

EFFECTIVE BEHAVIORS OF PARENTS RAISING A CHILD  
WITH AN AUTISM SPECTRUM DISORDER

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A dissertation to fulfill the requirements for a  
DOCTOR OF PSYCHOLOGY IN COUNSELING PSYCHOLOGY

at

NORTHWEST UNIVERSITY

2016

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### **Abstract**

Autism Spectrum Disorder (ASD) is a developmental disorder that can present with a variety of symptoms such as impaired social interactions, difficulty with verbal and nonverbal communication, repetitive behaviors, and severely limited activities and interests. Depending on the severity of symptoms, the challenges presented for primary caregivers, typically the child's parents, can be significant. Research has shown that the demands of the caregiver role can create challenges in areas such as marital relationships, physical health, social relationships, financial demands, and scheduling difficulties. The primary purpose of this study was to draw on the experiences of parents who have raised a child with ASD to identify common behaviors they identified as helping them to be more effective in parenting a child with ASD. This study was comprised of direct interviews and focus group discussions with 20 parents of children with ASD, in an effort to identify common behaviors which contributed to their effectiveness across five domains of common impact: marriage, health, social, financial, and schedule. Participants were able to identify a variety of behaviors as being useful for increasing effectiveness in dealing with the challenges they experienced in the five domains. Specific behaviors as well as categories of behavior common across multiple participants were identified. Those categories were tallied and used to identify the most common behaviors parents engaged in to address the challenges they experienced in raising their child with ASD. The most commonly endorsed behaviors were related to being adaptable, actively teaching children needed skills, activities of self-care, seeking or accepting support from friends, family, and autism service or treatment providers, and participating in or getting their children involved in activities outside the home. Other

behaviors were endorsed as well and are addressed with the results. Based on this outcome, it is plausible that parents of young or newly diagnosed children with ASD could incorporate some of these behaviors into their own parenting behaviors to help increase the effectiveness of their parenting and help mitigate some of the stressors associated with raising a child with ASD.

### **Dedication**

This research is dedicated to the parents who willingly and generously shared their experiences of raising children with ASD, both the struggles and the triumphs, for the benefit of future generations of parents, and to those parents who are just beginning, or are already on, a special journey with their child impacted by autism.

### **Acknowledgements**

First of all, I am most grateful to God for allowing me the opportunity to take on this project and to gain the education that came with it, as well as for His continued help and support throughout the process for me and for my family.

I want to express my sincere gratitude to my wife and children for their patient endurance and unwavering support, as well as to the Curd, Canup, Lee, Erbes, and Baril families for their practical and emotional support during the pursuit of this degree.

Thanks to my Dissertation Chair, Dr. Jacqueline Gustafson, Ed.D., and Dissertation Committee, Dr. Forrest Inslee, Ph.D., and Dr. Kim Lampson, Ph.D., for their advice, guidance, and encouragement.

I am also grateful to Dr. Steve Becker, Ph.D., Dr. Robert Carsrud, Psy.D., and Dr. Jeff Baird, Psy.D. for their valuable guidance and mentoring.

A big thank you to Dr. Mark Travers, D.C. for his treatment and generosity that helped me finish in spite of two significant car accidents during the process of earning this degree.

Thank you to Adam Lubanski at SurroundMedia for the urgent technical support.

Thanks also to Grace Community Fellowship for their encouragement and prayerful support.

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## **Chapter 1: Introduction to the Study**

Autism Spectrum Disorder (ASD) represents a variety of symptoms that cause significant challenges for both children and adults who are affected by the condition. Symptoms often occur across a variety of systems, which can influence cognition, behavior, and physical health. Depending on the severity of their symptoms, individuals affected by ASD can be limited in their ability to interact with others and to function independently.

In their publication, “Learning about Autism” (2012), the National Institutes of Health (NIH) described ASD as a varied cluster of developmental disorders, which included symptoms such as impaired social interactions, difficulty with verbal and nonverbal communication, repetitive behaviors, and severely limited activities and interests. Other than the core elements described by the NIH, many of those who are affected by ASD also displayed a variety of behavioral characteristics that included agitation, aggression, self-injury, and hyper-activity (Handen & Lubetsky, 2005).

Depending on the severity of symptoms, the challenges presented for caregivers of children with ASD can be significant. These caregivers, who are often parents and family members of the person affected by ASD, are frequently called upon to provide advanced levels of care for prolonged periods of time. The demands of the caregiver role can create problems for the provider in areas such as physical health, interpersonal relationships, and finances, just to name a few.

### **Rationale**

The role of a parent can include very challenging tasks at times. However, for most parents, the role is also rewarded through the reciprocal aspects of the relationship.

This is often not the case for parents of children with ASD since the challenges can be even greater while the rewards are less frequent and reciprocal interaction is hindered. Effectiveness as a parent certainly has an impact on the child's development and on the person they become. Many books and courses have been written on how to be an effective parent. However, it seems that few, if any, have attempted to identify the behaviors of an effective parent of a child with ASD.

Much of the recent research on the subject of ASD has been focused on topics such as causes, cures, and effective treatments for this public health crisis that is more commonly being described by many as an autism epidemic. Many of the questions being asked have to do with details such as the reasons for the perceived increase in ASD, effective ways to slow or stop the increase, identifying the most effective treatments, and determining where the financial burden for treatment belongs. An important part of ASD research that may be often overlooked lies in the realm of what is currently being done well. When the focus is shifted from what needs to be done better to what is currently being done well, other equally important questions begin to emerge.

Along with the other important investigations, researchers need to be asking questions about what is working and what is creating successes. Questions about behaviors, interventions, treatments, and responses that are helping individuals who have been diagnosed with ASD need to play a larger role in the overall body of evidence. At the very least, answers to these questions might provide valid directions for other studies about causes and cures. At the same time, these answers could also provide direction for parents, practitioners, and researchers that would provide immediate help to those impacted by ASD until the other questions about causes and cures are answered.

### **Research Questions and Methodology**

This study was designed to examine the behaviors of parents raising a child with ASD, with particular attention to behaviors that are related to their parenting, coping with stresses specific to the child's diagnosis, and how the parents related to their spouse and family members. The primary research question for this study was, "Do parents who raise a child with an ASD have common behaviors that contribute to their effectiveness in raising their child?" After confirmation that common behaviors did exist, the secondary research question was, "What are those common behaviors that contribute to their effectiveness?"

Therefore, the purpose of this study was to determine if there were common behaviors among parents raising a child with ASD, which contributed to their effectiveness in parenting, and if so, identify what those behaviors were. This research was done in an effort to look at the issue of ASD intervention from the perspective of current successes and to determine what has been done well, specifically on the part of the parents of children with ASD. The goal of this approach was to determine what behaviors were helpful and could be applied to other families in order to help parents who are not as far along in the parenting process or have just received a diagnosis of ASD for their child. Potentially, information about what has worked well, if applied to their own families, could help new parents of children with ASD identify more effective behaviors in raising their child with ASD.

This was a qualitative research study that employed ethnographic methods to connect with participants and collect data in the field. Participants were volunteers who were parenting a child of at least 15 years of age who had ASD. The parents were

recruited through a local autism treatment provider. Data was gathered from participant interviews and from focus group discussions with the parents. Collected data was then coded and compared for similarity across the sample to identify common behaviors of the participants.

### **Definitions and Terminology**

Key terminology of this study included terms such as effective parenting behaviors. For the purpose of this study, the operational definition of effective parenting behaviors included actions involved in the raising of, and relating to children so that the child is equipped to realize his or her potential (Alvy, n.d.). For this study, effective parenting behaviors included the care, teaching, and nurturing of a child with an ASD such that a favorable or more desirable outcome is achieved that is substantially preferable to the outcome that would have resulted had there been mediocre, poor, or no parenting. Specifically, Dr. Steve Becker, who assisted with participant recruitment indicated effectiveness by identifying potential participants as parents of children who had made progress according to the *Severity Levels for Autism Spectrum Disorder* found in the DSM-5. These were children who had shown progress in either social communication or restricted, repetitive behaviors, or both if the child previously exhibited impairment in both areas. Effectiveness also implied that the parenting of their child was not at substantial expense of the parents' own health, or the expense of their relationships with their spouse or children if applicable. The term behavior was used to describe the actions and decisions made by the participants with regard to parenting, as well as relational choices in the parent child relationship such as the establishing and communication of healthy boundaries.

**Limitations and Assumptions**

Assumptions for this study included, first, that there were specific behaviors that fostered effectiveness in parenting a child with ASD. In order for the parents to be able to identify what fostered their effectiveness, a second assumption was that parents would be sufficiently aware of their own behaviors that they would have insight into which behaviors contributed to their effectiveness.

One potential limitation of the study was that all of the participants were recruited through an autism treatment provider who was already addressing the needs of the child and their family. Therefore, the parents were already involved in treatment for their child, which is a behavior on its own that would likely contribute to the effectiveness of the whole sample. Additionally, due to time and cost restrictions, this study had a comparatively small sample size. However, it was hoped that 20 participants would provide a sufficient amount of data to identify trends and help focus future research.

Furthermore, the scope of this study primarily examined the behaviors and actions of the parents of children with ASD from the parent's perspective alone. No observations were sought from other sources such as their other children or family members and friends, or treatment providers who could describe parental behavior from the perspective of an outside observer.

**Summary**

This first chapter included an introduction to the topic of this research study and discussed the rationale for implementing a study of this nature. This chapter also explored the research question and an overview of the methodology that was used in the attempt to find the answers to the research questions. Key definitions and terminology

used in this study as well as assumptions and anticipated limitations of this research were also covered. The next chapter will examine relevant literature related to the premise of the research topic and provide background information critical to the execution of this study.



## **Chapter 2: Review of Literature**

This study was focused on an aspect of ASD that no previous research was found to have addressed. As such, the literature review that follows pertains primarily to the premise underlying this study. Specifically, this information provided a basic description of ASD, described, and substantiated the significant stress and impact on individuals and family members who are in the role of caregiver to a child with ASD.

### **Epidemiology of Autism Spectrum Disorder**

The spectrum of symptoms and behaviors that comprise the ASD diagnosis cover a wide range of attributes. While some of the diagnostic criteria have changed in the last few years with the implementation of the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association [APA], 2013), many individuals affected by ASD, their parents, and some treatment providers, are most familiar with the revised text fourth edition of The Diagnostic and Statistical Manual of Mental Disorders (4th ed., text rev.; DSM-IV-TR; American Psychiatric Association [APA], 2000). Individuals affected by ASD often use labels and descriptors from the DSM-IV-TR to describe themselves and their unique manifestations of ASD. Some of these include Asperger's Syndrome, High Functioning Autism (HFA), and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). These specific identifiers were removed from the DSM-5, but remain commonly used nomenclature. Both the DSM-IV-TR and the DSM-5 have identified some of the common symptoms of ASD as impaired social interaction, impaired communication, and restricted or repetitive patterns of behavior, interests, and activities. For many children with ASD the condition often manifests itself through preoccupation with particular

interests, repetitive motor mannerisms, intense resistance to change, repetition of words, phrases or sounds, or behavioral challenges (APA, 2013; APA 2000).

Though other disorders with autistic features were written about previously, Leo Kanner (1943) first described the disorder that would come to be known as autism. Statistics concerning prevalence indicate that ASD has been exponentially affecting more and more children every year since that time. For the year 2006, the Centers for Disease Control and Prevention (CDC) estimated that the number of children diagnosed with ASD in the United States was approximately 1 out of every 110, an increase of 57% from 2002 (Rice, 2009). In 2007, a nationally representative study of children in the U.S. measured the prevalence of ASD based on reports by parents of children currently diagnosed with ASD. Results indicated that 1 in 90 children had a diagnosis of ASD, representing an estimated 673,000 US children between three and 17 years of age who had received an ASD diagnosis (Kogan et al., 2009). Data collected just two years later in 2008, indicated an overall ASD prevalence of 1 out of every 88 children (Centers for Disease Control and Prevention, 2012). Then in 2016, the CDC published a report based on 2012 data, which indicated a prevalence rate of 1 in 68 children with a diagnosis of ASD (Christensen et al., 2016). It is important to note there are some places where the prevalence rate has been reported to be even higher. For example, in the CDC evaluation of 2008 data, the prevalence rate in Utah was assessed to be 1 in 47 children with an ASD diagnosis. Additionally, the data collected from Utah indicated a much more rapid increase in the years since 2002 than in any of the other states monitored in the same study (Centers for Disease Control and Prevention, 2012).

There has been much debate as to whether the increase is the result of actual increase, improved diagnostics, increased awareness, or some other variable. The number of children between the ages of six and 21 who received services for an ASD in public school special education programs increased from 54,064 in 1998, to 258,305 in 2007. However, some children with ASD have received services designated under a different category specific to a particular symptom they experience, therefore, these numbers are not a complete representation of the total number of ASD cases in the public schools (Centers for Disease Control and Prevention, 2009).

All of these findings have indicated the size and seriousness of the crisis surrounding ASD. This trend has been emphasized by the fact that ASD has become the most commonly diagnosed developmental disorder and continues to increase at a rate between 10 and 17 percent each year (“Learning About Autism,” 2012). In the United States alone, 1.5 million people have been estimated to have ASD. This figure did not include other ASD disorders such as Asperger’s Syndrome and PDD-NOS. The financial burden of ASD has been estimated at over \$137 billion in the U.S. alone. It has also been projected that more children will be diagnosed with ASD over the course of the next year than will be diagnosed with cancer, AIDS, and diabetes combined (Talk About Curing Autism, 2012).

### **Traditional Treatments**

Research on ASD treatment modalities has typically focused on the treatment of ASD symptoms, and on the efficacy of various therapy components such as symptomatic pharmacological interventions, behavioral treatments, and social skills training. Langworthy-Lam, Aman, & Van Bourgondien (2002) found that almost half of

individuals with ASD were prescribed psychotropic medications. To this point, pharmacological interventions for ASD typically focused on specific symptom treatment rather than on treatment of the disorder as a whole since the underlying causal factors are not yet known and the symptoms occurred from a variety of categories (Herbert, Sharp, & Gaudiano, 2002). Medications have been prescribed for individual symptom categories such as social impairment, repetitive behaviors, hyperactivity, inattention, and irritability to name a few (Blankenship, Erickson, & McDougle, 2010). Behavioral intervention as a treatment for behavioral symptoms of ASD has been shown to be very effective in many of the individuals who participated. Like many interventions, improvement increased when intervention was initiated early (Osborne, McHugh, Saunders, & Reed, 2008). Improvement naturally varied by individual and severity of symptoms, however, in one representative study all 29 participants who received behavioral intervention showed at least some improvement, while some experienced significant improvement (Goin-Kochel, Myers, Hendricks, Carr, & Wiley, 2007).

As mentioned previously, two areas where individuals with ASD are often limited are in social initiation and social response. Social skill intervention has been shown to be an effective method for increasing the social initiation and response in children with ASD. The efficacy of social skill intervention was reported by Licciardello, Harchik, & Luiselli (2008) who found an increase in both social initiation and social response for the children in their study who received social skill intervention. The model of intervention used in their study included pre-teaching, prompting, praise, and rewards. Each of these elements were used in the attempt to increase the frequency of the subject's efforts to engage others in social interaction and to respond appropriately when engaged socially by

others. While data was not recorded on the individual efficacy of each element, the overall use of all four intervention steps proved successful in increasing the children's engagement and reciprocation.

### **Burden on Caregivers**

Like any other significant health problem in a child, the effects of ASD have been shown to have a significant impact on families, caregivers, and in particular, the parents of a child with ASD. Managing the physical health needs for a child with ASD while dealing with their behavior issues and relationship difficulties can be an overwhelming scenario for parents. It can be very difficult for parents to watch, often feeling helpless, while their child, who seemed to be developing normally, begins to withdraw from them socially and relationally. Mothers of children with ASD have reported higher levels of stress, decreased social support, and more negative views of their child than mothers of children with other developmental disorders (Abbeduto et al., 2004). Parents of children with ASD have been reported to be particularly vulnerable to irrational beliefs and negative thoughts that have the potential for fewer positive emotions about their children with ASD (Tiba, Johnson, & Vadineanu, 2012).

The burden of treatment has also had a significant impact on families in terms of time, physical energy, and financial cost. Common interventions have included applied behavioral analysis (ABA), speech therapy, psychopharmacological intervention, auditory integration training, sensory integration, occupational and physical therapy, nutritional interventions, alternative therapies, social skills training, and specialized school services (Francis, 2005; Robson, 2013). Early intervention through therapies and treatments has been shown to result in outcomes that are more beneficial for children

diagnosed with ASD (Cohen, 2011). Therefore, many families have engaged in multiple therapeutic interventions at the same time in an attempt to help the child as much as possible in their early years.

As any other treatment provided by a doctor or therapist, the responsibility has typically belonged to the parents for not only getting their child to therapy, but also for practicing and applying the principles learned in therapy with their children. Since consistency has been shown to be a key to progress, parents are not able to practice with their child for a little while and then take a break. Rather, these principles must be applied consistently, all day, every day. Osborne, McHugh, Saunders, & Reed, (2008) described the relationship between increased therapeutic gains and greater input of time on therapeutic tasks. Deviating from the prescribed interventions for even short periods has often resulted in regression. This has added significant burden and obligation to the parents of children with ASD. Like the previously mentioned behavioral therapies, social skills trainings must also be carried out consistently and uniformly, again adding increased responsibility and burden to the already overloaded task list of the child's parents.

**Domains of burden.** In this review of literature and in the experience of this researcher, five general domains of burden or impact on families of children with ASD that stand out include marital relationship stress, health challenges, barriers to social involvement and support, financial strain, and scheduling difficulties. While these are not the only areas in which families raising a child with ASD have been impacted, these represent some of the more common and significant categories.

*Marriage domain.* Although any relationship can be impacted, the marital relationship of parents has been cited as one of the relationships most significantly impacted by raising a child with ASD (Ramisch, Timm, Hock, & Topor, 2013). Stress on the marriage relationship resulting from difficulties associated with the needs and behaviors of a child with ASD have been indicated as a factor often dealt with by these parents (Dutra, 1999). For reasons already cited, families of children with ASD are subjected to a greater variety of stressors over and above the typical challenges associated with parenting. Couples raising a child with ASD found it to be more difficult to spend quality time with each other, which created more marriage and relationship stress. Because of their parenting responsibilities, they reported getting less sleep, less time for self-care, and more time spent engaged in care for their child (Koshti-Richman, 2009; Smith et al., 2010). Due to the special needs or behavioral concerns of their child, these parents were often not able to simply call a babysitter and go out on a date or spend time investing in their relationship. Additionally, more of their time was spent taking care of day-to-day duties, dealing with special challenges, and responding to crises than parents of children who do not have ASD.

Another challenge that affected some marriages is the realization that their child with ASD may never be able to move out of their home and the knowledge that their treatment and caretaker burdens may be lifelong. Where these stressors have combined, the situation has created an environment that fosters dissatisfaction in the marriage. Unfortunately, for some couples, as well as for their children, marriages that have children affected by ASD have been shown to have a higher divorce rate than that of the general population. Some research has indicated the rate of divorce among couples who

have a child with ASD may be almost twice as high as marriages without a child with ASD (Hartley et al., 2010).

***Health domain.*** The physical demands of raising a child with ASD have been reported as very high. These physical demands have created even more stress for parents, or caused the effects of stress to be more acutely experienced. One study indicated that 41% of parents raising a child with a disability felt that their health had declined in the previous year due to the demands of caring for their disabled child. Almost all of the participants reported sleep deprivation as a significant factor in their health challenges. More than three quarters of the participants indicated that they had struggled with anxiety, depression, or guilt (Murphy, Christian, Caplin, & Young, 2007). In other research, Johnson, Frenn, Feetham, & Simpson (2011) found that while men and women were impacted differently, the stress of caring for a child with ASD was correlated with a negative impact on both parents mental health, and more acutely for the mother's physical health than for the father's. Many children with ASD experience sleep disturbances that keep them awake at bedtime, cause them to wake very early, or to have intermittent sleep patterns. Obviously, if their child is awake, parents typically are too. Sleep deprivation has been indicated as an issue for the parents that relates directly to their ability to function and to the quality of care they are able to provide for their child (Koshti-Richman, 2009). Many children with ASD have often needed more help with hygiene and take longer to toilet train. Again, this responsibility has primarily belonged to the parents to help teach these independent skills, no matter how long it has taken. The physical stress of parenting has also included protecting the child from outside dangers or self-injurious behaviors, or protecting themselves or other family members from the child



if the child has exhibited aggressive behavior. These factors, when combined, were found to cause fatigue and distraction, and place limitations on parental well-being because the environment was more physically and emotionally challenging than for parents of children without ASD (Smith et al., 2010)

Caregiver health has been identified as a significant factor in the care of children with ASD. Lach et al., (2009) also found that caregivers of children with neurodevelopmental disorders and behavior challenges, such as those often seen in ASD, reported greater frequency of both physical health problems and psychosocial challenges. This may be due, in part, to the lack of time off afforded to parents since they become the full-time caregivers. A significant lack of availability or access to respite care has created a demand that takes a significant toll on parents. According to Whiting (2014), respite care to provide caregivers with breaks for rest, social interaction, and time away from their duties was one of the single greatest areas of unmet need for parents of children with disabilities.

***Social domain.*** In a personal account, Grosso (2014) described significant social isolation that can take place for parents after their child is diagnosed with autism. During a study of parental support group efficacy, Hames & Rollings (2009) reported that parents of children with disabilities often join support groups expressing loneliness and feelings of being misunderstood. Koshti-Richman (2009) identified friendship as a significant factor in parental ability to manage the other stressors in their lives including the difficulties associated with raising a child with special needs. Even though they may live on the same street, work together, play together, or worship together, families of children with a disability often live and operate in a culture that is very different from that

of those around them. Even though the normalization of autism in current society is underway and social and political powers are working to decrease the isolation from services and benefits, for families of ASD, the social isolation has been found to be an ongoing issue (Estrella, 2013). The result has been described as a situation in which children with disabilities and their family members often feel cut off from activities and opportunities that are available to other children and their families or from their pre-autism life (Grosso, 2014). While some of the reasons may have been valid, such as safety concerns for the children, the outcome has been that children with ASD and their family members have often missed out on leisure and recreation activities. This can happen as a result of the child's difficulties with interpersonal interaction, social relationships, or because of their need for predictability, consistency, and familiarity (Brewster & Coleyshaw, 2011).

People have often misunderstood why a child with ASD has not engaged socially or perhaps has been overly engaging, or why the child flapped their arms, touched their own genitals in public, drooled excessively, or yelled and hit. As a result, these outsiders may have passed judgment on the child and their parents without an understanding of the factors involved. For many parents of children with ASD, the stigma of being identified as bad parents has been stressful and isolating. Gray (2002) looked at two forms of stigma for parents of children with an ASD. The first, actual stigma or enacted stigma, occurred when the individuals with ASD and their families were stigmatized through the reactions of others because of behavior or some other outwardly manifested characteristic of their child with ASD. The second type, perceived stigma or felt stigma, took place when the stigmatizing event happened and the child or family member perceived

stigmatization coming from others, even though there was no observable reaction on the part of the other individuals to confirm that stigmatizing was taking place. Regardless of the type, each felt very real and created a stressful and isolating event in the experience of the parent and their child.

For some children with ASD, sensitivity to external stimuli such as motion, noise, lights, and texture, or even the fear of leaving a familiar place such as home or school has created anxiety or challenging behaviors that imposed limitations on the family's ability to travel, or to participate in social activities and events. Other common limitations on family members' social interaction have included the child's behavior, bath-rooming needs, or access to preferred activities (Hall & Graff, 2010). In these cases, some activities that may have been taken for granted by many families have simply not been an option for families of children with ASD. When they are able to participate in social events, parents of children with ASD may need to take turns, meaning that one parent misses out altogether. When this has occurred, dating and attending special events together or even something as simple as a movie or a meal out may have become so difficult that the parents simply chose not to participate and forgo these privileges commonly engaged in by other parents. Any of these situations can have a role in what Bromley, Hare, Davison & Emerson (2004) found when more than half of their sample reported significant psychological distress associated with decreased levels of support due to raising a child with highly challenging behavior.

***Financial domain.*** Another struggle faced by many parents is the financial cost associated with raising a child with ASD. Having enough financial resources to meet their child's needs was found to be one of the top rated concerns of parent's raising a

child with a disability (Koshti-Richman, 2009). For many parents, payment for doctors, therapists, behavior specialists, and tutors added up quickly. Special education tools, communication aids, special hygiene products related to delayed development and age-appropriate bathroom behaviors, medications, dietary supplements to treat intestinal and digestion difficulties often associated with ASD, and a variety of other products, services, and needs all contributed to an immense financial cost. Jarbrink, Fombonne, & Knapp, (2003) found significant costs in the areas of informal care, out-of-pocket expenses, service usage, and income losses as a result of care associated with a child's symptoms of ASD.

The lifetime cost of raising a child can vary greatly depending on factors such as cost of living, geographic location, price and availability of health insurance, and actual healthcare charges. A study published by the U.S. Department of Agriculture estimated the lifetime cost of raising a non-ASD child born in 2011, in a two-child family, with both parents, at between \$212,370 and \$490,830 (Lino, 2012). Estimates of the costs of raising an individual child with ASD have varied widely, but some estimates placed the cost at more than \$3 million (Ganz, 2006). Part of the reason for the vast disparity in cost has to do with the fact that while the cost of raising children without ASD often ends at age 18, or thereabout, the cost of raising a child with ASD often continues since many of these children are not able to leave home. As a result, the children remain in their parents care, in some cases, as long as their parents are alive.

***Schedule domain.*** The scheduling domain is a prime example of the interconnectedness of the five domains identified in this literature review. Prior research has indicated that many parents report a significant lack of availability and a shortage of

time due to the amount of time spent addressing the needs of their child. This lack of time can be related to situations such as a shortage of respite care options or the quantity of appointments needed to address the treatment needs of their child. Difficulty in the scheduling domain also indirectly affects the health domain as some parents neglect their own care to address the seemingly more significant needs of their child (Murphy, Christian, Caplin, & Young, 2007). For some families, the challenge of adhering to a busy schedule has been very difficult at times. However, when that busy schedule has been driven by the need for continual medical, behavioral, and emotional health treatment, the stress levels have been magnified. For many, the hectic pace became a significant limiter in the development of social relationships, self-care, and seeking outside assistance. Other parents report significant impact on their mental and psychological well-being due to the significant amount of time spent in caregiving activities for their child with ASD (Sawyer et al., 2010). In many cases, the treatment needs of the child created physical, social, and even financial limitations for the whole family that may have resulted in feelings of isolation and loneliness. For some parents, this kind of social isolation has been linked to an increase in depressed mood and a decrease in overall sense of well-being (Benson, 2012).

For many families, as ASD became apparent in their child, what appeared to be normal development often seemed to derail and take a dramatically different course than that of typically developing children. Many children with ASD began to withdraw socially and decrease interpersonal communication (APA, 2013). This deterioration, combined with the knowledge that early, intensive intervention produces more favorable results, places significant pressure on parents to get their children involved in multiple

therapies and treatments at the same time to try to regain what has been lost, or at least slow the deterioration (Osborne, McHugh, Saunders, & Reed, 2008). An increase in treatment appointments also increases the demand on parents' time, as they are typically the ones who transport the child for treatments and therapies. Because the quantity or frequency of treatment appointments are likely to increase with heightened severity of symptoms, it seems logical that Lyons, Leon, Roecker Phelps, & Dunleavy (2010) found that severity of symptoms has been found to be one of the strongest predictors of parental stress for parents of children with ASD.

Depending on the severity of their symptoms, parent-child relationships often seemed to dissolve just as they were beginning to develop meaningful and reciprocal interactions. The desire to regain skills and abilities the child once had, but seems to have lost, has also been a significant stressor. These parents often felt that time was running out for their child and that the medical community was not acting quickly enough on behalf of their child (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). For many parents, this placed further burden to do as much for their child as possible in the shortest amount of time.

### **Summary**

This chapter contained a review of relevant literature concerning the epidemiology and prevalence of ASD. It provided a basic discussion of common treatment and intervention modalities, and covered research that established some of the impact of ASD on individuals and families. Additionally, the burden that raising a child with ASD creates for their families was discussed along with specific domains of impact. In chapter three, the research design and methodology will be described which was used

in this research to identify behaviors that help parents in their efforts to effectively raise a child with an ASD.

### **Chapter 3: Research Design and Methodology**

This study was designed to explore the behaviors of parents who have children with ASD in an effort to identify common behaviors that have helped them be more effective in their parenting. The purpose was to identify effective behaviors and attempt to measure the rate of prevalence among the participants. This chapter covers the methodology for the study, including the philosophical worldview, as well as information about the population and sample, the research design, data collection and analysis, and steps that were taken to protect the human subjects from any anticipated harm.

#### **Philosophical Worldview**

This study was conducted through the philosophical worldview of pragmatism and utilized a naturalistic-qualitative strategy. This naturalistic perspective used direct inquiry during individual interviews and through focus group interactions to collect qualitative data and relied on participant responses to guide areas of further inquiry. The data was then analyzed for continuity and similarity across participants.

Patton (2002) described the quantitative-experimental research design and the qualitative-naturalistic research design as historically being viewed as two separate and competing research paradigms. Each of these paradigms has held prominent positions in the overall debate regarding which is the best and most appropriate research methodology. Patton, however, argued for an alternate approach that avoids a strict adherence to either of these designs. He made a case for a pragmatic design in which methods are matched with questions and, if appropriate, methods are even mixed for a more practical approach. He went on to say that pragmatism in research is identified by discerning the quality of a study by the intended purpose, available resources, procedures,



and results, when viewed from the perspective of the context and audience. Patton described one advantage of pragmatism as being the way that it allows the researcher to avoid methodological orthodoxy by favoring methodological appropriateness.

An essential feature of the pragmatic worldview is the latitude it provides for method development all the way through data collection and analysis. As a term, research design indicates a structured plan for carrying out the investigation and analysis process. However, a naturalistic design refers more to planning for a wider range of possible scenarios without restricting the possible range of responses to each (Lincoln and Guba, 1985). According to Patton (2002), a qualitative study should be flexible and open so that the researcher is free to explore whatever dynamic becomes apparent through the course of the research. He further described the qualitative research design as being emergent, and therefore, allowing for refinement even after the data collection process begins.

In further discussion of the pragmatic approach, Patton (2002) indicated that the concrete, practical questions asked by those who are working to make the world a better place, can be asked without categorizing the study into one of the common theoretical frameworks. He further endorsed the theory that pragmatic and utilitarian frameworks can be used for the purpose of informing qualitative inquiry without being connected to or resulting from a theoretical tradition. The practical side of qualitative methods has been described as asking open-ended questions of people and observing pertinent details in a real-world setting for the purpose of solving problems. With this type of paradigm, the researcher is free to test pre-determined theories, but is also open to information that becomes evident through open-ended phenomenological observation. As patterns then

become more evident from the data, through discovery, or from inductive processes, the researcher is free to verify and unpack patterns that begin to emerge through a more deductive analysis.

Levin-Rozalis (2000), who has been described as a follower of the pragmatic school of thought, contrasted the discovery and generation of theories during the research process with the formation of hypotheses prior to constructing the study, and labeled the former as abduction. This process of abduction was previously explained by Denzin (1978) as a combining of inductive and deductive thinking that is guided by logic. This process has been used to organize subjects in such a way as to promote better understanding of the underlying problems experienced by the social group being studied. The purpose has been described as an effort to find both the questions and the answers that will make the social group more easily understood. This requires that the researcher does not attempt to force a preconceived set of assumptions onto the situation. This type of research is often motivated by a desire to understand or illuminate features of the social group that may be taken for granted by others or seem to be routine. As a means of accomplishing this task, the researcher typically begins with the consequence and traces it back to the antecedent by looking back over time and then reconstructing the events that took place in an effort to understand where the process in question began.

### **Population and Sample**

The geographic context for this study was the Puget Sound region of Washington State, which included the Seattle metropolitan area and surrounding suburbs. With the exception of the focus groups and two interviews, the data collection for this study took place in the homes of the participants. This environment was intended to provide a safe

and comfortable environment for participants to share openly about their experiences and observations.

Participants were volunteers recruited by Dr. Steve Becker, a local autism treatment provider. The demographic criteria for those who were selected to take part in this study designated they would be parents who were raising a child with ASD of at least 15 years of age. This age qualifier was intended to help assure that the parents had been through a sufficient amount of the parenting process to experience many of the typical challenges of parenting a child with ASD. Dr. Becker identified potential participants from his patient records who met the qualifying criteria and contacted them to inquire about their willingness to participate in the research study.

Participants were parents who described themselves as able to identify behaviors that had helped them mitigate the impact that the stress associated with caring for their child with ASD had on their lives and resources. Similarly, if the participants were married, they also indicated that they could identify behaviors that were of benefit to their marriage in overcoming the stressors related to raising a child with ASD. Additionally, participants were identified by Dr. Becker as being parents of children who had made progress in the areas in which they were impacted by their ASD symptoms. Prior to contacting potential participants, Dr. Becker utilized the *Severity Levels for Autism Spectrum Disorder*, outlined in the DSM-5 as a rubric to assist in identifying potential participants who could be described as effective in their parenting skills. This meant that to be identified as having effective parenting behaviors, parents needed to self-identify as being able to describe behaviors that they felt helped them to be more effective as a parent of a child with ASD. Additionally, as the referring treatment provider, Dr. Becker

also endorsed the presence of effective behaviors, and indicated that the child had progressed by at least one level in either the social communication or the restricted, repetitive behaviors category, or both if applicable. For example, this meant that the child had improved in social communication functioning from level two, “requiring substantial support”, to level one, “requiring support”. Additionally, the participants were able to report that progress had been made by their child in the basic areas in which ASD had impacted their development and behavior.

All of the 20 participants needed to have at least one child diagnosed with ASD to be eligible. The participants were also required to be living together in the same home with their child affected by ASD. The families all needed to indicate that their family typically functioned with at least one parent as the primary caregiver to the child, rather than having a hired primary caregiver.

### **Research Design and Methodology**

The purpose of this study was to identify behaviors that were effective for parents in their efforts to raise a child with ASD. It was the hope of this researcher that the information would prove useful to other parents who are currently, or will at some future time, be raising children with ASD. This study was conducted using a qualitative design and was carried out through participant interviews and focus group discussions. The study used an ethnographic model in which participant interviews were approached as informal conversations that created a form of guided reflection. Stringer (2007) described the interview process as one in which the participant is invited to explore his or her experiences in a way that brings details to light and reveals some of the features of their experience that may prove relevant to the research topic. In this manner, the

interviewer attempted to grasp the participant's point of view and understand his or her experience in the way he or she perceives it. This meant that the interviewer did not engage in debate with the participants or attempt to alter the understanding of any of the experiences the participants related.

Stringer (2007) characterized the focus group as a type of group interview in which a similar opportunity is afforded to the participants to relate their own experiences in the way they perceived them. Like the individual interviews, the focus group was not an atmosphere where the interviewer engaged in any debate with the participants, but rather guided them through a reflective process in which they shared their memories of events and circumstances related to the research topic. While this format required a bit more structure to ensure that all participants were able to express their views, this format also had the added advantage of participants being able to interact in a way which provided an opportunity for participants to be reminded of otherwise forgotten details of their own experiences.

This combination of methods allowed for the necessary latitude in data collection to guide the participants in the discussion of the topic without being overly directive. This method also provided opportunity for the participants to redirect the conversations into areas that may not have been anticipated areas of relevance.

### **Data Collection Process and Procedures**

In part, the focus of this study was directed according to the five domains of impact described in chapter two as relationship, health, social, financial, and schedule. These domains were of particular interest during the data collection phase of this study. In addition, emerging domains of impact were screened for in the responses given by the

participants. For this study, the data collection procedures included two separate steps described as semi-structured interviews and focus group discussions. These methods were used for the diversity of perspective and for relevance to the topic.

**Semi-Structured Interviews.** The parent interviews were conducted for the purpose of gaining the insight and perspective of the participants in this study. Each participant was interviewed using open-ended questions in a non-directive interview method. This type of questioning allowed the participants to answer from any domain they felt was relevant to the topic. In order to minimize biasing the participants with the perspectives of the researcher, the concepts of domains were not introduced to the participants until the latter part of the interview. Other domains were carefully screened for as the families shared their experiences and perspectives.

Participants were asked general questions about how ASD had affected their children and in what areas they had observed their own behaviors that had been effective in helping to mitigate the stress associated with raising a child with ASD. Participants were also asked to identify what behaviors, actions, or responses they felt contributed most to the effectiveness they had experienced in raising a child with ASD. After the answers to the general questions were recorded, participants were then asked questions about effective behaviors across the five specific domains identified as commonly affecting the lives of individuals caring for a family member with ASD.

In order to facilitate collection of the most useful information without biasing the participants toward a particular perspective or the expectations of the researcher, the interview process began with very general questions about the life of a family dealing with ASD. The opening interview question was, "Tell me about what it's like to be the

parent of a child with ASD.” The lack of specific parameters in this first question allowed the participants to answer according to their own experience and across any domain they perceived to be important or relevant. Gradually, questions progressed toward more specific inquiry of details about the impact and behaviors related to specific relationships and life domains.

This interview portion was semi-structured in such a way that it followed the interview discussion guide (see appendix A), but was also open to other topics of relevance proposed by the participants. This interview method produced a narrative style of data that was recorded to be later transcribed and coded for common themes in the general responses and along the five domains previously identified as relevant to the study. During the interviews, dialog points were screened for, to be used in further discussion and analysis during the focus group sessions.

**Focus Group Discussions.** The second area of data collection occurred during the focus group discussions in which the participants who contributed during the interview portion gathered to discuss their parenting experiences in a group format. This discussion was structured according to the focus group discussion guide (see Appendix B). This environment provided an opportunity for participants to discuss similarities in their experiences with the purpose of further identifying areas of common experience and behavior. Additionally, this discussion allowed the opportunity for participants to recall forgotten events as they heard the experiences of the other participants. The focus groups also provided an opportunity for follow-up to confirm or disconfirm areas of suspected relevance identified during the interview phase. Like the participant interview sessions, the focus group sessions were also recorded to be transcribed and coded at a later time.

**Domains of Impact.** The impact of having a family member with ASD has been shown to be far reaching and potentially challenging in many different areas for parents. Prepared interview questions and focus group discussion topics were, in part, concerned specifically with the five domains that have been previously observed by the researcher and described in the literature review as being some of the most common in terms of potential for negative impact on the family. However, other domains of impact were screened for in the comments of the participants. These five domains, marriage, health, social, financial, and schedule, were addressed in the interviews and focus groups as primary areas of burden on the parents. This allowed the participants to have an opportunity to share their effective behaviors specifically related to each of these domains.

**Marriage domain.** Parents of children with ASD have been reported to experience lower levels of marital satisfaction and happiness, lowered family adaptability, and decreased family cohesion (Higgins, Bailey & Pearce, 2005). Due to the amount of time spent in care for the ASD affected child, which often leaves little time available for a spouse or for other family members, the first area of impact discussed was the marriage domain. If the participant was married during the time they were raising their child with ASD, this question focused on the behaviors involved in preserving and maintaining the marital relationship.

**Health Domain.** Murphy et al., (2007) indicated in their research that most parents of children with ASD reported experiencing sleep deprivation, anxiety, and more than forty percent reported a decline in overall health due to the demands of caring for their child. The effect of ASD care on the parents' health was discussed to determine the



commonality of impact on parents and their effective responses to the high demands of raising their child with special needs. This included topics such as sleep disturbance, interruption of normal routines, and the lack of time for self-care.

***Social Domain.*** Parents of children with ASD often report feelings of loneliness, social isolation, and of being misunderstood (Estrella, 2013; Hames & Rollings, 2009). The social domain was also evaluated for behaviors used to increase or maintain participants' level of interaction and involvement. Amount of social involvement and support from their social support network was discussed in addressing the social domain and identifying any behaviors used to counter feelings of social isolation.

***Financial Domain.*** Koshti-Richman (2009) indicated that having enough financial resources to adequately provide for the needs of their child was a top rated concern for parents of children with ASD. Family finances were discussed due to the intense demands placed on the family's monetary resources in efforts to care for health and other needs of their ASD affected child. Because so many external factors can influence a family's finances, effectiveness in the financial domain was not determined through a measure of resources or income, but rather through the families responses to the needs and by behaviors used to help cope with their level of income and expenses.

***Scheduling Domain.*** Parents of children with ASD have also reported challenges with scheduling because of the quantity and frequency of appointments that their children have often been expected to attend. Parents of children with ASD often spend 10 or more hours every week providing or coordinating treatments and care (Kogan et al., 2008). These appointments were not limited to, but have often included medical treatments,

mental health counseling, occupational or physical therapy, sensory integration therapy, behavioral interventions, and social skills groups, just to name a few.

### **Data Analysis Process and Procedures**

After the semi-structured interviews and focus group discussions took place, the recorded information was transcribed into a written narrative. The next step in the analysis was a review of the transcribed data to determine the quality of the gathered data and to identify potential limitations of the information that could have negatively impacted the results (Taylor-Powell & Renner, 2003). Particular flaws that were screened for to help assure the quality of the gathered data included any answers provided by the participants that appeared to indicate that they did not understand the question being asked, or answers that did not address the intent of the questions being asked. After this was completed, the explanation of the data limitations was compiled so that it could be included in the final results.

Taylor-Powell & Renner (2003) described the next step in the process as one of focusing the analysis. For the purposes of this study, this step involved focusing the analysis by topic. In this stage, all of the responses were separated according to the domain associated with the question or topic, rather than by participant. Focusing the analysis on the domain and the corresponding question or topic allowed for comparison between participants to identify areas of similarity and difference across each domain and each question. This also allowed for categorization of the experiences of the participants and facilitated identifying common behaviors shared by the participants.

The next step, coding, involved the categorization of the collected data. According to Taylor-Powell & Renner (2003), this stage is the core of qualitative

analysis. This was the stage where meaning was derived from the statements that were collected from the participants. During this process, statements made by the participants were coded according to anticipated categories and any others that emerged during the analysis process. In the coding process, category names were used to label the category of each participant response or identified behavior. Where appropriate, a dual label was used to connect the response or described behavior with a first category and a second category. An example of the coding spreadsheet can be seen in Table 1.

Table 1

<i>Coding Spreadsheet Example</i>				
Participant #	Question #	Response	Category A	Category B
06	01	You have to learn to be flexible	adaptability	N/A
01	05	Asperger's group (for child)	treatment	outside support
10	07	Seeing a therapist (for parent)	self-care	outside support

Some categories that were anticipated to be relevant included supportive/encouraging behaviors, teaching activities, self-care behaviors, use of coping skills, relationship-building activities, and asking for help from non-family members. This list was by no means exhaustive. Other categories were predicted to emerge including sub-categories of these behaviors that were expected to be added to the list during the coding process. A second coder was used to help provide perspective and prevent bias that could cause some relevant data to be overlooked. This second coder was a clinician experienced in qualitative research who held a doctorate degree in Counseling Psychology. The primary responsibility of the second coder was to categorize the data in the same manner as the primary researcher and began with the printed responses given by the participants. Like the first coder, the second coder also evaluated the responses according to the behavioral categories. The two sets of coded information, one from each coder, were then compared for similarity. Any areas of

discrepancy were discussed between the coders to arrive at consensus on all of the responses provided by the participants. The result of the categorized analysis was then compared for similarity of answers between participants within each domain, and then tallied to identify the behaviors most commonly engaged in by participants to help them cope with the stressors unique to each domain.

Finally, this study was designed using strategies of data triangulation in an effort to increase the validity of this research. While numerous authors have written about and provided definitions of triangulation, some discrepancy exists in the terminology, descriptions, uses, and even how many types of triangulation exist. Most refer back to the foundational works of Denzin or Patton on the topic of triangulation methods. However, in doing so, some have diverged to varying degrees from the format described in these earlier texts, while others have expanded on Denzin's and Patton's concepts.

This research was intended to use a form of methodological triangulation described as between-method triangulation. Guion (2002) describes methodological triangulation as a process that involves using multiple qualitative and/or quantitative methods to study a particular topic. Bryman (n.d.) discussed the distinction that Denzin identified within methodological triangulation as being the difference in a within-method and a between-method format. While the within-method format utilizes variations in a single data collection method, the between-method format uses contrasting methods such as direct observation and a questionnaire to collect data for triangulation.

For the purpose of this study, triangulation occurred across data collected between the individual interviews and the focus group discussions. Results that were identified as being present across both methods of data collection were sorted by participant so that

duplicate answers, those given by the same participant in both the interviews and the focus groups, were only counted once, rather than as two separate responses, to avoid artificially inflating the total count for the response category.

### **Protection of Human Subjects**

Participants in this study were volunteers who were recruited through an ASD treatment provider. All participants were informed of the purpose of the study prior to their involvement and were provided with a Disclosure and Consent for Participation form (see Appendix C). Participation consisted of answering questions about parenting behaviors related to raising their child with ASD. The questions were asked during both the interview and focus group discussions. For the purpose of confidentiality, in the recordings and narrative data collected, the participants were identified only by number and no personally identifiable information was requested during the interviews or focus groups. Contact information necessary for the researcher to communicate with the participants was stored in a separate and secure location.

The anticipated risks for participation in this study were minimal. There was no experimentation involved in this study and no exposure to substances or materials that would compromise physical or psychological safety. The participants' involvement in this study was solely comprised of responding to questions asked during the interviews and focus groups. There were no anticipated risks to physical safety that were over and above those associated with most people's day-to-day lives. The only risks that were anticipated as possibilities were those related to a stress or anxiety related response due to the recalling and describing of previously stressful events, or mild interpersonal conflict if the participants memory of a past event differed from their spouses memory of the

event. Participants were provided with a resource list containing contact information for therapists who were familiar with the treatment of mental health issues including the specific demands of families with a child who has ASD. Participants were encouraged to seek professional help if they felt they experienced any distress. Finally, compromise of the participants' anonymity was considered to be at minimal risk since the participants were identified only by a number in the collected data, and participant contact information was kept separate from the data in a secured location. No documents were produced which reflected participant responses and personally identifiable information together. Participant contact information and signed consent forms were stored in the secured data storage cabinet in a locked office on the Northwest University campus where only the primary researcher and approved university staff had access to the information. Names mentioned by the participants in the recordings were changed during transcription to protect the confidentiality of the participants, their children, and any persons who were mentioned in the participant narratives. Compensation to the participants consisted of a research summary that provided the results, findings, conclusions, and limitations of the study.

### **Summary**

This third chapter has provided a description of the research design and methodology of the study. A detailed description of the philosophical worldview that guided the methodology was provided to give the reader an understanding of the perspective of the researcher. This chapter also provided a description of the population and sample from whom data was collected for this study. Information was also included regarding the data collection and data analysis process, and a description of the steps that

were taken to protect the human subjects from any anticipated risk or harm as a result of participating in this study.

## **Chapter 4: Findings and Results**

This chapter contains illustrations of the experiences and behaviors described by the participants in this study. The purpose of collecting this data was to identify those behaviors that parents found helpful for increasing their effectiveness in raising a child with ASD. Specifically, data was collected along five domains of common experience identified in previous literature. Domains included marital relationship stress, health challenges, barriers to social involvement and support, financial strain, and scheduling difficulties. Additionally, responses were collected regarding the general experiences of parents related to the impact that raising a child with ASD had on their lives, and the ways in which they intervened on their children's behalf to help their child make progress in the areas where they were impacted by ASD.

This chapter also contains examples of the responses from the interviews and discussion groups, which were held between April and July of 2016, and the findings indicated by the data. A description of the data and specific examples were used to clarify the findings and illustrate the experiences of the participants, and more specifically, the behaviors they identified as having helped them effectively parent their child with ASD.

### **Demographics**

Participants for this study were recruited by Dr. Steve Becker, Ph.D., an autism treatment provider in the Seattle area who worked primarily with families and individuals impacted by autism or other disabilities. Dr. Becker's experience prior to earning his doctoral degree in Abnormal Psychology and Special Education, included 12 years of work as a special education teacher and a developmental disabilities consultant. During



the recruitment process, Dr. Becker utilized the *Severity Levels for Autism Spectrum Disorder*, outlined in the DSM-5 (2013), as a rubric to assist in identifying potential participants who could be described as possessing effective parenting skills. For example, the children of the participants needed to have progressed from level three to level two, or from level two to level one, in the areas of either social communication or restrictive/repetitive behaviors. This progress was interpreted as one indicator that the parents had experienced areas of effectiveness in some of their parenting related behaviors.

The twenty participants in this study were comprised of seven married couples and six single parents who were raising 13 children between the ages of 15 and 49 with an ASD diagnosis. Mean age of the participants' children was 25.1 years. Twelve of the children of the participants were male and one was female, a statistic that was not very surprising since ASD is more than four times more prevalent for males than for females (Christensen et al., 2016). Two participants were African-American, while the other 18 were Caucasian. All of the participants lived in the Puget Sound region of Washington State, and resided within a 60-mile radius of one another. Most were still actively employed, even though some had already passed traditional retirement age.

To protect confidentiality, each participant was assigned a two-digit number. This number was used to identify the recordings of the interviews and focus group discussions. The same number was also used in the transcribed narratives of the interviews and focus groups, and the individual responses that were compiled for coding. Any potentially identifying information that the participants disclosed on the recordings was removed during the transcription process. For example, if the participant mentioned

one of their children by name, the transcribed narrative of the recording contained only “child” or “sibling” in place of the child’s name. Other names were omitted to protect confidentiality. Signed consent forms and participant contact information was kept separate from the data and secured in a locked data storage cabinet.

As expected, the parents’ descriptions of the children revealed some similarity of symptoms and presentation, but also a considerable variation in the individual presentation and ways in which they were each uniquely impacted by the ASD. Many were described as having areas of unusual ability, such as graduating from high school with honors, while also having areas of profound disability, such as significant impairment in social skills or poor comprehension and utilization of independent living skills. While all of the participants in this study would commonly be described as having High-Functioning Autism (HFA), or Asperger’s Syndrome (though Asperger’s is no longer officially recognized as a diagnosis under the DSM-5), their individual mastery of independent living skills varied significantly. Some of these adult children were still living at home and were very dependent on their parents, while others were living on their own while studying or working with only occasional outside support.

### **Interviews**

With two exceptions, interviews were conducted in the participants’ homes to provide a safe and familiar location for the participants, and a reasonably well controlled environment to facilitate the audio recording of the interviews. One participant requested that the researcher meet her at a public location since she was not comfortable having someone in her home who she did not know. This interview was held at a local public library meeting room where privacy and control of environmental noise could also be

achieved. One other participant requested that the interview be conducted at his office to accommodate his work schedule. None of the children of the participants were present during the interviews to limit distraction and provide more freedom to answer questions candidly without concern regarding the participants' children overhearing responses about their behaviors or challenges.

All of the participants appeared willing, some even eager, to share their experiences and the stories of their lives raising a child with ASD. As they answered the questions asked by the researcher, most went on to provide much more information than was asked for by citing specific examples, recounting related stories, sharing experiences of others parents who they were aware of, and even disclosing background information about their child to give context to the answers they provided. When done with the interviews, many expressed deep gratitude for the opportunity to tell their story and discuss their experiences.

While each parent's story contained many common elements, each also had aspects that made their experience uniquely individual. Some of the more relevant variables that became apparent during the interviews included the age of the child, the age at which the child was diagnosed with ASD, the specific ways in which ASD symptoms manifested in their child, responses of outsiders, the parents' perspective on their own situation, as well as the specific domains examined in this study.

In answering the questions presented by the researcher, many parents became somewhat sidetracked, sharing information relevant to their child and their experience, but not necessarily related to the questions in a direct way. While the data was collected with the perspective that all of the information shared by the participants was useful and

relevant to their own experience and understanding, as well as being potentially beneficial to others, some of what was shared fell outside the scope of this study. Most of the time, the researcher would simply allow the participant to continue in order to see if some information relevant to the question might be shared, or if their response might circle back to the question asked. However, in some cases the researcher would rephrase the question or provide some question clarification to try to bring the conversation back on topic for the purposes of this study.

### **Focus Groups**

Focus groups were held in order to provide the participants an opportunity to interact with one another while they discussed the same topics covered during the interviews. It was anticipated that this interaction would prompt participants' memories of prior behaviors by hearing the experiences of other parents. The intended purpose was that the focus group dialog would produce either additional responses that may have not been provided during the interviews, or at least confirmation of the previous responses from the other participants by identifying common experiences.

The original plan for this phase of the data collection called for only one focus group, with all of the participants attending at the same time. However, as participants were recruited, a significant geographic separation, as well as differences in work schedules and caregiving responsibilities became evident. Therefore, in an effort to promote maximum participation, three separate focus groups were held on different days and times, and in different locations with the goal of accommodating schedule demands and the geographic distance that existed between the locations where the participants lived. Even with these accommodations, focus group participation was just under 50%.

Two participants had medical emergencies that prevented their attendance, one was physically unable to attend due to a longstanding degenerative health condition, while others cited work or other schedule conflicts. The goal of participant interaction to identify additional responses that were not provided during the interview process was accomplished during the focus group sessions. However, due to poor attendance, actual focus group dynamic as a source of evidence was not achieved since two of the three focus groups were only attended by two participants each. Having two participants did allow for interaction and dialog, however, better attendance would have likely increased the interaction and possibly the quantity of useful responses.

As was anticipated, the focus groups provided an environment that fostered an interactive and collegial atmosphere where parents discussed their experiences and compared their children's unique and common challenges, as well as their successes. Some of these participants appeared to connect personally after the conclusion of the focus group by staying to talk and exchange contact information. One participant even contacted the researcher several days after the focus group to express her gratitude for the opportunity to connect with other parents of children with ASD. This point was interpreted to be relevant to the social isolation domain, which has been identified in previous literature and will be discussed further in this chapter.

During the focus groups, confirmation of many of the responses shared during the interviews did occur, and most often took place in the form of agreement about experiences. Many parents would simply respond with something like, "Oh yes, we did that as well" or "We experienced that, too." The data collected during the focus groups also contained some responses that were unique to the individual participant. For

example, a participant mentioned how they would use exercise as a means of coping with their stress to benefit their health. Other parents also mentioned exercise during their interviews, but in this case was a unique response from this participant. Other responses during the focus groups were completely new answers that had not been previously discussed by any participants in either the interviews or the focus groups.

One area of significant diversion in parental experiences included the topic of school support. Some parents indicated that they had wonderful experiences with understanding and knowledgeable teachers and staff who collaboratively supported them and their child. However, other parents indicated that their experience was one of frustration due to a lack of knowledge and resources on the part of their particular school district, and perceived blame directed at the parents by the teachers for the challenges that the children experienced. Others indicated a more neutral experience in which teachers may not have been knowledgeable about how to work with their child, but that they were open to learning what they needed to learn and to working with the parents to achieve a better outcome for the child.

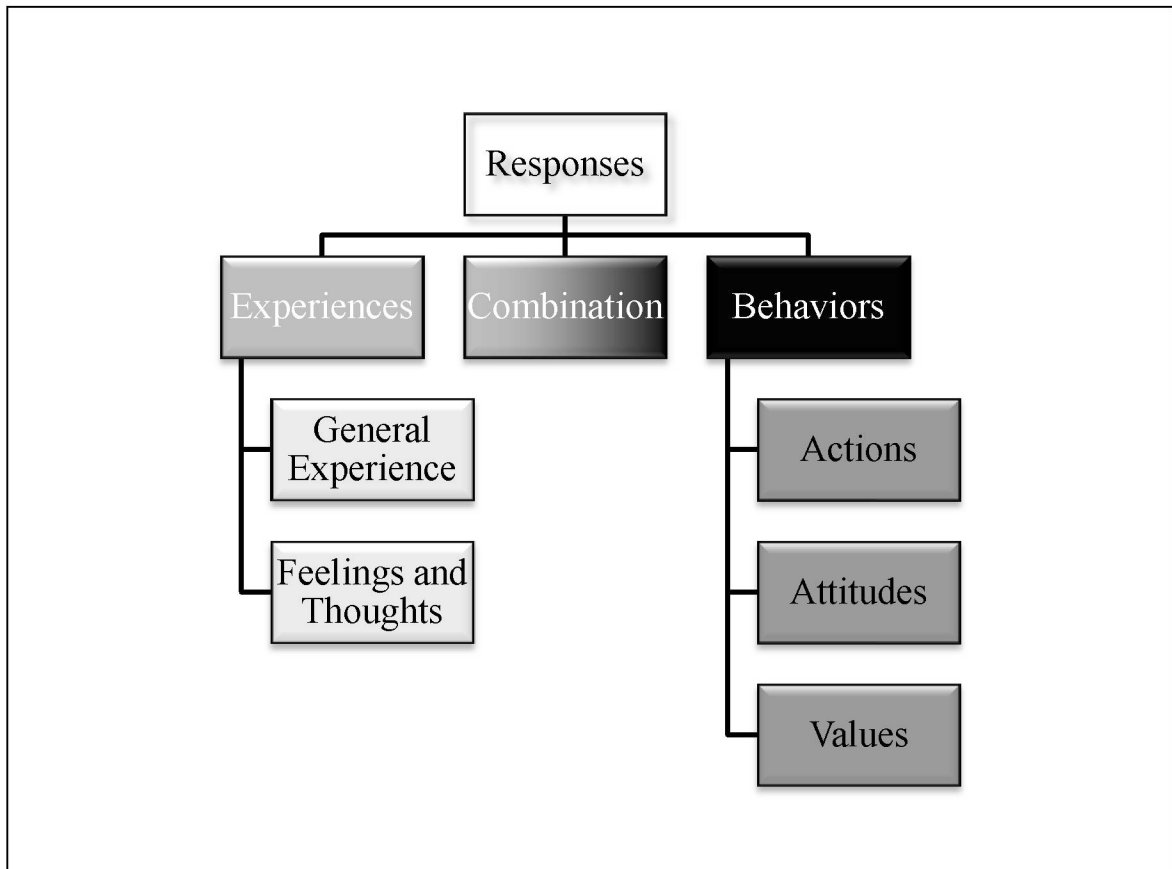
### **Data Analysis**

The interviews and focus group sessions were each recorded and later transcribed to collect the narrative data in a written form. The written format provided the researcher with a script of the interview, which was then reviewed to identify the specific behaviors the participants identified in their answers. This allowed for separation of the responses into sections based on question domain (e.g., financial, social) or most relevant topic. These responses were then coded using an emergent categories strategy, rather than using

predetermined categories, to identify relevant patterns in the categories of responses (e.g., boundaries, or accepting help from outside support sources).

As the data was reviewed and analyzed, it became apparent that both the interview questions and focus group discussions produced similar data with both containing the same two distinct types of responses, with several subtypes, as illustrated in Figure 1. The two primary types of responses were labeled as “experience” and “behavior,” with the experience-based responses providing more retrospective information about the first person experience of having a child with ASD, while the behavior-based responses, being the primary topic of this study, focused on past or current responses to the challenges presented by the child’s ASD.

Figure 1. Categories of Responses



The first three interview questions most commonly resulted in experience-based answers in which the participants discussed their overall experience of raising a child with ASD. These responses included details about how they were impacted by having a special needs child, and in some cases explored some of the ways in which their life seemed to have been altered from what it might have looked like had they not had a child with ASD.

The last eight questions more commonly produced answers that were identified as being behavior-based, meaning that they identified behaviors that the participants had previously or were currently engaged in to help them in their parenting role. These included the questions about the five specific domains, and three questions that were more general. Behavior-based responses typically included answers describing more tangible or observable activities.

Within the experience category, two subcategories were identified, with the first, “general experience”, being more related to the external experiences of raising a child with ASD. The second category, “thoughts and feelings” related more to the internal perception of the experience of raising a child with ASD. While these responses were insightful and provided context for the participants’ narrative, the experience-based responses were not included in the results of this study.

Within the behavior category, three subcategories of responses were identified. These responses were identified as actions, attitudes, and values. While attitudes and values may not be commonly classified by some as behaviors, because behaviors are commonly believed to follow thoughts, attitudes and values can have a significant impact on behavioral choices. Therefore, these responses related to attitudes and values were



included in the results because of their close relationship to behaviors and their potential benefit to the outcome of the study. An example of an attitude-based response was seen in the answer given by a participant when asked what they did to help their child improve in the areas where they were impacted by ASD. The participant responded by saying, “Just being grateful for the slow progress,” (11, personal communication, May 24, 2016). This response was categorized with the attitude-based category of “gratitude”. One example of a values-based response was seen in an answer to the same question when the participant replied, “I think we've learned to be patient and not try things like that until he feels like he is ready,” (11, personal communication, May 24, 2016). This response was categorized with the values-based category of “patience”.

Some answers were found to contain elements of both the experience and the behavior-oriented responses, illustrated in Figure 1 as combination responses, while others were relevant to more than one behavior category. Therefore, when the answer included elements of more than one category, the answers were given a dual code with a second code assigned after the original category was identified. In the final count of responses, original codes and second codes were tallied the same and neither was given priority or weighted more than the other. One example was seen in a participant’s response to the question, “What areas of your life have been most significantly impacted?” The participant replied, “I had to take an evening or night shift. I could not work during the day so I had to completely alter by my job because he couldn't be in daycare,” (18, personal communication, June 16, 2016). Since this response described the participant’s personal experience of having to take a night shift and being unable to work during the day, it was coded with the original category of experience. However,

since this response was also indicative of a behavior, that being the parent's action to respond to the child's need to avoid daycare, it was also coded with the action category of adaptability. Similarly, in response to the question about what they have done to strengthen their marriage, one participant replied, "We did intentionally talk more and we eventually did some couples work," (05, personal communication, May 8, 2016). As this response was related to both the behavioral category of communication, and to the behavioral category of seeking outside support, it was coded as both and was tallied in both response categories.

The second coder also reviewed the responses and categorized the data in the same manner as the primary researcher. Using the collected behavior-based responses, the second coder evaluated the responses according to the questions and domains. The two sets of coded information, one from each coder, were compared for similarity and any areas of discrepancy were reconciled between the coders to arrive at consensus on all of the responses provided by the participants. The results of the coders analysis was then sorted by category and domain, and then tallied to identify the behaviors most commonly used to help in coping with the stressors unique to each domain.

Table 2 contains a list of the behavior-based categories along with a working definition of each category.

Table 2

<i>Behavioral Categories with Definitions</i>		
Type	Category	Definition
Actions		observable or describable activities engaged in as a response to a current or anticipated need.
	Adaptability	changes in perspective or approach in response as new information about need or effectiveness becomes apparent
	Advocacy	to endorse a course of action, treatment, or response on behalf of the child or family
	Balance	behavior-based on decisions made by assessing cost and benefit to avoid extremes of response
	Boundaries at Home	establishing and acting on healthy emotional and behavioral guidelines for interactions within the family
(continued)		

Type	Category	Definition
	Boundaries with Outsiders	establishing and acting on healthy emotional and behavioral guidelines for interactions outside the family
	Collaboration	cooperative effort to lighten the individual burden of a situation by sharing responsibility or resources with a family member, friend, or other individual
	Communication	an active approach to listening and expressing concepts such as thoughts, ideas, emotions, needs, and plans
	Determination	the decision to continue with a choice or action even when meeting resistance or experiencing fatigue or discouragement
	Inclusion	efforts intended to reduce the stigma or separation that can be felt when one is perceived as different
	Individual Support	direct assistance provided to the child with a task, choice, or behavior
	Organized Activities	participation in structured events taking place outside the home
	Outside support	assistance provided by an individual, agency, or service provider not living with or a part of the family household
	Planning	preparation in anticipation of expected challenges or needs
	Proactive	initiating a response to an anticipated or emerging need
	Realistic expectations	anticipating an outcome that is consistent within a logically deduced range of possible results
	Self-Care	actively engaging in behaviors intended to diminish or eliminate the harmful effects of stress or to maintain or improve physical, mental, or relationship health
	Self-Education	seeking out information and knowledge about diagnosis, behaviors, and expectations
	Setting expectations	assisting the child with understanding upcoming events with the goal of reducing the stress associated with unanticipated change
	Social Involvement	seeking out and making opportunities for social interaction with peers
	Structure	creating schedules and routines to provide organization and predictability in daily events
	Teaching	direct assistance provided through various forms of instruction or modeling to aid in learning skills or abilities necessary for more independent living
	Treatment	intervention provided by a professional agency or practitioner
Attitudes		a mental perspective used as a lens through which one interprets the meanings and outcomes of events
	Gratitude	a perspective of being appreciative for what one has or progress made, regardless of remaining needs or deficits
	Positivity	choosing to hold a perspective of optimism and focus attention on things that are successful, rather than on what is not
Values		concepts perceived as important to guiding choices and behavior
	Commitment	devotion to engage with all necessary resources to achieve a beneficial outcome
	Faith	belief in purpose and meaning for the events in life beyond mere random happenings
	Moderation	avoiding reactions that involve extremes of thought and behavior
	Patience	the act of consciously waiting for a better outcome even though the drive for an immediate solution is tempting

Since the focus of this study was on behaviors, codes were only created and assigned for the behavior-based responses of the participants. Experience-based responses were identified by general type, but no corresponding system of categories was created for the experience-based responses since they fall outside the focus of this study. However, the experiences described by many of the participants appeared to further validate the domains identified in previous literature as areas of common impact for parents of a child with ASD. While not all of the participants experienced all of the

domains, all domains were reported by at least some of the participants, indicating common, but not universal applicability of the domain related challenges.

When the coding of relevant participant responses was complete, the responses were then sorted by their categories to identify the most commonly endorsed effective behaviors of parents raising a child with ASD. This allowed the results to be identified by frequency of response according to category of behavior and by the domains that were addressed in the interviews and focus groups.

After separating the experience-based responses, a total of 263 behavior-based statements were identified from the interviews, while another 21 behavior-based statements were identified from the focus group narratives. Focus group totals were arrived at after duplicate answers that had already been provided by the same participant during the interviews were removed from the focus group responses. This was done to avoid counting the same answer by the same participant as two separate answers simply because it was given in response to the same question in both the interview and the focus group sessions. This provided a total of 284 participant statements. After all of these statements were categorized, 164 statements had been given dual codes with other behavior-based categories resulting in a total of 448 responses with behavioral codes when the dually coded statements were counted once for each category.

## **Findings**

**Interviews.** Initial questions asked during the interview portion of data collection elicited responses primarily related to the first-person perspective of the participants' experiences of raising a child with ASD. The first question, "Tell me what it's like to be a parent of a child with ASD," produced numerous experience-based responses such as,

“Um, currently, hellish. Always challenging. I don't know if I would say fun, but there are definitely rewards to it,” (02, personal communication, May 1, 2016). Another parent reported that, “Each year you have different challenges. With Asperger’s or autism it kind of magnifies because you have the standard challenges of growing up and then you have the issues of the autism or Asperger’s along with that,” (15, personal communication, June 12, 2016). Another common sentiment, that of feeling isolated, was endorsed by many and expressed by one participant as, “It’s very isolating. It feels somewhat like being on an island by myself to a great extent,” (14, personal communication, May 29, 2016).

The remaining questions were focused on effective behaviors, three of which were more general questions allowing participants to draw from any of their behaviors. The other five questions focused specifically on the five domains identified in the literature review as particular areas of interest common to many parents raising a child with ASD. Those domains were identified as marital relationship stress, physical health challenges for the parents, scheduling difficulties, financial strain, and barriers to parental social involvement and support. These eight questions elicited answers primarily related to behaviors identified as actions, attitudes, and values.

***Most commonly endorsed behaviors.*** In the narrative accounts of the participant responses, 284 individual statements related to behavior-based actions were identified. This quantity of answers was received because many participants gave multiple replies to individual questions. For example, when asked about how they responded to health challenges, one participant replied, “I take supplements, I go to a naturopath, I go to the chiropractor, and I see my doctor regularly,” (10, personal communication, May 22,

2016). Because each of these behaviors was a separate action, each was counted as a separate response and given individual codes to indicate the types of behavior.

During the review of the participant responses, which were identified as behavior-based, 28 separate categories of behavior emerged as relevant, based on the answers provided. These included all of the actions, attitudes, and values expressed in the participants responses. Those 28 categories are the same as those identified and defined in Table 2.

*Adaptability.* Of all the categories, the most frequently identified behavioral characteristic was that of being adaptable. Adaptability, in the participants' responses, indicated changes in perspective or approach, often after new information about need or effectiveness had become apparent. Adaptability was connected with responses varying from parents being adaptable in their concept of what their child was capable of, to being adaptable in their perception of their child's motivations, and even being adaptable in their work schedule in order to better meet their child's needs. Concepts of adaptable behaviors were identified in 61 participant interview responses.

Examples of responses that illustrated adaptability included comments such as, "There was a time when it switched in my mind that it wasn't that he was defiant, it was that he just didn't get it. It's not 'no, I won't do it your way'. It was that for whatever reason, 'your way just doesn't work for me.' So, when I could make that switch, that really made a difference in our lives, when I could do it, which wasn't always," (04, personal communication, May 8, 2016). Another participant remarked, "So a lot of this is trial and error and you go with not getting pissed off and flying off the handle because it is not going to help him and it's not going to help me," (13, personal communication,

May 25, 2016). Other parents made simple comments such as, “You have to learn to adjust,” (06, personal communication, May 22, 2016), “Your expectations have to change,” (19, personal communication, July 17, 2016), and “Mellowing out. Realizing it is what it is and is not going to change,” (07, personal communication, May 22, 2016).

*Teaching.* The next most frequently occurring behavioral category, identified in 36 of the participant responses, was the category of teaching. Teaching indicated a proactive response by the parent to personally educate their child or address their educational needs in an area where a deficit of knowledge or comprehension hindered their abilities.

One parent said she explained to her child, “When you get into this situation, this is the kind of questions you ask. This is what you need to do. This is...you know...I want you to learn to advocate for yourself,” (06, personal communication, May 22, 2016). Another parent reported, “Just basically, what my focus is to teach him to be independent. It will be important for him in the future to be independent,” (13, personal communication, May 25, 2016). Participants also indicated they had worked with their children to teach them concepts such as “talking about his feelings, rather than being angry and throwing things,” (16, personal communication, June 12, 2016), “helping him learn how to budget money better,” (08, personal communication, 22 May 2016), and “we would work with him on social skills stuff,” (04, personal communication, 8 May 2016).

*Outside Support.* After teaching behaviors, seeking outside support was the next most commonly endorsed behavior identified as contributing to parents’ effectiveness. For this study, outside support was defined as assistance provided by an individual,

agency, or service provider not living with or a part of the family household. For these families, behaviors that were categorized as outside support activities indicated either a willingness on the part of the participant to accept assistance from an outside source when offered, or the proactive seeking out of support from a potential source of assistance.

Speaking about outside support in the form of financial assistance, one parent said, “A lot of people don't want to ask for money but when they ask for paperwork you can always ask if there is an application for or possibility for scholarship or financial assistance,” (06, personal communication, May 22, 2016). Another participant mentioned emotional support from an outside source when they said, “And we had good friends. A lot of support from good friends,” (12, personal communication, May 24, 2016). Other parents referenced more general support such as, “Seeking out resources [and] listening to the resources,” (13, personal communication, May 25, 2016) and “One of the keys to success has been getting good help,” (02, personal communication, May 1, 2016).

*Self-Care.* Activities associated with self-care were the next most frequently endorsed behaviors identified as helpful for parents to be more effective in raising their child with ASD. Behaviors of self-care, identified in 33 responses, are those that involved proactively engaging in activities intended to diminish or eliminate the effects of stress. Many of the self-care activities endorsed by participants were related to a specific domain such as social involvement or marital relationship, while others were more general and universally applicable.



Several participants indicated that one of their strategies was simply to get away from the stress for a short time, either by themselves, or as a couple. One parent replied, “We started just making sure we got time away. We would get someone to stay with the kids. We would go away,” (04, personal communication, May 8, 2016). Another parent identified specific activities she engaged in to aid in their self-care. “We do what we can to relieve stress, you know any kind of daily stress, whether it’s go for a swim, exercise, eat healthy,” (15, personal communication, June 12, 2016). Another behavioral strategy used by one parent was simply stated as, “Sometimes I sleep in on the weekends,” (14, personal communication, May 29, 2016).

*Boundaries at Home.* Responses identified as being related to boundaries at home were endorsed 22 times in the participant narratives. Behaviors involving boundaries at home referred to establishing and acting on healthy emotional and behavioral guidelines within the family. Some of the motivations for setting these boundaries and acting on them appeared to be primarily for the good of the child, while others seemed to be focused on the good of the parent, and others appeared to have benefits for both.

Examples of setting boundaries at home included responses like, “I think the biggest thing was we would back each other up. You know, if [Mom] said something, even if I didn’t agree, I would not disagree, in front of the kids, so having a united front was our approach,” (17, personal communication, June 16, 2016). This example illustrates a situation where the boundary was set to benefit the parents, but could also be of benefit to the child by not creating a situation where the child could manipulate or work one parent against the other. Another parent said, “That’s become something that we’ve become intentional about, is making time away to just not think about it,” (10,

personal communication, May 22, 2016). One comment indicated that the parent knew boundaries were necessary, but said, “Knowing that, it doesn't make sense still to me that to be a better parent I need to give more time to myself,” (01, personal communication, April 29, 2016). Both of these last two responses were also dually coded as being related to self-care behavior.

*Communication.* Behaviors related to communication were also identified in 22 participant responses. Most of those responses were associated with communication between parents either as a means of improving their effectiveness in parenting or in addressing issues related to challenges in the marriage domain. Other communication behaviors were identified between parent and child, while the remaining few indicated communication that took place between parents and outside resources for the purpose of acquiring some type of assistance or even financial support.

In citing an example of communication between parents for the purpose of parenting, one participant said, “We have to keep communications open between us, cause as he said, we have different approaches,” (03, personal communication, May 1, 2016). Another parent identified one of his communication strategies with his child when he was asked about what he has done that has been effective. “I think listening and basically picking up on the cues when he wants me to come in close. Making time for that,” (13, personal communication, May 25, 2016). Communication with others for support or assistance was illustrated in the statement made by one participant when she said, “Find those people in your life that you can talk to about it, outside of, I think, your spouse. If it is your parent, or best friend, or neighbor or something, I think you need

somebody else to just, that isn't involved in it, to be able to kinda talk to," (20, personal communication, July 17, 2016).

*Organized Activities.* A behavior mentioned by many parents was getting their children involved in organized activities outside the home. There were 21 responses that described the benefits that their children received after the parents made the decision to get the children involved in these activities due to the structure and the opportunities for social interaction.

When asked what kinds of things helped her child, one parent responded, "having him go into these classes, like dance class, music class, all of these things got him out there and he had to communicate with other people, he had to be up on stage which was frightening. And so I think we broke a couple of barriers by doing that," (16, personal communication, June 12, 2016). Other parents spoke of the kinds of activities they involved their children in such as, "We found an autistic group, an adult family group for guys," (08, personal communication, May 22, 2016). Another participant said, "Some of it was through the church. We also put the kids in cub scouts," (12, personal communication, May 24, 2016). Scouting was an activity mentioned specifically by at least four of the participants.

*Collaboration.* Another behavior identified in 20 responses as an effective strategy for helping them in raising their child with ASD was that of collaboration. For the purposes of this research, collaboration implies a cooperative effort to lighten the individual burden of the situation by sharing responsibility or resources with a family member, friend, or other individual. With one exception where a parent referenced a collaborative behavior between her and her child, all of the responses coded as

collaboration were provided by participants who were married and raising their child together with their spouse. The responses they provided were in reference to collaborative behaviors between the parents.

Behaviors described by parents included, “What has been essential to any success that [child] has had and that we have had is that we work together. And if we don't [child] will divide and conquer and nobody wins when he does that,” (03, personal communication, May 1, 2016). Another participant reported, “We have different approaches. [Mom] is very direct and that is what it needs to be, and I am sort of a lot softer and am more empathic possibly. The combination has worked well,” (02, personal communication, May 1, 2016). Similarly, another participant said, “We also had our department, which I guess is typical for most parents, right? You know ‘you’re good with that when [child] does that, and I’m good with...’ so we honed in on that,” (16, personal communication, June 12, 2016).

*Social Involvement.* The behaviors identified in the next most frequently occurring category of responses were related to social involvement and were seen in 15 participant responses. However, almost all of these answers were in response to a single question related only to the parent’s social domain, which will be addressed in the section on responses by domain.

*Proactive.* The category identified as proactive was used to indicate behaviors in which the participant preemptively or actively engaged in response to an anticipated or emerging need. These behaviors were identified in 14 of the participant interview responses. These behaviors often had to do with preparing the child ahead of anticipated

changes, responding to needs quickly rather than avoiding or procrastinating, and planning ahead for ways to respond to anticipated situations.

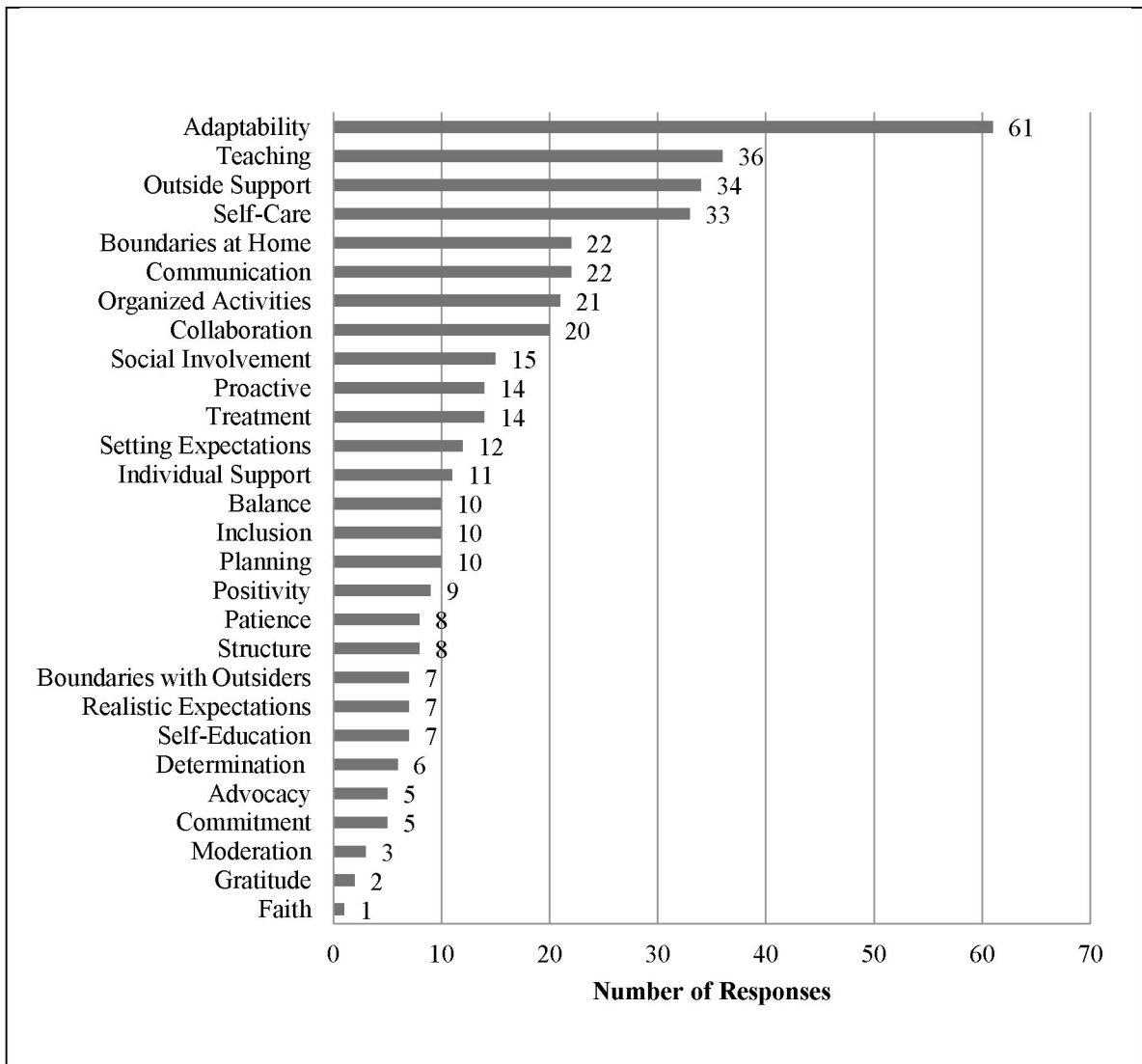
One proactive strategy identified by a participant was related to being responsive to stressors in the marriage domain. In his response, he indicated that, “Part of our success in our relationship has been that we sit and we talk about it. ‘What are we going to do? What is our game plan?’ Strategizing. So we pull together more than we pull apart,” (15, personal communication, June 12, 2016). One parent reported that being proactive was how they responded to their social isolation. Rather than waiting to be included or invited by others, he said, “We do a lot of inviting people here,” (03, personal communication, May 1, 2016). Another participant identified their proactive behavior in helping their child when they said, “With his anxiety, what helps him the most is helping him know what to expect. So either reminding him he has experienced this before and this is how it went, or just talking through this is what is likely to happen. If this happens, you can do this....so he has got a plan,” (04, personal communication, May 8, 2016).

*Treatment.* The treatment category was confirmed by 14 responses from the participant narratives. Responses coded as treatment referred primarily to behaviors related to receiving intervention provided by a professional agency or practitioner such as a doctor or therapist. Participants reported having their children involved in many different types of treatment to address the specific ways in which they were impacted by the ASD. Some of those treatments included vision therapy, auditory therapy, sensory integration therapy, counseling, group therapy, and pharmacological treatment to name a few.

One participant endorsed treatment behavior while identifying the challenge in the financial domain that can be associated with those treatments. “We spent years doing therapies and interventions, and most of it not covered by insurance,” (03, personal communication, May 1, 2016). Another participant said, “We were thinking of having [child] go through video game addiction treatment and Dr. Becker... said, you know, ‘treat the autism’,” (02, personal communication, May 1, 2016). Speaking of ways to treat her child’s issues with anxiety, the same participant said, “There are lots of different therapies around here that will help with [how] the brain processes information and will kinda reduce his anxiety,” (02, personal communication, May 1, 2016).

The participants provided several other categories of responses, though the categories not covered to this point were mentioned less frequently. Since the focus of this study was to identify the most common effective behaviors of parents raising a child with ASD, only those categories with 15 or more responses have been discussed and illustrated here. Those categories with less frequent responses were not specifically illustrated in this section. However, some of the other categories will be relevant in the domain specific discussion of effective behaviors. Figure 2 shows the total number of responses for all of the 28 categories during the participant interviews.

Figure 2. Interview Responses



***Most commonly endorsed behaviors by domain.*** During the interview portion of the data collection, five specific questions were asked of the participants related to the specific domains previously identified in the literature. The responses given by the participants regarding these domains were tallied separately to allow for a topic specific analysis of most frequent behaviors identified as helping the parent be more effective in that domain.

*Marriage.* All of the participants who either were married at the time of the interviews, or had been married during the period of time when they were raising their child with ASD, were asked about the behaviors they engaged in that were helpful for improving or maintaining their marital relationship. The most commonly endorsed behaviors for the marriage domain were related to the communication category and, as illustrated in the earlier examples, involved behaviors associated with verbal communication with the participants spouse, child, or other individuals able to assist the participant in their parenting responsibilities. After communication, behaviors associated with collaboration were the second most endorsed areas of behavior related to improving their marriage, followed by boundaries at home and self-care, which tied as the third most often endorsed behavior categories. As the only category of that list that has not already been described and illustrated in previous examples, commitment in this context can be described as devotion to engage with all necessary resources to achieve a beneficial outcome.

Examples of commitment behavior expressed by participants included comments such as, “All the statistics that I read in my counseling program told us that 80% of marriages that went through what we went through were going to end. And so, you know, we talked about it and just agreed that’s just not going to happen,” (10, personal communication, May 22, 2016). One husband described the commitment in his marriage by saying, “We were like overachievers at committing to try to do things right. You know, we made a lot of mistakes, but we were very, very, committed that this was going to work,” (17, personal communication, June 16, 2016). Another participant described



her marriage by saying, “And we were committed because of our strong faith and that’s why we’ve been married all these years,” (18, personal communication, June 16, 2016).

*Health.* When asked about behaviors that have helped the participants respond to health related challenges they experienced as a result of the stress and demands related to the care of their child, half of the participants reported that they had not experienced any significant health challenges. If they did have health challenges, some reported that they did not feel that their health difficulties were directly related to the care of their child. For those who indicated that they did engage in specific behaviors to help cope with the demands that raising a child with ASD had on their physical health, the most commonly endorsed behavior category by far was actions related to self-care.

Some responses were very general such as, “I guess it comes down to self-care,” (01, personal communication, April 29, 2016), while others were very specific behavior related responses. One participant indicated that one behavior she engaged in to help with her overall health was “Seeing a therapist,” (07, personal communication, May 22, 2016). Other answers contained some overlap and were dually coded with responses related to the social involvement category. One example was in the response of a participant who said, “I do go out and do other things. Mostly go out and see films or um, do some things with friends, have dinner, lunch, breakfast, whatever,” (14, personal communication, May 29, 2016). Other examples of social involvement responses will be addressed under the social domain.

*Social.* In the social isolation domain, seven participants indicated they did not feel particularly isolated by their child’s diagnosis or the associated demands or restriction on their lives. However, the remaining participants most frequently reported

behaviors associated with actively pursuing and maintaining social relationships. These were categorized as social involvement. Others reported that getting involved in structured events helped diminish the social isolation they experienced. These behaviors were categorized as organized activities.

As an example of behaviors aimed at maintaining social relationships, one participant said, "I work to keep friends. I will stay in touch with friends because a lot of people suck at that and, um, it's partly because I think it is important. Community is important to me and we have no family" and "We work really hard on maintaining relationships," (03, personal communication, May 1, 2016). Another participant indicated that rather than waiting for others to involve them, the participant would initiate social activities and relationships with behaviors such as, "We have just insisted and we have been the hosts," (02, personal communication, May 1, 2016). A few of the organized activities participants reported to be helpful in diminishing their social isolation included things like, "[Having a church community] helped tremendously," (18, personal communication, June 16, 2016) and "We were really heavily involved in the sailing community. That's where most of our friends were," (08, personal communication, May 22, 2016).

*Financial.* For this particular sample, half of the participants also indicated that financial difficulties associated with the care of their child with ASD was not a significant factor for them. Some reported that their income was simply sufficient to meet their needs, with others reported that they had to make adjustments to take care of what was needed, but that it did not cause significant stress for them. Of those who did experience financial hardships, behaviors related to adaptability and behaviors of seeking

or accepting outside support were reported equally as being most beneficial in responding to their financial needs.

Seeking or accepting outside support was endorsed in responses such as, “Accepting gifts that are for me that are helpful to him,” (01, personal communication, April 29, 2016) and in dealing with service providers and agencies, “It is asking those places for help. You really have to talk to them,” (06, personal communication, May 22, 2016). Adaptability was identified as helpful by a participant who said, “Giving something up [to have something else]. That month I’ll do this, but we won’t do this. [For example] we don’t have internet,” (01, personal communication, April 29, 2016).

*Schedule.* Like the health challenges domain, most participants indicated that scheduling difficulties, identified in the literature as a problem for many parents of children with ASD, was not a common experience for most of the parents in this study. Those who did experience problems with arranging appointments and meeting time demands identified responses most closely associated with the adaptability category of responses.

One participant reported, “You have to learn to adjust. It is not like everything is going to be the same for every child,” (06, personal communication, May 22, 2016). Another parent reported that his spouse altered her work schedule in order to be available during weekdays to get their child to the needed appointments. “You know it was like, we can pay daycare, or we just, you know, [Mom] just sucked it up and did two shifts on Saturday and two shifts on Sunday. Thirty-two hours in a weekend. She never scheduled stuff for Monday mornings,” (17, personal communication, June 16, 2016). Other participants provided answers identified as related to the planning category when they

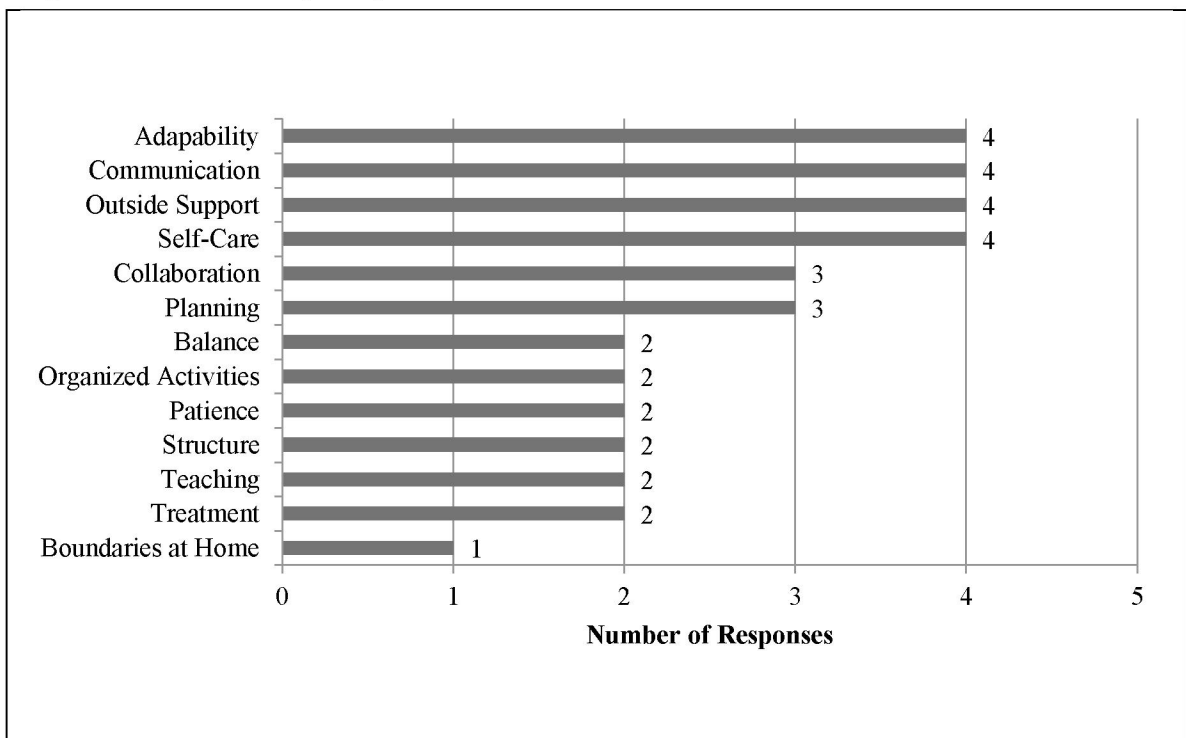
said, “What I try to do is plan out where it is less stressful,” (13, personal communication, May 25, 2016) or behaviors like “just being very organized, we had to be very organized [Like keeping a schedule],” (16, personal communication, June 12, 2016).

**Focus Groups.** As anticipated, the focus groups provided opportunities for the participants to interact and to discuss the common and the unique aspects of their experiences raising a child with ASD. Since most of the participants had limited availability, the focus groups were scheduled to last only one hour. In an attempt to complete the group within that timeframe, questions were limited to addressing behaviors associated with the five domains and one additional question about behaviors contributing to overall parental effectiveness.

Most of the participants provided many of the same responses they gave during the interview portion of the data collection, sometimes with additional details. Since these responses were duplicates of answers that had already been collected, coded, and assessed for frequency, they were not added to the total count of responses that were gathered from the interviews. However, as anticipated, the focus group discussions did prompt some additional responses from some of the participants that had not already been given. This additional data provided 21 unique responses regarding behaviors the participants engaged in, with 14 being dually coded for a total of 35 identified behaviors. Some of the responses were completely new answers that had not been seen in any of the other participant responses, while others were similar or the same as responses given previously, but by different participants. In these cases, the responses were added to the overall count of frequency for each category.

***Most commonly endorsed behaviors.*** After being categorized, the new responses gathered from the focus groups fell into 13 different categories, with four of those categories tied for most frequent at four responses each. Those categories included adaptability, communication, outside support, and self-care. Figure 3 contains the complete breakdown of the categories for the unique answers provided during the focus group discussions. Unique answers were those that had not already been provided by the same participant during the interviews.

Figure 3. Focus Group Responses



***Adaptability.*** Similar to a response provided by another participant during the interviews, one parent reported that in order to meet the scheduling demands, “Early on, when [child] was younger, we had split shifts, where my wife would work evenings and I would work days. She kinda had the day shift [with the child] and I took over the evening shift, so, that is how we juggled the schedules when he was younger,” (15,

personal communication, June 25, 2016). This response was also dually coded with the additional category of collaboration because of the cooperative effort between the parents. Another participant also spoke of adapting their work schedule to meet their child's needs when they said, "I was self-employed. I had to do something flexible. I started doing massage because it was a way for me to have a part-time [job], actually it was full time for a while, and still have kids. So I worked it so I could take kids where they needed to go," (03, personal communication, June 23, 2016).

*Communication.* Three participants reported communication related behaviors as being effective in situations related to the marital, scheduling, and financial domains. One parent indicated that, "you have to communicate, you know, about finances, and otherwise it's going to take a toll on your marriage. You have to get creative and figure out how you are going to make this work". The same parent also said communication helped she and her husband be more effective with the scheduling domain and described an example of their method when she said, "We just communicated. We just said, "Hey can you take him to speech therapy?" (18, personal communication, June 23, 2016). Another participant said, "So, being honest with each other" was helpful for improving their marriage (04, personal communication, June 25, 2016).

*Outside Support.* Finding and receiving assistance from sources outside the family was another behavior identified in both the interviews and the focus group discussions. The three individuals who reported during the focus group that their behaviors associated with seeking outside support helped them to be more effective were not the same individuals who had described the same behavior during the interviews.

One parent identified getting medical treatment for herself as helping her to be more effective in parenting her child. Her behavior, dually coded as also being a self-care behavior, was identified in her comment, “I think getting diagnosed for hypothyroidism helped,” (03, personal communication, June 23, 2016). Another participant reported “Sometimes family counseling. Or my son did have a counselor early on, which helped him, and we would also talk with the counselor also to help with our mental health,” (15, personal communication, June 25, 2016). Similarly, another participant indicated that simply finding “good counselors” had helped them be more effective, (16, personal communication, June 25, 2016).

*Self-Care.* Three participants also indicated additional behaviors of self-care, beyond those identified in the interviews, as having contributed to their parenting effectiveness. All three of these participants mentioned exercise or physical activity as having helped them. One parent said, “So I just exercised and that was a very good stress reliever for me,” (16, personal communication, June 25, 2016). Another participant indicated “exercise” in her list of behaviors, (03, personal communication, June 23, 2016), while another specifically mentioned “yoga or [similar] classes,” (07, personal communication, June 26, 2016).

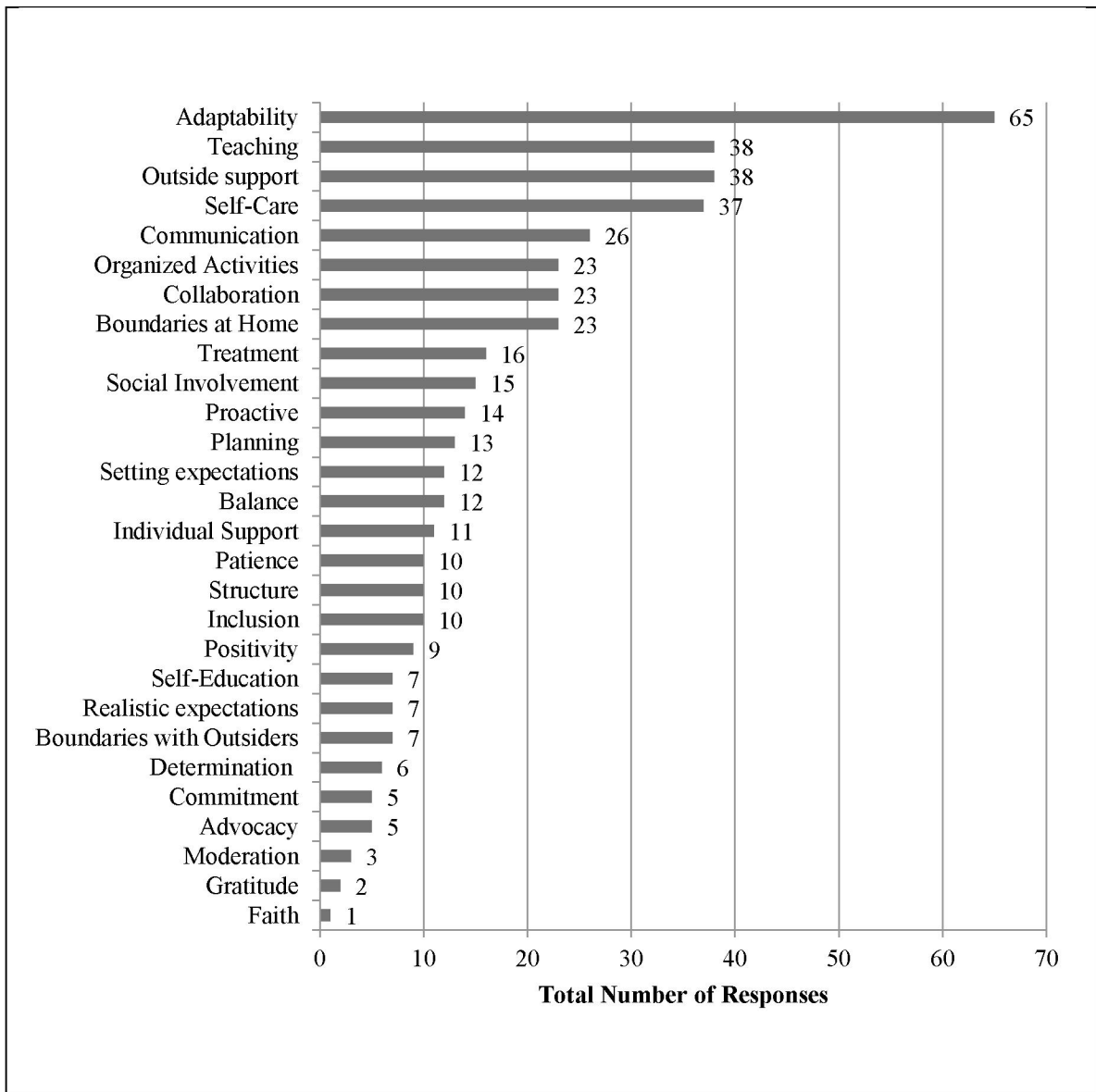
*Other Behaviors.* Additional specific behaviors were identified in the focus group discussions that did not come out in the interviews. In describing boundaries she had with her child, one parent said, “I didn't allow [child's] situation to interfere in every piece of my life. I wouldn't give it all to him cause I was stronger if I was healthy,” (16, personal communication, June 25, 2016). Another parent found it helpful to teach the

child about “helping him understand his day” by discussing it after the fact to help him process the events of the day, (04, personal communication, June 25, 2016).

**Interviews and Focus Groups Combined.** When all interview responses were combined with the non-duplicate focus group responses, the top five categories accounted for almost half of all the responses received. Behaviors linked with adaptability were identified in 65 statements. Teaching and outside support behaviors each received 38 responses, while activities of self-care followed closely with 37 responses. Behaviors related to effective communication were recognized in 26 participant responses. Figure 4 contains a full tally of all of the combined interview and focus group responses.



Figure 4. Interview and Focus Group Responses Combined



### Summary

In this chapter, participant demographics were described and a review was provided on some of the finer points of the methodology. The findings and analysis of the data collected during the participant interviews and focus group discussions was also described according to the most common categories of participant responses. Some background information was also covered to provide context to the behaviors shared by

the participants. The next chapter will review the focus of the study and present the conclusions and implications of this data, as well as describe the limitations and suggested areas for further research.

## Chapter 5: Discussion and Conclusions

The primary driving purpose for conducting this research and collecting the data presented in the previous chapter was to compile a body of information that could potentially be used to help parents, caregivers, and treatment providers of children with ASD. Information of this type could prove useful by preparing new parents of children with ASD for the challenges, and the successes, they will likely encounter. The information gathered regarding behaviors that were found beneficial to the participants could also provide new parents with models of behavior which could help them in responding to the stressors and the behaviors they will likely see in their own children. The participants' experiences could also help other parents prepare their children for the optimal level of satisfaction, independence, and accomplishment they are individually capable of attaining. To accomplish that purpose, this research was focused on the question, "Do parents who raise a child with an ASD have common behaviors that contribute to their effectiveness in raising their child?" Upon receiving confirmation that common behaviors did exist among this sample of parents, the secondary research question was, "What are those common behaviors that contribute to their effectiveness?"

### Discussion

**Interviews.** All of the participants in this study acknowledged the significant difficulty they experienced in relation to parenting their child with ASD. For those who also had children without ASD, many described the comparative experiences they had raising children with and without ASD. Most were able to identify specific behaviors they found helpful or that increased their effectiveness in response to at least some of the five domains. Some parents did not have responses related to some of the domains

because they did not feel they had experienced those specific challenges. Similarly, a small portion of the questions went unanswered by some participants because they felt they had not experienced any specific progress or had not identified any behaviors that allowed them to be more effective in those specific areas. While all of the participants endorsed many areas of similarity in their experiences, some identified aspects of their experiences that were unique among this sample. For example, most parents reported some degree of behavioral difficulty from their children in relation to social behaviors, outbursts, or seemingly defiant behavior. However, one parent in particular reported that his child's ASD was a less significant stressor than some of the other challenges he had faced, in part due to the absence of resistant behaviors or emotional outbursts. Eventually, along with describing the experiences, challenges, and backgrounds of the events surrounding their parenting, most parents were able to respond with behaviors they found to help them be more effective in relation to most, if not all of the questions and domains asked about in these interviews.

***Most Commonly Endorsed Behaviors.*** Of the 448 behavior-based responses provided by the participants, almost half of all the answers were attributed to 5 of the 28 categories of response. Those five most commonly reported categories of behavior, in order from most responses to least, were actions described as being related to adaptability, teaching, outside support, self-care, and communication.

***Adaptability.*** The category of adaptability was used to identify behaviors which involved being willing to change their perspective or behaviors to respond as new information was learned about a situation. In this way, these parents were flexible so as to adjust to changing situations or needs, or they adapted their expectations of themselves

or their child to a more realistic perception. Examples of behaviors categorized as adaptability included reports by parents that they changed their parenting strategies to better meet their child's needs, parents who altered their work schedules or career plans in order to be able to be with their child for support, or even altering family events to be thoughtful about the child's needs related to their ASD.

*Teaching.* The teaching category was most often related to activities of direct instruction or the modeling of behaviors for their child to help them gain skills or learn concepts useful to their understanding of themselves, social expectations, or the world around them. Responses in this category ranged from helping the child learn how to budget, interact socially, or acquire new independent living skills, to things such as teaching them to cope with their feelings, how to drive a car, or even how to appropriately advocate for themselves. While these are common topics that most all parents need to teach their children, several of these parents of children with ASD indicated that these things often take longer to teach and some of that teaching takes place at later ages than for most developmentally typical children.

*Outside Support.* Those behaviors categorized as outside support included activities related to seeking out or simply being willing to accept assistance from agencies, providers, or individuals who were not a part of the family's household. Parents who reported behaviors related to outside support indicated they had sought out and received assistance from treatment professionals such as doctors or counselors to help with their child's ASD symptoms. Others indicated they had received care from a counselor or therapist to help with their own issues related to raising a child with ASD. Still others reported that assistance from friends or family had been very helpful to them.

*Self-Care.* Behaviors categorized as self-care often described activities with the purpose of protecting, maintaining, or improving physical, mental, or relationship health. Self-care behaviors identified by participants included activities such as exercise, time away from caregiving responsibilities, and date nights with their spouse. Some responses included caring for physical health through nutrition, treatment by a naturopathic physician, or receiving massage therapy. Other participants reported mental health care behaviors related to taking breaks from their caregiving responsibilities, or participating in spiritual or personal groups.

*Communication.* The category labeled as communication was used to identify behaviors that involved actively listening to and expressing concepts such as thoughts, ideas, emotions, needs, and plans. Communication behaviors included parents communicating needs ideas or strategies of response to one another, parents listening as their child verbally processed stressful events, communicating expectations to their child, preparing the child for anticipated changes, or even communicating with treatment providers.

*Most Commonly Endorsed Behaviors by Domain.* When sorted by domain, interview responses were grouped according to topic, and therefore could be viewed as responses used to address particular issues experienced by the participants.

*Marriage.* For parents raising a child with ASD, the marriage relationship is one of the most significantly impacted by the stresses and difficulties that are presented by the special needs of the child (Ramisch, Timm, Hock, & Topor, 2013). These stressors were found in events that occurred frequently, and therefore created situations that these parents must deal with on a regular basis (Dutra, 1999). Specific impacts were reported

in a variety of areas such as decreasing the amount of time a couple is able to spend together, decreased quality or quantity of sleep, and having diminished time available for activities of self-care because of the added time required for the care and parenting of the child (Koshti-Richman, 2009; Smith et al., 2010). The effects of this type of stress on the marriage relationship have been shown to have detrimental effects for the parents involved. Those effects included varying degrees of dissatisfaction, which, as other research has demonstrated, can lead to divorce rates among parents of children with ASD that could be as high as twice that of couples not raising a child with ASD (Hartley et al., 2010).

In this effort to identify behaviors that were beneficial to participants in strengthening or maintaining their marriage, more than any other, participants indicated that communication was the effective behavior they engaged in for the benefit of their relationship. Communication was described in participant responses as involving expressing and listening, often about plans, division of duties, and even honest expression of feelings and needs. Following closely in overall number of responses, behaviors associated with collaboration was a category identified in specific behaviors such as sharing caregiving responsibilities, helping each other with household duties, income earning, and even taking turns as point person in dealing with their child's needs or challenging behaviors. The next two categories of behaviors most commonly recognized in the marriage domain were equally endorsed. Boundaries at home was connected with behaviors in which the parents established healthy boundaries with their children. For some this involved setting limits, not allowing the children to dictate schedule, or even trying to make sure that siblings did not feel left out when a majority of time and energy

was being directed toward the child with ASD. Self-care behaviors within the marriage were described as activities intended to preserve and maintain the strength of the marriage relationship. For most parents these self-care behaviors focused on things like date nights, hiring someone to stay with their child to give them a break, and having time away as a couple.

*Health.* Previous research has described how raising a child with special needs can have a negative effect on parents' health. Almost half of the parents in one study indicated that their health had been negatively impacted the year prior to the study. These parents indicated that the cause of their health decline was directly related to their caregiving responsibilities for their disabled child. The effects of those demands were not limited to the parents' physical health, but also had detrimental effects on their mental and emotional health as well (Murphy, Christian, Caplin, & Young, 2007). The physical and emotional demands of caring for a child with ASD have been found to affect both mothers and fathers. Although in different ways, the effects for both have included symptoms such as sleep deprivation, fatigue, and distraction to the point that it can compromise parental well-being and negatively impact the quality of the care they provide for their child (Johnson, Frenn, Feetham, & Simpson, 2011; Koshti-Richman, 2009; Smith et al., 2010).

Half of the participants in this study did not feel they had experienced any health related challenges as a result of the stress associated with raising their child with ASD. For those who felt they had experienced health issues related to their child's diagnosis or indicated they had engaged in specific behaviors to prevent health challenges, self-care was the primary category of behaviors endorsed. Self-care behaviors ranged from



physical health care such as exercise, nutrition, and medical treatment when needed, to other self-care activities intended to address mental, emotional, and spiritual health with behaviors such as seeing a therapist, spending time with friends, or participation in church or spiritual groups.

*Social.* Friendship and social support have been indicated as mitigating factors that can help parents of children with ASD better manage the stressors associated with their child's diagnosis (Koshti-Richman, 2009). Unfortunately, feelings of isolation, loneliness, and lack of connection to others are common issues that many of these parents have dealt with on a regular basis (Hames & Rollings, 2009). The potential causal factors for feelings of social isolation are many, but are often related to the child's need for predictability and structure, or their challenges with social skills and interactions (Brewster & Coleyshaw, 2011).

While not very surprising, participants who indicated they had experienced social isolation as a result of their child's ASD indicated that behaviors associated with social involvement were the most frequent manner of response to try to alleviate the isolation. Many of their responses indicated actively pursuing social relationships rather than passively waiting on opportunities or for other people to take the initiative. Social involvement behaviors included activities such as intentionally maintaining existing social relationships and purposefully pursuing new relationships. Participants also indicated that participating in group events, which were categorized as organized activities, helped to diminish their feelings of social isolation. Some of the organized activities where social needs were met included church events, spending time with other parents from their child's sports team, or even hobby based community activities.

*Financial.* The monetary burden associated with raising a child with a disability has been shown to be significant, and as such, has been described as one of the most significant concerns for parents of children with a disability (Koshti-Richman, 2009). Many of the expenses unique to raising a child with ASD were found to be out-of-pocket costs because they were not covered by traditional health insurance (Jarbrink, Fombonne, & Knapp, 2003). Other research has reported that the lifetime costs of raising a child with ASD far exceed those of raising a child without ASD (Ganz, 2006).

Since many of the participants in this study did not experience some of the financial difficulties identified as common in previous literature, not as many behaviors were reported in this domain. Some of this was due to parents who reported that they had significant income levels or that their insurance was adequate to meet many of their child's needs, or perhaps both. Those who did indicate the need to engage in behaviors aimed at dealing with financial struggles associated with their child's needs reported behaviors related to the categories of adaptability, and the need to seek or accept outside support. Reports of adaptability typically required the participants to alter some aspect of their lives, such as number of work hours, income, or even giving something up in order to meet the financial need. Outside support, as the name suggests, indicated behaviors like asking for or being willing to accept assistance from individuals or agencies such as scholarships or financial assistance programs.

*Schedule.* A significant lack of available time was identified as a common issue for many parents of children with ASD. This lack of time was often related to the abundant responsibilities and time demands associated with treatment and caregiving responsibilities. These duties made scheduling necessary appointments and activities

difficult, but also created problems in other domains as the stress of time demands impacted parents health as well (Sawyer et al., 2010).

Like some of the previous domains, the scheduling domain was also one in which many of the participants indicated they were not acutely familiar with that particular challenge. Those who were familiar described helpful behaviors mostly associated with the behavioral category of adaptability. Some reported behaviors such as changing their work schedule to meet their time demands, or alternating shifts with their spouse so that one of them would be available to get the child to the necessary appointments. Others mentioned behaviors related to organization and time management, which were categorized as planning behaviors. These activities had to do with things like keeping a schedule and preparing ahead of time to be where they needed to be.

### **Focus Groups.**

In order to facilitate maximum participation, three separate focus groups were held in an attempt to accommodate the varied schedules and geographic separation that existed between the participants. Even so, less than half of the participants were able to attend a focus group session. Those who did attend were able to interact and provided many of the same answers to the question they had provided during the interviews. However, some of them also responded with some unique answers, possibly as a result of the group interaction and having previously forgotten details brought to mind by the discussion format and the responses of other participants.

Responses provided by a participant during their focus group that matched the response they provided during the interviews were excluded from the categorization and overall tally of responses in order to prevent those answers from being counted twice and

artificially inflating the count for those categories. After duplicate answers were removed, four categories of response tied for most frequent. Those categories were adaptability, communication, outside support, and self-care. Behaviors of adaptability, outside support, and self-care have already been described and illustrated. As a category, communication was used to identify behaviors that involved proactively expressing and listening to thoughts, ideas, emotions, and needs. Specific communication behaviors were described by participants as helping them to be more effective in the marriage, finances, and scheduling domains. This included things like honesty with their spouse, openly discussing and even problem solving with financial matters, and talking about schedules and timing, as well as planning how to meet all of the time demands.

### **Implications**

Since no prior research was found to have addressed the same topic or the specific issues addressed in this study, the results do not confirm or contradict previous studies. Instead, the results of this study include new information to be implemented, analyzed, and further clarified going forward. Previous research was beneficial to this current study in providing information about typical presentations of ASD, confirmation of the issues commonly faced by parents of children with ASD, and the effects of those issues on parents and children. The implications for the data collected in this study involve the application of the information by those who stand to benefit from its use, and in guiding future research to further refine the results.

While it could be argued that the behaviors reported in this study could contribute to parental effectiveness in raising any child, whether or not they are impacted by a special need, these behaviors were specifically identified as being effective in raising

children with autism. Because these are behaviors that were specifically identified by parents in response to the special needs of their children with ASD, it could be that these are some of the more important behaviors for raising a child with ASD when considered against all of the possible effective and positive behaviors that a typical parent employs. Additionally, it may be that these behaviors are simply needed in greater quantity and frequency for parents of children with ASD.

Cohen (2011) indicated that more therapeutic intervention early in the life of the child has been shown to be more effective. Osborne, McHugh, Saunders, & Reed (2008) also indicated that early interventions for children with ASD increased the level of improvement they experienced. However, high levels of parent stress were identified as a factor that reduced the child's level of improvement. Therefore, if parents of younger children with ASD were to implement some of the effective behaviors identified in this research, gains could be possible for both parents and children. For example, parents who employ strategies contained in this study to help them with the financial and scheduling difficulties associated with raising a child with ASD, may discover greater availability of time and money to provide their children with more frequent access to effective treatments early in life. Additionally, by incorporating these effective behaviors into their own routines, these parents may experience lower levels of personal and situational stress and effectively reduce the degree to which their own situation and behaviors limit the progress of their child.

Additionally, if applied, these behaviors identified in the lives of experienced parents of children with ASD could help to provide new parents with expectations that are more realistic, thereby limiting the amount of unanticipated change and readjustment

required, and diminishing the amount of “trial and error” parenting described by several of the participants in this study. Furthermore, by providing areas to focus their effort and guidance as to where to foster particular behaviors, parents of children newly diagnosed with ASD can be more aware, and therefore better prepared for the challenges they will face related to their child’s diagnosis and presentation, as well as to the stressors they will likely encounter.

Application of the data collected here appears possible in two primary methods. The first being a responsive manner in which a parent could identify a particular challenge they are experiencing in raising their child with ASD, and then incorporate the behaviors identified as effective in this study into their own behavioral responses. For example, marital relationships have been identified as being particularly vulnerable to the stress related to raising a child with ASD (Ramisch, Timm, Hock, & Topor, 2013). For parents experiencing the stress in their marriage, the application of effective behaviors identified in this research could be used to alleviate some of the stress they experience.

A second means of application of this data could take place in a preventative fashion in which parents who are not yet experiencing difficulty in a particular domain could implement the behaviors identified in this research in an effort to prevent or lessen the negative impact in their lives and in the life of their child. For example, Koshti-Richman (2009) indicated in previous research that parents health can be negatively impacted through a lack of rest and sleep deprivation. With this information, new parents of a child with ASD could prepare by arranging for respite care or other schedule adaptations to allow for increased opportunities for sleep.

Similarly, for treatment providers, teaching these behaviors where they are missing and affirming them where they are present could prove beneficial for other parents of children with ASD. Additionally, using this data to normalize the experience of parents could also prove useful. For parents who may be asking themselves questions about whether or not they are making any progress, or if there is any hope for their situation to improve, this information could be very beneficial for restoring hope and helping to set realistic expectations for change and improvement. Social isolation was described by Estrella (2013) as an ongoing issue for parents, and previous research has indicated that parental support groups are a useful resource for parents feeling lonely and isolated, as well as a place to connect with resources and information to aid in parenting (Hames & Rollings, 2009). As such, these groups are a resource that knowledgeable treatment providers should be willing and able to refer and help parents connect with due to the potential benefit for parents as well as for their children. These types of groups can provide a connection that will allow parents to actively pursue relationships and social support as described by participants in this study.

### **Strengths of this Study**

In spite of the fact that there was very little time to build rapport with the participants, all appeared very willing to share their experiences and their stories of life with a child impacted by ASD. The level of participation and willingness to be involved in a study where they shared both the successes as well as the struggles associated with raising a special needs child, was helpful to the purpose of study, and at times the candid and transparent participation of the participants was even surprising.

These interviews and focus groups produced a significant amount of first person narrative data describing both the experiences and the behaviors of the parents. Many of the behaviors shared by the participants were specifically targeted at ways to respond to the domains that were previously identified as being areas that were particularly stressful for parents raising children with ASD.

### **Limitations of this Study**

While this research produced a substantial amount of narrative data and gathered the voices of individuals who have a combined 327 years of experience in the area of raising a child with ASD, several limitations became apparent through the data gathering and analysis process. While these limitations do not negate the accuracy or utility of the results, they do provide some direction for improving the quality of data gathered in future research.

Previous studies indicated that many parents of children with ASD experience a significant financial burden related to the costs of treatments, schooling, and other care related activities for their children. Many of the participants in the current study reported that they were not able to identify with this financial burden aspect. This may be due, in part, to the fact that all of the participants live in a region with a higher than average income and standard of living, and many of the participants were employed by large technology, engineering, or biotech companies with above average wages. Additionally, because the participants were recruited by an autism treatment provider who does not bill insurance for services, many of the clients who receive services from the provider are either private pay clients who can afford to pay out of pocket, or they may submit their payment invoice to their insurance company directly for what is often only a partial



reimbursement. This factor may have limited participants to a higher than average income level and socioeconomic status, thereby effectively reducing the severity of the financial burden they experienced, if any.

Earlier research indicated scheduling challenges as another significant difficulty for many parents. For this study, most of the participants were parents of adult children. Because many of their children were experiencing the childhood effects of autism at a time when autism was not understood as well as in present day, there were not as many treatment options available for many of the participants. For this reason, it appears that many of the participants did not experience to the same degree, the scheduling challenges of getting their children to multiple treatment providers for various therapies. Additionally, because some of the parents reported that their children were not diagnosed with autism until later in life, some even well into adulthood, the parents did not know exactly what they were dealing with, and therefore did not expend as much time and money on treatments and therapies as many parents with younger children on the spectrum. For these reasons, it seems that some of these participants were not able to speak to the challenges of scheduling and finances to the same degree that some of the other participants were.

Even though the goals of participant interaction and identification of unique responses were both achieved during the focus groups, limited attendance during the focus groups did not allow for actual focus group dynamics in the quantity of interactions or the number of responses that were anticipated. While interaction did take place, even in the groups where only two participants attended, more interaction may have provided additional responses useful to this research.

Another apparent limitation of this study was the fact that almost all of the participants described their children as being on the high-functioning end of the autism spectrum. While this does not mean that these parents had it easy, or that the information they provided is irrelevant, rather it simply limits the scope of the input provided such that it does not include the voices of parents of children with more significant disability, such as many who are at the lower functioning end of the autism spectrum.

Finally, some of the attitude-based and values-based responses such as gratitude, positivity, faith, and patience, were identified in some of the participant's responses, but were not mentioned frequently. This may have been partially due to the fact that some of the participants may not identify these as behaviors and therefore omitted describing some of their own values and attitudes that helped them to be more effective in raising their child with ASD.

### **Recommendations for Further Research**

In gathering these voices of experienced parents of children with ASD, it seems that this research has resulted in an initial body of data that could be useful to new parents or parents of younger children with ASD. To increase the quality and relevance of the data, repeating this research with a larger sample size could provide opportunity for more viewpoints to be expressed and a larger quantity of relevant skills to be gathered.

As a part of gathering a larger sample, intentionally including parents of children on the lower functioning end of the spectrum could further augment the applicability of the results. This would allow for the identification of effective parenting behaviors that

could be helpful in the unique aspects experienced by parents raising children with more significant behavioral and communication difficulties.

As discussed in the limitations section, the relative geographic and socioeconomic homogeneity observed in this sample could be addressed in future research by collecting data from a more economically and geographically diverse population. Similarly, future research limiting the group of participants to those having children between the ages of 15 and 20 years old, and from a broader variety of ASD presentations, but who were all diagnosed at an early age, could also broaden the scope of potential experiences while narrowing the applicability of the data received. Furthermore, by targeting participants of children in the 15 to 20 year old range, it seems likely that more of them will have been diagnosed at an earlier age, giving the parents greater context and more autism specific experience to draw from in describing their experiences and behaviors.

Additionally, in repeating a study of this nature, using a survey-based method for data collection could also narrow the range of responses to be more directly applicable to the questions asked. Since parents would be able to see and review the question in print prior to and during the process of providing their answer, more specific and directly applicable answers may be received. Similarly, because participants would be providing their answers in a written format, it seems probable that participants would be less likely to veer off topic and discuss experiences, background, and other contextual information. However, because the experiences, background, and contextual information are also deemed to have value, a separate study focused on gathering those experiential responses could be undertaken to identify common experiences of parents raising a child with ASD,

which could also be useful in preparing new parents beginning their journey of raising a child with ASD.

Since the attitudes and values of these participants were only peripherally addressed in this study, more research on this topic may identify other areas beneficial to parents of children with ASD. In order to accomplish this, research specifically designed to identify and measure the prevalence of the attitudes and values that help parents to be more effective in raising a child with ASD could provide additional useful information for parents and practitioners.

### **Conclusions**

Based on the responses provided by the participants in this study, experienced parents of children with ASD who were well acquainted with the struggles and challenges of parenting a child with special needs, there appeared to be several categories of behaviors that were much more frequently endorsed as effective behaviors. Other parents who are currently, or at some future time, will be raising a child with ASD could explore the use of these behaviors in their efforts to teach and prepare their child for the most independent and successful future they are capable of achieving.

As the results of this study indicated, behaviors associated with adaptability were endorsed more frequently than any other category. Adapting to changing situations, emerging needs, and challenging expectations, appeared to be a necessary behavior category identified by almost all of the parents in this study. Similarly, behaviors related to actively teaching their child appropriate interactions, ways to cope, social skills, and other needed information was frequently reported as an effective behavior category. While seeking and being willing to accept support and assistance from outside sources

may be a struggle for some, these parents identified this behavior as another commonly engaged in behavior that helped them to be more effective as parents. For the benefit of the parents, as well as for the child's benefit, behaviors associated with self-care were identified as necessary to the physical, emotional, and spiritual well-being of the parents. Effective communication was identified as another helpful behavior category that allowed parents to be more effective in their parenting and in their relationships with their child, their spouse, and with other individuals relevant to the care of the child and the functioning of the family. Additionally, seeking out and participating in organized activities related to social involvement was identified as a response of substantial benefit to these parents for developing and maintaining social support. Collaboration was reported as useful in the efforts to address specific challenges in a cooperative effort with the participants spouse or other caregivers. Behaviors related to setting and maintaining effective boundaries at home were also reported to increase parental effectiveness and support both the caregiver and the child.

Responses from these eight behavioral categories represented more than half of all of the responses given by the participants in this study. While the other response categories (see Figure 4) were also identified as effective behaviors by the participants as well and could be of great benefit to other parents, the purpose of this study was to identify the most common effective behaviors of parents raising a child with ASD.

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APPENDIX A  
INTERVIEW GUIDE

### **Interview Guide**

Tell me what it's like to be a parent of a child with ASD.

In what ways has your family been impacted due to having a child with ASD?

What areas of your life have been most significantly impacted?

In what ways do you feel you have been effective in parenting your child with ASD?

What are things you have done that have contributed to your effectiveness as a parent?

If married, what have you done to help improve your marital relationship?

If you have had any health challenges, what have you done that has helped you cope with  
or overcome them?

If you have experienced scheduling difficulties related to your child's needs, what have  
you done that has helped you overcome those difficulties?

If you have experienced financial challenges related to your child's needs, what have you  
done that has helped you overcome those financial challenges?

If you have experienced social involvement difficulties related to your child's needs,  
what have you done that has benefited your social life and relationships?

What have you done that has helped your child improve in the areas where they are  
impacted by ASD?

APPENDIX B

FOCUS GROUP DISCUSSION GUIDE



### **Focus Group Discussion Guide**

Topics:

Marriage and ASD.

Health and ASD.

Finances and ASD.

Social isolation and ASD.

Scheduling and ASD.

What are things you have done that have contributed to your effectiveness as a parent?

APPENDIX C

DISCLOSURE AND CONSENT FORM

**DISCLOSURE & CONSENT FOR PARTICIPATION**

M. PAUL CURD

DOCTOR OF PSYCHOLOGY STUDENT

at

NORTHWEST UNIVERSITY

Under the supervision of Dr. Jacqueline Gustafson

5520 108th Avenue NE, Kirkland, WA 98033

425.822.8266

Effective Behaviors of Parents Raising a Child with an Autism Spectrum Disorder  
Consent Form  
Doctoral Dissertation, Northwest University  
M. Paul Curd

You are invited to participate in a research study conducted by Paul Curd, M.A., Psy.D. Candidate, at Northwest University. The study is being conducted as a degree requirement for the Doctor of Psychology program. The purpose of this study is to determine if there are common behaviors among parents raising a child with ASD that could contribute to their effectiveness in parenting, and if so, what those behaviors are.

If you agree to participate in the study you will take part in an interview to be recorded, and participate in a focus group discussion, which will also be recorded. Total time investment on your part will likely take approximately 3 hours or less.

There are minimal risks associated with participation. Some individuals may be uncomfortable answering personal questions. You may choose not to participate in this research study. Anticipated risks for participation in this study are minimal. The study is solely comprised of data collection and analysis. There are no anticipated risks to physical safety that are over and above those associated with most people's day to day lives. Anticipated risk to psychological health could include the possible elicitation of stress or anxiety due to the recalling and describing of previously stressful events, or mild interpersonal conflict if the retelling of an event differs from a family members memory of the event. Finally, the breach of confidentiality is considered to be at minimal risk since participants will be identified only by a number in the collection of the data and participant contact information will be kept separate from the gathered data and in a secured location. This study may increase the participants knowledge about effective behaviors of other parents raising a child with ASD. Additionally, the participants will

be provided with a research summary that will contain the results, conclusions, and limitations of the study.

Participation in this study is voluntary. You may choose not to participate in this study at any time and for any reason. Withdrawal from the study will not alter the support offered. There will not be any negative consequences for you if you refuse to participate. You may refuse to answer any questions asked. All responses are anonymous. You will be provided a copy of this consent form for your records. By signing this form, you are giving permission to use your responses in this research study.

The results from this study will be presented in the defense of the researchers doctoral dissertation. All data forms will be destroyed by October 2016.

If you have any questions about this study, contact Paul Curd at 253.797.9427 or by email at [paul.curd@northwestu.edu](mailto:paul.curd@northwestu.edu). If further questions, please contact my faculty advisor Dr. Forrest Inslee at [forrest.inslee@northwestu.edu](mailto:forrest.inslee@northwestu.edu). You may also contact the Chair of the Northwest University IRB, Jim Heugel, at [jim.heugel@northwestu.edu](mailto:jim.heugel@northwestu.edu) or 425-889-5237.

Thank you for your consideration of this request.

Paul Curd, MA, Psy.D. Candidate  
Dr. Forrest Inslee, PhD

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Participant name (print)

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Participant signature

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Witness name (print)

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Witness signature

Paul Curd

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Researcher name

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Researcher signature