know what to think." I went through the neuropsyche report that I got from [a clinic], and I highlighted every time they talked about perseverative behavior, rigid thinking, and lack of social skills, or social skills deficit. Lots. So, we know he's got all these things, but then I also found out that the tests that are typically done—they didn't do any of those. So, how could they rule it out without doing the appropriate [tests]? So, we're on the road.

This mother was very frustrated by the experience of having some professionals concur with her beliefs about what she was seeing about her son, yet not having her concerns taken seriously by others. In the midst of all the different messages she was receiving, she continued to educate herself about her son's behaviors, and all the different possibilities there were for getting support for him.

In contrast to the mother above experience, when another mother made the decision to have her son assessed, the assessment results indicated that he qualified for services. While the results were not quite what she expected, she chose to accept the assessment results as they stood, because those results meant that her son could get help.

> Well, he was diagnosed by a behavioral pediatrician at the [clinic], with Autism Spectrum Disorder. The thing with my son—he's kind of complex. I mean, he doesn't have just one set of symptoms—he falls all over the board. So when the school district did their testing, they did do an autism test, and also an Asperger's test, and he had symptoms in each, but he fell just outside. So basically they gave him a DD label (developmental delay), which is kind of broad. We could have changed it, but it means now having him re-tested. So, since he qualified for the same services whether he has autism label, or DD, I just said, we'll just hold off. Because he's had so many [tests]. And since then, he's been diagnosed with epilepsy.

One mother attended a presentation by a well known parent educator after several

exasperating experiences with her daughter. One day, after the ordeal of getting her

daughter on the bus was more than she could handle, she called the parent educator at

home. At the end of the conversation, she decided that professional intervention was

needed, and she took charge.

> Of course, the next thing I did, I decided it is time to go see an
> occupational therapist. We have got to call in the experts here. This is
> pathological. This is not within normal limits. I had her evaluated at
> [clinic] and [because of the evaluation results] she started OT. She did
> therapy in March, April, May, and the beginning of June.

In a different family, another mother had already inquired about a speech

evaluation because of her concern about her son's language. She was told to wait "a

couple of months." But things seemed to be deteriorating quickly, so she moved forward

with the evaluation process.

> I was reading so much, and I thought this kid needs to be exposed, and
> he needs to be evaluated. And so, I was smart enough to get him
> evaluated. By January (so now he's home like 7 months), [he
> qualified for a label] he was receiving speech and OT services through
> Early Childhood Special Ed. We got him on an IFSP [Individual
> Family Service Plan] and he started to do that [work towards the IFSP
> goals and objectives].

One mother's son had already qualified for services after receiving a label of

developmentally delayed when he was about 17 months old.

> He was 2 months premature. He never crawled. He would scoot on
> his butt. He never got the right, left coordination. He didn't walk until
> he was 15 months old. He was developmentally delayed. When he
> was 17 or 18 months, I contacted [our local school district] and they
> came out and did some intervention with him—some PT and OT work
> with him to try to get him to crawl or pull himself up on things. He
> met the goals they wanted him to attain so we moved on.

Later, when her son's behavior was beginning to cause problems at daycare, she

contacted her pediatrician about another evaluation of her son's development, and was

referred to physical therapy.

> The physical therapy teacher was asking me questions, and asking my
> son to do different things. "Can you stand on your right foot?" He
> looked at her like, what? Should a kid at the age of 3 do that? They
> should be able to do that. He doesn't. Then she'd ask him to walk on
> the balance beam, and he didn't want to do that. Should kids be doing
> that? Yeah, they should at least be doing a little bit. So the more
> things that we needed to work on started adding up.

When asked how that felt, she replied

> How she was saying it, she was saying it in a very positive manner.
> Yes, they should be, but as a result of these should-be's, maybe we can
> have some intervention. She presented it very well. She didn't say it
> in a condescending manner at all. I'm very happy now that we're
> getting [intervention]. He's doing things that we can do at home easily
> as well, but it's somebody who is trained to do physical therapy.

This mother had familiarized herself with the process for getting help for her child, and

knew that the likelihood of him getting services through the school district were very

slim. "I was told that only 1% of the school district [children] qualified [for services].

He probably wouldn't qualify through the school district because he wasn't lacking so

severely, but he qualified through our medical."

One mother's daughter continued to exhibit more challenging behaviors at

preschool that neither she nor the teachers could successfully intervene in. A local

intervention agency was called in to conduct an assessment of the behaviors that her

daughter presented in the classroom.

> They actually come into the centers, and the gal came in and she
> observed her [my daughter] twice the first months. So for a day, she'd
> just watch her, take notes on her. Then [she] called us, and we got
> together. We filled out a survey and she also had a survey, and then

she collected [more] data. Then she told us she saw strong signs of sensitivity integration [needs], so that right away that's what we were diagnosed, so she had us read a book on sensitivity.

From this process, her daughter qualified for occupational therapy services.

Sometimes Parents Questioned the Value of the Labeling Process

One mother expressed much frustration with the assessment and labeling process that her son had gone through. It was often confusing, and didn't always make sense to her. What she knew about her son did not always fit with the information she was presented with and she was quite surprised with the diagnosis he received.

> His diagnosis—I was surprised about—the autism. Because when he was in early childhood, one thing my son mastered was puzzles. He was very, very good in puzzles. I brought puzzles to show his teachers there. They couldn't figure out if he was doing patterns or colors. There were these circles, but they had shapes, and they had color, so they [the teachers] were real amazed—and at how fast he could do it. I even mentioned to them if they thought he was autistic, because you know how they [autistic kids] get stuck. Oh, no. A lot of them worked with them [autistic kids], and one was a mother of an autistic child. . . .

For clarification, I asked if there seemed to be a broad spectrum of autism where you can be anywhere on the spectrum?

> Bill Gates has Asperger's. The woman at [the intervention agency] told me that. He needs somebody to help <u>him</u>?? Then just some of the other stuff that my son does that doesn't fit in there. With the affection. He's very affectionate here [at home]. This psychologist told me about a woman who's very intelligent and has wrote about autism and her growing up autistic. She has a writer with her, and when they greet, they look at each other and then they bow because she won't hug her. My son loves to be hugged, especially by me. He'll climb up on your lap and want you to tickle his feet. He wants to sit right by you. And he has eye contact. Stuff that isn't typical [for kids with autism].

Based on what I was hearing her say, I commented that, as a parent that must have been confusing.

It's still confusing. It's like almost, is it just a diagnosis to give him a
diagnosis? Every different thing that I've dealt with, with my son,
they come with . . . a wastebasket term. It's just a term we use, throw
it in the wastebasket and it means nothing . . . they say there's more
and more cases of autism. Are they just labeling him autistic because
there's nothing else?

They Don't Really Give You Any Answers—They Just Keep Pushing You Through

While one mother understood that the "sensitivity integration" label had had some

positive outcomes for her daughter, she also expressed a certain level of frustration that

the process moves slowly, and that ultimately, there seem to be no answers at the end.

Once we went to a meeting [with the child psychologist] without our
daughter, and she [the child psychologist] said that our daughter has an
amazing imagination. She has little voices for the people, but
everything is always aggressive in play: "You can't play with me so
you stand over there. I don't like you." Always breaking or hitting,
not loving the babies.

They don't really give you any answers, they just keeping pushing you
through. So our hope is the [clinic]. We've been on a waiting list for
quite some time. We've given them all sorts of information, we've
sent them photographs of our child. I mean they want everything. . .
.We've been on the list for a year.

This mother continued to describe her frustration with the labeling process, questioning if

there ever would be answers at the end. She understood that sensory sensitivity or

sensory integration concerns refer to the way in which a child orients to his or her sensory

world, and that helped her to have more understanding about her daughter's behaviors,

sometimes make changes in her daughter's environment. Common sensory issues are

sensitivity to noise, light, touch, food texture, clothing texture, and temperature. But it

can also refer to how a child orients her or himself in their physical space—these children

often bump table corners and door edges because they misperceive where they are in

space. They also misjudge where their bodies are in relationship to where the bodies of

their playmates are, which means that children get knocked over, children's structures get knocked over, children get stepped on and sat on. The problem is that the behavior is misinterpreted by both children and adults as an aggressive or hurtful behavior that needs to be punished. The sensory-impaired child has no clue as to what has happened, and responds with indignation because she or he feels that they have been wrongly accused.

> I thought I could figure it out. I'll be creative—I'll figure this out. I thought, "I'm smarter than she is. She's only 3." [But] the system kept pulling me in. And that's one thing I learned after going through all this, and not finding out anything (I mean chiropractors and whatever) is that I think it wears you down. There's no answer at the end.

For clarification I asked if there had been an actual diagnosis, and if so, did the label make any difference.

> Well, it has, in that we've done things like we always have sunglasses in the car—we just deal with it. When she's on the floor, we say, "you're fine, get over," and we just walk right past her. And I kind of wish we'd go back to that a little bit, because the more information you get, the more differently you treat them. And she's gonna have to survive. She's not always going to have people around that are going to protect her from all this. So, I'm kind of going back to that again, 'cause I'm tired of all these places that I've been to. So we're just trying to treat her like a normal kid, and put her out there, and that's why [we made the public] kindergarten choice.

Summary

Parents are truly caught between "a rock and a hard place" with the labeling process. Initially, as parents get used to the idea that the child they have is different than the child they envisioned, there is always the hope that things will get better on their own. A label makes it all real, and at this point, it is difficult for parents to embrace their current reality. Parents want the reality that they dreamed of prior to the birth or arrival of their child—not the reality that they wake up to every morning. At some point though,

it becomes apparent that an evaluation, and a possible label, might help their child move forward. Unfortunately, at this point, they are faced with the snail pace and bureaucracy of the educational system. Sometimes parents feel guilty that they should have started the process earlier. Sometimes parents are frustrated because now that they are ready to "go," there is no place to "go to!" And like one mother said, "Once you start receiving special education services, you become one of "those" families. It is truly an awkward place to be.

<center>Theme #8: Our Realities Are Much Different Than Our Dreams</center>

When the realities of life are different than the dreams anticipated, Mitchell and Anderson (1983) describe the experience as an "intrapsychic loss that is likened to the experience of losing an emotionally important image of oneself, losing the possibilities of 'what might have been,' abandonment of plans for a particular future, and the dying of a dream."

In his book, *Loss of Dreams,* Ted Bowman says that while grief is a part of life, it is not something that we readily embrace, especially when the loss is intangible. Therese Rando (1993) suggests that there are two kinds of losses, the physical loss of something tangible, and the psychosocial loss of something intangible, such as having a dream shattered. Bowman further expands on this idea, using this definition:

> A loss of dreams relates to images or pictures of our personal world
> that we create and to which we attach strong emotional investment . . .
> the way things are supposed to be. (Rando, p.16)

When children are born with a disability, or develop a disability after birth, parents' dreams of what 'might be' change. Several parents talked about having such an image or dream in which they anticipated how life would be with the child: the

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pregnancy, their child as an infant, the growing up years, and their child as an adult.

While the parents who talked about a dream did not all describe their experience as a

sense of loss, they did describe a sense of incongruence between the dream or image that

they had in mind, of what might have been, and the reality of the experience of parenting

their child.

Early on, I Knew Something was Different

Three parents recognized early on that their child and their experience with their

child was different than what they had anticipated. One mother described her 'pre-

pregnancy' dream and how quickly life became different from her dream the moment her

daughter was born.

> You have this dream of how your child will be. Then from the day she
> was born, it was all different—she was hard to comfort, hard to feed,
> etc. My daughter is a wonderful child but she has presented me with
> challenges since the day she was born. She had a complicated
> delivery. She had early feeding problems. She was allergic to milk.
> When she had trouble with the nursing and we gave her formula, she
> reacted by, she broke out in a rash from head to toe, she had a runny
> nose, she had bloody stools and she was inconsolable. So it was a
> challenge from the get go. And not her fault. Just a challenge. She
> evolved into this complex little creature who required a lot of
> stimulation, a lot of interaction. So many things have been a struggle.

Like the mother above, who anticipated the "new mom-new baby" experience to

be one way, but found reality to be a different story, another mother's "pre-pregnancy"

ideas quickly changed the moment her son was born 2 months premature.

> You have this dream of how your child will be. Then he was born 2
> months premature. There was just a lot of catch up time. He's doing
> well, but he'll probably always have to work a little harder. I don't
> want him to be the little kid who can't.

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She projected her altered reality forward into the future, anticipating what life might be like for her son for many years to come.

Another mother's child also had unique needs early on, and her reality soon became different than her dream.

> You have this dream of how your child will be. Then you notice very
> early on, he's not like the other children. He's always on the move,
> taking things apart, taking risks, not relating to other children as
> people but as objects to be manipulated. You get used to it, and think
> of it as normal, but when you get together with other families, you see
> that other children aren't doing those things.

This mother needed the comparison of observing other children's behaviors to see that her child's behavior was not typical.

Early into the interview, one mother described how she knew her son had some special needs, but she was not sure what they were.

> People say kids are so different, but at that point, I had a great niece
> that was 4 months older than my son, and a nephew 2 months younger
> [than my son]. So I could see that there was something. I know kind
> of where you should be. When I took him for his 1 year picture, he
> couldn't even sit up. [I said] This is just ridiculous.

Near the end of our interview, she talked about how she had anticipated life as a mother, and how she had come to accept what life would, and would not most likely be as the mother of her son.

> You get your child and then your life is supposed to go a certain way.
> They go through school, they graduate, they get married, and they
> have kids. And the cycle. All of a sudden I hear he has a disability,
> and I'm like, my first thing is, I'm not going to be a Grandma. I'm not
> going to have some of those things that I wanted having a child.

Later, I Realized the Future Would be Different.

One mother's voice quavered as she expressed concern about her son's future.

It's very tough to then not know the future. That's another thing that's so hard for me. On top of just knowing in general, I feel like, is he going to be able to hold a job? Sometimes, I think if we can just keep him out of prison, that will be—my standards have changed. If we can just keep him alive and out of prison, I'll feel fairly good.

Another mother described a scenario in which her daughter's behavior got out of control in public. Other parents were angry with her because they feared for their own child's safety. At the end of the story, she contemplated a personal dream for her child's future.

Sometimes it's really hard. I visualize Montana—open space, not a lot of neighbors, that would be my dream. But that's not realistic.

Later into the interview, she expressed her lack of expectations for her daughter as she grew older.

I have no expectations for her in life. I don't see her doing the typical things you want for your child, like going to college. If she possibly can, she will go, (with a questioning look on her face), but . . .

She's going to have to survive. She's not always going to have people around that are going to protect her from all this. So, I'm kind of going back to that again [treating her normal], because I'm tired of all these places that I've been to. So we're just trying to treat her like a normal, and put her out there, and that's why she's in public kindergarten [rather than home schooling].

While this mother was well aware of her daughter's uniqueness, she also believed that her best chance for have a "normal" experience would be if her family continued to have realistic expectations of her—the same expectations that others in the 'real world' would have.

Even though her son was 2 months premature, and one mother's parenting expectations were altered from the beginning, the reality of her son's future became more

evident as he grew older. While early intervention had been successful, she anticipated that he would always experience challenges.

Summary

Mothers described in detail the unsettledness of coming to grips with their child's "difference," and what that meant, both for their child, and for themselves as mothers. For their children, they described walking a fine line between understanding and accommodating to the possible limits of their child's development, yet wanting their child to have as normal an experience as possible. For themselves, they understood that the experience of being a parent to their adult child might be different than they had hoped for, such as the possibility of not becoming a grandparent.

CHAPTER 4 – DISCUSSION OF FINDINGS AND EXTANT LITERATURE

Consistency Between Findings and Literature

In the discussion in this chapter and in the conclusions and recommendations in Chapter 5, the study reported in the previous chapters will be referred to as "the present study." The mothers in the present study talked about their experiences of parenting their young children who engage in challenging behaviors across a wide variety of situations: the process of accepting the reality that their child needed help, interacting with pediatricians and other medical professionals, interacting with education professionals, and dealing with the day-to-day reality of parenting children they didn't understand (feeling embarrassed and angry about their child's behavior, blaming themselves for their child's behavior, and not knowing what to do about their child's behavior). Throughout all of these experiences was one constant theme—mothers wanted to be heard. Sometimes their experiences regarding wanting to be heard included relief that somebody had acknowledged their concerns as real (and supported them in getting help for their child), and sometimes it included feeling anger because their intuitive concerns about their children were not taken seriously.

Parents Want to be Heard

The finding in the present study that is most similar to the findings in the literature concerns parents' frustrations about not being 'heard' by their medical and education professionals. There seems to be agreement among professionals that parents are vital to the process of children getting help (Achenback, 1992; Glascoe et al., 1991; Jenkins et al., 1982; Minde & Minde, 1977; Stallard, 1993; Stone & Lemaneck, 1990). Even though the literature about problem behaviors indicates that parents' reports to the

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medical and education community are vital to the well-being of their children, many of

the professionals in those communities seem unwilling to validate parents' concerns

about their children's needs. This experience was initially very frustrating to parents who

were well tuned in to their children, as they were eager to start the process of seeking

help as soon as they became concerned about their children. Parents' initial frustration

turned to anger when they had to wait so long for help because their doctors or teachers

would not take their concerns seriously. One study reported in the current literature on

parenting young children who engage in challenging behaviors parallels the concerns

outlined above. This study is summarized below.

The Parents in Partnership (PIP) Project was conducted by the Edmund S. Muskie

Institute of Public Affairs at the University of Southern Maine (USM) with grant funding

from the U.S. Maternal and Child Health Bureau. Outcomes of the project included the

book *From the Heart: On Being the Mother of a Child with Special Needs* (edited by

Jayne D.B. Marsh, 1995), and several videotapes to help parents and professionals form

more effective partnerships by learning improved communication skills.   To sincerely

address the issues of parent-professional communication skills, the forward of the book is

written by pediatric geneticist D. Robert Marion. Marion describes the gap in his medical

school learning between the theory of what patients want, and what he discovered his

patients really wanted.

> After some consideration, it has become clear that a problem exists
> here.   Somehow, in the training of physicians, an important
> component has been eliminated from the loop: patients are never
> asked what it is, exactly, that they want. It's always only assumed that
> the lesson that's taught is correct [what is taught from the textbook
> represents real life]. But after all, what else is it that a patient in his
> right mind could want? (Marsh, 1995, p. *xiv*)

Through participation in the PIP project, Marion developed the sensitivity to understand that parents want to be heard, and they want their opinions and experiences to be validated. What he had learned through listening to the mothers in the PIP project is reflected in Marion's description of this interaction with Madeline, the mother of a dying child:

> There is, however, a great deal I can do for Madeline. Although I've gotten her into regular counseling with a psychologist, she still comes to my office regularly, just to talk. . . . So last week, she sat down on my couch and started to talk. . . . She didn't need me to say anything; she didn't need me to cure her daughter (although, clearly, she would have loved that); all she needed was to have someone to talk to, or, more accurately, to talk at, someone who wouldn't criticize her, or answer her back, or feel guilty. And when she was finished, after she'd been unburdened, she was ready to head back into the fray that was her life, at least for a while. Unburdener: That's the role I've come to play with Madeline D. (Marsh, 1995, p. *xviii*)

Through his participation with the mothers who participated in the Parents in Partnership (PIP) project, Dr. Marion realized that there was much more to medicine than he could ever have imagined beyond diagnosis, treatment, and cure.

Nine mothers of children with special needs participated in the PIP project. The special needs of the children included autism, pervasive developmental delay, attention deficit hyperactivity disorder, speech disorders, dyslexia—all disabilities that often manifest challenging behaviors. Three of the themes in Marsh's (1995) book are similar to the themes in my study: Being Heard, Feeling Understood, and Isolation. One mother and her husband were going to marriage counseling around the issues of having a child with special needs. Very similar to an experience of one mother in the present study, the mother in Marsh's (1995) book described how dumbfounded she was when the marriage therapist turned the focus to her:

As I was sitting with this professional and my husband talking about all these issues—the emotions, how constant the struggle is, doing it alone, the therapist stopped me and said, "This would be a good time for us to really look at something here. Don't mind that I've interrupted, but what I think is that down the road we are going to need to look at getting you, Kathy, evaluated for manic depression. A little medication," he said, "will make you feel better, more able to sleep, and you'll be able to deal with your husband more happily."

I just sat there, and I thought, this is it, I'm not being heard, and now it's so bad that I have been shut up. I have to be medicated. He's going to medicate me. This is insane. There's something absurd about my being labeled "sick" because I shared my feelings, my pain. . . . And I scream out, "Does anybody really get it?" Whether it's teachers or professionals, there are times when I think we have a really hard time being acknowledged or respected, and our perspectives validated. (Marsh, p.7)

Similar to the mothers in the present study, another mother described her frustration with the unwillingness of her son's teachers to look at methods for dealing with her son's behavior other than the "life-space" room where children who acted out were sent to think about their behaviors. They were unwilling to hear the suggestion that her son responded really well to positive reinforcement rather than the "life-space" room which he considered aversive. Once the teacher "discovered" this on her own, things changed dramatically for her child. The mother was grateful, but still frustrated that her knowledge of what worked for her son was neither recognized nor validated by her son's teacher.

Several mothers in the present study had talked about loneliness, or feeling isolated. One mother in Marsh's (1995) book described it like this.

It affects the relationship I have with my neighbors. It's easier for them not to get to know me or like me because we are so different, because of Jeremy. He is visibly very different. It pours over into everything. The hard part as a parent is that we are the ones, every time, who just have to keep picking ourselves up and putting on that

strong face and going ahead. It matters, though; it hurts. Sometimes
you think you'll get used to it, but you don't ever get used to it, and it
just keeps happening over and over, and it's hard. (Marsh, p.59)

Another mother in Marsh's (1995) book commented that "many times, family and

friends, not knowing what to say or do, will avoid conversation regarding the child, or

even avoid the parents altogether" (Marsh, p. 118).

The difference between the present study and Marsh's (1995) book lies in the

primary goal of each project. The primary goal of Marsh's (1995) book was to capture

the stories that the mothers of children with special needs routinely shared at the

beginning of each Parents in Partnership group. Because mothers felt that hearing the

stories of others offered them strength and support in dealing with their own issues, there

was a desire to make their experiences available to other parents.

The mothers and staff of the project wanted share these stories with
other parents, to extend the parent group process and offer something
to parents after the project ended. All the mothers felt that hearing
stories of other mothers in similar situations was very affirming, and
offered them support and strength in dealing with their own issues.
They felt less alone. (Marsh, p. *ix*)

In contrast, the primary goal of the present study was to have a deeper understanding of

mothers' daily lived experiences when parenting their young children who engage in

challenging behaviors.

Goranson (2001) interviewed 5 mothers of obsessive-compulsive (OCD) children

for the study titled *Mothers of Obsessive-Compulsive Children: Their Story*. The (OCD)

children all engaged in challenging behaviors such as severe temper tantrums,

aggressiveness toward peers, and self-injurious behaviors toward themselves. One

similarity between the present study and Goranson's (2001) study is her finding that all of

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the mothers reported difficulty being heard by medical and mental health practitioners during the process of diagnosing their children. Several of the mothers in the present study reported similar experiences. Goranson (2001) indicated that her study was phenomenological and "heuristic" in nature, the goal of the study being to "explore, in depth, their experience with mothering a child with OCD" (p.36). However, Goranson (2001) further describes the goal of the study as follows:

> In particular, they [mothers] were asked to describe their coping mechanisms and attempts to receive support for themselves or their symptomatic child. (Goranson, p. 36)

Although the stated intent of the Goranson study was to explore mothers' experience of mothering a child with OCD, the focus seemed to be more on the children's behaviors, and the mothers' reactions to their children's behaviors. Goranson collected descriptions of mother's experiences but did not expand the study to learn about the meanings of the mothers' lived experiences.

Observing the increased interest in the science of child development in recent years, particularly relative to early childhood and young children with challenging behaviors, Worcester (2005) noticed that the voices of parents are often left unheard. This void in the research data is significant in that it is acknowledged that "home is a child's first learning environment and parents are their children's primary and most influential teachers" (Minnesota Department of Education, 2003; Horn, 1999). Worcester (2005) conducted a qualitative study titled *Giving Voice to Parents of Young Children with Challenging Behavior.* The children's challenging behaviors were similar in nature to those in the present study, and some of the parents' responses to and experiences with the behaviors were similar in both studies (avoiding things that they

know create issues, difficulty in accessing services and support for their child, difficulty in finding child care). The goal of Worcester's study was "to obtain detailed parent reports of experiences raising young children with challenging behavior." While parents had the opportunity to voice their experiences, I did not find that the essences of those experiences were well articulated.

Turnbull and Ruef's (1996) study titled *Family Perspectives on Problem Behavior* focused on three interview questions that were conducted via telephone:

1. What are family perspectives about the current challenges and successful approaches for individuals with mental retardation who experience problem behavior?

2. What are family perspectives about the current challenges and successful approaches for families of individuals who experience problem behavior?

3. What types of information do families want that would make a significant and sustainable difference in reducing or eliminating problem behavior? (Turnbull & Ruef, p.280)

Many of the responses reported in their study paralleled some of the situations reported by parents in the present study: parents have no down time, parents are concerned about their child's behavior in public settings, their child's behavior stresses family routines, and parents feel isolated. But the Turnbull and Ruef study was very different from the present study in that it was designed only to elicit families' perspectives, which it did. Because it was not intended to elucidate the essence of their daily lived experiences, I did not experience a sense of "knowing" those parents like I felt I "knew" the mothers in Marsh's (1995) book.

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Gallagher, Fialka, Rhodes, and Arceneaux (2002) examined the concept of denial in parents of children with disabilities. They suggest that professionals would do well to consider thinking of a family as being "in hope" rather than thinking of a family as being "in denial." They caution that "if professionals categorize parents as 'in denial,' unaccepting, or difficult, professionals may lose the chance to understand and learn from the parents" (Gallagher et al., 2002, p.11). They also propose that "professionals should be cautious not to expect all parents to integrate new information about their child in the same manner or within the same time frame as the professional." This perspective exemplifies the stories of the mothers in the present study.

While the literature *specific* to the topic of parents' experiences of parenting children who engage in challenging behaviors was limited, I was able to find other literature that *included* parents' experiences with their children who engage in challenging behaviors. Fox et al. (2002) reported themes that reflected families' initial concerns about their child, concerns about the constancy and relentless demand of their child's problem behavior, and social isolation, which is similar to the present study's findings. Travell and Visser (2006) studied parents' and young peoples' experiences with and perceptions about Attention Deficit Hyperactivity Disorder. Some parents in this study complained of not being listened to by education and health professionals over a number of years prior to diagnosis, which is similar to mothers' reports in the present study. Tocci, McWilliam, Sideris, and Melton (1997) interviewed 75 families of children with special needs, including 9 mothers who had or were receiving early childhood services. In response to the question, "what advice would you give?" many parents responded, "Keep fighting and don't ever give up" (Tocci et al., p. 2).

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According to Stone and Lemanek (1990), the limited number of studies utilizing parent report is surprising:

> The paucity of controlled studies utilizing parent report methodology is surprising in light of the integral role that parental reports play in the diagnostic process (Marcus & Baker, 1986; Schreibman & Charlop, 1987). Parents' unique perspective as reporters derives from their long-standing history of transactions with their children as well as their ability to observe behaviors that may not be apparent in a clinical setting (e.g. peer relationships). A systematic method for gathering specific information from parents regarding the social development of their young autistic children would be of potential value in the understanding and early diagnosis of this disorder. (p. 514)

I indicated earlier in the present study that there is a paucity of research focused on parents' experiences of parenting their children who engage in challenging behaviors. I was only able to locate four studies specific to the experiences of parenting children with challenging behaviors. While Stone and Lenmanek's (1990) study utilized parent reports given on the Preschool Social Behavior Checklist (PSBC) rather than information gained through open-ended qualitative interviews, their concern about the lack of any attempt to glean information from parents is noteworthy. Some of the research that I reviewed was about mothers' experiences of parenting children with other disabilities, which sometimes included situations of dealing with their child's challenging behavior. In closer reading of the myriad of research articles about challenging behaviors, I found references to parents' experiences that are similar to two of the themes identified in the present study: Theme 8 (Our Realities are Much Different Than our Dreams) and Theme 2 (It is Painful, and Often Demoralizing, to Receive so Much Negative Information About Your Child).

Our Realities are Much Different Than our Dreams

Findings in the present study reflect findings in the literature concern parent's process of accepting the reality about their child being 'different,' (Naseef, 2001, pp.37–40; Marsh, 1995, pp. 28–32), embarrassment about their child's behavior in public (Goranson, 2001, p.137; Turnbull & Reuf, 1996, p.284), and concern about their child's future (Goranson, 2001, p. *iii*). These findings also parallel the professional experiences that I have had with many families during the last 20 years. Every parent's dream is that their child is unblemished—free from problems. Accepting otherwise is a slow, painful process in which parents hold on to any and every hope that there really is no problem or that the problem will go away.

It is Painful, and Often Demoralizing, to Receive so Much Negative Information About Your Child

Most of the mothers in the present study had intense feelings about the interactions with their child's teachers. Sometimes they commented on the negativity of the interactions, and sometimes they focused on how the teachers presented information about their child to them. This area of stress between parents and teachers related to children's challenging behaviors was only reflected in three studies (Goranson, 2001, p.139; Marsh, 1995, pp. 8, 14–16, 69, 91; Naseef, 2001, pp. 231–232). It is a significant topic for discussion, as many children spend a significant part of their early years in school settings, and it is often the teacher that first brings the behaviors of concern to light. Why? Parents may not be discussing the behaviors because they have over-accommodated their home environment to meet the child's needs, and do not perceive the behavior to be a problem. Also parents may be terribly embarrassed by their child's

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behavior, and like the mothers in this study, have no idea what to do about it, but expect the teachers to 'figure it out,' because the teachers are the professionals.

<center>Findings Not Discussed in the Literature</center>

<center>Relationship Between Cognitive Skills and Challenging Behaviors</center>

One finding not reflected in the literature is the tendency for the children who engage in challenging behaviors to have strong cognitive skills. They are often described by both their parents and teachers as being very "bright." This has been my professional experience during the last 20 years when working with the teachers and families of young children who engage in challenging behaviors. Sometimes it has been the child's teacher who describes the challenging behavior, then adds, "but s/he is really smart." Sometimes it has been the child's parent who says, "but my child is really smart," after listening to a detailed list of their child's transgressions. While there is much research about children's cognitive skills, the relationship between challenging behaviors and cognitive functioning does not seem well understood nor illumined by research.

Another finding of the present study not reflected in the literature was the initial response of some of the mothers. While they were very aware of their child's behavior, some mothers were not initially concerned, because they thought that they had reasonable explanations for the behaviors. One mother described other family members as being "out there," so considered that her child just had a family trait. Another mother of a recently adopted child thought that her child was still transitioning to the new surroundings. Another mother described her child as just "precocious—and you try to think the best of your child." One mother thought that her child's difficulties were only related to not speaking the same language as the other children in the child care—once

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the language barrier was overcome, she thought things would be fine. Once these

mothers determined that their child's behavior was not temporary, they sought out help.

In contrast, several of the mothers in Marsh's (1995) book had a "sense" early on that

something was not normal about their child's development.

<center>Limitations of the Study</center>

A primary component of hermeneutic phenomenological research is the ability of

the researcher to bracket his or her foreknowledge about the experience that is being

studied. Because the experience of parenting children who engage in challenge behaviors

is near and dear to my heart, I was less successful at dealing with my foreknowledge and

presuppositions than planned, as indicated in Chapter 2. This had the potential to affect

the study in three areas.

Closed-end Questions

While I often asked mothers to expand on comments by asking "how did you feel

when . . . ?", there were a few situations in which I asked closed-end questions such as,

"Did that happen often?" to which the mother replied, "It happened a few times." A

more appropriate question would have been, "How did you feel when the teachers

responded to you that way?" In this example, after another prompt, the mother continued

to describe the situation, ultimately saying, "The one teacher was just making us feel that

there's something we're doing or not doing."

Missed Opportunities

The above situation is an example of the second way in which my interview skills

could have been a limitation to the study—missed opportunities. I sometimes failed to

follow up on the mother's comment by asking, "How did you feel about that?" or "Can

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you tell me what that felt like?" An even more appropriate follow-up would have been, "Can you say more about that?" It is possible that at the time, I thought I knew what they meant, so didn't think I needed further input. In reviewing the texts multiple times, I found situations in which I could have asked mothers to expand on comments, which would have given me a deeper understanding of their experience. While there were many situations where I did follow up on mothers' comments, I could have done this more consistently.

Text Interpretation

The third area of possible study limitation was evident in my interpretation of the texts. Initially, I forgot that it was just as important to bracket my foreknowledge and presuppositions when interpreting the text, as it was when conducting the interviews, and was fortunate to have my initial interpretations strongly challenged by my advisor. I gradually became aware that I often interpreted mothers' words through my own lens and my own experience, rather than letting their words guide me towards understanding their lived experiences. This is a process for which I can claim improvement, but not mastery.

CHAPTER 5 – CONCLUSIONS AND RECOMMENDATIONS

What does the present study contribute to the existing body of knowledge about

mothers' experience of parenting their young children who engage in challenging

behaviors? It goes beyond merely describing the activities that children and their

mothers are involved in, and what the mothers' responses are to those activities. This

study focuses on the essence of what those experiences mean to mothers. This

perspective invites the reader to really listen to what mothers are saying about their

experiences of parenting their young children who engage in challenging behaviors. It

also invites the reader to ask the question, "is there anything that can be done to support

mothers of young children who engage in challenging behaviors?"

Conclusions

Parents are Tireless Advocates for Their Children

"Keep fighting and don't ever give up," and "you have to fight for your child,"

are sentiments expressed by parents in the study conducted by Tocci et al. (1997, p. 1).

Parents in the present study and in other literature reviewed voiced similar concerns. One

parent in Worcester's (2005) study who had recently moved to Florida reported the

difficulty in trying to maintain the array of comprehensive services that were authorized

for her child in Minnesota, but were not yet honored in Florida. One mother in the

present study described that many aspects of getting help for her son were "a fight."

Another mother in the present study described the stress of the two additional bus rides

she had to make each day in order for her son to attend the new preschool he was finally

accepted into—a setting that she thought would be good for him. Other mothers in the

present study described the difficulty of getting on waiting lists for appointments with

specialists that were 6 to 12 months long. One of the mothers in Marsh's (1995) book

described with much frustration how hard she had to work to get beyond the school

receptionist in order to get an appointment with the principal of the school that her child

would be attending the next fall. In reference to how hard she worked to educate her

daughter's doctors about OCD, one of the mothers in Goranson's (2001, p.136) study

posed the question, "why do I have to do all the digging?" One mother in the present

study talked about the stress of choosing the best school environment for her child, which

meant visiting several sites, meeting with the staff at the sites, and making the final

placement decision for which she alone would carry the responsibility for the

consequences if it didn't work out.

Parents' advocacy is only one part of their experience of "wanting to be heard."

These advocacy behaviors are often the precursors to getting to the place where parents

still have to work hard to "be heard," and they represent the additional work that parents

often have to continue even after they "are heard."

Parents Want to be Heard

Parents of young children who engage in challenging behaviors want to be heard.

They want their intuitive knowledge about their children to be heard and validated by

their families and friends, and by the professionals who work with their children and have

the power to make decisions about what kind of help their child gets. Mothers

acknowledged that initially they didn't understand what was happening with their

children, and may have even been in denial. Being treated respectfully, and with

empathy, was very important. Most often, this meant not being blamed for their child's

behaviors. Once they could accept the reality of their child's (and their own) situation,

they wanted to make the best choices that they could for their child. They could move

forward.

Parents Don't Cause Their Children's Challenging Behaviors

Even after accepting the reality of their situation, mothers still wanted to be heard.

At this point, they often were receiving support for themselves and for their child, and

trying to manage their child's behavior with intentionality. They were giving clear

messages to their children, stating expectations, and following through with

consequences. These were the situations in which mothers overheard comments such as,

"some people just can't manage their children," or were told directly to be consistent.

One of the ways that we can "hear" parents is to not blame them for their child's

behavior. When we blame parents for the child's behavior, we are saying that the

behavior is the result of their poor parenting practices. In so many situations, this just is

not true. As two mothers in the present study said, "Walk a mile in my shoes."

All Parents of Children Who Engage in Challenging Behaviors May Not Have Similar

Experiences

The mothers in the present study all met the single criteria of being the parent of a

young child who first engaged in challenging behaviors between the ages of 2 and 5 years

of age. Many of the studies that I reviewed involved children for whom a primary

disability was evident at birth (such as mental retardation, Down syndrome, or cerebral

palsy) and the challenging behaviors were secondary. I decided that inclusion of those

studies was appropriate, because I determined that the source of the challenging behavior

was not as important as the parents' experiences dealing with the challenging behaviors.

In reflection, I have come to question the similarity of the parents' experiences, on two

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levels. First, are there differences in the level of acceptance? When a child is born with

an identifiable disability such as Down syndrome, parents are faced with the pain of

accepting the reality of their child's disability from the day the child is born. There is no

possibility for the hope that "things will get better," because the disability never goes

away. It is as though these parents begin their parenting experience at ground zero,

knowing that there will always be a limit to what their child can achieve, but they are

always moving forward. In contrast, when children appear disability-free at birth, parents

begin their parenting experiences with dreams and hopes of a myriad of successes that

can happen for their child—"the sky's the limit" here. Rather than continually moving

forward, these parents may have to continually adjust their dreams and hopes backwards,

as the reality of their child's situation becomes more apparent, and the future becomes

less certain. Second, are there differences in the level of accessing resources? For

children who receive early diagnoses of disability, service systems are already in place.

When confronted with challenging behaviors, parents are in a position to request

additional support to the services that are already in place. For parents of children who

appear more typical in many aspects of their overall development when the challenging

behaviors first become apparent, accessing services is more of a challenge, because they

must convince the educational and medical communities that their child has a need.

Recommendations

My overall recommendation is that there needs to be more research and training

about parents' experiences of parenting their young children who engage in challenging

behaviors. This is especially relevant for those parents whose children appear to be

typically developing at birth, but for whom challenging behaviors become evident as the

child grows older. I make this recommendation from two premises. First, the primary conclusion of the present study is that parents of young children who engage in challenging behaviors want to be heard. This is supported by the consistency between some of the sub-themes in the present study (regarding mothers being misunderstood by doctors), and some of the themes in the extant literature (about mothers not being heard). Second, the prevalence of challenging behaviors is well documented (Bird et al., 1988; Caspi et al., 1995; Fergusson, Horwood, & Lawton, 1990; Lavigne et al., 1995; McGuire & Richman, 1986; Mulatu, 1995; Stallard, 1993; Weiss, Sigman, Weiss, & Mosk, 1993), appears to be increasing (Kelleher et al., 2000; Walker, 1998), and a correlation between early onset of challenging behaviors and later deviancy has been established (Campbell & Ewing, 1990; Chandler & Dahlquist, 1997; Klass, Guskin, & Thomas, 1995; Ritchie & Pohl, 1995; Vitaro, DeCivita, & Pagani, 1995; Webster-Stratton & Herbert, 1994). Practitioners need to be better informed about parents' experiences of parenting young children who engage in challenging behaviors. As one parent in Marsh's (1995, p.8) book said, "Isn't there some way for professionals to develop an understanding of the issues for parents of children with special needs, that taps into some of their own life experiences?"

Why It is Important to Focus on Understanding Parents' Experiences

Parents are the link between their children and all of the systems that their children will encounter. If our educational and societal goal is to provide young children with the skills that they need in order to achieve their developmental potential, then our goal must also include working with and understanding parents—especially parents of children with challenging behaviors. Of all the research referenced in this study, only

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Marsh's (1995) book presents the essence of mothers' experiences when parenting their young children who engage in challenging behaviors. It is one thing to read that parents are frustrated and tired. It is quite another experience to understand what it means to be frustrated and tired—that their frustration comes not just from their interactions with their child, but also from not being taken seriously by their child's doctors and teachers. From not being heard. Mothers were frustrated when their child's teachers were unwilling to accept that they might really understand what aggravates their child's behavior and what helps calm their child. Mothers in this study also talked about their fears for their child. Can professionals understand that when parents of children whose problem behaviors emerge years after birth accept that their child needs help, these parents are jumping into a huge chasm of uncertainties: Will their child be treated fairly? Will the parents be treated with respect? From the professional's side of the fence, it seems reasonable to say, "Have your child evaluated by ECSE." But like one mother in the present study said, "But then you're one of THOSE families—my friends don't have children in special ed."

Recommendations for Researchers

Carefully select recruitment sites. In conducting further studies with parents of young children who engage in challenging behaviors, I recommend that researchers recruit participants through agencies that are already working with parents of young children who engage in challenging behaviors. Such agencies include, but are not limited to: occupational therapy clinics, school district ECSE programs, behavioral guidance clinics, and developmental pediatric programs. Because of my experiences as a teacher and as a program administrator, I knew that early childhood programs were likely places

to find young children with challenging behaviors. But I was shocked that I had such initial poor response. What I did not consider was that parents who are in the process of accepting their child's behavior are not yet ready to talk about the experience because the experience is too new, too raw. The parents who were just newly receiving the reports about their child's behavior were not ready to talk about it, because talking about it would make it real. They were clinging to the hope that the behaviors "would go away," and discussing the situation from any other perspective would destroy that hope. In further thinking about the families with whom I had recently worked, I realized that the last thing that they wanted was to agree to participate in my research study. They were still angry with me, because I had delivered the "bad news."

In contrast, the mothers who asked to participate in this study through the contact at the occupational therapy clinic were already experiencing different levels of acceptance about their child's challenging behavior. While still challenged by their child's challenging behavior, they had experienced some successes, and were hopeful about the future. Most important, the mothers were in a place where they wanted to talk about what the experiences had been like for them. In addition, the connections made during recruitment with the agencies already serving these parents, will facilitate sharing findings with practitioners who have the potential to make a difference in parent's lives.

Utilize research methodologies that aid understanding parents' experience for future research. I recommend that researchers use hermeneutic phenomenology when conducting further research focused on understanding the meaning of the experiences of parents whose young children engage in challenging behaviors. As stated earlier in this present study, there have been several studies conducted about parents' experiences of

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parenting their young children who engage in challenging behaviors using questionnaires

and structured interviews. I suggest that there are two problems with this methodology.

First, only certain questions are asked, so only certain questions can be answered.

Second, there are limited opportunities for parents to give information about things that

they consider important, but have not been addressed in the questionnaire. If the

professionals who work with the families of young children who engage in challenging

behaviors believe that it is important to understand the meaning of parents' experiences,

then researchers must use the methodology that captures the essence of parents' lived

experiences.

Recommendations for Medical/Diagnostic System Professionals

Professional internships. I recommend that residents in family practice, pediatric,

and pediatric nurse practitioner training programs spend part of their first or second year

rotations in any or all of the following three interactive observational settings: settings

with children who have typical developmental patterns, settings with children who

engage in challenging behaviors, and parent support group settings with and without

parent-child interaction time. The goal of this observation/interaction would be for the

residents to become more familiar with what typical and atypical development looks like

within the context of same-age peers, and to observe these children and their parents

interacting in individual or group settings. This information can be helpful when

listening to a parent describe how their child is reported to interact in a classroom,

because the resident is familiar with how challenging behaviors look within the context

of a classroom. Environments that could provide such internships include full-day child

care centers, part-day nursery schools, Head Start programs, ECFE programs, and ECSE

programs. From his own participation in the PIP project, Dr. Marion stated:

> I became convinced that neither I nor any of my colleagues in
> medicine, no matter how tuned in or attentive we be believed ourselves
> to be, had even an inkling concerning what our patients viewed as
> important. (Marsh, 1995, p. *xx*)

The relationship between Marion's statement and the recommendation for observational

internships is that doctors may have a better chance of understanding what patients view

as important if they have a working knowledge of what their patients are talking about.

In this case, doctors may be more inclined to listen to the parent's concern, rather than

quickly say to a parent, "There's nothing to worry about—your child will grow out of the

behavior."

It is very important to prepare practitioners in pediatrics and family practice for

working with the parents of young children who engage in challenging behaviors. Why?

They are one of the first places that parents turn to with concerns about their child's

development. The intent underlying this recommendation is for physicians to have a

deeper knowledge of what typical development really looks like, so that when a parent

brings a concern to their office, the physician then has a working memory of what typical

development looks like, and may be better able to "hear" what the parent is trying to say.

Pre-service observations. I recommend that non-physician medical professionals

who will be working with families and their young children who engage in challenging

behaviors have interactional observations during their professional preparation with at

least one of the following: children who have typical developmental patterns, children

who engage in challenging behaviors, or parents in individual or group settings.

Dissemination of information. I recommend that medical professionals working with young children who engage in challenging behaviors and their families write about their knowledge and their experiences. Articles could be submitted to their professional journals, to trade journals, and to parenting magazines. Additional sites for dissemination of information include neighborhood school and church settings, physicians' waiting rooms, and teacher inservice days. Information shared through church settings and articles in newsletters also has the potential to reach another population of concerned people: grandparents, extended family members, and friends.

Recommendations for Professional Training Programs of P–12 and Parent Educators

Pre-service teacher training. I recommend that teacher pre-service training curriculum include training protocols that utilize research about parents' experiences of parenting their young children who engage in challenging behaviors. Many young children spend a significant part of their early years in school settings, and it is often the teacher that first brings the behaviors of concern to light. Why? Parents may not be discussing the behaviors with their child's teacher because they have over-accommodated their home environment to meet their child's needs, and do not experience their child's behavior to be a problem. Alternately, parents may be terribly embarrassed by their child's behavior. Like the mothers in this study, parents may have no idea what to do about the behavior, but expect the teachers to 'figure it out,' because the teachers are the professionals. Unfortunately, initial teacher training programs do not prepare most teachers for interacting with parents when there are concerns about a child's behavior. It is essential that teacher's skills exceed the initial knowledge base of understanding typical child development and implementing daily curricular expectations. Teachers

need opportunities to practice listening to parents so that they can authentically "hear" what the parents are saying and sensitively respond to parents, within the context of where the parents are "at." The protocol for this training is already established in the social work, counseling, and mental health professions in the form of supervised role play and supervised practica. How can such a protocol be included in pre-service teaching programs? This is an institutional issue that requires examining existing curriculum and determining where study and experiences with such protocols can be included in courses, practica, and field experiences. Such training should be part of initial licensure programs so that teachers enter the classroom prepared to successfully interact with young children who engage in challenging behaviors and their families.

Inservice training. I recommend that agencies and institutions that serve young children who engage in challenging behavior and their parents provide inservice training consisting of modules that focus on communicating with parents during the early stages of concerns about their child's behavior or development. Such training modules should reflect research on the lived experiences of these parents. The training should be incorporated into annual inservice training requirements for nurses, social workers, mental health practitioners, occupational therapists, physical therapists, speech-language therapists, and P–12 and parent educators.

Additional Recommendations for Inservice P–12 and Parent Educators

I strongly recommend that educators conduct a personal self-check if they find themselves overly frustrated when working with a child who engages in challenging behaviors. The self-check needs to include this question: is the perceived problem really

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with the child, or is the perceived problem actually with how I, the teacher, think and feel about the child?

Joseph Sottile (1991) described his experience of waiting for a child in his class to be moved into a school for emotionally disturbed children. When the child was finally excused from the principal's office after having taken another child's money, the child returned to Sottile's desk to speak his mind.

> "I thought you might be different," he declared angrily. "I thought you might like me. None of my other teachers ever like me." Sottile wrote] Those words struck me like a bolt of lightning—right in the heart. Not only had I failed to acknowledge this child, I'd written him off and actually made him feel unwanted. Whether Matt was going to be with me for the entire year or only part of it was unimportant. What was important, though, was realizing that Matt had no chance of making any gains unless I accepted him. I resolved to do better by Matt. (p. 48)

While the child definitely had some challenging behaviors, Sottile realized that his own responses to the child helped to exacerbate the child's behaviors. Sottile was true to his word, and made a special effort to keep his cool when the boy's behavior disrupted his lessons. But he also began to find humor in some of the situations, used his humor to bring the class together, and ultimately helped the student have a respectful and respected place in the classroom.

In another setting, McDermott (1993) and others collected classroom data regarding 8- and 9-year-old children for 2 years. In one classroom, they became aware of a child with Learning Disability (LD), accepted how others saw him, and began to see him in the same way that the teachers and children saw him—*learning disabled*, because of the frequency with which he was unsuccessful in the classroom. At one point, they began to question their wisdom.

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> After following Adam for 18 months, we gave up on specifying his
> traits as the explanation of his behavior and began talking instead
> about what happened around him daily that seemed to organize his
> moments as an LD person. (McDermott, p. 273)

They discovered that many people were involved in making Adam look inattentive and disruptive, and that they had adopted the same attitude about Adam. They then began to ponder the idea that, "It is not so much that Adam is disabled, as that he participates in a scene well organized for the institutional designation of someone as LD" (McDermott, p.274). I feel strongly that teaching professionals should be willing to question their personal frame of reference about a child, if they are challenged by their interactions with that child.

Another area in which educators need to be sensitive to their own biases is in regard to parents' and teachers' perception that children who engage in challenging behaviors are "really bright." While this reported phenomenon is not substantiated in the research, it was brought to light by several mothers in the present study, and is similar to teachers' reports to me throughout the years. The caution here is that sometimes adults' perceptions of a child's cognitive skills becomes an expectation that the child should be able to perform and interact at the child's chronological level in all areas of development. The adult's attitude often is, "she's smart enough—if she really wanted to follow the rules, she would—she's just being non-compliant." In reality, some areas of the child's cognition may be very well developed, but in other areas such as the ability to decode social cues, the cognitive function may be delayed. Educators really need to take the time to learn about the child's areas of strength, rather than only focusing on what the child is challenged by.

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Recommendation for Agencies That Provide Services for Young Children Who Engage in

Challenging Behaviors: Provide Parent Support Groups

I recommend that agencies that provide services for young children who engage

in challenging behaviors also provide facilitated support groups for their parents. While

the PIP project provided such mothers with a much-needed opportunity to share their

experiences, strengths, and hopes, none of the mothers in the present study had found

such a group. Several of the mothers in the present study had connected individually

with other mothers of children with challenging behaviors, and found the experience very

supportive. Two mothers indicated that they were interested in starting such a group,

because the rewards of having a place to be "heard" were immeasurable, but they weren't

sure how to make it happen. Developing such groups and then informing parents about

them (through physician's waiting rooms, the agency's waiting room and staff, churches,

and neighborhood groups) would help parents who experience constant isolation find

their way to an understanding and supported context.

Agencies could also consider modeling parent support systems after the Positive

Behavioral Support (PBS) program. PBS is an existing program that refers to "the broad

enterprise of helping people develop and engage in adaptive, socially desirable behaviors

and overcome patterns of destructive and stigmatizing responding" (Koegel, Koegel, &

Dunlap, 1996, p. *xi*). It is an ecological perspective that "guides the interventionist to

look beyond a narrow focus on the problem behavior of the individual and toward an

understanding of the individual as a member of his or her immediate environments and

settings as well as larger social contexts" (Dunlap & Fox, 1996, p. 33). This is a system

that is in place and working well.

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Another organized system is the study conducted by Tocci et al. (1997). Through the federally funded Early Childhood Research Institute Service Utilization, they interviewed 75 families about their experiences with early intervention services. The resulting information helped them to see how to improve the existing service system.

Recommendations for Parents

I recommend that parents seek out individuals or groups who can help them understand the process of how to become advocates for themselves and for their children. One organization that supports parents in this way is PACER, the Parent Advocacy Coalition for Educational Resources. Several of the mothers in Marsh's (1995) book described situations in which they persevered until they spoke directly with their child's teachers, school principals, and doctors, not leaving the conversation until they felt that they had been heard. While it may not seem right that the person who wants to be heard must teach others how to listen, that may be the most effective way to help others understand.

<div align="center">Summary</div>

Parents want to be heard and understood by their families, their friends, and the professionals from whom they seek help. Parents want to be acknowledged for their intuitive knowledge about their children. The best way for professionals to hear parents is for them to have access to parents' experiences, have a vehicle through which they can understand what those experiences mean, then use that knowledge appropriately and sensitively when interacting with parents.

There are many people for whom understanding parents' experiences can be beneficial. Prior to children getting help, many people are involved with children and

their families: child care teachers, ECFE teachers, P–6 teachers, program directors, school principals, preschool screening specialists, family practitioners, and pediatricians. During the evaluation process, another group of people become involved: occupational therapists, physical therapists, developmental pediatricians, speech language clinicians, and mental health professionals. If the evaluation indicates that the child could benefit from receiving some services, another group of people becomes involved: child guidance clinic staff, ECSE staff, and possibly social workers. At any point along this continuum, any one of these people has the responsibility to listen to parents' concerns in a respectful and empathic manner, and to provide support that will help parent make the best choices possible for their child and themselves.

APPENDIXES

Appendix A

Definition of Challenging Behaviors

When talking about "challenging behaviors" professionals are referring to the behaviors that some children use to interact with the world around them. We call them "challenging behaviors" because adults are challenged about how to intervene and guide these behaviors (personal communication with Dr. J. Reichle at the University of Minnesota, May 10, 2001). Examples of common challenging behaviors are: crying that lasts for approximately 5 minutes three to five times per day, throwing objects for 20–30 seconds approximately one to two times per week, hitting students with fist for approximately 5 seconds 10 to 20 times per week, and hitting self on head with fist for 3–5 minutes approximately 10 times per day.

For the purpose of this study, the terminology *problem behaviors* and *challenging behaviors* will be used interchangeably, since that is how they are presented in the literature. It is when the child's behavior exceeds the frequency, severity, and duration of behavior exhibited by typically developing peers that there is cause for concern. Respecting the work of Dr. J. Reichle at the University of Minnesota, I will use the following definition to describe challenging behaviors: the personal conduct of a child that results in injury to self or others, causes damage to the physical environment, interferes with the acquisition of new skills, and/or socially isolates the child.

Aggression and Other Problem Behaviors

As noted above, several behaviors fall under the umbrella of challenging behaviors. When a child's actions result in injury to others, the behavior is usually labeled as aggression and is considered a problem behavior (Crick & Grotpeter, 1995) as

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it is disruptive for parents, teachers, and peers. Crick and Grotpeter suggest that "*overt aggression* consists of behaviors that are intended to harm another through physical damage or the threat of such damage. *Relational aggression* includes behaviors that inflict harm on others by manipulating their peer relationship" (p.11). Physically aggressive behavior has numerous forms (hitting, pinching, biting, punching, slapping) and numerous functions (obtaining possession of materials, escaping from situation, getting adult attention). Other behaviors defined as problematic are hyperactivity, disobedience, non-compliance, disruptiveness, inattentiveness, poor impulse control, and defiance. Again, most children exhibit some of these behaviors some of the time. This study focused on parents' experiences with their children for whom the frequency, severity, and/or duration of problem behaviors sets them apart from children with typical behavior.

Frequency, Severity, and Duration

In my master's thesis (1991), I documented behavior problems as a common occurrence in young children (Bhatia et al., 1990; Del'Homme, Sinclair, & Kasari, 1994; Feil, Severson & Walker, 1990; Funk & Ruppert, 1984; Glascoe, MacLean, & Stone, 1991; Haswell, Hock & Wenar, 1982; Hunt, Johnson, Owen, Ormerod, & Babbitt, 1990; Jenkins, Owen, Bax, & Hart, 1982). In 1987, Rapp and Hutchinson attempted to delineate when problem behaviors, such as the ones described earlier, were no longer tolerable as a common occurrence, but indicative of child pathology. In 1991, Doss and Reichle examined these behaviors within the construct of ineffective communication strategies, identifying them as "challenging behaviors," carefully distinguishing typical from atypical occurrences.

Needlman et al. (1991) report that "temper tantrums occur once a week or more in 50% to 80% of preschool children, but that 5% to 20% of the children who tantrum have tantrums of sufficient frequency, severity, and duration to cause parental concern" (p.77). These parameters are very important, as most children exhibit some of these behaviors some of the time, at certain stages of development.

Frequency. Needlman et al. (1991) suggest that one or more temper tantrums a week is a normal occurrence in 50%–80% of preschool children. When the frequency of the tantrums is daily, that frequency is considered outside the realm of typical development, and if frequent tantrums are the child's only response to the people, places, and things in the child's environment, there is cause for concern.

Severity. Severity of the temper tantrum is also significant, as tantrums that occur only once or twice a week, but result in damage to the child who has tantrums, peers, adults, or the environment are also cause for concern.

Duration. Duration of the tantrums is also significant. If a tantrum only occurs once or twice a week, but the tantrum lasts for 30–60 minutes and the child is unapproachable or inconsolable during that time, there is cause for concern.

Although most children 24 to 60 months of age have tantrums, as they acquire language (expressive *and* receptive) and develop social interaction skills, the frequency, severity, and duration of temper tantrums usually decreases. The behavior of all the children included in this study exceeded the typical limits of frequency, and/or severity, and/or duration of behavior.

Similarities Between Challenging and Typical Behaviors

Challenging behaviors and typical behaviors sometimes look similar, as most young children exhibit some challenging behaviors some of the time.   In 1991, Needlman et al. acknowledged behavior problems as a typical phase of normal development in 2- to 5-year-old children, even suggesting that temper tantrums occur once a week or more in 50% to 80% of preschool children, "but that 5% to 20% of the children who tantrum have tantrums of sufficient frequency, severity, and duration to cause parental concern" (p.77). It is these degrees of frequency, severity, and duration that define the difference between more typical behaviors and challenging behaviors.

Frequency. A child who hits another child on two occasions during a 1 month period is probably an example of more typical behavior, and may even be considered typical development. Conversely, a child who hits other children with a frequency of 10–20 times per week for durations of 5 seconds would be considered to be presenting a "challenging behavior" (Reichle & Johnston, 1993). The difference is that the child with the two occasions of hitting most likely responds to the adult's intervention, *and has other strategies for engaging their environment*, which is likely why there are only two incidents in a month period. The child who hits 10–20 times a week for durations of 5 seconds is most likely *not* responding to adult intervention, *and does not have other strategies for engaging their environment*, as evidenced by the repetition of the behaviors.

Severity. It is common for young children to occasionally use their open hands to hit or slap other children in order to gain, or regain a possession. Dodge (1991) considers this to be instrumental aggression, in which "the aggression itself is incidental to the main

goal: acquisition of the object (p. 204)." Use of one's fist, however, is considered an intense way to use hands to hurt self or others. The severity of fist use either to hit self on head (self injurious behavior) for 3–5 minutes approximately 10 times per day, or to hit others for approximately 5 seconds 10–20 times per week, would qualify this behavior as a challenging behavior.

Duration. Many aggressive acts by children are occasional, situational, and fleeting—a "hit and run" so to speak, in which one child approaches another child, hits the child once or twice with an open hand, then flees with the desired object or privilege. In contrast, a child who hits another child, or other children, for durations of 5 seconds 10–20 times per week would be considered to be presenting a "challenging behavior (Reichle & Johnston, 1993)." Also, throwing objects for the duration of 20–30 seconds approximately 1–2 times per week is an example of the duration of a behavior that would qualify the behavior as a challenging behavior.

Appendix B

Initial Recruitment Flyer

ARE YOU CHALLENGED BY YOUR CHILD'S CHALLENGING BEHAVIOR

My name is Sherilyn Goldsmith and I am a Doctoral Candidate in Work, Community,

and Family Education at the University of Minnesota.

I would like to interview parent(s) about their experiences with their children who have

challenging behaviors. Below are the criteria for inclusion:

1.   child is currently 2½ through 5 years of age, or was 2½ through 5 years of age when the

         behaviors were first identified

2.   at least one of the behaviors below must have occurred at least 5–8 times during a 2-

         week period within the last 4 years

    - child causes injury to self or others

    - child causes damage to the physical environment

    - child's behavior interferes with the acquisition of new skills, and/or socially

       isolates the child

Examples include, but are not limited to biting, hitting, kicking, and breaking classroom

materials.

Participants will receive Target gift cards. If you are interested in participating, please contact

Sherilyn Goldsmith at 612-627-4014.

Appendix C

Amended Recruitment Flyer

ARE YOU CHALLENGED BY YOUR CHILD'S CHALLENGING BEHAVIOR

My name is Sherilyn Goldsmith and I am a Doctoral Candidate in Work,

Community, and Family Education at the University of Minnesota.

I would like to interview parent(s) about their experiences with their children who have

challenging behaviors. Below are the criteria for inclusion:

1. child is currently 2 through 5 years of age, or was 2 through 5 years of age when

the behaviors were first identified

2. at least one of the behaviors below must have occurred at least two to five times a

week for 2 or more weeks, sequential or non-sequential, while the child was aged

2–5 years of age

- child causes injury to self or others

- child causes damage to the physical environment

- child's behavior interferes with the acquisition of new skills, and/or socially

isolates the child

Examples include, but are not limited to biting, hitting, kicking, and breaking classroom

materials.

Participants will receive Target gift cards. If you are interested in participating, please

contact Sherilyn Goldsmith at 612-627-4014.

Appendix D

Initial Phone Screen For Parents Responding to Recruitment Flyer

Thank you for responding to the flyer at your child care center. I have four questions to ask you to be sure that your child's behaviors are similar to what was described on the flyer. Are you ready? (yes)

1. Your child is currently 2½ through 5 years of age, or was 2½ through 5 years of age when the behaviors were first identified?

2. Your child must have been involved in the following behaviors at least 5–8 times a week during a 2-week period within the last 4 years.

    - child caused injury to self or others

    - child caused damage to the physical environment

    - child's behavior interferes with the acquisition of new skills, and/or socially isolates the child

    Examples include, but are not limited to biting, hitting, kicking, breaking classroom materials.

3. Do these behavior descriptions fit your child? (If yes, "can you give me an example?" if no, "I'm sorry, but this study really needs to focus on children with these specific behaviors. Thank you for calling.)

4. If yes, I will describe the 60-minute open-ended audiotaped interview session and tell them the three basic questions I will be asking.

    - what was your experience at home and at school before the idea of challenging behaviors was presented to you?

- how was this information presented to you and by whom?

- Since becoming more familiar with the idea of your child having challenging behavior, has your life changed, and if so, how?

5. Where would you like to meet for the interview? I can come to your home, meet at your child care center if the director permits that, or we can choose another place that is convenient for you. What time will work for you?

6. I will be asking you to sign a consent form which indicates your personal consent to be interviewed by me for the purpose of being in the study. If you would like me to mail that to you in advance, I can mail it to you, or we can wait until the interview. Which would you prefer?

7. About the Target gift cards: if you complete the interview you will receive a $15 card. If you complete only part of the interview, you will receive a $10 card. All gift cards will be given at the completion, or partial completion, of the sessions.

8. Do you have questions for me?

9. I look forward to meeting with you on _____.

10. Is there a number I can reach you at in the event that I unexpectedly need to make a change to our meeting date and time?_____

Thank you.

Appendix E

Amended Phone Screen For Parents Responding to Recruitment Flyer

Thank you for responding to the flyer at your child care center. I have four questions to ask you to be sure that your child's behaviors are similar to what was described on the flyer. Are you ready? (yes)

1. Your child is currently 2 through 5 years of age, or was 2 through 5 years of age when the behaviors were first identified?

2. Your child must have been involved in the following behaviors at least 2–5 times a week for 2 or more weeks, sequential or non-sequential, while the child was aged 2–5 years of age:

   - child caused injury to self or others

   - child caused damage to the physical environment

   - child's behavior interferes with the acquisition of new skills, and/or socially isolates the child

   Examples include, but are not limited to biting, hitting, kicking, breaking classroom materials.

3. Do these behavior descriptions fit your child? (If yes, "can you give me an example?" if no, "I'm sorry, but this study really needs to focus on children with these specific behaviors. Thank you for calling.)

4. If yes, I will describe the 60-minute open-ended audiotaped interview session and tell them the three basic questions I will be asking.

   - what was your experience at home and at school before the idea of challenging behaviors was presented to you?

- how was this information presented to you and by whom?

- Since becoming more familiar with the idea of your child having challenging behavior, has your life changed, and if so, how?

5. Where would you like to meet for the interview? I can come to your home, meet at your child care center if the director permits that, or we can choose another place that is convenient for you. What time will work for you?

6. I will be asking you to sign a consent form which indicates your personal consent to be interviewed by me for the purpose of being in the study. If you would like me to mail that to you in advance, I can mail it to you, or we can wait until the interview. Which would you prefer?

7. About the Target gift cards: if you complete the interview you will receive a $15 card. If you complete only part of the interview, you will receive a $10 card.   All gift cards will be given at the completion, or partial completion, of the sessions.

8. Do you have questions for me?

9. I look forward to meeting with you on _____.

10. Is there a number I can reach you at in the event that I unexpectedly need to make a change to our meeting date and time?_____

Thank you.

Appendix F

Interview Script

Thank you for choosing to participate in this study about parent's experiences when their children have challenging behaviors. First, we need to read through the consent form. I will be asking you three basic questions about what it has been like to be the parent of a child with challenging behaviors. What was your experience with your child at home and at school before the idea of 'challenging behaviors' was presented to you? How was this information presented to you and by whom? Since becoming familiar with the idea of 'challenging behavior' has your life changed, and if so, how? If there are questions that you would rather not answer, you can say so. If at any time, you want to end the interview you can say so. After the information is transcribed and interpreted for themes, I will ask you to meet for an addition meeting to determine if I have interpreted and presented your experience accurately. If you agree to these things, I will ask you to sign this consent form. Do you have questions?

Basic question #1: What was your experience with your child at home and at school before the idea of 'challenging behaviors' was presented to you? Additional questions (if necessary):

- How did other family members experience your child?

- How did other adults in your life experience and/or support your child? you?

- If there were any activities that your family could not participate in because of your child's behavior, what were they?

- How were your child's teachers responding to you? to your child?

- If there were people especially supportive of you and your child, who were they, and why were they so supportive?

- If there were people especially not supportive of you and your child, who were they, and why were they not supportive

Basic question #2: How was this information presented to you and by whom?

Additional Questions (if necessary):

- If you had ever expressed concern to your child's physician, what was the response?

- If this information was surprising for you to hear, why do you think that might be? (ex: teachers had never commented, or you had learned to do such a great coping job at home that you did not see the behavior as problematic)

- If this information was not surprising for you to hear, at what point in the experience of you and your child do you think you "knew?"

Basic question #3: Since becoming familiar with the idea of 'challenging behavior,' has your life changed, and if so, how? Additional Questions (if necessary):

- How have the changes impacted other areas of your life, such as work, leisure, etc.?

- If you thought something would change that didn't change, what might that be?

- Is there anything else you would like to tell me about your experience?

Thank you taking the time to share your experience with me. I will get back to you in approximately 3 weeks so that you can look at what I have written, and tell me if I have presented your information accurately. Here is the Target gift card.

Appendix G

Consent Form

Parent's Experiences When Their Child Has Challenging Behaviors

You are invited to be in a research study of parent's when their child has a

challenging behavior.

Challenging behavior encompasses terms such as problem behavior, behavior

disorders, and aberrant behavior. It is defined as a child's personal conduct that results in

injury to self or others, causes damage to the physical environment, interferes with the

acquisition of new skills, and/or socially isolates the child. You have been selected as a

participant because you have a child who is 2–5 years old and has challenging behaviors,

or was 2–5 years old when challenging behaviors were first identified. I ask that you

read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Sherilyn Goldsmith, Doctoral Candidate in Work,

Community, and Family Education under the advisement of Dr. Marilyn M. Rossman,

Work, Community, and Family Education.

Background Information

The purpose of this study is to examine and better understand parent's

experiences when their child has a challenging behavior. Behavior problems and temper

tantrums are acknowledged as a typical phase of normal development in 2- to 5-year-old

children. When problem behaviors are no longer tolerable as a common occurrence,

parents must develop new expectations concerning the child, their role as parents, and the

support services that are designed to meet their needs. Few studies reflect parent's

experiences with young children and challenging behaviors. Most research documents

families' or service providers' priorities and perspectives, but not the actual experiences of the parents. One theme that emerged in a previous study was the child's incessant demand for attention. To determine what other themes exist, this study will ask the question "What do parents experience when their child has challenging behaviors?

Procedures:

If you agree to be in this study, we would ask you to do the following two things: First, you will be asked to participate in an audiotaped open-ended 45- to 60-minute interview session conducted by the Principle Investigator at a site that is convenient for you. The three basic interview questions are:

1. what was your experience at home and at school before the idea of your child having challenging behavior was presented to you?

2. how was this information presented to you and by whom?

3. Since becoming more familiar with the idea of your child having challenging behavior, has your life changed, and if so, how?

Risks and Benefits of being the Study

RISKS: You may experience unpleasant certain feelings when discussing your experience being the parent of a child with challenging behaviors. The likelihood is minimal, no more than you might experience in any other conversation about your experiences with your child and challenging behaviors. However, if at any you wish to take a break, or end the interview, you may.

BENEFITS: There are no direct benefits for participation

Compensation:

You will receive a nominal payment for your time in the form of a Target gift card according to these conditions:

1. You will receive a $15 Target gift card if you complete the full interview.

2. You will receive a $10 Target gift card if you complete part of the interview. Gift cards will be presented at the end of each session.

Confidentiality:

The records of this study will be kept private. In any sort of report I might publish, I will not include any information that will make it possible to identify a subject. Research records will be stored securely. Only the Principle Investigator and the person transcribing the tapes will have access to the tapes. The tapes will be destroyed 6 months after they have been analyzed for themes. Subjects will be identified only by pseudonyms that will not reflect characteristics that may identify them.

Educators are required by Minnesota State Law to report concerns of suspected neglect or physical or sexual abuse of children to the local welfare agency (Child Protection Services in Hennepin or Ramsey County). If, during the interview process, such information is communicated by the parent, the Principle Investigator is mandated to report the information to the above named agency.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota, University of Minnesota Child Care Center, Hopkins Early Learning Center,

Lasting Impressions Child Care, or Commonwealth Child Care. You are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions:

The research conducting this study is Sherilyn Goldsmith. You may ask any questions you have now. If you have questions later, you are encouraged to contact her at University of Minnesota Child Care Center 612-627-4014, or golds009@umn.edu. You may also contact Sherilyn's advisor, Marilyn M. Rossmann at 325J VoTech, 612-624-3082, rossm001@umn.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the Research(s), you are encouraged to contact the Research Subjects' Advocate Line, D528, D528, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455: (612) 625-1650.

You will be given a copy of this information to keep for your records.

Statement of Consent:

I have read the above information. I have asked questions and have received answers. I consent to participate in the study.

Signature: _____

Date: _____

Signature of Investigator: _____

Date: _____

Appendix H

Follow-up Letter to Mothers

May 01, 2008

Between October 2004 and January 2005, you participated in an interview for my doctoral dissertation "Mother's Experiences of Parenting Young Children Who Engage in Challenging Behaviors That Were First Observed Between the Ages of 2 and 5."[1] Ten mothers participated in these interviews, and they each had a different story, but also a similar story to tell. The themes reflect the similarities of many of the mothers, and the sub-themes capture the individual uniqueness of some of the mother's experiences. It is possible that you may recognize your experience in some of the themes and/or sub-themes, but not in others.

While your child is now older than when we met, the themes and sub-themes reflect what we talked about *at that point in time*. Please take a few minutes to read the outline of the Themes and Sub-themes of the Findings chapter. These Themes and Sub-themes became evident to me through listening and re-listening to the audiotape of our interview, and reading and re-reading the transcription (text) of our interview.

If the themes and sub-themes reflect the meanings of your experiences that we discussed, it is not necessary to contact me. If the themes and sub-themes do not reflect the meanings of your experiences that we discussed, please contact me by Wednesday May 07, 2008 so that we can talk about your concerns.

Thank you.

Sheri Goldsmith   golds009@umn.edu   612-708-5785 HM

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[1] In September 2008, the title was changed to read "Experiences of Mothers Whose Young Children Engage in Challenging Behaviors" which identifies the focus of the study as mothers' overall experiences, rather than suggesting that the study is about their actual parenting practices while their children are actively engaged in challenging behaviors, or that the study is primarily about challenging behaviors. This is changed throughout the entire document.

Appendix I

Outline of Dissertation For Mothers to Read

Theme #1: I Was Puzzled and Dismayed by My Child's Behavior and Didn't Understand its Cause or Know What to do About It

- Early on, I thought I had reasonable explanations for my child's behavior.

- My child's bright—maybe that's why she's challenging.

- Because I didn't know what to expect, I wasn't sure there was a problem.

- I was stunned by my inability to manage my child's behavior.

- I felt embarrassed.

Theme #2: It Is Painful, And Often Demoralizing, To Receive So Much Negative Information About Your Child

- Sometimes teacher gave me notes or talked to me privately about my child's behaviors.

- I felt angry when teacher talked about my child's behaviors in front of other parents.

- I felt disheartened when I thought teachers were unfair, and sometimes, even unprofessional.

Theme #3: I Sense That Others Think I'm To Blame For My Child's Behaviors

- Some people tell me to my face that it's all my fault.

- When I sense that others think my child's behavior is my fault, I worry about what they think of me as a parent.

- Sometimes I need help—there are better ways I can interact with my child.

- I'm beginning to question myself—IS it my fault?

Theme #4: I Feel Isolated From Most People but Am Grateful For The Few Who

Understand And Support Me

- I keep to myself.

- Others exclude us.

- A few people understand and support us.

Theme #5: I Am Extremely Challenged By My Child's Behavior In Public Places

- Sometimes I feel angry, or embarrassed and humiliated by my child's behavior.

- I have learned that certain activities trigger my child's behaviors and I avoid them

- Things that many families do regularly are very unpleasant with my child.

Theme #6: I Struggled And Worked Very Hard And Still Found It Difficult To Get Help

For My Child

- A few doctors were helpful.

- I felt angry and frustrated when doctors misunderstood me, or didn't seem to take my concerns seriously.

- It's up to me to pick the right environment for my child.

- I make personal sacrifices to be sure that my child gets what s/he needs.

    Theme #7: I'm Not Sure About Having My Child "Labeled"—

    Sometimes Labels Are Helpful, But Sometimes They're Not

- Labels can make a difference.

- Some parents question the value of the labeling process.

- They don't really give you answers.

    Theme #8: Our Realities Are Much Different Than Our Dreams

- Early on, I knew something was different.

- Later I realized how different the future would be.

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