

October 2018

The Intervention Path: The Experiences of Mothers Seeking Help for Their Child with Atypical Behavioral Development

Renee Hoopes

University of South Florida, Renee@Hoopes.com

Follow this and additional works at: <https://digitalcommons.usf.edu/etd>



Part of the [Education Commons](#), and the [Psychology Commons](#)

Scholar Commons Citation

Hoopes, Renee, "The Intervention Path: The Experiences of Mothers Seeking Help for Their Child with Atypical Behavioral Development" (2018). *USF Tampa Graduate Theses and Dissertations*.
<https://digitalcommons.usf.edu/etd/7523>

This Ed. Specialist is brought to you for free and open access by the USF Graduate Theses and Dissertations at Digital Commons @ University of South Florida. It has been accepted for inclusion in USF Tampa Graduate Theses and Dissertations by an authorized administrator of Digital Commons @ University of South Florida. For more information, please contact digitalcommons@usf.edu.

The Intervention Path: The Experiences of Mothers Seeking Help for Their Child with
Atypical Behavioral Development

by

Renee Hoopes

A thesis submitted in partial fulfillment
of the requirements for the degree of
Education Specialist
Department of Educational and Psychological Studies
College of Education
University of South Florida

Major Professor: Linda Raffaele- Mendez, Ph.D
Rose Iovannone, Ph.D
Jennifer Wolgemuth, Ph.D

Date of Approval:
August 2, 2018

Keywords: qualitative, families, challenging behavior, help-seeking

Copyright @ 2018, Renee D. Hoopes

DEDICATION

First and foremost, I would like to dedicate this project to my husband, Elliott Hoopes. He has stood by my side supporting me and encouraging me throughout graduate school and the thesis process. Thank you for those nights when you stayed up late so that I would not have to eat dinner alone. I would also like to dedicate this project to my son, Jude. He shares the patience of his father as he spent many days playing alongside me as I worked to complete this project. Lastly, I would like to dedicate this work to the mothers I met while working on this project. These mothers spend every day advocating for their children's needs, learning about their children's weakness and celebrating their children's successes. My hope is that this project has given them a voice during times that they have felt unheard

TABLE OF CONTENTS

List of Tables	iii
Abstract	iv
Chapter 1: Introduction	1
Problem Statement & Purpose of the Study	6
Research Questions	7
Significance of the Study	7
Chapter 2: Literature Review	8
Early Identification of Behavioral Concerns	12
Labeling	15
Continuity	18
Parent Perceptions'	21
Parent's Help Seeking Behavior	25
Purpose of the Present Study	28
Chapter 3: Research Methods	29
Participants	29
Measure	30
Recruitment Procedures	31
Inclusion and exclusion criteria	31
Participant Compensation	31
Procedures	31
Research Design	32
Setting	33
Informed consent procedures	33
Data Collection	33
Measures	34
Interview Guide	34
Data Analyses	34
Theoretical Framework	35
Ethical Consideration	36
Chapter 4: Results	37
Pattern-Level Analysis of Themes	38
Question 1: At what point in their child's life did parents or others first note concerns about the child's development?	38
Question 2: What prompted parents to seek formal help from a	

Professional	43
Question 3: What treatment options have parents pursued for their child over time?	50
Question 4: How have the parents understood their child's atypical behavior over time?	65
Chapter 5: Discussion	68
Journey from Birth of Child to First Concern	68
The Importance of Early Intervention	69
The Intervention Path	72
Parents Understanding of Their Child's Atypical Behavior Over Time	76
Implications for Research and Practice	83
Conclusion	84
References	85
Appendices	96
Appendix A: Recruitment Flyer	96
Appendix B: Interview Guide	97
Appendix C: Themes	101
Appendix D: IRB Approval Letter	104
Appendix E: Consent Form	106

LIST OF TABLES

Table 1: Demographic Characteristics of Study Participants	30
Table 2: Demographic Characteristics of Children Discuss	30

ABSTRACT

Pre-school aged children experience challenging behaviors at a relatively common rate. Research shows that approximately 10–25 % of preschool-aged children engage in challenging behaviors to a greater degree than would be expected for their age (Lavigne, Gibbons, Christoffel, Arend, Rosenbaum, Binns, Sawon, Sobel & Isaacs, 1996). Problem behaviors are often the result of a child not following a typical developmental trajectory. Atypical development appears when a child either lags behind or jumps ahead of typical peer progress in physical, cognitive, behavioral, and social development or in adaptive life skills.

When children with challenging behaviors are left untreated, their everyday functioning can become significantly impaired, and many will require more intensive supports and services over time (Kauffman, Mock & Simpson, 1996). The presence of chronic challenging behaviors negatively impacts important aspects of a child's development and puts him or her risk for a number of adverse circumstances over time, including a dysfunctional family life, conflicts within interpersonal relationships, alcohol and drug use, physical and sexual assault, suicide, academic failure, unsuccessful employment, and involvement with the justice system (Boulter & Rickwood, 2013; Durand & Hieneman, 2008)

The purpose of this study was to develop a better understanding of the interventions parents try for their children. Including their thoughts, feelings and perceptions of each intervention. Previous research has provided insight into factors that influence parents' help-

seeking process and how parents begin the help seeking process (i.e., seeking formal or informal support). However, little is known about their thoughts, perceptions, and feelings towards the different types of interventions used and how they've affected their children's problem behaviors. Qualitative methods were used to better understand their help-seeking journeys. The experience of 5 mothers raising children with complex and challenging behaviors were captured through open-ended interviews in this study.

The results of this study found several notable themes to emerge from the interviews of mothers raising children with atypical development. Specifically, several mothers reported a typical pregnancy and early development. Participants described a difficult first year with feeding their child, their child not meeting developmental milestones and having several unique quirks. Several parents also described their infant as experiencing higher rates of sickness when compared to other infants. Parents also described the age in which problem behaviors were first identified in their child, who first became concerned with their child's behavior and their initial help seeking steps. Parents described behaviors of concerns including; difficulty eating, delayed speech and motor development and restricted interests. Themes emerged that described the parent's process in seeking out early interventions for their child which included the evaluation process and the therapies that were first recommended to them. At the conclusion of the evaluation, parents were typically given a diagnosis. Themes emerged that discussed the parent's initial reaction to the diagnosis and their self-driven research to find answers. All but one parent discussed taking their child to their pediatrician when they first had concerns. Through the school years, parents discussed the difficulties they faced in finding school based interventions and supports for their child. Some of the interventions included; medications, behavioral

therapies, and occupational and speech therapy. With medication specifically, parents discussed their experience in trying to find the right medication.

This study provides a better understanding of the experiences of mothers raising children with complex and challenging behaviors. It also provides information on how practitioners can approach parents when and if they have concerns with a child's development. In addition, data from this study supports the needs for increased advocacy, supports and services for these families.

CHAPTER ONE:

Introduction

In typically developing children, parents often see the emergence of prosocial behaviors in their children as early as two years of age (Brownell, Svetlova, Anderson, Nichols and Drummond, 2013). Prosocial behaviors refer to positive interactions with other people, including helping, sharing, cooperating, and comforting (Brownell et al., 2013). When children demonstrate unusually low rates of prosocial behaviors, they may be at risk for behavioral problems and/or affective disorders (Hay, 1994; Eisenberg & Fabes, 1998). Problem behaviors are often the result of a child not following a typical developmental trajectory. Atypical development appears when a child either lags behind or jumps ahead of typical peer progress in physical, cognitive, behavioral, and social development or in adaptive life skills.

When children experience atypical development in behavior, they often demonstrate higher levels of problem behaviors. These behaviors are typically associated with poor impulse control, motivation, and concentration; difficulty with cooperation and anticipating consequences; and low empathy and self-esteem. Children whose difficulties in these areas are chronic may eventually receive a diagnosis of Attention Deficit/ hyperactivity Disorder, Oppositional Defiant Disorder, and/or Conduct Disorder (Lee & Stone, 2013). Alternately, the child may be diagnosed with a developmental delay, Autism Spectrum Disorder, or a chronic mood disorder like Disruptive Mood Dysregulation Disorder, which was first introduced in DSM-5 (American Psychiatric Association, 2013).

Challenging behaviors in young children are relatively common. Research shows that approximately 10–25 % of preschool-aged children engage in challenging behaviors to a greater degree than would be expected for their age (Lavigne, Gibbons, Christoffel, Arend, Rosenbaum, Binns, Sawon, Sobel & Isaacs, 1996). For children on the Autism Spectrum (ASD) and those living in poverty, these estimates can be even higher (Qi & Kaiser, 2003). Montgomery, Martin, Shooshtari, Stoesz and Heinrichs (2013) grouped common displays of challenging behavior into four distinct categories: (a) physical and verbal aggression towards others (e.g., spitting, hitting, biting, property destruction); (b) disruptive behavior (e.g., inappropriate verbalizations, temper tantrums); (c) stereotyped (repetitive) and self-stimulatory behavior; and (d) self-injurious behavior (e.g., self-biting, skin picking, head punching, and head hitting).

When children with challenging behaviors are left untreated, their everyday functioning can become significantly impaired, and many will require more intensive supports and services over time (Kauffman, Mock & Simpson, 1996). The presence of chronic challenging behaviors negatively impacts important aspects of a child's development and puts him or her risk for a number of adverse circumstances over time, including a dysfunctional family life, conflicts within interpersonal relationships, alcohol and drug use, physical and sexual assault, suicide, academic failure, unsuccessful employment, and involvement with the justice system (Boulter & Rickwood, 2013; Durand & Hieneman, 2008). Byrd and Weitzman (1994) analyzed data from the Child Health Supplement (CHS) and the National Health Interview Survey (NHIS) to determine what health and social factors are associated with early school retention. The study sample was pulled from the 1998 CHS and NHIS surveys. The CHS randomly selected a child from families living in the United States and collected data on 17,100 children ages 0 to 17 years old. The end analysis was limited to 9,996 children aged 7 to 17. Researchers found the single

best predictor of early school failure was the presence of behavior problems. This study showed that behavior problems predicted school failure better than poverty, speech and hearing impairments, and low birth weight.

Children whose school performance is negatively impacted by behavior problems may qualify for special education services. Depending on the child's needs, he/she may meet criteria for Other Health Impaired (OHI), Specific Learning Disability (SLD), Emotional or Behavioral Disorder (EBD), or Autism Spectrum Disorder (ASD). Many children receiving special education services in schools meet criteria to receive services under multiple categories (Mandell, Davis, Bevans & Guevara, 2008). Being identified with these types of labels can lead children to experience unwanted stigma and may do damage to their self-image (Thomson, 2012). However, many professionals perceive that labels facilitate communication and allow for appropriate provision of services. Nonetheless, labels also follow children throughout their lifetime, which can be detrimental to students who "grow out" of their problem behaviors.

Research shows that specific symptoms of various disorders typically change as the child gets older (Lee & Stone, 2012). Lee and Stone (2012) believe that this is caused by changes in expressions of biological development, cognitive level, social status, duration, and type of experiences. Previous studies show that the origin of many adult mental health disorders can be found in behavioral characteristics present since the first years of life (Anselmi et al., 2007) and that externalizing problems are the strongest predictors of disorders in adulthood (Anselmi et al., 2007). Many of these externalizing behavioral problems cause parents extreme distress, although parents often do not start seeking help for their children until they believe that the children will not "grow out" of these problems (Raviv, Sharvit, Raviv & Rosenblat-Stein, 2009). Data suggest that between 17% and 20% of children have a diagnosable psychological disorder, with

externalizing behavior problems being the most commonly diagnosed (Miller & Prinz, 2003). However, only 2 to 25% of these children are seen in a given year by a mental health professional (Costello, 1986; Leaf et al., 1996), and fewer than 5% of children ever receive mental health treatment.

Parents play an important role in seeking help for a child's mental and behavioral health. Often times they are the "gateway providers" who control their child's access to mental health services (Raviv, Sharvi, Raviv, & Rosenblat-Stein, 2009; Costello, Pescosolido, Angold, & Burns, 1998). However, several variables can limit a child's likelihood of receiving mental health services, including parental beliefs about the cause of the child's problem and their ability to manage it; their perception of the burden that the child's problem imposes on them; and their knowledge of available services and their attitudes towards these services (Raviv et al., 2008).

In order to begin the help seeking process, parents must first recognize that their child is experiencing a problem with their mental or behavioral health. Research shows that rates of parent perception of a problem in their child range from as low as 13% (Teagle, 2002) to as high as 20% (Verhulst & van der Ende, 1997). Even when symptoms of a behavior problem are apparent, the majority of parents do not perceive a need for professional help. According to Bussing and colleagues (2003), 66% of parents of children who met criteria for Attention-deficit/Hyperactivity Disorder (ADHD) did not perceive a service need.

There are several factors that impact when a parent will begin the help seeking process. Many parents only begin the help seeking process when they no longer feel like they can "handle" their child's behavior or if their child experiences a severe, persistent, comorbid mental health problem (Bouter & Rickwood, 2008). At this point, parents start to experience parental burden because of the severity of their child's symptoms. Additionally, parents are more likely to

seek help if their child's problem impacts their own emotional well-being or sense of competency. This means that parents will typically seek help faster for children who demonstrate externalizing problem behaviors as compared to internalizing symptoms (Boulter & Rickwood, 2008). The child's gender also plays a role in when and why a parent will begin the help seeking process. Raviv et al. (2003) found that parents were more likely to express concerns with and start the help seeking process more quickly for boys than girls. This may be due to the fact that boys have higher rates of disruptive behaviors, which have a greater impact on the parents' well-being when compared to other types of behavior problems (Gupta, 2005). Even when parents are able to correctly identify symptoms of ADHD in their children, parents frequently seek help more often for boys than for girls (Bussing et al., 2003).

Parents' beliefs regarding the cause of their child's problems also influence their help-seeking behaviors. Parents are more likely to seek help when they can attribute their child's problem to a pre-existing internal disposition. Additionally, they are unlikely to seek help when they believe the problem will ultimately fix itself or if they perceive the child's behavior to be normative (Boulter & Rickwood, 2008). A parent's own psychopathology also influences his or her ability to recognize a problem in the child, which also impacts help-seeking behaviors. Parents who seek help for their own mental health were also more likely to seek help for their child's mental health than those who were more reticent about seeking help for themselves (Boulter & Rickwood, 2008).

Rogler and Procidano (1986) noted that parents' help seeking behavior can be separated into two approaches. The first approach centers around how many resources are available to the family. With this approach, the probability of seeking help is a function of the availability of sources of support, their attitudes toward support providers, and their attitudes toward helping

seeking in general. When first suspecting a problem, parents typically turn to their friends and family for support (Raviv et al., 2008). This type of support is known as informal support and includes family acquaintances and other relationships that maybe relied upon in times of need. The second approach to seeking help may include more formal sources of support such as community mental health clinics. Access to formal sources of support, however, does not necessarily mean families will use them. Some parents simply do not trust these sources. Parents also may avoid seeking help due to the psychological costs that are involved in the help-seeking process. These include the damage or discomfort seeking help places on one's sense of self. Individuals weigh these costs against the potential benefits that help may bring them. This comparison can be influenced by situational variables including the characteristics of the help source and the relationships between the helper and the help- seeker (Raviv et al., 2008).

Problem Statement and Purpose of the Study

Although previous research has provided insight into factors that influence parents' help seeking (i.e., availability of resources, the ability to recognize problems, etc.) and how parents begin their help seeking process (i.e., seeking formal or informal support), little is known about how parents make sense of their child's atypical behaviors over time and what drives them to seek particular types of interventions. The aim of this study is to discover how parents interpret their child's atypical behavior and respond to this behavior over time. Through the use of qualitative methods (e.g., interviews), this study aims to better understand the journey parents travel in understanding and seeking help for their children with atypical behavior. Specifically, this study will explore the thoughts, feelings, and perceptions of parents as they pursue help for their children with atypical behavior, including how they perceived their children's behavior.

Research Questions

1. This study will examine the following research questions: At what point in their child's life did parents or others first note concerns about the child's development?
 - a. Who was concerned and what was the nature of the concern(s)?
 - b. When concerns arose, with whom did parents discuss these concerns?
 - c. What advice did they receive?
2. What type of professionals did mothers seek out after receiving an initial diagnosis?
 - a. What was the professional's advice or plan for the child?
3. What treatment options have parents pursued for their child over time?
4. How have the parents understood their child's atypical behavior over time?

Significance of the Study

This study will provide insight into how parents understand and respond to their child's behavioral difficulties over time. It is expected that the in-depth interviews to be conducted in this study will provide greater understanding of parents' perceptions and feelings at various stages in the process of making sense of their child's atypical behaviors and attempting to address them, what drove them to seek particular interventions, how these interventions impacted them and their child, and how they came to understand their child's behavioral challenges over time

CHAPTER TWO:

Literature Review

A child's behavior development typically follows a familiar and predictable trajectory. There are times, however, when children's behavioral development deviates from what is expected, and children demonstrate behaviors that fall outside of the normal, expected range of development. Atypical behavioral development often results in children lagging behind typically developing peers in the area of prosocial behaviors and emotion regulation (Campos, Savelsbergh, & Rocha, 2012). Problems with early behavioral development are often manifested through poor impulse control; lack of motivation and concentration; difficulty with cooperation and anticipating consequences; and low empathy and self-esteem (Campos, et al., 2012; Samarakkody, Fernando, McClure, Perera & De Silva, 2011). These deficits can lead to conduct problems, aggression, oppositional behavior, hyperactivity, and delinquency (Campos et al., 2012). Deficits in behavior regulation are part of the clinical picture of a number of mental health disorders in youth including Attention-deficit/Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD), Oppositional Defiant Disorder (ODD), Conduct Disorder (CD), Tourette Syndrome (TS), Intermittent Explosive Disorder, Disruptive Mood Dysregulation Disorder (DMDD), and Bipolar Disorder, among others. Across these varying diagnoses (and among those with subclinical symptoms), it may seem that youth who demonstrate atypical behavioral development have more intense reactions to environmental stimuli than do typically developing youth. However, Cole, Hall, and Hajal (2013) noted that it is not necessarily the intensity of an emotional response that leads to maladaptive behavioral responses. Rather, it is

the child's capacity to regulate emotional responses by calling upon other processes (e.g., shifting attention, invoking problem-solving strategies) that serve as mediators between emotion and behavior.

Difficulty with behavioral development can have serious implications for school success. Youth who struggle with demonstrating appropriate behavior may be suspended or expelled from school (e.g., due to aggressive responses to teachers or peers); experience academic underachievement (e.g., due to giving up easily when faced with a challenging task), and/or be teased or bullied by classmates (e.g., due to developmentally inappropriate crying or tantrums at school). Child behavior problems also have a negative impact on family life. Research shows that of parents raising children with various types of special needs, including chronic illness, those raising children with behavior disorders experience the highest levels of stress (Gupta, 2005).

National survey data suggests that the rate of problematic, aggressive behaviors can be as high as 12% in preschool and early school aged children and 25% in low income children (Webster-Stratton & Hammond, 1998). These rates are fairly consistent across the literature and across countries with similar numbers ranging from 3 to 36 percent (Webster-Stratton & Hammond, 1998; Samarakkody, Fernando, McClure, Perera & De Silva, 2011; Schlack & Petermann, 2013). In a large sample of youth from the general population, MacLure, Jones, Holmes, and MacRae (2012) found that the prevalence rate of externalizing disorders (i.e., ODD, CD, and hyperactivity) was about 5%. More specifically, 6% of children in the general population exhibited behaviors of physical aggression and inattention; between 10 and 16% demonstrated oppositional or defiant behavior; and at least 17% and up to 36% of the children exhibited hyperactivity on a frequent basis. Of note, Oppositional Defiant Disorder (ODD) is one

of the most prevalent and resource-demanding mental health problems among children and adolescents (Helen, Johansen, & Manger, 2011). Prevalence rates range from 2.6% to 15.6% in community samples, and from 28% to 65% in clinical samples (Helen et al., 2011).

Many behavior problems can be identified during the preschool years. Youth with significant behavioral challenges are at risk for negative long-term outcomes including academic problems, school dropout, substance abuse, delinquency, and violence leading to substantial social and economic burden (Webster-Stratton & Reid, 2003; Edwards, 2014; Hayes, Giallo & Richardson, 2010; Brennan & Shaw, 2012). Notably, problem behaviors can become persistent patterns of behavior by age 8. However, providing families with early interventions can interrupt the progression of aggressive behaviors and improve life-long functioning for children at risk for emotional/behavioral disorders (Eron, 1990; Hester, Baltodano, Hendrickson, Tonelson, Conroy & Gable, 2004). Research has found that the most effective intervention programs target multiple domains and are implemented early in life (Hayes et al., 2010). In order to provide early interventions, however, identifying early warning signs is imperative (Samarakkody, Fernando, McClure, Perera & De Silva, 2012). Early warning signs have become of considerable interest to researchers due to their association with later diagnoses of developmental delays, disruptive behavior disorders, and ASD (Koegel, Koegel, Ashbaugh & Bradshaw, 2014; Goin & Myers, 2004).

As children and adolescents grow, so does their ability to regulate their emotions. Successful development of emotion regulation allows children to control their own behavior and react flexibly to their environments (Forbes, 2003). Emotion regulation helps children organize their behaviors, accomplish developmental tasks, and achieve developmental milestones (Gross, 1998b). When children have difficulty regulating their emotions, they experience emotion

dysregulation (Macklem, 2008). Emotion dysregulation occurs when patterns of emotion regulation negatively impact long-term functioning (Cole, Hall & Hajal, 2013). When symptoms of emotion dysregulation are temporary, they can include feelings of anxiety, intense discomfort, and poorly controlled behavior and/or withdrawal. However, if these symptoms remain constant, emotion dysregulation can be manifest in several childhood disorders described in the DSM-5 (Gross, 1998b). Symptoms of emotion dysregulation can be found in both externalizing disorders, such as conduct or disruptive disorders, and internalizing disorders, including anxiety and mood disorders (Gjone and Stevenson 1997; Martin 2003).

Students with internalizing disorders typically display emotions that are far too intense for the situation. These students demonstrate emotions more frequently, have difficulty decreasing negative emotions, and choose irrelevant, avoidant, or aggressive strategies to deal with negative emotions (Macklem, 2008). Students with externalizing disorders display many of the same challenges in regulation emotions. In addition to having difficulties with identifying emotional cues, they also often have weak emotional understanding and do not easily recognize their own emotions.

One of the most common disorders seen among school-aged children is Attention Deficit/Hyperactivity Disorder (ADHD). ADHD is primarily a disorder of self-regulation (Barkley, 2015). Children with ADHD often have trouble identifying and regulating emotions and have difficulty responding to situations that cause them to feel frustrated. When presented with challenging situations, they often have difficulty using coping strategies and react with anger and hostility (Macklem, 2008). Similar responses are found in children with other disruptive behavior disorders like ODD and CD. These children exhibit more behavior problems and have more angry interactions with their peers when compared to typical children. Students

identified as having conduct problems have deficits in emotion regulation along with weak emotional understanding and expression (Macklem, 2008).

Another disorder involving emotion dysregulation, seen more rarely than ADHD and involving more complex behavioral challenges is Autism Spectrum Disorder (ASD). Children diagnosed with ASD receive psychiatric services 12 times more often than their non-ASD peers for problems associated with anxiety, depression, aggression, defiance, self-injury, and tantrums (Mazefsky, Borus, Day, & Minshew, 2014). These youth tend to employ fewer adaptive strategies (i.e., cognitive reappraisal) than typical peers when presented with frustrating situations, and many of them experience higher levels of negative emotions when compared to neurotypical youth (Samson, Huber, & Gross, 2012).

Early Identification of Behavioral Concerns

As mentioned earlier, early identification of behavioral concerns is important in that early identification paves the way for early intervention. Early identification and treatment has been showed to be particularly important for youth with ASD, who do not seem to be naturally as “tuned in” to the world of people and language. Although not always easily identified, the impairments associated with ASD can be severe and pervasive. Due to its severity, a number of studies have targeted the identification of early warning signs of ASD. Through the use of retrospective studies, researchers have gained insight into the early development of these youth. Several of these studies used home movies as a tool to observe young children before they were diagnosed with ASD. This method was first used by Massie (1975) to study childhood psychosis, which included autism at that time. Although they coded both the mothers’ and the infants’ behaviors, their focus mainly revolved around the mother's behaviors and the presence of "psychotic" behaviors in the infant. A control group consisted of typically developing infants and

their mothers. This researcher found group differences in mothers' eye contact, touch, and attachment behaviors. They also found lower activity levels in the infants beginning at 1 month of age. Later, Rosenthal, Massie, and Wulff (1980) used home movies to examine sensorimotor development in 14 children who were later diagnosed with childhood psychosis, six of whom had a diagnosis of autism. The children were 24 months in age and were compared to a control group of typically developing children. Similar to findings of their first study, the children in the psychotic group displayed fewer age appropriate behaviors.

Although these studies aided in advancing our understanding of the early warning signs seen in children with autism, they contained several methodological weaknesses. First, the role of intellectual disability in the early identification of autism was never addressed. The differences between typically developing children and those with autism may have been due to differences in levels of cognitive functioning between the two groups. Second, there was no consistent way to ensure that each of the children's tapes were represented equally, and the observation tapes were not recorded so that each child could be compared to one another. Lastly, little attention was paid to the early social, communicative, and affective development of infants with autism (Osterling & Dawson, 1994).

To address these issues, Osterling and Dawson (1994) analyzed home videos of children's first birthday parties among 11 children later diagnosed with ASD and 11 typically developing children. Participants with autism were recruited from the Autism Research Program at the University of Washington while the typically developing children were recruited through the infant subject pool at the University of Washington. Each group consisted of 10 boys and 1 girl. An interval coding system was used to document the presence or absence of developmentally appropriate behaviors including social, affective, joint attention, and

communicative behaviors and autistic-like behaviors such as self-stimulatory behaviors, covering ears, failing to orient to name being called, staring blankly into space, and blunt affect. The videotapes varied in length from 3 to 29 minutes with a mean time of 10 minutes. To ensure each child had the same amount of time on camera, the number of times a child displayed a particular behavior was divided by the total number of minutes the child's behavior was coded. Raters who were blind to the child's diagnosis watched the videos for one minute and coded the presence or absence of developmentally appropriate or autistic-like behaviors. Inter-rater reliability was assessed by double coding 27% of the tapes. Several group differences were observed for four specific behaviors. The children who were later diagnosed with autism were more likely to fail to orient to their name being called, less likely to show objects to another, less likely to look at the face of another, and less likely to engage in pointing behaviors than the typically developing children. Based on these behaviors, a stepwise discriminate analysis correctly classified 91% of the subjects. The one behavior of looking at the face of another correctly classified 77% of the children alone. The results of this study suggest that differences in children with ASD compared to typically developing children can be seen as early as one year of age.

Similar results were replicated in a separate study conducted several years later by Werner, Dawson, Osterling and Dinno (2000). Although they also used home movies to classify the behavior of children later diagnosed with ASD, their sample size was larger. Fifteen children were in each group, and their population consisted of infants between 8 and 10 months of age. The home videos were, on average, 15 minutes long. The researchers developed a behavioral coding system to document the presence or absence of developmentally appropriate social, communication, and repetitive behaviors. A multivariate ANOVA was conducted for each of the three general categories of behavior. Results showed that the behavior that best predicted a later

diagnosis of ASD was when a child failed to orient to his or her name. They concluded that ASD can be detected as early as 8 months of age.

Brief screening measures distributed to parents, teachers, and other caregivers are often used as an initial step in identifying early behavior problems (Racz, Wu, McMahon, King & Witkiewitz, 2013). Teacher and parent ratings of aggressive behaviors and hyperactivity in preschool have been found to predict child behavior problems at the end of preschool as well as 5 years later (Doctoroff & Arnold, 2004). Similarly, Bates and Bayles (1988) found that mothers' reports of irritability and fussiness in infancy predicted ratings of behavior problems in kindergarten. In a longitudinal study, Fischer and colleagues (1984) found that when parents reported high levels of externalizing behaviors on Child Behavior Checklist and the Vermont Behavior Checklist in pre-kindergarten, specifically discipline problems and aggression, their ratings predicted continuing problems five to seven years later.

Doctoroff and Arnold (2004) illustrated the benefits of using multiple informants and different methods of parent ratings to better predict behavior problems in preschool-aged children. They found that through the use of multiple rating scales (Eyberg Child Behavior Inventory; Child Behavior profile), structured interviews (Diagnostic Interview Schedule for Children- Parent Versions), and videotaped classroom observations that informants from different settings provided complementary information about variability in children's behavior across contexts. Further analysis showed that teacher ratings consistently predicted later school outcomes, including school adjustment and social competence as late as the end of high school. Additionally, the observed problem behavior reported by the pre-school teacher significantly predicted future parent-reported behavior problems 6 months after the collection of baseline data.

Labeling

In recent years, there has been much debate regarding whether the use of categorical labels to describe and define children with behavioral challenges are helpful or harmful to the child. Grove (1980) defined labeling as the attachment of a deviant name to some action or attribute(s) of an individual. A label can be imposed formally, by a psychologist or diagnostician, or informally, through other children on the playground (Broomhead, 2013). Historically, the primary function of labels has been to facilitate the process of treatment; however, in recent years, labels also have been used to bring consistency to research while providing a foundation for the prevalence and etiology of a disorder (Fernald & Gettys, 1980). Additionally, labels allow for professional shorthand. They may facilitate communication, elicit more patient and tolerant attitudes regarding behavioral diversity, and provide a better understanding of a behavior that might have otherwise been unexplained (Thomson, 2012; Ohanm Visser, Strain & Allen, 2011; Fernald& Gettys, 1980).

Despite these benefits, some believe that labels have been associated with stigmatizing, isolating, and stereotyping individuals (Thomson, 2012). Labeling students often results in a diminished self-concept, peer rejection, reduced levels of aspiration, lowered levels of expectation for achievement, and poor adult adjustment (MacMillan, Jones, and Aloia; Thomson, 2012). Several studies have found that children labeled with Conduct Disorder, social maladjustment, or emotional disturbance have low quality interpersonal relationships with their teachers, school psychologists, and special education teachers compared to their peers who do not have labels but may exhibit similar behaviors (Fox and Stinnett, 1996; Thomson, 2012).

In describing the labeling theory of deviance, Thomson (2012) noted that labels impose a negative status on an individual, resulting in an identity assigned to a person that is altered to his

or her discredit. Labels can carry with them many of the negative qualities that have been assigned to them. A child who receives a deviant label may experience many debilitating consequences of the label. Being seen as a deviant individual can cause damage to the child's self-image, increase a child's levels of peer rejection, reduce levels of aspiration, lower levels of expectation for achievement, and produce overall poor adult adjustment (Thomson, 2012). Goldberg (2009) warned that a label can be a lasting stigma that, in many cases, follows students throughout their school careers.

Labels are used in special education to identify individuals or groups based on categories. However, many professionals believe that the use of categorical labels causes children to be treated as a member of a general group such that services are not matched to their individual needs (Smith and Luckasson, 1992; Hobbs, 1975). Along these lines, Kauffman and Pullen (1996) noted that labels used in special education are often demeaning, imprecise descriptions of need, and sometimes are wrongly assigned.

Research indicates that parents of children with behavioral problems are often aware of how the use of labels can bring unwanted stigma to their child. dosReis and colleagues (2010) interviewed 48 participants whose children were newly diagnosed as having ADHD. Each interview was conducted within one month of the child's diagnosis. The authors found that many of the parents ($N=21$) expressed concerns with their child receiving a label. Specifically, they did not want their child to be treated differently because of the label. They feared that society would view their child as a "bad kid," and that they would be perceived as bad parents. Three parents experienced negative reactions from family members who had strong opinions on the use of medication, which eventually influenced their decisions to not use it with their child. Ten parents expressed their own stigmatizing beliefs based on how the media has portrayed children using

stimulant medications. Their concerns centered on how many children appear to be "zombie like" or drugged and worried that this behavior may interfere with their ability to learn in school.

It is important to note that although the fear of stigma often causes some families to hide or conceal their child's difficulties (Clausen & Yarrow, 1955; Lefley, 1992; Wahl & Harman, 1989), other studies have found that once families receive a formal diagnosis, the blame for the child's behavior shifts from the parents onto an uncontrollable, biological condition, giving the families a sense of relief (Ryan & Runswick-Cole, 2008; Blum, 2007; Harborne et al., 2004; Litt, 2004). Midence and O'Neil (1991) interviewed five families whose children were diagnosed with ASD and found that four of the families felt relieved to know what was wrong with their child. The diagnosis helped to dissolve their guilt and allowed them to begin to seek the proper help for their child.

Continuity

Labels have the potential to be both beneficial and harmful to a child. Researchers have often questioned the validity of labels due to the discontinuities in behavior that is seen in children with atypical development. These discontinuities can last throughout the child's life time. (Anselmi, Barros, Teodoro, Piccinini, Menezes, Araujo, & Rohde, 2008). In other words, although the behavioral patterns that were observed and resulted in a label may continue, it also is possible that they may change. Consistent behavioral patterns reflect continuity; inconsistent patterns reflect discontinuity. Several factors have been found to influence the continuity of externalizing problems throughout a child's lifespan, including those relating to genetics and environment (Anselmi et.al., 2008).

In order to better understand the continuity of childhood psychopathology, Reef and colleagues (2009) used multiple sources (i.e., parents and self) to identify which childhood

behavioral and emotional problems continued into adulthood. Baseline data was collected in 1983 on 2,076 randomly selected parents in the Zuid- Holland province. Each parent completed the Child Behavior Checklist on their child whose ages ranged from 4 to 16 years old. Through January of 2006 and June of 2007, 1365 of the original participants were approached and asked to complete the Adult Self-Report (ASR). Results show a significant association between parent-reported problems in their children and the self-reported problems in their children as adults 24 years later. Specifically, children who demonstrated aggressive or delinquent behaviors and anxious or depressed problems were strongly predictive of adult psychopathology. Aggressive behaviors in childhood predicted somatic complaints and thought problems in later adulthood while delinquent behaviors predicted externalizing behaviors in adulthood, including aggressive behavior and rule-breaking behavior.

Two years later, Reef and colleagues (2011) conducted a follow up study using the same data from the 2009 study to examine the relationship between childhood trajectories of the four different types of externalizing behaviors including aggression, opposition, property violations, and status violations. All four types of externalizing problems were associated with disruptive behavior in adulthood. Specifically, children who demonstrated oppositional behavior also experienced anxiety disorders in adulthood. Those who demonstrated status violation behaviors (i.e., runaway, truancy, drug and alcohol use) showed higher levels of substance use, anxiety, and mood disorders in adulthood. Finally, children with high levels of externalizing behavior trajectories are most at risk to suffer from both internalizing and externalizing disorders in adulthood.

Discontinuity of disruptive behaviors can be seen in children as early as 17 months of age. Baillargeon and colleagues (2007) found that children at this age who exhibit disruptive

behaviors on a frequent basis did not behave that way one year later. Additionally, children at 29 months of age who displayed disruptive behavior on a frequent basis did not demonstrate these behaviors one year earlier. Similarly, Jenkins, Owen, Bax, and Hart (1984) found that children who displayed disruptive behavior on a frequent basis at 3 years of age had not done so 1 year earlier. They also found that children who exhibited temper tantrums on a daily basis at 3 years of age had not done so 1 year earlier. Recently, Baillargeon and colleagues (2012) replicated their earlier study with children between 29 and 41 months of age and found that children who exhibited disruptive behavior on a frequent basis had not done so 1 year earlier. However, at 41 months of age, these children were found to exhibit the same amount of problem behaviors, or higher, than at 29 months of age.

Although there is some evidence to support the discontinuity of problem behaviors in young children, other researchers have found that disruptive behaviors are, in fact, relatively stable across the lifespan. For instance, several studies have found that the symptoms of Antisocial Personality Disorder are highly stable from childhood to adulthood (Lynam, Caspi, Moffitt, Rolf, & Magda. 2007; Moffitt 1993; Forsman et al. 2008). Additionally, prospective studies have shown that individuals who are diagnosed with a mental health disorder in adulthood showed signs and behavioral symptoms in their first year of life (Caspi, Moffitt, Newman, & Silva, 1996; Maughan & Kim-Cohen, 2005). These same studies found that externalizing problems are the strongest predictors of disorders in adulthood.

In a later study, Wichers and colleagues (2013) examined 1,480 sets of twins across their childhood and adolescence. Data was collected at four separate intervals beginning when the children were between 8 and 9 years old and continuing at 13 to 14 years old, 16 to 17 years old and lastly at 19 to 20 years old. To better understand the differences between environmental

effects versus genetic effects, the authors identified which sets of twins were monozygotic and dizygotic. The data included 489 male monozygotic (MZ) twins, 345 male dizygotic (DZ) twins, and 372 male twins of an opposite sex pair. Additionally the sample included 496 MZ twins, 382 female DZ twins and 375 female twins of an opposite sex pair. Questionnaires were administered to each child during the 2nd, 3rd, and 4th wave of data collection while parents completed questionnaires during all four waves. Parent ratings were assessed using the Child Behavior Checklist (CBCL) at ages 8 to 17 and the Adult Behavior Checklist at ages 19 to 20. Youth completed a self-report measure (YSR) that assessed for externalizing disorders at ages 13 to 17 and the Adult Self Report Form at ages 19 to 20. Results from this study found evidence of a large genetic effect (80%) on variability in externalizing disorders. The genes operating at age 8 to 9 years old continued to explain a moderate amount of variability (26%) at 19 to 20 years old. This study also found no evidence of a significant influence of a shared environment on externalizing disorders. These authors explain that this may be the case because certain genes are expressed only within certain environmental contexts.

Parent Perceptions

When a child experiences any type of developmental delay, parents play a key role in advocating for supports and services. Parents are typically the first to notice early signs of developmental deviations and often turn to their friends and family for support before seeking out a professional's opinion (Boulter & Rickwood, 2013). According to Dempster and colleagues (2013), externalizing behavior problems are the most commonly diagnosed psychological disorder in children, but only 2 to 25% of these children are seen by a mental health professional in a given year. Parents appear to be the largest contributing factor to whether or not a child receives treatment, although there are several reasons why parents may delay the help-seeking

process. Parents often wait to begin the help seeking process until they recognize that their child's behavior is a problem, that they cannot handle the problem by themselves, and that the benefits of seeking professional help will outweigh the costs (Dempster et al., 2013; Raviv, Sharvit, Raviv, & Rosenblat-Stein, 2009). Boulter and colleagues (2013) found that 66% of parents of children who met the diagnostic criteria for Attention Deficit Hyperactivity Disorder (ADHD) did not perceive a service need. Externalizing symptoms tend to be more obvious and disruptive than internalizing symptoms, and parents have been shown to seek help more often for adolescents with Conduct Disorder and Oppositional Defiant Disorder than other types of disorders (Raviv et al., 2009).

Boulter and Rickwood (2013) interviewed 15 parents between the ages of 25 and 61 in regard to their experiences of seeking help for their children with mental health problems. Parents were eligible to participate in the interviews if they sought psychological help from a mental health professional at any point in time for their child's mental health problem. They were recruited from their local mental health services, parent support groups, and community mental health education groups. A semi structured interview was used to gain a better understanding of the parents' perception of the nature of their child's mental health problem, how the parents coped, the types of help that parents sought, how they went about seeking help, and the factors that influenced decisions to seek help (Boulter et al., 2013).

Results of the study found three main themes including (a) pathways to mental health care, (b) intra and interpersonal influences on help seeking choices, and (c) the impact of service use experiences (Boulter & Rickwood, 2013). In regard to the specific pathways to mental health services, children received services either through a parent-initiated pathway or a teacher-initiated pathway. Parents of children with emotional problems received services through both

pathways while children with behavioral problems received services through the parent-initiated pathway only. Each of the fifteen parents reported being in contact with multiple services including psychiatrists, pediatricians, general medical practitioners, psychologists, teachers, and counselors (Boulter et al., 2013). Twelve of the fifteen parents stated that they sought help sequentially rather than concurrently. If parents found that the specialist service provider did not meet their needs, then they reported back to their general practitioner (GP) for further guidance. Those that returned to the GP felt that the services they were receiving were not effective.

The second theme centered on what influenced the parent's decision to seek help (Boulter & Rickwood, 2013). Results show that 10 of the 15 parents reported intrapersonal concerns, such as their desire to alleviate their frustration, guilt, stress, anxiety, or fear and their difficulties in coping with their child's mental health problem. Parents also endorsed seeking help due to not being able to manage their child's problems by themselves and the impact their child's behavior had on their family. In addition, interpersonal influences were identified, including other people's concerns regarding the decision to seek help, specifically, the child's own concerns or suggestions of family, friends, or the child's teacher.

For the third theme, parents described the services they found helpful or unhelpful (Boulter & Rickwood, 2013). Useful services included having knowledgeable service providers who gave useful strategies and advice including how to manage their child's behavior. All participants reported the importance of emotional support. Specifically, they described how helpful it was to have their child's problems validated as real and not to be judged by mental health workers. Several unhelpful practical experiences were reported as well, including insufficient support and information, stigma associated with a label or diagnosis, and poor availability of services.

Emotional support is a theme that is prominent throughout the literature (Ho and Chung 1996; Raviv et al. 1992, 2009). Raviv and colleagues (2009) found that parents typically preferred to seek informal help from family, friends, parental support groups, and self-help resources such as the Internet and books. They also were more willing to refer friends to professionals than seek them out for themselves. Similarly, Fox and colleagues (2002) interviewed 15 families whose children demonstrated problem behaviors at home and discovered the importance of emotional support. Specifically, parents felt a sense of unconditional acceptance from the people in their lives and described how important it was for them to have someone to call when they felt overwhelmed. Parents expressed how important support from parents with similar experiences was in making them feel connected to other individuals and not feel isolated. In regard to seeking help from professionals, many of the parents expressed gratitude for their doctors who offered words of advice and were available when they needed them.

In addition to finding emotional support as a theme, Fox and colleagues (2002) found that parents experienced difficult beginnings when first noticing something "wrong" with their child. They reported that their child experienced delays in meeting developmental milestones such as walking, talking, and making social connections. Parents also described how the problem behaviors impacted the entire family system by dictating family roles and activities. Many families described how they used work as an escape from their troubles at home, while other families described feelings of isolation because they were too afraid to bring their children to places outside the home.

Worcester, Nesman, Raffaele Mendez and Keller (2008) sought to provide a more detailed and focused report on parent's experiences obtaining services and supports for their

young children with challenging behaviors. This study used an interview format to provide a voice to a population that has been "historically silenced and marginalized." In this study, eight parents were interviewed. Parents first noticed concerns at an average age of 15 months. Several of the children had a medical or a developmental diagnosis which was accompanied by a variety of challenging behaviors including self injury, noncompliance, tantrums, excessive crying, feeding difficulties, property destruction, biting, screaming, hitting, stuttering, scratching, and throwing objects. Two semi-structured interviews were conducted with each family. Five primary themes emerged from the data including: Obtaining accurate and useful information, obtaining services and supports, financial stress, stress among members of the family, and community isolation.

When parents sought help from their pediatricians, many felt that the support was inadequate and that more information would have been useful (Worcester et al., 2008). Others felt that the information that was provided to them by the pediatrician was lacking or irrelevant to their concerns. Due to this lack of knowledge, many parents felt that they had to seek information on their own through the use of the Internet or books. In addition, parents also reported difficulties with logistical issues such as scheduling doctor's appointments and frustration with their doctor's training and experiences in working with children with behavioral challenges. Paying for supports and services were another burden for these families. Because many of the children in this study had medical diagnoses, parents often struggled to pay the medical bills that were the result of surgeries, medications, and doctors' appointments. Feeling isolated and difficulties with other family members were additional concerns these parents voiced. Challenging behaviors made it hard for parents to take their children out in public, including seeing close friends or family members. This caused parents to feel isolated and alone.

This study filled in many of the gaps in the literature of children with challenging behaviors by providing a better understanding of the broad challenges parents face when raising a child with problem behaviors. However, there continues to be a lack of detail needed to fully understand why, how, and when parents seek different types of interventions for their children.

Parents' Help Seeking Behaviors

When a child first begins to demonstrate challenging behaviors, their parents are typically the first to notice such problems. Several studies have shown that for children on the Autism spectrum, parents report concerns around one year of age and seek advice from professionals around 27 months (Kishore & Basu, 2011). Similarly, parents whose children are later diagnosed with Asperger's syndrome typically reported their first concern around 26 months (Noterdaeme & Hutzelmeyer-Nickels, 2010). Among the most common concerns reported are delays in speech and language development, some medical concerns, poor eye contact, extremes of temperament and behavior, and atypical development (Coonrod & Stone, 2004; De Giacomo & Fombonne, 1998; Young, Brewer, & Pattison, 2003). However, several of these studies used forced-choice response questionnaires or symptoms checklist to identify parents' concerns (Lung, Shu, Chiang, & Lin, 2010). More research is needed to further explore in parents' own words how, when, and why they sought help for their children's atypical behavior.

The aim of the current study is to explore further parents' help-seeking process and its outcomes for families raising youth with atypical behavioral development. The study will include information on who identified the initial concerns for their child; with whom they discussed their child's development and from whom they sought help; how they have understood their child's atypical behavior over time; and the treatment options they have pursued for their child. Several studies have examined the difficulties parents experience when first seeking

answers for their child's behavior problems, but few go into great detail regarding the interventions parents have tried in order to remediate the behavior problems.

Summary

Atypical behavior development is observed in children who lag behind their typically developing peers and do not demonstrate age appropriate behaviors. These children typically exhibit conduct problems, aggression, oppositional behavior, hyperactivity, impulsiveness and delinquency (Campos et al., 2012). Up to 12% of preschool aged children demonstrate these behaviors in school settings, and many of these children will continue to demonstrate inappropriate behaviors into adulthood. Early interventions that target these negative behaviors are crucial to helping these children become successful members of society. In order for these children to receive early interventions, their parents must advocate for their needs by seeking help through informal or formal avenues.

Purpose

The purpose of the current study is to develop a better understanding of the interventions parents try for their children and how they come to try these interventions. Research has provided insight into factors that influence parents' help-seeking process and how parents begin the help seeking process (i.e., seeking formal or informal support). However, little is known about their thoughts, perceptions, and feelings towards the different types of interventions used to address their children's problem behaviors. Additional research is needed to better understand the timeline of the help-seeking journey because the journey is not always linear (Boulter & Rickwood, 2008; Logan & King, 2001). The few quantitative studies available on this topic suggest that there is no uniform way in which parents seek help for their children (Logan & King, 2001). Through the use of qualitative methods (e.g., interviews) this study aims to better

understand the journey parents travel in seeking help for their children. Specifically, this study will explore, in depth, the lineage of each intervention parents sought out and their thoughts, feelings, and perceptions of how each intervention affected their child's development.

CHAPTER THREE:

Research Methods

The purpose of the current study was to better understand the journey of parents whose children struggle with severe and complex behavior problems from the perspective of the parents themselves. Specifically, the following research questions guided the study:

1. At what point in their child's life did parents or others first note concerns about the child's development?
 - a. Who was concerned and what was the nature of the concern(s)?
 - b. When concerns arose, with whom did parents discuss these concerns?
 - c. What advice did they receive?
2. What type of professional did mothers seek out after receiving an initial diagnosis?
 - a. What was the professional's advice or plan for the child
3. What treatment options have parents pursued for their child over time?
 - a. How have the parents understood their child's atypical behavior over time?

Participants

Five mothers raising children with challenging behaviors between the age of 8 and 14 participated in the current study. All lived in southwest Florida. Demographic information for

each of the mothers is shown in Table 1. Table 2 shows demographic information for the children whom they discussed.

Table 1. Demographic Characteristics of Study Participants

Pseudonym	Gender	Child's Pseudonym	Occupation	Ethnicity
Anna	Female	Anthony	Registered Nurse	Caucasian
Cathy	Female	Casey	Stay at home mom	Caucasian
Denise	Female	David	Bilingual Assistant	Hispanic
Marie	Female	Mark	ESE associate	Caucasian
Ellie	Female	Emily	Youth Librarian	Caucasian

Table 2. Demographic Characteristic of Children Discussed

Child's Name	Gender	Child's Age	Ethnicity	Diagnosis
Anthony	Male	13	Caucasian	Attention Deficit Hyperactivity Disorder (ADHD) and Bipolar Disorder
Casey	Female	9	Caucasian	Autism and ADHD
David	Male	12	Hispanic	Autism
Mark	Male	14	Caucasian	Sensory Processing Disorder Anxiety and Depression
Emily	Female	8	Caucasian	Sensory Processing Disorder, ADHD, Anxiety and Autism

Recruitment. Participants were recruited using purposeful sampling, specifically, snowballing procedures with the intention of recruiting approximately six to eight families. However, saturation was achieved with five families (Sandelowski, 1995). Initial contact was made after the participant became aware of the study through mutual friends or relatives. Typically, the initial contact was made via email. One parent was contacted in person due to the proximity of her work place to the researcher's work place. During the initial contact, the researcher described the current study's aim and interview procedures. Parents were told that during the initial interview informed consent would be discussed, and if they choose to continue their participation, then would be asked to discuss their child's development from birth to the present day. They were asked to bring any pictures, psychological reports, or evaluations that would better help them recall their child's life.

Inclusion and exclusion criteria. To be eligible to participate in the study, parents had to live within a one hour driving distance of the researcher's home. "Parents" were defined as the child's primary caretaker(s). Each parent or set of parents had to live with the child full-time and have had at least part-time custody of the child since birth. Grandparents, step-parents, aunts, uncles, and adoptive parents were all eligible to participate. Each participant also had to have a child between the ages of 7 and 15 and answer yes to at least 3 of the following 8 questions:

1. Does your child have challenging behavior at home or at school that have not been fully resolved despite numerous interventions?
2. Have you taken your child to more than one mental health professional (e.g., psychiatrist, psychologist) and received different diagnoses from each provider?
3. Has your child been diagnosed with more than one mental health disorder (e.g., ADHD, ODD, OCD, ASD, anxiety, depression, other)?
4. Have you tried more than one medication to address your child's behavioral issues?
5. Do your child's behavioral issues have a significant negative impact on your family life?

6. Have you struggled to find a solution to your child's behavioral issues for more than one year?
7. Do you worry that your child's behavioral issues will have a negative impact on the quality of his or her life over time?

This age range was selected because children younger than 7 may not have had the opportunity to see multiple doctors or experience several interventions and exhibit atypical behaviors in multiple settings. Parents also had to speak fluent English and consent to participate in the interviews.

Participant compensation. Parents earned up to twenty-five dollars for participating in one to two interviews. The participants were typically paid after the first interview. The second interview was conducted so that the parents were given the opportunity to reflect on their initial interview, to add details and/or clarify any misconceptions. Three out of the five participants participated in the second interview. The second interview was held so that the parent could review the timeline that was made during the first interview and make any changes they deemed necessary. Parents could also add to the timeline anything they may have forgotten during the first interview. Two of the parents were not able to be contacted for the second interview.

Procedures

Research Design. A basic interview approach was used with individual mothers in order to answer the research questions. This design was chosen because it provided the opportunity to develop an in-depth understanding of the path parents followed in seeking help for their child (Roulston, 2010) and examine common themes that emerged. A Romantic perspective of interviewing was used because this style of interviewing recognizes the place of the researcher in the study. The relationship between the interviewer and the interviewee is imperative to generate

the kind of conversation that is both intimate and self-revealing (Roulston, 2010). Research that uses this perspective typically demonstrates that they are aware of their subjective positions in relation to the research participant (Roulston, 2010).

Setting. The interviews took place in several different locations across Pinellas and Hillsborough Counties. Three out of the five parents requested to meet at a local library, one parent requested to hold the interview at her home and one parent requested to meet at her place of work. Several of the mothers brought pictures, reports and videos to share with the author.

Informed consent procedures. The author met with the parents at a time and location convenient to the parents. During the meeting, the author reviewed the consent form with the parent, and provided them an opportunity to ask questions. Once all questions had been answered, parents were given a copy of the consent form to keep for their records. Additionally, they were given the contact information of the author and told that if they were to have any follow up questions about the study or their rights as a participant that they may contact the primary investigator at any time.

Data collection. Families participated in one to two interviews depending on how long the family needed to discuss their entire story. Each interview lasted approximately one to two hours in length. The first interview began with the primary investigator explaining the purpose of the study. Informed consent will be obtained. To begin the interview, the primary investigator explained that her aim was to understand the path the parents have traveled in understanding and responding to their child's challenging behaviors over time. The interview guide was used to help facilitate conversation. A second interviews was held so that the parent was able add anything they may have forgotten during the first interview and reflect on what they already

shared. Interviews were semi-structured but designed with open-ended questions so that participants were able to direct the course of discussion in the interview (Roulston, 2010). As part of the interview, the author mapped out the parent's journey using a timeline which helped to provide a visual representation of parents' initial concerns with their child's behavior and help-seeking efforts/outcomes over time. All interviews were audio recorded and later transcribed by the author.

A pilot study was completed with the first family found eligible for this study. By completing a pilot study, the researcher was able to determine if the questions that were asked were understood by the participant and if the questions are extracting the information needed to answer the research questions.

Interview Guide

An 8-item interview guide (shown in Appendix B) was developed by the researcher to address the research questions. The guide was used flexibly to elicit information related to the research questions while also allowing parents the freedom to tell their child's story in their own words.

Data Analysis

An initial auditory review of the data was completed by the author following the first interview to ensure that the interview adequately addressed the areas of investigation. If the author did not feel that all areas of interest were addressed, the author followed up with a second interview to address and areas that were lacking sufficient details. Each interview was transcribed and analyzed by the author and a codebook was developed. The data was analyzed

using a thematic analysis to identify themes present in the interviews. Thematic analysis is defined as a method for identifying, analyzing and reporting patterns (themes) within data (Braun & Clarke, 2006). The author used guidelines for developing a codebook that provided structure to the coding process (MacQueen, McLellan, Kay & Milstein, 1998). Once codes were identified, they were assigned to a theme. Next, a list of themes were created. The author worked with her major professor to develop and clarify definitions. Definitions of each theme, examples of statements, as well as parameters for when to apply the code were all included in the codebooks.

In order to ensure the credibility of the data, member-checking and reflections were utilized. Member-checking took place during the second interview and allowed the participants to review the data collected through the interview. It also provided the opportunity to clear up any misconceptions or misinterpretations. A peer colleague provided peer examination of each interview.

Theoretical Frameworks

The researcher used two theoretical frameworks to guide the data collection, analysis, and interpretation. The first of these theories is Jones, Heflinger and Saunder's (2007) theory of help-seeking behavior, which builds on Bronfenbrenner's ecological model. This model was adapted from Aday and Anderson's (1974) conceptual model of health service use, which recognizes the role of community factors in help-seeking behavior. Jones and colleagues purposed a multi-level framework that describes the individual, cultural, and environmental factors that impact a person's ability and desire to seek help for behavioral and mental health concerns including: (a) the needs of a population (the family's reasons for seeking services and a child's clinical status);

(b) predisposing factors, such as family history of mental illness; and (c) enabling factors, including family beliefs about help-seeking and knowledge of relevant resources.

The second framework guiding the study is Hupcey's (1998) theory of social support. Hupcey noted that social support occurs in the functional context of relationships and can be divided into four types of supportive behaviors including (a) informational support, (b) appraisal support, (c) emotional support, and (d) instrumental support. Informational support is the provision of advice, suggestions, and information that a person can use to address problems. Appraisal support is the provision of standards for self-evaluation such as social comparison and norms. Appraisal support is often used to affirm an individual's sense of value and competence. Emotional support includes the use of empathy, trust, love, and caring towards another individual. Finally, instrumental support is concrete assistance, such as money, books, or babysitting services (Sarafian, 2012; Sterrett, Jones, McKee, & Kincaid, 2011).

Individuals can be provided social support through both informal and formal networks. Informal networks are made up of the individual's friends, family, coworkers, or supervisors. Informal networks include health care professionals and human service workers. Each member is likely to provide differing amounts and types of support (Heaney & Israel, 2008). Developmental psychologists have focused their research on mothers' social networks because each social network tends to have an effect on their maternal morale and child rearing competence which, in turn, may affect the child indirectly (Cochran & Brassard, 1979).

These two frameworks helped to inform the examination of patterns in parents' help-seeking behavior over time; biological and environmental risk factors contributing to a child's development; and how parents use support systems to aid them in the journey of raising their

child. A semi-structured interview was used to capture parents' perceptions of their experiences without the constraints of discrete categorical units of analysis

Ethical Considerations

The University of South Florida Division of Research Integrity and Compliance Institutional Review Board (IRB) reviewed and approved of the current study before interaction with participants or data collection began. To protect the identity of study participants, pseudonyms were used; all real names were replaced in each interview and in the final document. In order to participate in the study, participants were asked to sign a consent form which explained the reasoning, rationale, risks, and benefits of the study. With the parent's permission, each interview was recorded and transcribed. Recordings will be destroyed in compliance with IRB specifications to eliminate the possibility of voice recognition of subjects. Transcripts with pseudonyms will be retained to comply with IRB records requirements.

CHAPTER FOUR:

Results

This chapter includes the results of this study both as they relate to the initial research questions the examiner sought to explore as well as the theoretical frameworks the author chose as a lens for examining these findings. Table 3 provides an overview of each of the themes described below.

Table 3. *Themes found in the experiences of mothers raising children with atypical development.*

Theme	Theme Description	Number of participants who were included.
Theme 1: Fussiness Age range: birth to 1 year	Participants describe their children is the first year of life. Participants describe the many difficulties they faced during this time.	4
Theme 2: Early Detection Age range: 12 months to 3 years old.	Participants describe the age in which problem behaviors were first identified in their child. They describe the behaviors that first caused them to worry. They also describe who first became concerned with their child's behavior and what their initial help seeking steps were.	5
Theme 3: School Struggles Ages 3 to 13 years old.	Participants describe the struggles they've encountered when trying to find a place for their child within the school system.	5

Table 3: (continued)

Theme 4: Initial Evaluation Age range: 7 months to 10 years old	Participants describe the process in seeking out early interventions for their child. Specifically, they describe the process of evaluations and the therapies that were first recommended to them.	5
Theme 5: Trial and Error Age range: 5 years old to 13 years old	Participants discuss their thoughts and feelings behind starting their children on medication. They describe who initially suggested the use of medication and how it affected their child over time.	4
Theme 6: The Diagnosis Age Range: 7 months to 13 years old	Participants discuss how it felt when they first received a diagnosis for their child.	5
Theme 7: Finding Answers Age range: 3 to 13 years old	Participants discuss their self-driven search for knowledge and understanding After receiving the first diagnosis for their child.	4
Theme 8: Acceptance	Participants discuss how they've come to view themselves as parents over time, as well as, their child's atypical development.	3

Pattern-Level Analysis of Themes

Question 1: At what point in their child's life did parents or others first note concerns about the child's development? The response from mothers to this initial question resulted in general information regarding their pregnancies and their child's early development. Specifically, parents described their child's first year of life. Two themes emerged from the data: Fussiness and Early Detection. The theme Fussiness focuses on the parents' descriptions of their child's first year of life. Specifically, it describes at the parent's experiences with feeding their child, their child not meeting developmental milestones, and having "unique quirks". The second theme, Early Detection focuses on parents' descriptions of behaviors that first caused

them to worry that their child may not be developing typically. This includes difficulty eating, being a picky eater, hyperactivity and restrictive interests.

Under the first theme, three of the mothers described unremarkable pregnancies and typical delivery without complications. One mother explained that her doctor reported concerns with her child's development in utero which resulted in a premature delivery. One mother reported that although her son was adopted, she was involved throughout the entire pregnancy and was able to go to the doctors' appointments with the birth mother. She did not report any concerns with the pregnancy and was present in the delivery room during the birth of her son.

Almost every one of the mothers interviewed described their child as "fussy" or hard to console when upset during the early stages of development. Several mothers noted that some of the "fussiness" were caused by a medical reason such as colic or acid reflux. Two mothers noted that their child suffered so significantly from acid reflux that they needed medical intervention. Two mothers reported that their children were "sickly" quite a bit during their first year of life. In reflecting, Anna reported:

Well, there are a couple of things in the first year that are significant now that I think about it. He was sick a lot like clinically I knew something was going on with him, and I took him back, he was getting sick like every couple of weeks. Like vomiting and cold, runny nose, just not your typical stuff and I knew, my gut just told me he had an immune deficiency or something. So when he was 12 or 13 months he was sick again. I waited to take him in and I shouldn't have because I could hear wheezing and the pediatrician said "no Anna" that is not asthma so he put the stethoscope in my ear, I'm an RN, and I listened and I said yea it is and he said no it isn't and we literally got into it. I thought it

doesn't matter I'm going to take him to Dr. Pediatrician. He's a friend of mine. His wife and I are dear friends and he's a pediatric pulmonologist. He's in it for totally the right reasons. He's wonderful and he admitted Anthony right away. That tells you something. You have to go with your gut."

Concerns that started before the age of one were typically due to the child being very picky eaters or being unable to keep food down completely. Several mothers noted their initial concerns began with their child's eating habits. Ellie noted that she first became concerned with her daughters development at 13 months when her daughter wasn't eating. She reported that:

[Emily] couldn't do anything thicker than the consistency of milk. She would gag on it, couldn't figure out how to swallow. (She) was not able to eat so that was the biggest thing. I called the doctor and was like we're having a problem. Basically in a week she wasn't eating, she quit walking, trying to walk, she quit talking, because she had been pulling up, (she was) just going backwards. With all the babbling, she just stopped. It was like something's wrong, I don't know what but something's wrong.

Cathy also reported similar concerns with her daughter Casey's eating habits as an infant. She reported that:

...As a baby she was very fussy. Just a very, very fussy baby. It was very hard to console her. I tried to breast feed but it didn't take. She was on a special formula. I can't remember the full name of it but it was something with Gold in it. It has special protein and all sorts of vitamins and stuff like that in it. It was very, very expensive too. It was like four times the amount of regular formula and was very hard to find but we did it...She had a lot of problems feeding and was very messy with the bottle. She was just

dripping constantly so it was really hard to know how much she was actually getting because it was just dripping and that sucking mechanism wasn't quite there yet.

The second theme to emerge from the data, Early Detection, focused on the age at which parents first identified problem behaviors in their child. The age of first concern was lower when the behaviors were identified by the parents and higher when an outside party brought the behavior to the parents' attention. Two parents reported that their child's pre-kindergarten teacher was the first person to become concerned with the child's development. This was typically the first time the child entered a classroom at approximately three years of age. Additionally, these children were often times the first born or only children where the parents did not have other children to use as comparisons. Anna reported:

She (the teacher in the pre-kindergarten classroom) pointed at Anthony and said "has that boy ever been evaluated before?" Of course inside I felt defensive, indignant, defensive again and like what do you mean? And the truth is he didn't have impulse control you know, even though kids are two years old or whatever, you tell them enough or you tell them strongly enough and they listen and go on and do something else, but Anthony didn't exercise that.

Marie had a similar experience when she enrolled her son into preschool. She recalled that:

Here he was just 3 with his little innocent backpack and from the notes your child did this, your child did that, it felt like they were picking him apart. It was horrible. Then when he was two to three and a half it really started to snowball for him both emotionally and sensory. He wasn't the kid that could sit still. He would react to sounds differently. The stimulation was just too much for him and looking back now I would not have put

him in pre-school.... When he was three and a half his teacher took my hand and said there is someone I want you to go see at All Children's. His name is Dr. Pediatrician.

This Pediatrician assessed him for about an hour and he goes "he has Sensory Processing Disorder and slow processing."

Diane reported that a family friend was the first to suspect developmental concerns with her son David. She stated that:

Everything started when he was about 1 year old. I didn't notice, it was my friend. He had things where he would turn cars and spin their wheels. And he wouldn't talk it was just like sounds. He wouldn't talk and for me he was my first kid so it was normal.. I never payed attention to that until she was telling me oh I saw this on TV and it was talking about kids with autism and I've seen things that David does... So she said that and I was a little upset like what is she doing telling me that. But then there was something in the back of my head where I was like just let me make sure nothing is wrong. . I took him for an evaluation. They didn't do anything at the beginning they just gave him some therapies. We gave him about six months to see because sometimes kids only need therapy and then they are fine. However, 6 months past and he wasn't doing the things he was supposed to be doing and then this psychologist came to the house and he saw him for a whole afternoon and that's when they gave me the Autism diagnosis and it was a really hard thing for me. So it was bad after that he was 2.5 when he was diagnosed.

When the parents were the first to become concerned with their child's development, the child was younger and there were other children in the house that were often used for comparison.

Cathy whose daughter, Casey, had a twin brother. She mentioned:

What was interesting though is we would compare them, not as in you're a boy and you're a girl but we were able to see the route a "typical child" was supposed to go through versus what we saw Casey going through so we knew fairly quickly that she was delayed. Probably around 7 or 8 months we could tell she had developmental issues. You see that commercial my child doesn't smile could they be autistic and that's really true. My husband Josh and I would say man it's really hard to get her to smile. We could not get her to smile. We knew she was happy but we couldn't get her to smile. Looking back it was like oh that kind of made sense. So around 3 months or so Nick started rolling over and constantly moving around and trying to pull himself up and we didn't get any of that with Casey. Her muscle tone was so low that she could barely lift up her head. So from day one we always took them to the doctor and Nick would always get a great check-up but with Casey around 7 months the doctor suggested we go to a neurologist.

Ellie reported that in raising her older son, who met his developmental milestones on time, she was better able to identify the milestones that her daughter had difficulty meeting when she was just 13 months old. She stated:

I do think that helped a lot because my son was very much here's a milestone, he's on it, here's the next one. Yep here he is. Here's the next one, yep there he is. That little guy was like clockwork. There was no question there.

Question 2: What type of professional did the mothers seek out after receiving an initial diagnosis?

Three themes emerged from the data to help answer this question: The Diagnosis, Initial Evaluation, and Finding Answers. The Diagnosis refers to the experiences each mother had after

receiving the initial diagnosis for their child including what their reactions were and how they felt after receiving the diagnosis. Initial Evaluation described what the mother's initial help seeking steps were after concerns with their child's development had been identified. Additionally, parents described the process in seeking out early interventions for their child. They described the process of evaluations and the interventions that were initially recommended to them. They discussed how they felt about each of the therapies and what types of advice were provided to them by the professionals working with their child. The third theme, Finding Answers, focuses on the parents' self-driven search for knowledge and understanding after receiving the initial diagnosis for their child.

Four mothers discussed how they addressed their initial concerns with their child's pediatrician. In almost every case, the parents reported that their pediatricians were in agreement with their concerns and referred them to additional specialists. Two parents reported that their pediatrician took the "wait and see" approach. One mother reported that she sought help from a specific specialist after their child's teacher referred them. Ellie reported that she immediately contacted her daughter's pediatrician when her daughter first began to struggle with eating. She reported that:

I started noticing some, but as soon as I said that (she doesn't eat), they said bring her in and let's get a weight on her... Then when they started asking I was like as a matter of fact she hasn't been babbling. We used to do mama and other random sounds and she's not doing that, she's quit trying to pull up to stand. (She's) just not doing a whole lot and as they ask more I was like she is really going backwards. At which point my son was in speech therapy at the time because he had a bit of an articulation delay, nothing major just kind of a typical delay, and it was at All Children's, so I had spoken with the feeding

specialist there and said are you familiar with this, and she said get a referral and get her in as soon as you can, so the pediatrician wrote out the referral.

Similarly, Cathy said:

We went to the neurologist and at around 8 months she had a battery of tests. She had just about everyone you could think of. She had the MRI in the whole machine kind of thing. She was such a tiny little thing. She was probably only around 7 or 8 lbs. by then. She had the MRI, she had an epilepsy test, the EKG is the heart one, the EEG is the brain one, she had the lights flashing around and stuff but she didn't have epilepsy which was good, she had lots of bloodwork of course.

Marie recalled:

I was on auto pilot at that point. His experience in pre-school was so unexpected. Nothing that I would even fathom for him. I'm like ok she [pre-school teacher] probably could have said jump off a bridge at that point and I would have jumped, so I went (to the pediatrician)... Part of you goes into mommy mode and you go ok help my son, what's going on Doctor? (The doctor was) very eccentric, kind of quirky himself, but he's very intelligent and just assessed Mark and let him play for about an hour, and he was right. He was spot on. So then I'm going home, I think this was before smart phones, and I'm on my computer going what is Sensory Processing Disorder and it was just a check. Everything that described him was just check, check, check.

Anna discussed how she followed up with her son's pediatrician when he was an infant and was physically sick. When behavior became a concern, she shared that she followed up with her son's school psychologist after his teacher introduced them. She recalled:

I did, I did follow up right away with her and she went and evaluated him she came to my house a couple of times and I can't tell you a diagnosis really that she gave him because he was so young and I don't think they really want to diagnose, but it appeared to me at that time he was on a path for ADHD.

One mother reported that she asked for guidance from her mother in law before taking her son to see his pediatrician after her friend initially brought up concerns with her son's behavior. Her pediatrician also used the wait and see approach but after several months of no progress, she advocated for an evaluation. Denise said:

Yes, I think I waited a couple of months before I did something. Then I talked to my mother-in-law and I told her I was concerned about this and she said just wait kids are different. I used to talk to the pediatrician and they said just wait and see and about a year later... I said well he isn't making any progress or gains so is there something I can do and she gave me a referral to take him to get evaluation.

Once the initial concerns had been identified, the child was evaluated by a specialist and was typically given a diagnosis. The initial diagnoses the mothers received for their children varied. Two mothers had children diagnosed with Sensory Processing Disorder (SPD), one mother's son was diagnosed with an Autism Spectrum Disorder (ASD). One mother received an initial diagnosis of cerebral palsy and one mother did not receive a formal diagnosis right away, due to her son's young age but felt that the doctors were leaning towards Attention Deficit Hyperactivity Disorder (ADHD). In every case, the initial diagnosis was the first stepping stone in the mother's journey. The second theme to emerge from the data was Finding Answers. Once

they received that initial diagnosis, several mothers reported doing their own research to better understand their child's diagnosis.

Ellie recalled:

At that point (her pediatrician) said it looks like she has Sensory Processing Disorder. I said ok I'm sorry I don't know what that is. So that started me researching everything I could find. I went to CDC, the Mayo Clinic library, and I talked with anybody and everybody I could find because I knew nothing about what this was. Sensory Processing Disorder, ok so she's not processing it right so what does that mean? What is that going to look like? What do I need to know?

Marie reported similar help-seeking behaviors. She said:

I felt that OK, we can call it something, he can't help it. It was like given a name and now what are we going to do to help him. So I was at the library reading everything I could, I just educated myself. You have to.

Anna reported:

...No man in my eyes is an island, so when you're facing these kind of things you have never been exposed to before, like I didn't have education in this, you do your own research (and you) talk to people. You want to identify with people who have similar stuff going on but no one is like my son.

Cathy reported that she opted to rely on professionals to answer questions regarding her daughter, rather than spending time on her own research. She said:

I did a little bit but not too much. I didn't really want to, I didn't read too many books because I almost felt like no one is going to know our situation, no one's going to understand what we go through every single day. Because the autism spectrum is so broad they are all different even though they all have autism. I did a little bit on the Internet but not much. I went more to the experts. I wrote down lots of questions for the doctors, and I had lots of questions for the therapist, so I took more of their advice than I did looking for my own.

Early intervention was the third theme to emerge from the interview. In almost every case, the child initially started with Speech and/or Occupational Therapy (OT). One child started with Physical Therapy (PT) but later received a recommendation for an OT and Speech evaluation shortly after. Another child started with feeding therapy and was evaluated for Speech Therapy at 16 months old, Occupational Therapy at 17 months and Physical Therapy at 18 months. The service delivery varied among the children. Two children received OT and Speech services in school, and three received them in their home. Each of the mothers expressed how beneficial each of these therapies were for their child and how helpful the therapists were in providing them with information on how to help their child at home. Ellie recalled how flexible her daughter's feeding therapist was during more difficult days:

There were a lot of times Emily would flat out refuse. Those were the days she was being hypersensitive to everything so we would have to turn the lights off in the room and kind of sit quietly. A lot of times she wouldn't sit in the high chair that was there so she would sit on my lap and (we would) kind of let her play with the food to get used to it, that kind of thing. We had many days like that so we worked on the desensitizing for lack of a

better word a lot of the times. It would be, so you don't want to eat today, ok we will set the food aside and let her chew on the stick. It was one of those nub brushes. Let her work that in her mouth to desensitize her a little bit. Each week they would be here try this at home or keep working with this. At the time we were working with baby food, baby cereal, mushy carrots, because typically at that age they are working on really soft foods, easy to chew, so keep giving her this and try her with this. Most kids it's ten times before they accept it or it might be thirty, so it's give her little bits and little bits usually it was just keep working, and have the brush in her mouth, or put something in there and move it with that to have her follow with her tongue and learn the pattern and all.

Ellie shared similar experiences with her daughter's occupational and speech therapist:

So as I sat in with her and she would show me what she was doing and I would show her some of the stuff I had done with her so we kind of traded ideas. The gal had had been a nurse and had worked with kids with special needs and had seen all kinds of things and she was like, "I don't know." She would come to do the typical stuff and it wouldn't work or Emily would look at her like why do you want me to do that, it's too easy. We were kind of having to make things up as we went along and we ran into that a lot with her. The occupational therapist, even with having the sensory processing disorders would be atypical in its own, but even with that Emily was very atypical, they couldn't find a pattern to what triggers them what they will avoid, but with her they couldn't find a pattern, couldn't sort out where she was coming from so a lot of it was just making things up, which I spent a lot of time doing so as well.

Marie expressed how influential her son's speech therapists were for his behavior during his pre-kindergarten year in school.

I can't remember how Sunshine County got involved, I don't know what the program was, but somehow we got him assessed by Sunshine County and they directed us to our zoned school because they had a pre-kindergarten program. At that time he was four, and the pre-k program had a speech teacher who is now like one of my best friends, and she worked with him that year and then she led me to a different teacher who is the only other Speech teacher at North County School and he blossomed with her. He won like best turn around student and I felt like I had won the lottery because it had been such a tough year and a half.

Cathy also expressed how grateful she was for the help from the therapists working with her daughter. She said:

The therapist was absolutely wonderful and she was really able to tell me a lot of what she saw and it really opened our eyes, like wow she really does have a lot of delays. We were doing physical therapy and she did start to walk which was great, but she didn't start walking until she was 2. It took a long time, but she did end up walking, so that was great. So around 2, not too long after she started to walk, the therapist told us we should probably start occupational and speech therapy as well. It was about 24 maybe 25 months that she started occupational and speech therapy as well and we had good therapist there as well. We have always been blessed to have good therapist along the way.

The OT, PT and speech services were just the beginning stepping stones in the mothers' journeys. As their children grew so did their behavior, emotional, and physical needs. These

parents continued to seek out additional interventions to help support their children in school, at home and in their communities.

Question 3: What treatment options have parents pursued for their child over time?

Two themes emerged from the data that focused on the treatments of these children throughout the years. Trial and Error describes the use of medication, which was a prominent theme throughout each of the interviews. Parents discussed who initially recommended medication, their concerns with starting their child on medication and how they felt towards if it did or did not help their child. Parents also discussed the different therapies they had tried over time. The second theme to emerge, School Struggles, focused on the parents' struggles in trying to find supports for their child within the school system. This includes trying to find the correct classroom and the struggles they faced when dealing with their child's teachers and other school personnel.

Cathy recalled that she first saw a need for medication when her daughter started pre-kindergarten and had difficulty sitting still for long periods of time. She reported:

So right around that time the pre-K program showed us that she really needed some medication as well. When she got into the normal school setting, they were like we love her, she's great, she's sweet but we can't get her to sit down. Like at all throughout the entire day she would not sit down. She was just go go, go, go all the time which obviously doesn't work with the schools. So we went back to Dr. Pediatrician again and he said we are going to have to try something. We have tried just about every medicine you can think of when it comes to ADHD. We have tried all the anti-depressants and regular ADHD meds and all that. (She reacted) pretty good actually, we got her to sleep

which was great. We gave her medicine that wasn't necessarily for sleep but was for ADHD which made her tired so it was pretty beneficial. Some of that medication takes weeks to work so it was definitely a learning experience. It was probably a good six months that we had to try different meds. Some would only last for a couple of hours and then she was up again, things like that. Some we had to add Melatonin to them and Melatonin didn't work for her at all, it was like nothing.

Cathy also discussed how difficult it was to find the right medication for her daughter. This “Trial and Error” approach was seen across several interviews. She reported that:

Trying to find the right medicine is just the most difficult. She has autism yes, but she also has the ADHD symptoms but then a lot of those medicines bring out OCD symptoms... She did a lot of pulling her hair, we had lots of scratching herself like on her arms and her legs, we had lots of issues with her taking off her clothes, which we still have issues with, lots of things like that.

Anna had similar experiences in trying to find the right medication for her son. She discussed:

Dr. Pediatrician was the first person to recommend medication for him. She did some intelligence testing on him. Anthony saw all kinds of specialists.....I've gone to different neurologists, therapists, everything. She started him on Risperdal...(The Private School, however, is urging me to try another physician whom I loved as well but he ended up putting Anthony on so many meds so I literally had to take Anthony somewhere and have him weaned off everything to see what was going on, who this child was.

In addition to the parents seeing a change in their child's behavior, two of the children also reported feeling better after starting medication. Marie recalled how her son's behavior began to escalate in middle school, which she felt was a cry for help. He was quickly diagnosed with depression and anxiety from The Brain Institute. She says:

The school brought that up....It was this past January, that it didn't even matter, five years ago if someone had said you have to medicate your son I would have been on the floor wailing, but at this point we are like ok let's explore it. Let's just explore it because he is 6'2 and he's 13, he's big and we didn't want him Baker Acted and I couldn't handle that. His doctor told me about that and I was like oh my goodness you really can't get to your child and he's in a hospital and they won't let me see him? I'm strong but I don't think I could handle that so we just tried it and they are so nice at the Brain Institute and some people aren't. They sold us on it. His doctor is so sweet and just let us talk. The medication is Lexipro and Abilify. Lexipro is for the depression and Abilify is for the autism and anxiety. The dosage has been tweaked twice but the one that he's on now seems to be working. Mark is so cute, you know I have spent all of these years trying to protect him and shield him and he didn't even know there was anything wrong... With the medication, I was cutting the pill the other night and he's like "it's ok mom it helps me" and he took my hand and he was reassuring me.

Ellie discussed that her daughter was additionally diagnosed with Generalized Anxiety Disorder (GAD) with Obsessive Compulsive Disorder (OCD) and later Attention Deficit Hyperactivity Disorder (ADHD). She discussed how Emily received therapy for her anxiety but was started on

a small dose of medication for the ADHD. Ellie reported that her daughter noticed that she was constantly on the go. Ellie says:

She talks non-stop, even in her sleep, sometimes I'm just like oh stop, she just go and go and go and it's exhausting, shouldn't you be exhausted because I am just watching you. She goes non-stop at home from the time she wakes up till the time she goes to sleep. It takes a lot for her to go to sleep. Sometimes I put her to bed at 6:30 and its 9 o'clock and she's like I'm awake. I'm like why are you so awake, we've had a full day.... There are some days she would come to the library and she would just start circling the room almost at a jog, and I would be oh I need to take you outside. She has ADHD. Not so severe, just mild enough to where a low dose of medicine would help and that made the biggest difference in the world. The first few days she was on it I didn't tell her she was on it but she said it's been better, my body is listening to my brain now. I'm happier now, I don't go cry in the corner, I was like I know you're not trying to make me feel horrible, but ah man. So that was able to slow things down and now she is able to come home and say we read this story and it was about this. It was so much better. I can't say her academics have improved because her levels were so high anyway but it did get better because she was able to focus more on what she was reading and if someone got up to move around there was a character in the book.... The medication helped a lot, she's been much more focused, she's been able to get through so much more, she writes things down because they aren't floating out of her head before she has a chance to get them out, so that's been helpful.

One mother reported that medication was not helpful for her son. Denise recalled:

He was never on medicine. I tried it once. I didn't like the effect on him. I tried just to see if he was able to concentrate more at school but then the teacher would tell me he was much, much better I don't think we need it. That was in first while in New York. We tried for about a month and I didn't like the effect. He was getting better and the dosage was very low so it didn't make a difference. The only thing I noticed with them is that he would get irritated for one period of time. He would get red and mad and he was just sit and do nothing.....He started changing a lot for the better so they said he didn't need medicine.

In addition to medication, several parents tried behavioral therapies. Two parents hired a behavior analyst to work with their children at home and in school. Denise shared:

He got a behavior therapist so she used to work with him at home and at school. It's a program they have for kids with special needs. So he qualified back in New York. (The insurance company) helped me and they gave me three therapists and I was able to interview all of them and pick whoever I liked. There was this lady oh my god she was an angel sent to me. I use to call her crying saying I don't know what to do! We started with the park because he needed social skills and so we started taking him to the park. She was a very tall lady and I thought oh she is going to be helpful. At the park she said ok let's see what he does let's see what happens. She noticed that to play he would always grab or push. Always do something that hurts the other kid. (When we tried to) make him do something there was always a fit. He would through a fit. It was an overreaction to everything. She told me he needed to be exposed to everything. For time outs, we had a

little timer and he needed to be in his room for 5 minutes and if he would get out then (we started the timer) again. (This would take) hours just to trying get him into time out.

Cathy shared:

(My husband and I) We were like these symptoms are very overwhelming, we need some help, we think we might somewhat have the meds under control but we don't have the behavior under control. We could take her out and be somewhat ok, but anywhere else she goes it is usually a disaster, so we needed some behavior help. We have military insurance which is actually quite good because they cover ABA Therapy. Maybe four times a week instead of five, it kind of depended on their schedule, and the lady, her name was Holly, she would come in and we had kind of like a little playroom and I would set it all up with the little table and her and Casey would just sit there. It sometimes took Casey literally like 3 hours to sit down, it was very grueling, but it taught Josh and I so much. It was almost like therapy for us too. How to deal with behaviors and non-preferred activities and stuff like that. We were fortunate enough to find an ABA therapist that would come to the house, so for that last year that's pretty much what we did all day. So we did school and ABA therapy and the next day school and ABA therapy.

Ellie discussed how she received parent training at the same time her daughter received therapy for anxiety:

It wasn't like typical therapy, it was done through a study for young children with anxiety for treatment. That worked out really well because the first three or four visits was just me and it was educational for me. Here's what anxiety is, here's what some triggers are,

here is what you are doing that made it worse but you didn't realize it because for a child that's not anxious this is what you would do. I was like I feel really bad, and they said don't feel bad because that's the typical response and that's ok, but we're going to modify your behavior too. Ok good. So that was really fantastic and it was so helpful for me because I learned more about anxiety. Before it was like when you get nervous about something, everybody does that, except she is twenty-four hours a day seven days a week. So learning about things that could trigger it, how to handle when she does, how not to feed into it when she without realizing it. Here's some phrases to use when she does, like oh it's your alarm systems, and what do we do with your alarm systems, well we need to turn those off I think. So it was good for me because I became aware of what I was doing inadvertently that was making things worse and I was able to help her more. The therapist was working with her once a week for twelve weeks I think and it was an hour each time....There was a huge decrease in the anxiety and the OCD. There are flair ups every once in a while, it's still there, it's kind of an everyday thing, it's so much less.

Ellis also discussed how helpful an online support group has been during her journey. She said:

I'm actually part of a support group on Facebook that the Early Steps coordinator got me into back when we were in Early Steps. It's parents of special needs kids, everybody on there has kids with different things going on, Down Syndrome, CF, CP, ASD, you name it I think we've covered every diagnosis under the sun on there. It's kind of nice because you can be hey has anyone heard of this, does anyone know about this, excuse me while I vent for a minute. It helps not having to try and find the time to meet up with anybody, at

some point somebody is usually online so it's kind of handy and makes for a good source.

School Struggles was the most prominent theme to emerge from the interviews. School Struggles describes how the family struggled with navigating the school system. This includes trying to find the right supports, teachers, and classrooms to serve their child. Almost every mother discussed how hard they've had to advocate for their child in order to receive the proper supports and services. In almost every case, their child had to move from classroom to classroom and even from school to school in order to find the right services. Several parents discussed the lack of training many of their teachers have had when working with children who have special needs, they discussed the insensitivities they were met with during the school's evaluation process and how they have learned to navigate through the school system in general.

Marie recalled:

The ESE services in this area, we've had to put Mark wherever they are and most of the zoned schools don't have all the ESEs so I've had to research where to put him. They've never been at the same school. It's still like that. In fact I had to pull him out of our zoned school, Public School, because they were failing him so bad, and I don't mean academically, I just mean there was a lack of ESE support....Mark had cancer when he was eight and a half and she called me his first day back in school and she said we need to get you to come in because we never finished the paperwork and we are entertaining the thought that he might have Asperger's, and she told me this on the phone, I think I dropped the phone at that point. I'm like Mark has only been out of the hospital for 12 hours and you just unload on me like this? She's just one of those people I hope to never

see again. She's just very cold... So at that point I think he was only at that school a couple of months more and I pulled him out and he ended up at a different public school in the ESE program for fourth and fifth grade. (His siblings) have never been to the same school except in elementary and that was for just a little bit because we had to find an ESE program for him and that's ok, but it's amazing. Even those that are qualified out there, the lack of compassion that they have, because I'm not like that. How can they call a mother whose son is just out of the hospital for cancer and hear we need to wrap up our paperwork. As good as it was for my daughters, they were phenomenal, safety patrol, this and that, picture perfect just cookie cutter, it was a failure for Mark.

Anna had similar experiences with her son. She struggled to find a school where her son was able to be successful.

Private School was great grade 1-3, but I had to take him out because he was getting kind of out of control and they weren't there to monitor all of that. It was too much, it was just too much. I couldn't find anywhere else that would be suitable. I have gone head to head with the school system here.

.....He ended up going back to his previous school again and he ended up staying there for a while, but it was too mainstream, one he wasn't ready for it, so I ended up sending him to another public school, and he was put into an EBD class, and he was in there for a year. Not he's in fifth grade for a year for an EBD class and then sixth grade for a year, but they said he's not, that he doesn't need the EBD anymore and (this school) it's not in a good neighborhood. He's vulnerable to this stuff. The second day of school someone brought a gun to school. That's the kind of stuff we're dealing with.

Anna discussed the challenges she faced when trying to advocate for more supports within the school setting.

I've asked for occupational therapy because he needed it. He excelled with occupational therapy at Private School, and when I asked for occupational therapy through the IEP meetings, they said they just did an assessment (screener) they didn't do a (full) evaluation, and they said from the initial assessment (he didn't need OT). I asked Anthony did the Occupational Therapist assess you? Did they pull you out? He said "yes, and they asked me to count backwards from one hundred down to one, and I said ok." So because of that they (the Occupational Therapist) said no, we didn't find a need to evaluate him. There's a difference between an assessment and an evaluation. This went on for a couple of years and finally when he was in middle school I was furious and said he needs it, and this is all for financial reasons that you were not giving him occupational therapy and honestly right before I took him back to Private School for seventh grade last year, they gave him OT starting at the end of the year.

Cathy also discussed how frequently her daughter was moved through classrooms and even through schools. She also spoke about the lack of training she saw in many of her daughter's teachers. She recalled:

So school wise we started them out at Public School and David was fine in his second grade class but Casey's second grade class did not go very well at all. It's ASD as well. Casey's ASD teacher, I don't remember his name, he was a nice guy but he was a brand new teacher just in general. Brand new to teaching at all let alone teaching ASD students and the first few months were a complete disaster. She was regressing a lot. She was

doing the hair thing again that we hadn't seen in a good year to year and a half or so, anything she could do pretty much to get attention and to get out of school that's what she was doing. Another thing we learned after a couple of months of her being there was that they were letting her sleep about six hours a day. We realized she was up so much at night again. Like oh no now she's regressing back to that again. We thought it was all this regression. Even though we would have IEP meetings it was never mentioned that we let her sleep most of the day until one of the aides mentioned, boy Casey sure sleeps a lot, and I said wait what do you mean she sleeps a lot? And they said well she sleeps under the table most of the day. And I'm like, no, no, no, no. And then we began to understand what was going on. To say I was upset would be putting it mild. So we got her ABA therapist involved again, her name was Meg, it was so nice because I understood what was going on with their school. I try my best to keep Casey in that school, I thought Meg could observe and give the teacher constructive criticism and it just didn't work. It was not a good fit at all. So I left David at Public school and I pulled Casey out and took her up to Private School, so I drove her every single day up to Private School which is one hour and fifteen minutes each way. Yes, it was a very, very long way, but I was, you know determined for her to have an education. So she went through half of the first, and all of the second grade.

.....[At Private School] All of them were of course trained in ABA therapy. The entire school is all autistic children. The lower level is Pre-K through fifth and upstairs is middle school and high school. They can do up to 22 to 23 I certainly got to meet a lot of people, a lot of parents, and kind of good ideas from them. Her teacher, during that six or seven months was one of the best teachers I have ever met. Absolutely wonderful. Really

in tune with the way autistic kids act, speak, and just really clicked with Casey. Her personality clicked with hers very well. Miss Sandy was her name. Super, super nice. They were great. Really wonderful. I should say, it was a good school. So what happened was, her teacher left. So the third year they didn't tell us until the day before school started that her teacher was not going to return. So I'm doing the same schedule. Driving up and stuff like that. Meeting their new teacher, she wasn't even certified or anything. She was actually a teacher's aide, the year before. And they couldn't find anyone they said so quickly. It was such short notice. She was a really nice lady. Very young, had a couple of her own kids really young. The teacher really couldn't handle it. It takes a certain kind of person to handle a class full of ASD students. We have been fortunate that Casey is not violent. We were a little worried. It was kind of creepy. I would come in and it was just wild. The kids were just flying all over the place. No one could handle it, and it just got too much.

..... We wanted to move Casey anyway, so we started looking for a school we could put both of them in. We went to Parks and County and they already knew of our situation because of David's illness and he had already done the homeschool when he was finally a little better, he had done that for about a month, so they kind of knew his situation and that he was out of school for so long and things like that so that was when he came to Public School. That was in the middle of his 3rd grade, so I would say January of this year he finished at Public School. Now they are both in Public School for the 4th grade. So that's where we are at right now.

Ellie recalled:

She's not getting anything through school anymore. Based on everything she's within acceptable limits with everything. In some cases she just squeaked over the line but since she's within (average) range (the school stopped services). I would like her to have a little more just to push her up there because I don't want her sliding back. With first grade it's not going to be fun. You look at the now but I have to look at my child long term, not just next year, but this second I don't know what it's going to look like but I know there is going to be issues because I know where we've been and I know there's going to be something and I want (accommodations) in place.

Two mothers discussed how difficult it was to find supports after moving from state to state both in and outside of the school setting. In both situations, each family had to move due to the husband's job for the Military. Denise discussed while living in New York, her son was placed into a classroom for students transitioning out of an ASD unit into a full time general education classroom. He was given an aid to support him with-in the general education classroom and as time passed those supports were slowly faded. However, once she moved to Florida they did not have a transitional classroom so he was placed back into a full time ASD classroom. She recalled:

Yea he was doing well! I think they had a class, in NY, a class just for kids who were trying to get into the general education classroom. It was a small group of kids who were transitioning into gen ed. Little by little David was transitioning (into the gen ed classroom). Then we moved here. At that time he was more verbal he still had some behaviors issues but it was not as bad as before. He doesn't have a filter in his mind. So he will say things that are not appropriate....They didn't have the support for him in the

(gen. ed) setting so they just decided to put him in an ASD (classroom). I was a little disappointed that he was put back and I know they didn't know him that well. Just give him a chance to perform in a gen ed setting... (His school opened a position for a bilingual assistant) I applied for it and I got it. I remember the teachers saying this is going to be an issue with you working here with him. They knew that I've always been on top. If he is going to get services then I'm on top of the services he needs. My husband has always been the same way. As soon as I started I said two times I want him in the gen ed class. They put him in the gen ed. They didn't have that transitional (classroom) so they just put him in third grade.

When Denise was asked what supports she was provided outside of the school setting after moving to Florida she responded with "nothing." The only supports her son was able to receive was through the school system.

Cathy's also discussed how difficult it was to find therapists for her daughter after moving. She recalled:

So luckily I was happy to move back down here since I'm from here. I know the area, I know the hospitals and know where we might have to go..... Sometimes it was very very hard because of course we have to go with our insurance and she goes once or twice a week so it does get difficult. Especially since I like them to be in the same group of commissions so they can talk to each other and so we don't have a lot of back and forth and the know our situation, they know Casey. They can talk about it and things like that afterwards. She can be very tough and difficult. I mean she can. She can also be very sweet but man when she gets in a mood watch out. So when I started looking here there's

really honestly not that many therapist in this area. There's a bunch up in Tampa of course by USF. I went to USF too and I know that area and there's a ton of therapist there but there's not that many down here.

Several mothers admitted to an ongoing struggle with the school system even as their child has grown older. Each parent expressed how they've grown in their ability to advocate for their child and they've educated themselves on their rights as parents who have children receiving Exceptional Student Education. At the conclusion of each journey the parents described the current supports their child was receiving. The need for support varied with each child. Cathy shared that her daughter is now in a center school for children on the Autism Spectrum. Denise shared that her son was transitioning into middle school with little to no supports. Anna shared that her son was doing very well in a school that also caters to children with special needs. Marie shared that her son was transitioning into high school but was too nervous to share the name of the school in fear of it not working out for her son and Ellie shared that her daughter was moving to a different elementary school over the summer but was doing very well with the current level of supports she was receiving through an accommodation plan.

Question Four: How have the parents understood their child's atypical behavior over time? The theme Acceptance emerged from the data to help answer this question. Parents discussed how they've come to accept that their child is going to face obstacles in life but know they will overcome them in their own time. They discuss how their views of themselves and of their child as changed throughout their journey.

Anna says:

I have to say, you know, you're orchestrating this thing I felt like on my own and there were a lot of tears too. To be called by the school repeatedly, even by the preschool, like repeatedly and that was hard. You just feel like, you feel doors close. If I could take the wisdom I have now today about it, back then, it would have been easier. I think the way I have changed partially has just come with age, just a lot more self-acceptance, learning to really go to bat when I believe in something. Acceptance of Anthony. He's doing great now at Private School. He is. I'm getting really glowing comments, not even asking just people coming up. It's such a far cry from where we were first through third grade and I even took him there through the years for summer camp or whatever, but to see him so proud of himself and to feel so good about himself, that's like thank you God.

Denise noted:

Oh I think he is awesome I feel so happy right now just to see him and you know all the things he has been able to do and he is doing right now. I think hard work it paid off. It did. If I have to go through it again then I'd do it. Well I think that it's been a long journey and it's been hard but like I thought and he's perfect. You have that picture ok this I have my first baby and you think everything is going to be good then all of these challenges come and it just like an obstacle course. That's exactly what it like is an obstacle course and you finish the race but it's been good. It's been he has been very helpful I see things different now. I've learned so much from both of them. Only them. Me too so much and no I feel I can do anything. I feel stronger. I feel so much better than when I had him. I had him when I was 26 now I'm 38 and I feel much better than when I did when I was 26. So now you know you can do anything

Cathy reported:

It took a lot to get pregnant in general and we were so excited to learn that we were pregnant, or I was pregnant, so we were excited to learn we were going to have one, then to find out we were having two was very exciting. Then of course when we found out she wasn't growing, which was around five months, we kind of prepared ourselves because every time we went to the doctors it was, well she's not really growing like she should and there might be some medical issues, we don't know what, but you will probably have medical issues. It was one of those things we kind of prepared ourselves for anyway.

When I got to about 6 months they asked if I wanted to have an amniocentesis and I will never forget my first ultra sound and the specialist told us they may both have Down's Syndrome and we were like holy jeez you have got to be kidding me, like both of them? And they were like yeah it's kind of what we see but we're not really sure so then we talked about the amniocentesis, and let's do that Yeah and the folds in the neck. I was 29 and had done all my career stuff and had travelled all over the United States and Canada and I was ready to have babies. So we had already prepared that whatever was going to happen was going to happen, we would just deal with it.

We just did it. You don't really think about it, you just go through the motions, but things started getting tough when we started noticing the difference between them at about a year, year and a half. David was already walking at 10 months and she wasn't even crawling. We noticed they were really different, but again it was just one of those things. We let David do his thing and tried to get her to catch up as much as she could. I think we're doing a pretty good job you know what I mean?

CHAPTER FIVE:

Discussion

The purpose of this study was to expand the knowledge base regarding the experiences of families raising children with complex and challenging behaviors. Specifically, the researcher sought to expand knowledge of the interventions parents sought out for their children once becoming aware of the child's challenging behaviors. Four research questions were posed. These questions focused on who first became concerned with the child's development; what prompted parents to seek formal help from a professional; what treatment options parents pursued for their child over time, and how have parents understood their child's atypical behavior over time. Participants were recruited through word of mouth using a snowball method. Five mothers raising children with complex behavioral challenges between the ages of 8 and 14 participated in the study.

Journey from Birth of Child to First Concern

The first research question focused on the journey from birth of the child to the first signs of concern. The purpose of this research question was to better understand families' experiences from birth to the early developmental concerns leading them to seek out medical, behavioral, or mental health interventions. This question also helped provide more information on who the parents sought advice from and their initial help-seeking behaviors. There were not necessarily any noticeable trends in pregnancy or birth patterns with most mothers saying that their pregnancy was fairly typical with no major complications. However, one mother reported that

her daughter had significant concerns while in utero. and her pregnancy ended in a premature delivery. This mother knew early on that her daughter may have special needs.

The age range when concerns were first noted among mothers varied from 8 months to 3 years of age. Although there was a wide age range, it appeared that concerns arose for children with no older siblings at an older age (at approximately the age when the child first began pre-kindergarten). When the child did have older siblings, the age of concern was younger. Also of note, there were several mothers who reported that they did not notice developmental concerns in their child but rather someone else such as the child's teacher or a family friend was the first to notice and bring the mother's attention to these concerns. Again, it was typically the mother who noticed concerns first when there were other children present in the family. It was someone besides the mother when the child was an only child. When the mother first noticed concerns about their child's development, the behaviors that caused those concerns also varied greatly, such as; colic, troubles feeding/eating; language delays; hyperactivity; restricted interests and motor development.

The Importance of Early Intervention

The second question posed in this study investigated the process of the help seeking behaviors in which parents engaged at the onset of noticing their child was not meeting developmental milestones or when someone pointed out to them that their child was not meeting developmental milestones. Additionally, the researcher was interested in learning what the journey to and through the evaluation process was like for mothers as well as better understanding their perceptions of each intervention. Specifically, this study examined the types of professionals that each parent sought out and why. Additionally, it examined what the professional's advice or plan was for each child.

Once parents became concerned with their child's development, their initial help seeking steps were to typically seek out advice from their child's pediatrician. In a similar study that examined help-seeking behavior among mothers in Jamaica, the majority of mothers interviewed reported that they brought their initial concerns to their child's pediatrician (Mann, 2016). In the current study, only one mother reported that she sought advice from her mother-in-law before turning to their pediatrician. Over half of the mothers noted that their pediatricians took their concerns seriously and were provided a referral or further evaluation by a specialty clinic. However, two mothers discussed how their pediatricians used a "wait and see" method and were initially dismissive of their concerns. Previous literature shows us that delaying a diagnosis is not an uncommon practice among clinical professionals. Research shows that professionals may delay giving the diagnosis for a variety of reasons including beliefs that the family is unable to cope with the diagnosis, that the parents may simply be neurotic or believing that the child's prospects or responses to treatment would most likely not be good and therefore not seeing a need for diagnosing (Seligman & Darling, 2007). Those mothers whose pediatrician delayed recommending an evaluation were uneasy with waiting and made the choice to advocate for earlier interventions.

Once the parents were given a referral for a specialist, the specialists that were contacted varied depending on the initial concern and the age of the child. Over half of the mothers contacted an early intervention team through the Child Find program which appeared to provide a comprehensive evaluation. This coincides with prior research noting that the most effective intervention programs target multiple domains and are implemented early in life (Hayes et al., 2010). Two mothers contacted specific specialists for behaviors such as not eating or a lack of motor development. At the completion of the evaluation, the child was given a diagnosis. The

diagnoses varied across each family but in several cases the initial diagnosis was Sensory Processing Disorder. One child was diagnosed with Cerebral Palsy and one was diagnosed with an Autism Spectrum Disorder.

With regard to how mothers reacted to first learning their child's diagnosis, their feelings changed with time. Interestingly, their journeys appeared to go through a cyclical process. Many of these children received several diagnoses at different times in their lives. The parents would receive a diagnosis, the child would receive treatment, additional behaviors would appear, and the process would start over again. At the beginning of their journeys, many of their initial reactions were fear, confusion, sadness, and sometimes relief, but as time passed, their feelings of relief and acceptance grew. With each diagnosis another piece of the puzzle was put in place. The feelings of relief came from understanding that once they were given a "name" for their child's behavior then they could find new information, answer their own questions, and seek out additional help. Mann (2016) found that mothers in Jamaica had similar reactions when they first learned of their child's Autism diagnosis. Specific to the Autism diagnosis, similar findings can be seen in other countries including; France (Chamack, Bonniau, Oudaya, & Ehrenberg, 2011), China (McCabe, 2008a), Iran (Samadi, McConkey, & Kelly, 2012), Turkey (Bilgin & Kucuk, 2010), and South Africa (Krauss-Mars & Lachman, 1994).

Once a diagnosis was given, parents simultaneously began to research the diagnosis on the Internet. The Internet is one of the primary ways in which parents gather information to inform their decision-making surrounding treatment (The Interactive Autism Network, 2008) Parents also reported that they visited several libraries and found support groups to help answer their questions. One mother, however, reported that she did not like conducting her own research

because she felt that her daughter's experiences were unique. She kept a list of questions that she would ask when seeing the specialists working with her daughter.

The Intervention Path

The third research question asked about the interventions that the children in this study received throughout their development. One of the primary contributions to the literature this researcher hoped to give was to better understand the experiences families had when trying different interventions for their child, including what their thoughts and feelings were about each intervention and if they found them to be effective. These mothers reported obtaining behavior therapy or applied behavior analysis services; speech and language therapy; physical and occupational therapy as well as pharmacological intervention for the child. The paths that these mothers described were not linear. Many times they tried several interventions all at once. They also described the difficulties they faced when trying to find services for their child within the school setting.

In most cases, the child first started with Occupational and speech therapy. Several parents reported that occupational therapy was used to strengthen the child's fine and gross motor movement, their ability to focus, hand-eye coordination, self-regulation, and sensory processing issues. Parents reported that speech therapy was used to help with their child's receptive and expressive language skills. In several cases, parents explained that the therapists came to their home to evaluate and provide services. The therapists working with their child typically involved them throughout the therapeutic process. This gave the parents the opportunity to learn what activities worked for their child and how to use them when they were on their own. Due to this family-centered approach to providing interventions, mothers reported feeling pleased with their child's progress. They also expressed their appreciation for how involved the

therapists allowed them to be during their time together. Research shows that parents report greater satisfaction with interventions when they are provided using a family-centered approach (King et al. 1996).

Several families also tried medications at different points in their children's lives. Pharmacological treatment is one of the most widely used evidence-based intervention for children suffering from a mental health disorder (Brinkman, Sucharew, Majcher, & Epstein, 2018; Reed, Vance, Luk, & Nunn, 2003; Howie, Pastor, & Lukacs, 2014). Research shows that 7.5% of children aged 6 through 17 were prescribed medication for emotional or behavioral difficulties in 2011–2012 (Howie, Pastor, & Lukacs, 2014). Within the current study, it was typically the child's doctor who initially recommended the medication. In one case, the mother reported that the school brought up the possibility of putting her son on medication. The reasons for starting medication varied with each family. Medications were prescribed to manage symptoms of Attention Deficit/Hyperactivity Disorder, Mood Disorder, Anxiety and/or Depression. The age of which families first tried medication varied from as early as pre-kindergarten to high school depending on the symptomology. Children were started on medication at a younger age when their behaviors were more externalizing. Miller and colleagues (2008) also found that stimulant medications, which are often used to treat symptoms of ADHD, were prescribed more frequently to younger children than older children and to boys than girls. This is not an uncommon trend when treating externalizing versus internalizing disorders. Raviv et al. (2003) found that parents were more likely to express concerns with and start the help seeking process more quickly for younger boys than girls. This may be due to the fact that boys have higher rates of disruptive behaviors, which have a greater impact on the parents' well-being when compared to other types of behavior problems (Gupta, 2005). In the

current study, children diagnosed with internalizing disorders were not started on medication until they were older, in one case, high school.

Several parents reported going through a “trial and error” way of identifying what medications worked best for their child. One mother reported that her son was put on so many medications that she had to wean him off each one before being able to identify which ones truly worked for him. Several mothers noted how different their child’s behaviors were once starting medication. In two cases, the child reported feeling better after starting the medications. One mother reported that she was unhappy with the side effects it appeared to give her son so she stopped giving it to him after a short period of time. This discontinuity of treatment is common among children using pharmacological treatments (Brinkman, Sucharew, Majcher, & Epstein, 2018). It is not uncommon for parents to discontinue treatment either by completely stopping the medication altogether or periodically stopping and restarting medicine (Brinkman et al., 2018).

In regard to the current study, families were accepting towards starting medication due to the severity of the behaviors they witnessed in their child. In some cases, even the internalizing disorders were manifesting through externalizing symptoms. Miller and colleagues (2008) noted that the presence of aggressive behavior may make the clinical problem more salient. Children with ADHD and aggressive behavior might present a greater burden to parents and teachers, or aggressive behavior might add to a child’s level of impairment (Miller, Cohen, & Johnston 2008).

As noted previously, the help seeking process was not linear, so at the same time parents were navigating the use of medications for their child they also sought out behavioral therapies. Two parents hired private applied behavior analysts to work one-on-one with their child. One mother received psychoeducation on anxiety while her daughter received cognitive behavioral

therapy that focused on her feelings of anxiety. Based on mothers' response to these interventions, it appears that behavioral therapies were the most helpful intervention when dealing with their child's problematic behaviors because they took a wrap-around approach. Research has found that the most effective intervention programs target multiple domains and are implemented early in life (Hayes et al., 2010). Mothers reported that behavior analysts not only taught their child prosocial behaviors but also taught the parents how to work with their child, respond to their child's problematic behaviors, introduce new experiences to their child, and advocate for their presence in the school setting. Behavior analysts worked with the children in their classrooms, in their homes, and in their communities. They also provided education to families in regard to looking at the antecedents and the consequences of their child's behavior.

Behavior therapists also provided a type of social support for the mothers. Both mothers reported being able to call their therapists during all hours of the day for support. They were able to ask questions or just vent their frustrations. The therapists also acted as advocates for the parents when dealing with the school system. Due to the nature of their job, the therapists were able to work with the child and their teachers within the classroom. They taught the teachers ways to work with the child and what behaviors to expect from the child. In one case, the therapist advocated for the child to be allowed back into the classroom. However, both parents reported difficulties in finding such specialized therapists as they moved around quite frequently. Both mothers reported having to rely heavily on their insurance and the military for help in finding each of their therapists.

A common theme among the behavioral therapies used was the psychoeducational component. One mother reported that when her daughter was diagnosed with anxiety, she was enrolled in a clinical study that provided her with information on what anxiety was and how it

affected her child's ability to function in day-to-day life. Her daughter was also provided cognitive behavioral therapy within the same study. Both mother and daughter reported a better understanding of anxiety and how it affected a person's thought processes. It allowed her daughter the ability to advocate for herself and gave her the language needed to do so. Her mother was also taught what might trigger the anxiety and ways to teach her daughter to cope with feelings of anxiety. Psychoeducation was also used by several of the physicians working with these families. One mother reported that her son's doctor was able to alleviate many of her concerns by discussing her son's anxiety and how it appeared to be affecting him within the school setting.

With every mother interviewed, the difficulties in finding support within the school system were apparent. Mothers discussed having to advocate for appropriate services and working with untrained teachers and school personnel. One mother discussed how her daughter's teacher let her sleep for several hours during the school day and never addressed this behavior with the parents. Several mothers reported having to change their child's classroom and even schools in order to find the appropriate supports for their child. In some cases, the schools asked that the child not be brought back claiming they did not have the supports that the child needed. Two parents discussed how their child was not at the same school as their "typically" developing siblings because of the lack of support. Parents also expressed their frustrations with the school's evaluation process, specifically how long the evaluation took and not understanding what was involved in the evaluation itself.

Parents Understanding of Their Child's Atypical Behavior Over Time

The fourth and final research question proposed by this study questioned how parents understood their child's atypical behavior over time. It was hoped that in asking parents to

reflect on their journeys that several pieces of information would emerge. First, the researcher hoped parents would reflect on their journey and provide information on how they had themselves change as parents across time. The second idea that the researcher hoped to understand is how parents have come to view and understand their child's behavior across time.

Although responses to this question varied, several mothers felt that they have grown tremendously in their parenting skills. One mother reported that after working with her son, she feels that she can now do anything. Another mom discussed how her self-acceptance has grown as well as her ability to advocate for her son. Several mothers also discussed how their families have grown closer in general. Specifically, the bond between themselves and their husbands had strengthened as, in many cases, they only had each other for social support.

The overall theme to emerge from their answers to this question was acceptance. These mothers expressed how they have grown to accept their child's behavior as just a part of who they are as an individual. They expressed having a more "go with the flow" attitude as they approach problems. One mother shared that her and her husband have grown to approach problems head on. They do not dwell on the situation but instead focus on how to solve the problem.

Interpretation

When considering all of these experiences through an ecological lens, two frameworks shaped how the results were interpreted. The first framework is a theory of help-seeking behavior developed by Jones, Heflinger, and Saunder's (2007) which builds on Bronfenbrenner's ecological model. Jones and colleagues purposed a multi-level framework

that describes the individual, cultural and environmental factors that impact the person's ability and desire to seek help from behavioral and mental health concern including: (a) the needs of a population, (b) predisposing factors, such as family history of mental illness; and (c) enabling factors, including family beliefs about help seeking and knowledge of relevant resources.

In regards to this specific study, each family discussed their help seeking behaviors throughout their journey in raising a child with behavioral and mental health needs. Specifically, five themes emerged that discussed the needs of the population and enabling factors, including family beliefs and knowledge of relevant resources. This study did not delve into the families predisposing factors. One mother, whose son was adopted, discussed knowing the birth mother's history of mental illness, which helped target the interventions used later in his life. Another mother discussed finding out her daughter was not growing in utero which allowed her to start the help seeking process early in her life.

In regard to the needs of the population, each mother described her child's behavior in the first year of life as being difficult or extremely fussy. Their struggles ranged from difficulties feeding their child to their child not meeting developmental milestones. Each mother identified the behavior that first caused them to worry that their child may not be developing typically. If they were not the first to develop concerns, they discuss who initially brought up their concerns and what their reactions were to the news. In several cases, a teacher was the first to voice a concern regarding the child behavior. This was typically seen in children who were first born or an only child. In either case, the concern was great enough that the parent's began their process of seeking out supports at an early age.

The family's beliefs also varied when it came to seeking out social supports. Each family was consistent with seeking out medical support for their child. Each family also tried several forms of behavioral therapies that ranged from individual counseling to private ABA therapy to group therapies. Educating themselves was also seen across each interview. Once the child was given a diagnosis, the parents typically started researching the diagnosis on their own. One mother reported that she did not like to do her own research because she felt that her child was unique and their experiences would not be the same as other people. She preferred to ask her daughter's medical providers or therapist's questions.

As parents discussed their social supports, three mothers discussed a lack of social support available to them. In two cases, the families moved around frequently and lived far from their nuclear family. All three of these mothers emphasized how much support they received from their husbands and discussed how they worked as a team to help support each other and their other children. Two mothers discussed their "village" of supporters. Both were single moms but lived close to their nuclear families. They both discussed how helpful their own mothers were in providing them with help, a shoulder to lean on and a second opinion. Both also had extended families that lived close by. Almost every mother discussed how she sought help from outside support groups or, when available, their own family members. One mother discussed how she relied mostly on her husband.

The second framework to help guide data analysis was Hupcey's (1998) theory of social support. Hupcey noted that social support occurs in the functional context of relationships and can be divided into four types of supportive behaviors including (a) informational support, (b) appraisal support, (c) emotional support, and (d) instrumental support.

Informational support is the provision of advice, suggestions, and information that a person can use to address problems. Several themes emerged from the data related to when parents began seeking out advice, whom they sought advice from, and the advice that was given to them. As parents discussed the early stages of their child's development, each mother discussed whom she first turned to when they became aware of their child's differences. In almost every case it was the child's pediatrician. One mother talked with her mother-in-law first but quickly sought out advice from her son's pediatrician. Informational support was seen throughout each mother's journey. They discussed receiving advice from family members and support groups. They also discussed conducting their own research to gain information regarding their child's diagnosis. One mother discussed how there were several "key" people throughout her journey who helped her identify exceptionalities in her child, including his gifted qualities.

Appraisal support is the provision of standards for self-evaluation such as social comparison and norms. Appraisal support is often used to affirm an individual's sense of value and competence. Often times, appraisal support was seen in the families that had multiple children. These mothers typically reported comparing the child of interest to her other children. This allowed her to identify skill deficits early in her child's life. One mother discussed how she was able to compare her twins to see how delayed her daughter was in meeting developmental milestones. Another mother was able to identify early feeding problems in her daughter due to having an older son. Two mothers whose child was an only child or the oldest child reported that they were caught off guard when someone first approached them about their child's delays.

Emotional support includes the use of empathy, trust, love, and caring towards another individual. Emotional support was prominent throughout the themes. Most of the mothers discussed receiving emotional support from their families and support groups they sought out.

However, several mothers discussed the lack of emotional support they received from family, friends and, most commonly, teachers. Two mothers discussed the lack of social support they received from family due to living in different states. Almost every mother discussed the lack of social support they received from their child's teachers at different points in their lives. This caused them to move from classroom to classroom or even from school to school. The lack of social supports within the school setting was seen across interviews.

Finally, instrumental support is concrete assistance, such as money, books, or babysitting services (Sarafian, 2012; Sterrett, Jones , McKee, & Kincaid, 2011). Instrumental support was discussed at different points throughout each interview. Again, it was typically discussed as a type of support that was missing for these families. For many of the families, babysitting services were hard to find because of their child's difficult behaviors. Their children were kicked out of daycares or were not allowed in play date situations. Several of the families reported finding books through their own research.

Limitations

There are a number of limitations inherent to this study that should be noted. The first is that the majority of the mothers in this study lived within one central Florida county. M Several major hospitals and many private practitioners work within this county, which also make it easier to find services. The county also in close proximity to a major research university that provides services in diagnosing and treating children. Due to the size of the district, parents also may have more choices in the school their child can attend. When a family was unhappy with their child's supports, they were able to move them to a different school. Florida has a program in which the state will pay part or all of the cost for a private school for children who have an IEP or 504 plan and have been in a public school for at least a year. Public school choice programs also allow

families to choose from among different public schools in their catchment area. Families living outside of this county may not have the option to change schools that was seen among the families in this study.

A second limitation in this study is the diversity within the families that participated in this study. All but one mother reported her ethnicity as Caucasian. One mother reported her ethnicity as Hispanic. As a result, this study lacks data on the help-seeking behaviors within minority populations. Previous research shows that African-American and Asian-American/Pacific Islander youth were half as likely to receive any type of mental health care when compared to their White American peers (Garland et al. 2005). White Americans may experience less stigma associated with mental health disorders. Woodward (2011) found that perceived discrimination by service users, negative experiences with service providers, and instances of institutional racism impacted minority parents' help-seeking behaviors.

The women in this study also reported having little social support to help guide them in their journey. This may have caused them to automatically seek out support from professional mental health agencies. Previous research shows families from minority cultures in the U.S. seek help from traditional mental health agencies at a lower rate than families from the majority culture (Lillie-Blanton, Martinez, & Salganicoff, 2001). Instead, they typically turn to their family and friends for initial supports (Chang, Chen, & Alegría, 2014; Lewis & Greene, 2009). Future research should include a more diverse population in order to get a broader perspective of general help seeking behaviors among parents.

Implications for Research and Practice

Despite the limitations of this study, this research makes several contributions to the understanding of the experiences of families raising children with complex and challenging

behaviors to the field. First, although previous research has looked at help seeking behavior among families they have typically focused on specific mental health disorders, such as, Autism Spectrum Disorders, Anxiety or Attention Deficit Hyperactivity Disorder. The parents in this study had help seeking behaviors that were ongoing and constantly changing due to the constant changes in their child's behaviors. These children did not fit into just one specific mental health category, instead one child may have received several diagnoses to date.

Due to the fact that these children's behaviors were constantly changing across time, practitioners should look into the importance of individualized support for these students. Several of the children discussed in this research study started out with the very similar if not the same intervention plans despite having different diagnoses. Targeted intervention plans that focus on the specific behaviors that the child is exhibiting may help prevent future behaviors problems as they get older. Individualizing behavior plans should be replicated within the school systems as well. Many of the mothers expressed frustration with the supports their children received within the school system. It appeared that they received a blanket type of support instead of individualized to their child's needs. This appeared to happen more frequently when parents sought help through child find programs within the school districts. Past research has focused mainly on formal mental health providers. Future research in this area may help schools develop more targeted interventions plans for children with complex behaviors that do not fit into just one category.

This study also provides a better understanding of the struggles these mothers faced navigating through the school system. Many of the mothers expressed their frustration with not understanding the evaluation process, needing the use of parent advocates during meetings held at the school and dealing with uncompassionate teachers and school staff. Highlighting these

areas of weakness may help future practitioners with how they provide support and information to families. The need for parent education is apparent throughout the current study and others (Mann, 2015).

Teacher trainings in how to work with families is also apparent. Several of the mothers discussed the lack of compassion they dealt with when working with school personnel, restricted support within the school system and a lack of proper placement for children with disabilities. Additional trainings for teachers will provide them with the knowledge in identifying early warning signs for children with complex and challenging behaviors. In many cases, the teacher was the first to voice a concern and recommend an evaluation. Training teachers will also allow for a more inclusive classroom design. Providing teachers with the proper support to work with children who have complex and challenging behaviors will decrease the mobility of these children. It may also decrease the need for specially designed classrooms and allow students with disabilities to stay within the mainstream classrooms.

This study also delved into the emotional component that is experienced by parents while they were seeking help for their child. Specifically, this study sought out a deeper understanding of how parents felt after receiving an initial diagnosis and regarding the specific interventions that were tried with their children. Results suggest that practitioners need to be more aware of the importance of using compassion and kind words when approaching parents with an initial diagnosis. This news can be incredibly shocking for parents. Results of this study show that parents typically feel anger, guilt, sadness and relief after receiving a diagnosis. These emotions were heightened when the child was an only child or the oldest child. In these cases, the mothers were not suspecting a problem and were often referred by teachers.

In addition to using a more empathetic approach when working with families, current practitioners should provide more informational support to families after providing a diagnosis. In similar studies, 44 percent of mothers reported unmet information needs during antenatal care and 39 percent during post-natal care (Scottish Government, 2014). McKenzie (2002) found that the barriers to informational support included instances of failing to “connect”, non-disclosure or evasiveness, and hesitant question and answers sessions. Mothers in the current study reported turning to the internet for more information on their child’s diagnosis. This behavior is seen across the literature (Mann, 2015; Loudon, Buchanan, and Ruthven, 2016). Future research and everyday practitioners may want to provide parents with information on what types of resources are available for them and their child.

Conclusions

This research provides a unique look at the experiences of raising a child with complex and challenging behaviors are from birth to the initial concerns; the behaviors that first caused them to feel concerned; the emotions experienced by parents after receiving an initial diagnosis; the experience of accessing supports and services; and the parents understanding of their child’s atypical development over time. These mothers identified the behaviors that caused their initial concerns that began the help-seeking process. They helped to bring awareness to what types of interventions are available to children with complex behaviors in addition to providing insight into the pros and cons of each intervention. These mothers also shed light on the struggles parents experience when navigating through the school system with child with complex behavioral needs. They highlighted the lack of training teachers receive when working with challenging students, the lack of supports provided within the school setting, and the perceived lack of compassion from school-based practitioners. Lastly, these mothers helped to provide a

better understanding of their child's atypical development over time. This research serves to inform existing literature in this area and to provide greater insight into the needs of children with complex and challenging behaviors.

Table 1. Demographic Characteristics of Study Participants

Pseudonym	Gender	Child's Pseudonym	Occupation	Ethnicity
Anna	Female	Anthony	Registered Nurse	Caucasian
Cathy	Female	Casey	Stay at home mom	Caucasian
Denise	Female	David	Bilingual Assistant	Hispanic
Marie	Female	Mark	ESE associate	Caucasian
Ellie	Female	Emily	Youth Librarian	Caucasian

Table 2. Demographic Characteristic of Children Discussed

Child's Name	Gender	Child's Age	Ethnicity	Diagnosis
Anthony	Male	13	Caucasian	Attention Deficit Hyperactivity Disorder (ADHD) and Bipolar Disorder
Casey	Female	9	Caucasian	Autism and ADHD
David	Male	12	Hispanic	Autism
Mark	Male	14	Caucasian	Sensory Processing Disorder Anxiety and Depression
Emily	Female	8	Caucasian	Sensory Processing Disorder, ADHD, Anxiety and Autism

REFERENCES

- Ahmadi, A., Sharifi, E., Azizi Zalani, H., Bolouk, S., & Amrai, K. (2011). The needs of Iranian families of children with autism spectrum disorder, cross-cultural study. *Procedia Social and Behavioral Sciences*, *15*, 321-326.
- Anselmi, L., Barros, F., Piccinini, C., Menezes, A., Araujo, C., & Rohde, L. (2008). Continuity of behavioral and emotional problems from pre-school years to pre-adolescence in a developing country. *Journal of Child Psychology and Psychiatry*, *49*(5) 499–507.
- American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). Arlington, VA: American Psychiatric Publishing.
- Baillargeon, R.H., Normand, C.L., S´eguin, J.R., Zoccolillo, M., Japel, C., P´erusse, D. et al. (2007). The evolution of problem and social competence behaviors during toddlerhood: A prospective population based cohort survey. *Infant Mental Health Journal*, *28*, 12–38.
- Baillargeon, R., Morisset, A., Keenan, K., Normand, C., Seguin, J., Japel, C., & Cao, G. (2012). Development of disruptive behaviors in young children: A prospective population based cohort study. *Infant Mental Health Journal*, *33*(6),633-650.
- Bakare, M. O., & Munir, K.M. (2011). Autism spectrum disorders (ASD) in Africa: A perspective. *African Journal of Psychiatry*, *14*, 208-210.
- Barkley, Russel. (2015). History of ADHD. Attention-deficit hyperactivity disorder: A handbook for diagnosis and treatment (4th ed.). New York, NY, US: Guilford Press.
- Bilgin, H., & Kucuk, L. (2010). Raising an autistic child: Perspectives from Turkish mothers.

- Journal of Child and Adolescent Psychiatric Nursing*, 23, 92-99.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research Psychology*, 3: 77–101.
- Broomhead, K. (2013). Blame, guilt and the need for labels; insights from parents of children with special educational needs and educational practitioners. *British Journal of Special Education*, 40(1) 15-21.
- Brownell, C., Svetlova, M., Anderson, R., Nichols, S., & Drummond, J. (2013). Socialization of early prosocial behavior: parents' talk about emotions is associated with sharing and helping in toddlers. *Infancy*, 1(18)91–119.
- Boulter, B. & Rickwood, D. (2013). Parents' experience of seeking help for children with mental health problems. *Advances in Mental Health*, 11(2)131–142.
- Byrd, R.S., & Weitzman, M.L. (1994). Predictors of early grade retention among children in the United States. *Pediatrics*, 93, 481-487.
- Campos, A., Savelsbergh, G., Cicuto, N., & Rocha, A. (2012). What do we know about the atypical development of exploratory actions during infancy? *Research in Developmental Disabilities*, 33, 2228–2235.
- Chamak, B., Bonniau, B., Oudaya, L., & Ehrenberg, A. (2011). The autism diagnostic experiences of French parents. *Autism*, 15, 83-97.
- Coonrod, E. E., & Stone, W, L. (2004). Early concerns of parents of children with autistic and nonautistic disorders. *Infants and Young Children*, 17, 258-268.
- Cole, P. M., Hall, S. E., & Hajal, N. (2013). Emotion dysregulation as a risk factor for psychopathology. In T. Beauchaine & S. Hinshaw (Eds.), *Child and adolescent psychopathology* (2nd ed.). Hoboken, NJ: Wiley

- Costello, E. (1989). Child psychiatric disorders and their correlates: A primary care pediatric sample. *Journal of the American Academy of Child & Adolescent Psychiatry*, 28(6), 851-855.
- De Giacomo, A., & Fombonne, E. (1998). Parental recognition of developmental abnormalities in autism. *European Child and Adolescent Psychiatry*, 7(3), 131-136.
- Dempster, R., Wildman, B., & Keating, A. (2013). The role of stigma in parental help seeking for child behavior problems. *Journal of Clinical Child & Adolescent Psychology*, 42(1), 56-67.
- Doctoroff, G. & Arnold, D. (2004). Parent rated externalizing behavior in preschoolers: the predictive utility of structured interview, teacher reports, and classroom observation. *Journal of Clinical Child and Adolescent Psychology*, 33(4) 813-818.
- Durand, V., & Hieneman, M. (2008). Helping parents with challenging children positive family intervention : Facilitator guide. Oxford, New York: Oxford University Press.
- Eisenberg, N., & Fabes, R. A. (1998). Prosocial development. In W. Damon (Series Ed.) & N. Eisenberg (Vol. Ed.), *Handbook of child psychology: Vol. 3. Social, emotional, and personality development* (5th ed., pp. 701-778). New York: Wiley.
- Fernald, C. & Gettys, L. (1980). Diagnostic labels and perceptions of children's behavior. *Journal of Clinical Child Psychology*, 229-232.
- Fink, I., Beirens, T., Butte, D., & Raat, H. (2014). Help-seeking behavior for internalizing problems: perceptions of adolescent girls from different ethnic backgrounds. *Ethnicity & Health*, 19 (2) 160-177.
- Fox, L., Vaughn, B., Wyatte, M., & Dunlap, G. (2002). We can't expect other people to understand": Family perspectives on problem behavior. *Council for Exceptional*

Children, 68 (4) 437-450

- Garland, A. F., Lau, A., Yeh, M., McCabe, K., Hough, R., and Landsverk R. (2005). Racial and Ethnic Differences in Utilization of Mental Health Services among High-Risk Youths. *American Journal of Psychiatry*, 162 (7)
- Gjone, H. & Stevenson, J. (1997). A longitudinal twin study of temperament and behavior problems: common genetic or environmental influences? *Journal American Academy Children Adolescent Psychiatry*, 36 (1), 1448-1456.
- Goin, R., & Myers, B. (2004). Characteristics of infantile autism: moving toward earlier detection. *Focus on Autism and other Developmental Disabilities*, 19(1)5-12.
- Gupta, A, & Singhal, N. (2005). Psychosocial support for families of children with Autism. *Asia Pacific Disability Rehabilitation Journal*, 16(2), 62-83.
- Hay, D. (1994). Prosocial Behavior. *Journal of Child Psychology and Psychiatry* 35(1) 29–71.
- Helen, L., Johansen, A., & Manger, T. (2011). Oppositional Defiant Disorder—Gender Differences in Co-occurring Symptoms of Mental Health Problems in a General Population of Children. *Journal or Abnormal Child Psychology*, 39, 577–587
- Horovitz, M., & Matson, J. (2011). Developmental milestones in toddlers with atypical development. *Research in Developmental Disabilities*, 32, 2278–2282.
- Horovitz, M., Matson, J., & Sipes, M. (2011). The relationship between parents' first concerns and symptoms of autism spectrum disorders. *Developmental Neuro-rehabilitation*, 14(6) 372–377.
- Howie, L., Pastor, P., & Lukacs, S. (2014). Use of Medication Prescribed for Emotional or Behavioral Difficulties Among Children Aged 6-17 years in the United States, 2011-2012. NCHS data brief, 148.

- Hupcey, J. (1998). Social Support: Assessing Conceptual Conherence. *Qualitative Health Research*, 8 (3) 304-318.
- Interactive Autism Network (2008). IAN research findings: special diet. Retrieved from http://www.iancommunity.org/cs/ian_research_reports/treatment_series_special_diets
- Jenkins, S., Owen, C., Bax, M., & Hart, H. (1984). Continuities of common behavior problems in preschool-children. *Journal of Child Psychology and Psychiatry*, 25, 75–89.
- Kauffman, J., Mock, D., & Simpson, R. (2007). Problems related to underservice of students with emotional or behavioral disorders. *Behavioral Disorders*, 33(1), 43-57
- Kishore, T., & Basu, A. (2011). Early concerns of mothers of children later diagnosed with autism: Implications for early identification. *Research in Autism Spectrum Disorders*, 5(1) 157-163.
- Krauss-Mars, A. H., & Lachman, P. (1993). Breaking bad news to parents with disabled children – A cross-cultural study. *Child: Care, Health, and Development*, 20, 101-113.
- Lavigne, J., Gibbons, R., Christoffel, K., Arend, R., Resenbaum, D., Binns, H., Dawson, N., Sobel, H., Isaacs, C. (1996). Prevalence rates and correlates of psychiatric disorders among preschool children. *Journal of the American academy of child and adolescent psychiatry*, 35(2) 204-214.
- Lee, E., & Stone, S. (2012). Co-Occurring Internalizing and Externalizing Behavioral Problems: The Mediating Effect of Negative Self-Concept. *Journal Youth Adolescence*, 41, 717–731.
- Loudon, K., Buchanan, S., & Ruthven, I. (2016) The everyday life information seeking behaviours of first-time mothers. *Journal of Documentation*, 72 (1) 24-46.
- Ludlow, A., Skelly, C., & Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal Health Psychology*, 17(702).

- Lung, F., Shu, B., Chiang, T., & Lin, S. (2010). Parental concerns based general developmental screening tool and autism risk: the Taiwan national birth cohort study. *Pediatric Research, 67*(2), 226–231.
- Lynam, D. R., Caspi, A., Moffitt, T. E., Loeber, R., & Stouthamer-Loeber, M. (2007). Longitudinal Evidence The Psychopathy Scores in Early Adolescence Predict Adult Psychopathology. *Journal of Abnormal Psychology, 116* (1) 155-163.
- Lyons, J., MacIntyre, J., Lee, M., Carpinello, S., Zuber, M., Fazio, M. (2004). Psychotropic Medications Prescribing Patterns for Children and Adolescents in New York's Public Mental Health System. *Community Mental Health Journal, 40*(2) 101-118.
- MacLure, M., Jones, L., Holmes, R., & MacRae, C. (2012). Becoming a problem: behaviour and reputation in the early years classroom. *British Educational Research Journal, 38* (3) 447–471.
- MacQueen, K. M., McLellan, E., Kay, K., & Milstein, B. (1998). Codebook development for team-based qualitative analysis. *Cultural Anthropology Methods, 10*(2), 31-36.
- Mann, A. (2015). The Experiences of Mothers of Children with Autism in Jamaica: A Exploratory Study of Their Journey. *Graduate Theses and Dissertations*.
<http://scholarcommons.usf.edu/etd/4722>
- Mandell, D., Davis, J., Bevans, K., & Guevara, J. (2008). Ethnic disparities in special education labeling among children with attention-deficit/hyperactivity disorder. *Journal of Emotional and Behavioral Disorders, 16*(1)42-51.
- Massie, H.N. (1975) The early natural history of childhood psychosis. *Journal of Academic of Child Psychiatry, 14*, 683-707.
- Miller, A., Kohen, D., Johnston, C. (2008). Child Characteristics and Receipt of Stimulant

- Medication: A Population-Based Study. *Ambulatory Pediatrics*, 8(3) 175-181.
- Miller, G. & Prinz, R. (2003). Engagement of families in treatment for childhood conduct problems. *Behavior Therapy*, 34(4) 517-534.
- Montgomery, J., Martin, T., Shooshtari, S., & Stoesz, B. (2013). Interventions for challenging behaviors of students with autism spectrum disorders and developmental disabilities: a synthesis paper. *Exceptionality Education International*, 23(1) 2–21.
- Moffitt, T. E. (1993). Adolescence-limited and life-course-persistent antisocial behavior: A developmental taxonomy. *Psychological Review*, 100, 674 –701.
- Morse, J. M. (1995). The significance of saturation. *Qualitative Health Research* 5: 147–149.
- Muris, P.(2006) Freud was Right. . . About the Origins of Abnormal Behavior. *Journal of Child and Family Studies*. 15(1)1–12.
- Noterdaeme, M., & Hutzelmeyer-Nickels, A. (2010). Early symptoms and recognition of pervasive developmental disorders in Germany, *Autism*, 15(6), 575-588.
- Ohan, J., Visser, T., Moss, R., & Allen, N. (2013). Parents’ stigmatizing attitudes toward psychiatric labels for ADHD and Depression. *Psychiatric Services*, 64(12)
- Osterling, J. & Dawson G. (1994). Early recognition of children with autism: A study of first birthday home videotapes. *Journal of Autism and Developmental Disorders* 24(3) 247-257.
- Onwuegbuzie, A., & Leech, N. (2007). A call for qualitative power analyses. *Quality and Quantity*, 41:105-121.
- Pastor, P., Reuben, C., Duran, C. (2012). Identifying emotional and behavioral problems in children aged 4–17 years: United States, 2001–2007. National health statistics reports; no 48.National Center for Health Statistics.

- Phelps, K., Hodgson, J., McCammon, S., & Lamson, A. (2009). Caring for an Individual with Autism Spectrum Disorder: A qualitative analysis. *Journal of Intellectual & Developmental Disability, 34*(1) 27-35.
- Qi, C. & Kaiser, A. (2003). Behavior problems of preschool children from low income families. *Journal of the Hammill Institute on Disabilities, 23*(4), 188-216.
- Raviv, A., Raviv, A., Edelstein-Dolev, Y., & Silberstein, O. (2003). The gap between a mother seeking psychological help for her child and for a friend's child. *International Journal of Behavioral Development, 27*, 329–337.
- Raviv, A., Sharvit, K., Raviv, A., & Rosenblat-Stein, S.(2009). Mothers' and Fathers' Reluctance to Seek Psychological Help for Their Children. *J Child Family Study, 18*,151–162.
- Reed, E., Vance, A., Luk, E., & Nunn, K. (2004). Single and combined Psychotropic Medication use in a Child and Adolescent Mental Health Service. *Australian and New Zealand Journal of Psychiatry, 38*, 204-211.
- Reef, J., Diamantopoulou, S., Van Meurs, I, Verhulst, F., van der Ende, J. (2009). Child to adult continuities of psychopathology: a 24 year follow up. *Acta Psychiatrica Scandinavica 120*, 230–238.
- Rosenthal, J., Massie, H.N., & Wulff, K. (1980). A comparison of cognitive development normal and psychotic children in the first two years of life from home movies. *Journal of Autism and Developmental Disorders, 10*, 433-443.
- Roulston, Kathryn. (2010). Considering Quality in Qualitative Interviewing. *Qualitative Research, 10* (2), 199-228.
- Samadi, S. A., McConkey, R., & Kelly, G. (2011). The information and support needs of Iranian

- parents of children with autism spectrum disorders. *Early Child Development and Care*, 2011, 1-15.
- Sandelowski, M. (1995). Focus on qualitative methods: sample sizes in qualitative research. *Research in Nursing & Health*, 18, 179–183.
- Sarafian, I. (2012) Process assessment of peer education programme for HIV prevention among sex workers in Dhaka, Bangladesh: A social support framework. *Social Science & Medicine*, 75(4), 668-675.
- Scourfield, J., John, B., Martin, N., & McGuffin, P. (2004). The development of prosocial behaviour in children and adolescents: a twin study. *Journal of Child Psychology and Psychiatry*, 45(5) 927–935.
- Seligman, M., & Darling, B. (2007). *Ordinary families, special children: A systems approach to childhood disability*. (3rd ed.). New York, NY: The Guilford Press.
- Singh, I. (2003). Boys Will Be Boys: Fathers' Perspectives on ADHD Symptoms, Diagnosis, and Drug Treatment. *Harvard Review of Psychiatry*, 11(6) 308- 316.
- Sterrett, E., Jones, D., McKee, L., Kincaid, C. (2011) Supportive Non-Parental Adults and Adolescent Psychosocial Functioning: Using Social Support as a Theoretical Framework. *American Journal Community Psychology*, 48, 284-295.
- Teagle, S. (2002). Parental problem recognition and child mental health service use. *Mental Health Services Research*, 4(4) 257-266.
- Thomson, M. (2012). Labelling and self-esteem: does labelling exceptional students impact their self-esteem? *British Journal of Learning Support*, 27(4)159-165
- Werner, E., Dawson, G., Osterling, J., & Dinno, N. (2000). Brief Report: Recognition of Autism Spectrum Disorder before one year of age: A retrospective study based on home

- videotapes. *Journal of Autism and Developmental Disorders*, 30(2) 157-162.
- Wichers, M., Gardner, C., Maes, H., Lichtenstein, P., Larsson, H. & Kendler, K. (2013). Genetic Innovation and stability in externalizing problem behavior across development: a multi-informant twin study. *Behavior Genetics*, 43,191-201.
- Worcester, J., Nesman, T., Raffaele-Mendez, L.,& Keller, H. (2008). Giving voice to parent of young children with challenging behavior. *Councilor Exceptional Children*, 74(4) 509-525.
- Young, R, L, Brewer, N, & Pattison, C. (2003). Parental identification of early behavioural abnormalities in children with autistic disorder, *Autism*, 7(2), 125-143

APPENDIX A:

RECRUITMENT FLYER



**Volunteers Needed for a Research Study,
The Path to Interventions**

**Do you have a child between the ages of 7
and 15 who has challenging behaviors?**



To how many of these questions would you answer **YES?**

- 8. Does your child have challenging behavior at home or at school that have not been fully resolved despite numerous interventions?**

9. **Have you taken your child to more than one mental health professional (e.g., psychiatrist, psychologist) and received different diagnoses from each provider?**
10. **Has your child been diagnosed with more than one mental health disorder (e.g., ADHD, ODD, OCD, ASD, anxiety, depression, other)?**
11. **Have you tried more than one medication to address your child's behavioral issues?**
12. **Do your child's behavioral issues have a significant negative impact on your family life?**
13. **Have you struggled to find a solution to your child's behavioral issues for more than one year?**
14. **Do you worry that your child's behavioral issues will have a negative impact on the quality of his or her life over time?**

If you answered **YES to 3 or more of the questions above, we would like to talk to you. Researchers at the University of South Florida are seeking volunteers for a study of families who have a child with persistent challenging behaviors. The study involves participating in up to three interviews that will take place within the parents or caregivers home. Participants will receive a \$25 gift card. If you are interested in participating, please contact Renee Ornduff at 727-735-2148 or rornduff@mail.usf.edu.**

APPENDIX B:
INTERVIEW GUIDE

Opening Statement to parents:

“Many people view having a child as going on a journey. You become pregnant, you give birth, you watch your child grow. For my thesis, I am interesting in learning more about the journeys of parents who are raising a child with complex and challenging behavior problems. I would like to ask you about your journey from the time you first had concerns with your child to the present day.”

1. How would you describe NAME as an infant?
2. How would you describe NAME’s development after the first year?
 - a. Probe about motor development, language development, social development, adaptive skills, and cognitive development.
3. Who was the first person to perceive that NAME was not developing typically? What did that person notice? (If not the parent), how did you respond to that person’s perception?
4. When did you as his/her mother/father first begin to become concerned about your child’s development? What did you notice? How did you explain (to yourself) what you were seeing?
5. When you thought that your child was not developing typically (i.e., saw X and Y behaviors that parents noted above), what did you do?

6. What was the result of what you did (question directly above)?
7. How did you react when you first heard the term (DIAGNOSIS) to describe your child's behaviors?
8. What support, advice, and/or information were you given by the diagnosing professional at the time of diagnosis?
9. Looking at this timeline, tell me what you can remember about how you thought and felt about your child at different points in his/her development. How have your perceptions of your child changed over time? How have your perceptions of yourself as a parent changed over time? What was the experience of creating this timeline like for you? What thoughts, feelings, and/or ideas has it evoked?

APPENDIX C:

THEMES

Theme	Theme Description
Theme 1: Fussiness Age range: birth to 1 year	Participants describe their children is the first year of life as being extremely “fussy”. Participants experienced difficulties with feeding their child, their child not meeting developmental milestones and having “unique quirks”. Many described physical differences such as larger heads or crawling differently. Several parents also described their infant as experiencing higher rates of sickness when compared to other infants.
Theme 2: Early Detection Age range: 12 months to 3 years old.	Participants describe the age in which problem behaviors were first identified in their child. They describe what the behaviors were that first caused them to worry that their child may not be developing typically. They also describe who first became concerned with their child’s behavior and what their initial help seeking steps were.
Theme 3: School Struggles Ages 3 to 13 years old.	Participants describe the struggles they’ve encountered when trying to find a place for their child within the school system. They discuss the struggles they have faced when dealing with their child’s teacher’s, classroom supports and additional school personnel.
Theme 4: Initial evaluation Age range: 7 months to 10 years old	Participants describe the process in seeking out early interventions for their child. Specifically, they describe the process of evaluations and the therapies that were first recommended to them. They also discuss the
Theme 5: Trial and Error Age range: 5 years old to 13 years old	Participants discuss their thoughts and feelings behind starting their children on medication. They describe who initially suggested the use of medication and how it affected their child over time.
Theme 6: The Diagnosis Age Range: 7 months to 13 years old	Participants discuss how it felt when they first received a diagnosis for their child.
Theme 7: Finding Answers Age range: 3 to 13 years old	Participants discuss their self-driven search for knowledge and understanding after receiving the first diagnosis for their child.
Theme 8: Acceptance	Participants discuss how they’ve come to view themselves as parents over time, as well as, their child’s atypical development.

APPENDIX D

IRB Approval Letter



RESEARCH INTEGRITY AND COMPLIANCE
Institutional Review Boards, FWA No. 00001669
13901 Bruce B. Downs Blvd., MDC203 • Tampa, FL 33612-4999
(813) 974-5638 • FAX (813) 974-7091

June 27, 2016

Renee Ornduff
Educational and Psychological Studies
Tampa, FL 33612

RE: **Expedited Approval for Initial Review**
IRB#: Pro00019966
Title: **The Intervention Path: Parental Help-Seeking for Atypical Behavioral Development.**

Study Approval Period: 6/27/2016 to 6/27/2017

Dear Ms. Ornduff:

On 6/27/2016, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

Approved Item(s):

Protocol Document(s):

[Protocol, Version #1, 06.22.2016](#)

Consent/Assent Document(s)*:

[Informed Consent, Version #1, 06.22.16.pdf](#)

[Verbal Consent, Version #1, 06.22.2016](#)

*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s). Consent forms granted a waiver are not stamped, eg, Verbal Consent.

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR46.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Your study qualifies for a waiver of the requirements for the documentation of informed consent as outlined in the federal regulations at 45CFR46.117(c) which states that an IRB may waive the requirement for the investigator to obtain a signed consent form for some or all subjects if it finds either: (1) That the only record linking the subject and the research would be the consent document and the principal risk would be potential harm resulting from a breach of confidentiality. Each subject will be asked whether the subject wants documentation linking the subject with the research, and the subject's wishes will govern; or (2) That the research presents no more than minimal risk of harm to subjects and involves no procedures for which written consent is normally required outside of the research context. (Verbal Consent)

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,



John Schinka, Ph.D., Chairperson
USF Institutional Review Board

APPENDIX E

CONSENT FORM

Study ID:CR1_Pro00019966 Date Approved: 8/27/2017



Informed Consent to Participate in Research Involving Minimal Risk

Pro # 00019966

You are being asked to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The nature of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:

The Intervention Path: Parental Help-Seeking for Atypical Behavioral Development.

The person who is in charge of this research study is Renee Omduff, MA. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. She is being guided in this research by Linda Raffaele-Mendez, Ph.D.

The research will be conducted at University of South Florida or in your home.

Purpose of the study

The purpose of this study is to:

- Examine the help-seeking behaviors of parents raising children with complex and challenging behaviors. The focus will be on the help-seeking behaviors of parents over time, from the point when they first became concerned about their child's behavioral development to the present
- A student in the school psychology program in the College of Education will complete this study to meet the thesis requirements of the Education Specialist degree at the University of South Florida.

Why are you being asked to take part?

We are asking you to take part in this research study because you have indicated that you have a child between the ages of 7 and 15 years of age that has struggled with behavior problems and have sought out several different types of interventions.

Study Procedures:

If you take part in this study, you will be asked to:

- Participate in two to three separate interviews in which you will share your experiences in raising a child with complex behavior problems.
- Each interview will be approximately one hour in length and may expand over several months.
- The interviews will take place in your home at a time that is convenient for you.
- Each interview will be audio recorded. The PI and Co-PI will have access to these tapes as well as the research group at the University of South Florida that will aid in the transcription. Participants will be asked to share their information using a pseudonym so they will not be identifiable. The tapes will be kept in a locked cabinet in the University of South Florida and will be destroyed a year after the study's completion.

Total Number of Participants

About 7 to 9 individuals will take part in this study at USF.

Alternatives / Voluntary Participation / Withdrawal

You do not have to participate in this research study.

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

Benefits

We are unsure if you will receive any benefits by taking part in this research study.

Risks or Discomfort

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

Compensation

You can earn up to twenty-five dollars for participating in three interviews. If you are unable to complete all three interviews or drop out at any time, you will be paid eight dollars for each interview completed.

Costs

It will not cost you anything to take part in the study.

Privacy and Confidentiality

We will keep your study records private and confidential. Certain people may need to see your study records. Anyone who looks at your records must keep them confidential. These individuals include:

- The research team, including the Principal Investigator, study coordinator, research nurses, and all other research staff.
- Certain government and university people who need to know more about the study, and individuals who provide oversight to ensure that we are doing the study in the right way.
- Any agency of the federal, state, or local government that regulates this research.
- The USF Institutional Review Board (IRB) and related staff who have oversight responsibilities for this study, including staff in USF Research Integrity and Compliance.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are. If at any point during the interview(s) current or ongoing child neglect or abuse is revealed this information will be reported to the appropriate authorities.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, call Dr. Raffaele- Mendez at (813) 974-1255.

If you have questions about your rights as a participant in this study, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at (813) 974-5638 or contact by email at RSCH-IRB@usf.edu.

Consent to Take Part in this Research Study

I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.

Signature of Person Taking Part in Study

Date

Printed Name of Person Taking Part in Study

Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. This research subject has provided legally effective informed consent.

Signature of Person obtaining Informed Consent

Date

Printed Name of Person Obtaining Informed Consent