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Caitlyn Bailey Gumaer
Claremont Graduate University

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APPROVAL OF THE DISSERTATION COMMITTEE

This dissertation has been duly read, reviewed, and critiqued by the Committee listed below, which hereby approves the manuscript of Caitlyn B. Gumaer as fulfilling the scope and quality requirements meriting the degree of Doctor of Philosophy in Psychology.

Marjorie H. Charlop, Chair
Claremont McKenna College
Professor

Kendall Cotton Bronk
Claremont Graduate University
Associate Professor

Tiffany Berry
Claremont Graduate University
Full Research Professor

Debra Berry Malmberg
California State University, Northridge
Associate Professor

Abstract

Needs Assessment of Parent Training Programs for Parents of Children with Autism Spectrum Disorder using a Phenomenological Approach

by
Caitlyn B. Gumaer

Claremont Graduate University: 2020

Parenting a child with autism spectrum disorder (ASD) is often associated with high stress, depression, anxiety, and reduced quality of life due to the ongoing nature of care (Seltzer, Krauss, Orsmond & Vestal, 2001; Evans, 2010). To remediate the difficulties that parents of children with ASD experience, parent training programs have become an integral and necessary component in the treatment of ASD. The most common type of parent training programs is behavioral parent training, based on the principles of ABA (Najdowski & Gould, 2014). Despite its advantages, researchers have found parent involvement in behavioral parent training to be more burdensome than beneficial; for some parents the demands and expectations are a source of stress. More recently, mindfulness-based parent training has been implemented with some success in reducing the stress of this population (Cachia, Anderson & Moore, 2015). However, parents often opt out of such programs because they want to learn more applied skills to manage their child's behaviors; these parental attitudes present a barrier for wide application of these programs. A review of the parent training literature indicates that parent programming is not sufficiently meeting the needs of parents (Cachia et al., 2015; Najdowski & Gould, 2014). To date, parent training research studies have examined either child-based outcomes or parent-based outcomes but never addressed these concerns simultaneously, despite the well-established connection between child behaviors and parent stress. Thus, there is a need to move toward more ecologically valid models of parent training programs that focus on parental and contextual

factors, while targeting both child and parent outcomes. From a developmental perspective, the Bioecological Model of Human Development (Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006) recognizes the complex, reciprocal relationship between parent and child that occurs in many contexts (e.g., within the family, in the home and community). In order to better meet the needs of this population it might be imperative to view the parent-child relationship within the broader familial context, or to create a good "contextual fit" between parent training and the family context. In light of the shortcomings of the current parent training models, a needs assessment of parent training programs should be conducted to better understand the lived experiences of parents of children with ASD and provide clear recommendations for future programming. Using a qualitative research design, the purpose of the present study was to examine parents' lived experiences while placing them in a relational, ecological context, assess factors and supports that will influence the effectiveness of parent training programming, and provide recommendations to help future practitioners determine what kind of parent training programs that parents of children with ASD may find useful. Self-report measures, semi-structured observations, and semi-structured, open-ended interviews were used to conduct a needs assessment of parent training programs using a phenomenological approach. The findings of the present study highlighted the unique experiences and confirm the known ways that parents of children with ASD experience autism and the ways that healthcare providers can support them. Similar to previous research, it was found that parents of children with ASD experience significant stress related to their parenting experience, and that ASD impacts many facets of day-to-day life including family functioning, marital relationships, siblings, and social contexts. Additionally, parents reported a need for parent training programming. They explicitly communicated their needs for behavioral parent training (i.e., learning how to engage their child and manage the child's more challenging behaviors), parent education (i.e., resources and information related to various aspects of ASD), and support (i.e., talking with other parents, voicing their concerns). Parents are in need of effective behavior management strategies and coping strategies, especially to address parental stress. Interestingly, new information was obtained that was not reported in previous literature. First, parents reported their experiences with grief throughout the child's lifespan. Parents reported experiencing grief and a sense of loss each time they were faced with developmental milestones that are not being reached by their child with ASD. Second, parents reported a need for support and programs for typically-developing siblings; parents reported concerns with the adjustment of their neurotypical children. Parents specifically reported a need for sibling programming with groups dedicated to typically-developing siblings to share their experiences, ask questions, and receive guidance on interacting with their sibling with ASD. Third, parents reported their need for more family-focused or family-orientated parent training programming; specifically, parents expressed wanting providers to view the parent-child dyad in their home context and within their family environment, and to create treatment plans and goals that fit the family context. Lastly, parents reported that their needs in future parent programming should consist of a mix of informal support systems (i.e., other parents of ASD) and formal support systems (i.e., healthcare providers). This recommendation supports the need for more collaborative efforts between practitioners and parents in parent programming. In conclusion, this needs assessment provides recommendations for sibling support programming given the unique experiences of neurotypical siblings of ASD. Additionally, this needs assessment provides recommendations for parent training programs that are ecologically-valid by considering the family context as well as focusing on equipping parents with the skills to cope and manage their stress by incorporating mindfulness-based strategies,

teaching behavior management skills, and providing both formal and informal support. Overall, the researcher suggests that a collaborative and integrated behavioral- and mindfulness-based model may be effective in meeting parent, family, and the child with ASD's needs. However, further research is needed to assess the effectiveness of this integrated parent training model.

Keywords: autism spectrum disorder (ASD), parent training, Applied Behavior Analysis (ABA), Mindful Parenting

Dedication

I dedicate this dissertation to my own parents, Vincent and Maria Gumaer; everything I am I owe to you. Also, to my cradle-to grave, my big sister, Dennica; thank you for setting an example to aspire to. This is also dedicated to all the parents and families of the Claremont Autism Center; thank you for allowing me to be a small part of your lives. Of course, to the children of the Claremont Autism Center; you have been the very best parts of this journey. And lastly, this is dedicated to the original parent-child dyad that set me on this path almost 15 years ago: M & A.

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Table of Contents

Index of Tables and Figures

CHAPTER 1

Introduction

Parenting, by general consensus is a rewarding but stressful challenge (Deater-Deckard, 2006; Pew Research Center, 2015). From childbirth onward, parenthood presents new challenges and rewards, but for some, these new demands carry some risk for stress that can lead to decrements in psychological health and well-being. Lower stress in the parenting role has been found to be critically important for both positive parent and child outcomes (Deater-Deckard, 2006). Conversely, psychological distress that arises from the demands of parenting has been shown to be an important risk factor for child development outcomes and a particularly important aspect of the development of dysfunctional parent-child relationships (Deater-Deckard, 2006). Thus, parenting stress directly impacts parenting behavior and child adjustment.

Parenting stress can be experienced as negative feelings toward the self and child, which is directly attributable to the demands and challenges of parenthood. In its simplest definition, parenting stress is the experience of distress or discomfort that results from the demands associated with the parenting role. It has been defined as the aversive psychological reaction to the demands of being a parent (Deater-Deckard, 2006). It is represented as a complex process linking (a) the task demands of parenting, (b) the parents' psychological well-being and behavior, (c) the qualities of the parent-child relationship, and (d) the child's psychosocial adjustment (Deater-Deckard, 2006). Parenting stress is a process, and it develops and changes over time within an enduring parent-child relationship (Deater-Deckard, 2004). It is a relationship in which the parent and child are co-contributors, with each influencing the other.

Parents and caregivers exert significant influence on their child's developmental trajectory and developmental outcomes. Parents influence their child's life at all times, both directly and indirectly, beginning formally during or after pregnancy and continuing throughout the lifespan (Lerner, Jacobs & Wetlieb, 2005). Research has found that that parent-child interactions and parent responsiveness are important contributing factors to the developmental outcomes that children attain, and account for a significant portion of the variability in children's developmental outcomes (Mahoney & Perales, 2003, 2005). Parental responsiveness has been identified as the primary characteristic that influences a child's cognitive, language and communication, and social-emotional development (Mahoney & Perales, 2003, 2005). Simply put, parents are active participants in the development of their children.

Parenting is often thought of as the behavior that a parent directs toward a child, and that the child "receives." However, parenting is not that simple as children influence the feelings, thoughts, and behaviors of parents (Bell & Chapman, 1986). The parent-child relationship is not unidirectional. From a developmental systems perspective, a child's development is inherently bidirectional and is the product of constantly changing interactions between the developing child and their environments (Lerner, 1991; Lerner et al., 2005). Development is a complex process that occurs because of the bidirectional and reciprocal relationships between the developing child and the stimuli in their environments; these interactions between the developing child and the stimuli in their environment are the mechanisms that produce development (Bronfenbrenner, 2000; Bronfenbrenner & Morris, 2006). Children are embedded within a developmental system that is comprised of many variables that not only influence their behavior and development, but also the behavior of those who raise them (e.g., Skinner, 1953; Lerner, 1991). While parents influence their child's life at all times, both directly and indirectly, the child in turn influences their parent's life at all times, both directly and indirectly. Parenting behavior and beliefs are strongly influenced and impacted by the developing child, from how parents view their child to their child's behaviors, personality, and development (Lerner et al., 2005). More broadly, children actively shape the nature of their social contexts (Miller, 2011). Thus, parents and children are active participants in their relationships and interactions, which influences the development of the child, and the parent's stress and well-being.

The transition to parenthood is stressful for nearly every parent. This transition involves dramatic shifts in feelings, thinking, behavior, relationships, and lifestyle (Deater-Deckard, 2004). Early in the child's life, parents may experience acute stress as the child is dependent on the parent. These early demands of parenting are stress-inducing, but they must be in order for the child to survive; infants and young children require immediate and constant care. When the parent-child relationship is functioning in a healthy and adaptive way, the child's demanding behaviors are a highly effective means of getting needs met long before the child is able to help herself/himself. Although parents experience acute stress early in the child's life as children are intensely dependent, parents experience stress across the child's lifespan. While children's abilities to care for themselves develop in time, this process takes years. Old demands are replaced with new ones that continue to present potentially stressful experiences for parents (Deater-Deckard, 2004). Some have found that parenting stress levels can increase over time as the child ages and enters adolescence. According to the US Department of Health and Human Resources (2014), parents of 12- to 17-year-olds experience significantly more stress than parents have children aged 0-5 years. As children age, parents are faced with new challenges and stressors: children entering school, interactions with peers, participation in extracurricular activities, and a growing sense of autonomy and independence. These challenges and stressors persist as youth enter adolescence, a period that is often marked by extreme emotions and angst (Villanueva, 2015). Adolescence can be an extremely stressful time for parents as the quality of the parent-child relationship may be strained, however, parental stress does begin to decline as their children move into late adolescence and early adulthood. For a parent, challenges will be present throughout a child's lifespan, but certain stressors are specifically associated with distinct developmental stages (White, McMorris, Weiss & Lunksy, 2011). Additionally, parenthood is considered an experience that covers the entire lifespan of the parent-child relationship; parents do not stop influencing or being influenced by their children, even once they are adults and living on their own (Deater-Deckard, 2004). Thus, parenting stress may always be present.

While all parents experience stress at some point (Cameron et al., 1992), parenting stress can be intensified by a child's additional needs (Burrell & Borrego, 2012). Parents of children diagnosed with a disability experience significantly more stress than families of typically-developing children (Hayes & Waston, 2012). Simply put, child-based factors, beyond the child's age, contribute to parenting stress (Bell & Chapman, 1986; Neece et al., 2012; Sameroff & Chandler, 1975). Moreover, considering the inherent bidirectionality of parent-child interactions, parenting stress can exacerbate child-based factors (Osborne, McHugh, Saunders & Reed, 2008; Patterson, 1982). Consequently, for all parents but parents of children with special needs, child-based factors significantly impact parenting stress and thus, children's developmental outcomes.

For parents of children with autism spectrum disorder (ASD; American Psychological Association, 2013), the challenge is considerably increased as the diagnosis presents significant and unique demands and stressors beyond typical parenting stress (Evans, 2010). ASD is a complex neurodevelopmental disorder characterized by impairments in social communication and interaction paired with restrictive and repetitive behaviors, which often results in restricted independence and ongoing care demands (Lecavalier, Leone & Wiltz, 2006). Having a child with ASD presents a distinctive set of challenges that impacts the entire family unit and individual family members' health, well-being, and experiences across the lifespan (Patterson, 2005; Turnbull, Turnbull, Erwin & Soodak, 2006). More specifically for parents, research continues to find that child characteristics and ASD symptom severity are strongly associated with the experience of parenting stress (e.g., Brobst, Clopton & Hendrick, 2009; Ekas & Whitman, 2010; Estes et al., 2009: Lecavalier et al., 2006; Tomanik, Harris & Hawkins, 2009). Additionally, as a pervasive, life-long disorder, parental stress is present across the child's lifespan: from infancy to middle childhood to adolescence, and even into adulthood.

Parents of Children with ASD

More than 90% of parents of children with ASD experience substantial parenting stress (deBruin et al., 2014; Nikmat et al., 2008) specific to the tasks and demands of raising a child on the spectrum (Hayes & Watson, 2013; Seltzer et al., 2004). The key diagnostic traits (i.e., impairments in social communication and interaction, and repetitive, restricted interests or behaviors) of ASD are particularly stressful (Bebko, Konstantareas, & Springer, 1987; Davis & Carter, 2008; Gabriels et al., 2005). Moreover, the presence of maladaptive or challenging behaviors contribute to the overall experience of stress (Kasari & Sigman, 1997; Wolf, Noh, Fisman & Speechley, 1989). Thus, parents of children with ASD are considered among the most stressed parents in society (Cachia, 2017).

While ASD is one of the most demanding disorders in terms of threats to parents' well-being and mental health (Seltzer, Krauss, Orsmond & Vestal, 2001), the severity of parenting stress and other mental health issues does vary. Specifically, parents' ability to successfully respond to the challenges and demands of raising a child on the spectrum can moderate parenting stress. Some parents report experiencing significant mental health problems while others report experiencing few of these difficulties (Benson, 2009; Costa, Steffgen & Ferring, 2017; Lazarus

& Folkman, 1984). However, in a recent research study, it was found that the impact of intellectual disability was distinct from the impact of ASD and that higher intellectual functioning of the diagnosed child did not appear to moderate a family's experience of stress (Rao & Beidel, 2009; Totskia et al., 2011). Therefore, any family with a child with ASD may be at increased risk for parenting stress.

Parental stress in this population is specific to the demands and challenges of an ASD diagnosis, which often results in restricted independence and ongoing care demands (Lecavalier et al., 2006). Children with ASD have more needs, such as physical care, financial, and social demands; parental stress may be due to child dependency, physical limitations, cognitive impairment, caregiving responsibilities, interference in daily activities, and long-term childcaring responsibilities (Bouma & Schweitzer, 1990; Koegel et al., 1992). Research suggests that parenting stress is directly associated with the perception of the severity of the child's disability and behavior problems (Brobst et al., 2009). More specifically, parents' own perceptions directly influence parenting stress and parenting behaviors. For example, embarrassment about the severity of their child's behavioral problems could prevent parents from approaching support services or seeking informal support from family members (Gray, 1993). Additionally, despite improvements in the awareness and acceptance of ASD, a diagnosis is still highly stigmatizing that often results in parent's grieving for the loss of the "hoped for" child (Ariel & Naseef, 2006; Blacher, 1984), and blaming themselves for their child's diagnosis. This stigmatization could stem from the early theories relating the disorder to poor parenting. Thus, parents might experience stress, anxiety, and isolation related to their inability to control their child, who in most cases appears to be physically normal (Martinez-Pedraza & Carter, 2009). Due to the ongoing nature of care specific to ASD, parental stress can be present across the child's lifespan.

Furthermore, research has found that having a child with ASD presents a distinctive set of challenges that impacts a parent's health, well-being, and experiences across the lifespan (Patterson, 2005; Seltzer, Krauss, Orsmond & Vestal, 2001; Turnbull, Turnbull, Erwin & Soodak, 2006). Parents often report reduced quality of life, high stress and parental burnout, feelings of isolation, and depression and anxiety (Cachia, Anderson & Moore, 2015; Dempsey, Keen, Pennell, O'Reilly & Neilands, 2008). Notably, parents of children with ASD experience significantly higher stress levels than parents of typically-developing children (Bitsika & Sharpley, 2004; Dumas et al., 1991; Estes et al., 2009), and parents of children with other developmental disabilities (Abbeduto et al., 2004; Dabrowska & Pisula, 2010; Dumas et al., 1991). Thus, parents of children with ASD are considered among the most stressed and at-risk parents in society.

Moreover, parental stress can have a direct impact on a child's psychological well-being, adjustment, behaviors, and overall developmental outcomes. High parenting stress is an important environmental risk factor (Neece, Green & Baker, 2012) as it can significantly impact a parent's ability to manage their child's behavior (Osborne et al., 2008; Symon, 2001), increase child behavior problems (Baker et al., 2013), increase negative parent-child interactions (Solomon, Ono, Timmer & Goodlin-Jones, 2008), and impede a child's development (Symon, 2001). Thus, parental stress can significantly impact both the parent and child in negative ways.

Sources of Parenting Stress

Parents of children with ASD encounter a number of challenges that are specific to raising a child with autism, such as coming to terms with their child's diagnosis and the stigma surrounding the diagnostic label, their child's personal attributes (i.e., presence of ASD symptomology, maladaptive behaviors), issues with support and satisfaction with services, perceptions of their child's treatment and future outcomes, and the impact of ASD on family members and overall family functioning.

Diagnosis of ASD. Caring for a child with ASD is associated with high levels of parental stress and increased burden across a child's lifespan, however, the research indicates that the most difficult time for parents is when receiving the diagnosis for their child (Deater-Deckard, 2004). This period is marked with increased distress as parents are faced with the realization that their child may not develop typically (Blacher, 1984) and is often followed by a period of mourning or grief for the "loss" of their "hoped-for" child (Fernandez-Alacantara et al., 2016). Research also demonstrates that many parents are dissatisfied with the diagnostic process (Howlin & Moore, 1997; Vostanis, Smith, Chung & Corbett, 1994), which has been attributed to delayed diagnosis or misdiagnosis due to the complexity of the syndrome (Smith et. al., 1994).

According to Deater-Deckard (2003), the impact of testing and diagnosis on parental stress and coping interacts with parents' expectations about and explanations for the most likely outcomes. For parents, accepting the diagnosis is associated with better parental adjustment, whereas resistance to or denial of the diagnosis is more likely to result in greater distress in the long-term. Dissatisfaction with the disclosure of a diagnosis may be inevitable for parents who have to come to terms with the fact that their child has a disability of some sort, but the literature has shown that parents of children diagnosed with ASDs are unhappier about the disclosure than parents of children diagnosed with other conditions (Sloper & Turner, 1993). An important distinction between parents of children with ASD and the parents of children with other disabilities is parents' perceptions of casual beliefs: parents of children with ASD appear to have distinctive causal beliefs about their child's condition, which places some responsibility for the disorder on themselves (Evans, 2010). Furthermore, the process may be particularly difficult for parents because a diagnosis of ASD may still carry negative connotations associated with the condition in the past (Wakschlag & Leventhal, 1996), despite the rise of awareness in recent years. A diagnosis of ASD may be more difficult for parents to accept as there is a social stigma regarding the behaviors of children with ASD, such as tantruming, self-injurious behaviors, and stereotypy. Parents' expectations and perceptions involving perceived and actual stigmatization of their children are crucial (Hall, Bobrow & Marteau, 1997, 2000; Sheeran, Marvin & Pianta, 1997) in their acceptance of the diagnosis.

Additionally, due to the complex nature of ASD, families are at-risk for a misdiagnosis or delayed diagnosis. There is a higher risk of misdiagnosis among children with ASD when compared to children with other mental and physical disabilities (Van Schalkwyk et al., 2014). Misdiagnosis is a risk as ASD is often presented alongside other behavior or developmental symptoms, such as intellectual disability (Bonde, 2000). Additionally, the possibilities for misdiagnosis are wide ranging because autism presents differently across the population making it difficult to identify, manage and treat. A delay in diagnosis, as ASDs are typically diagnosed later in a child's life, can lead to misattribution of behavior and/or inappropriate treatment (Mandell et. al., 2007) and can increase uncertainty among parents about their own parenting skills (Bailey, Skinner, Hatton & Roberts, 2000). The difficulties of the diagnostic process and the complex nature of ASD creates an environment for parents that can cultivate worry and uncertainty as they face difficulties associated with the diagnosis, problems with coming to terms with the child's diagnosis, limited child response to traditional services, co-occurrence of familial disabilities, broader family stressors, and lower expectations of the child's potential and of their own competence and self-efficacy.

To note, research indicates that parental adjustment improves over time following the child's diagnosis (Deater-Deckard, 2004). The outcome of testing and a diagnosis results in increased access to resources, ranging from information to social support to effective intervention and therapy. Ultimately, the goal of the diagnostic process and intervention is to accurately assess what needs to be done to minimize or eliminate the detrimental effects, and to provide resources that are necessary to achieve the desired outcomes for parents and children alike.

ASD: Symptomology & Maladaptive Behaviors. Characterized by deficits in social communication and social interaction, and repetitive and restricted behaviors, interests and/or activities (APA, 2013), parents have reported that these two key diagnostic traits are particularly stressful (Bebko et al., 1987; Davis & Carter, 2008; Gabriels et al., 2005). For example, a parent may not be able to understand what their child wants due to limited verbal skills, which can make parents feel inadequate in meeting their child's needs and ability to successfully parent. Some parents may avoid going out in public if their child engages in high rates of vocal and motor stereotypy as people often stare or comment on the child's behavior. Another example is a child's extreme fear of public bathrooms due to being overstimulated by automatic toilets flushing, automatic faucets running water, and automatic hand dryers humming, which makes using a public restroom impossible or can result in tantruming and elopement from the bathroom. For some, everyday tasks and routines are a battle that are easier to avoid or concede to, resulting in a reactive process that contributes to parents' stress. The severity and breadth of impairment varies widely across children with ASD, in general, the greater child impairment is accompanied by more parenting stress (Deater-Deckard, 2004). Parents of children with more severe impairments that persist over the child's lifetime show more signs of severe, chronic parenting stress (Deater-Deckard, 2004). Actually, researchers have found that the child's individual attributes, skills, limitations and problems are far more influential than any other predictor (i.e., age, gender, ethnicity) in predicting parental stress (Deater-Deckard, 2004).

Furthermore, the presence of maladaptive or challenging behaviors contributes to the overall experience of parental stress (Kasari & Sigman, 1997; Wolf, Noh, Fisman & Speechley, 1989) as these behaviors are often disruptive and hard to manage (Eisenhower et. al, 2005; Konstantareas & Homatidis, 1989). Stress is often heightened as the maladaptive behaviors associated with ASD can often place a considerable amount of restrictions upon a family; they can interfere with normal routines, such as shopping or holidays. Furthermore, high levels of parental stress can exacerbate the child's behaviors (Osborne, 2008), further contributing to the particular complexities of raising a child with ASD, as the behaviors associated with autism can be exceptionally challenging and difficult to manage. This may be the case because parents of ASD can experience further stressors due to having a child not only displaying externalizing behaviors, such as aggression, self-injury, pica, stereotypy, noncompliance, and property damage, but also a disability (Hastings, 2002). Children with ASD have impaired or limited social and communication skills, positioning them at even greater risk for developing problem behaviors that may lead to even greater parental stress (Borthwick-Duffy, 1996). Challenging behaviors are highly prevalent among children with ASDs. Serious forms of these behaviors, including those that cause harm to the person and others, are estimated to be present in 10% to 15% of this population (Lowe et. al., 2007).

An added stressor for parents of autism is that autistic spectrum disorders are lifelong disorders; the deficits associated with ASD and the presence of maladaptive behaviors are present across the child's lifespan. Parental stress is present across the child's age, from toddlerhood through middle childhood, adolescence, and into adulthood (Myers et. al., 2009).

Stigma & Perceptions of ASD. Researchers continually report that the stigma associated with ASD is a source of stress for parents (Papadopoulos, Lodder, Constantinou & Randhawa, 2019). A unique characteristic and challenge of ASD is the behavior-stigma connection: people with ASD look like everyone else (i.e., "normal") but may behave differently than expected (Gray, 1993). As Gray (1993) explained, "it is a unique combination of this pervasive disability and apparent physical normality that gives the sigma experienced by families with [children with ASD] its unique quality" (p. 114). Unlike children with physical disabilities, when children with ASD exhibit behavioral oddities (e.g., scripting television shows, hand-flapping or body rocking), it is not immediately clear to others that the child has a disability and people are more likely to stare or make comments. For example, if a child with ASD has a meltdown and tantrums in the middle of a grocery store because they look "normal," or it's not immediately known that they have ASD, people are more likely to stare or make comments toward parents about their "bad parenting" or "spoiled child." Rather than others understanding that the cause is ASD, parents are often stigmatized as bad parents who cannot control their child who looks normal. Whereas a child a physical disability or physical markers of a disability, such as Down Syndrome (i.e., genetic disorder that causes developmental and intellectual delays, and is marked by characteristic facial features; APA, 2013) tantruming in the grocery store is less likely to get stares and off-hand comments because there is an immediate explanation for the child's behavior.

Moreover, this behavior-stigma connection can place restrictions on the parent and interfere with normal routines. Parents are often stigmatized; they may be blamed for their child's behavior or that they lack competence in their caregiving role. This type of stigma can often lead to parents to being socially rejected (Gray, 1993; Papadopoulos et al., 2019). Parents of children with ASD often experience stress, anxiety, and isolation related to their inability to control their child, who in most cases appears to be physically normal (Martinez-Pedraza & Carter, 2009). This social isolation and rejection often extended to the family. Kinnear and colleagues (2015) found that 40% of parents reported that they isolated from friends and families because of their child with ASD's spectrum behaviors, and 32% reported that other people excluded them from social events and activities. Out of 502 parents, 80% reported that the stigma of ASD had been extremely, very, or somewhat difficult in their lives. One of the key contributing factors for parental stress and poor mental health outcomes for parents and caregivers is the stigma associated with ASD and the complex influence it has; research by Kinnear and colleagues (2015) found that the stigmatization of ASD plays a crucial role in how difficult life will be for parents overall.

Issues with Support. After receiving a diagnosis of ASD, parents enter a process of adaptation where they learn to adjust to the difficulties of raising a child with a lifelong impairment. It is crucial that parents adapt in order to meet the child's needs, nurture their own well-being and maintain coherence of the family unit (Deater-Deckard, 2004). Parents can adapt more successfully if they receive adequate levels of social support and appropriate levels of involvement in the child's life (Henderson & Vandenberg, 1992; Sanders & Morgan, 1997). However, parents often report dissatisfaction with formal and informal support.

Informal social support encompasses any information which makes individuals feel that they are cared for, and it manifests through a network of mutual obligation and communication (Cobb, 1976). Social support could include spousal support, extended family and friends, free time to engagement in leisure activities, professional help, involvement in community programs and the availability of services specifically for families with a disabled child (Siklos & Kerns, 2006). Of particular importance is the *quality* of support received by parents, rather than the quantity. The literature discusses several types of social support: formal and informal. Informal social support is defined as “a network that may include the immediate and extended family, friends, neighbors, and other parents of children with disabilities” (Schopler & Mesibov, 1984, p. 297). Whereas formal social support is services provided by an organized group or agency. Parents report that informal support provided the most assistance and were especially important when formal support opportunities (i.e., parent groups, services) were not available (Herman & Thompson, 1995).

Informal Support. Major sources of informal social supports for parents/caregivers of ASD are their spouses/partners, and support from family members outside the home, friends, and disorder specific support groups. Often, informal maternal support comes from the spouse or significant other, and as suggested by Herman & Thompson (1995), provides some of the most beneficial support. Parents also report that it is important to find friends who accept their child’s disability and help them lead a normal life (Gray, 1993). Konstantareas & Homatidis (1989) found that the stress levels of parents were negatively related to perceived level of social support, and many families with a child with ASD may require outside help to combat stress. Disorder specific groups form part of social support for parents of children with a disability; people who attend support groups typically report high levels of satisfaction from participation (Solomon, Pistrang & Barker, 2001). Parents report that disorder specific groups allow other parents to share tips, experiences, and restore parental confidence (Papagerogiou & Kalyva, 2010). Other benefits include feeling less socially isolated, more emotionally supported, better able to parent their disabled child, and have the opportunity to gain important information about appropriate services (Law et. al., 2001). However, parents report having difficulty accessing appropriate support groups, often citing time and childcare as barriers.

Parents of children with ASD reported more dissatisfaction with the social support offered to them than parents of typically developing children (Konstantareas & Homatidis, 1989) and parents of children with intellectual delays (Konstantareas, 1991). In comparison to other parents, receiving good social support appears to be a particular challenge for parents of children with ASD for a number of reasons. Embarrassment about the severity of their child’s behavioral problems could prevent parents from approaching support services or seeking informal support from family members (Gray, 1993). Moreover, parents have reported experiencing rejection and a lack of interest or understanding from social support (Farrell & Barnes, 1993), possibly due to the complexity of ASD. Yet, the influence of social support on parents’ stress has been well documented in the literature. Researchers revealed that even the belief that they are receiving adequate social support is enough to reduce stress and the possibility of depression, anxiety, and anger amongst parents of children with ASD (Fisman & Wolf, 1991; Gray & Holden, 1992). Parents who feel supported are more likely to cope successfully with raising their children (Donovan, 1988). Conversely, it was found that lower levels of social support served as the most powerful predictor of depression and anxiety in parents of children with ASD. Furthermore, the inability to locate or access social support can affect a parent’s overall well-being. Effective support services are particularly important for parents, as families raising a child with ASD are at a greater risk of experiencing negative outcomes than families of children with other disabilities.

Formal Support: Satisfaction with Services. Formal social support is defined as the “assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organized group or agency” (Schopler & Mesibov, 1984, p. 297).

While families of ASD do rely on informal social support from extended family members and friends, formal social support plays a significant role in the life of the child with ASD and their family. In addition to accessing services through the school system, children with ASD participate in a myriad of services, including behavioral therapy, speech therapy, occupational therapy, physical therapy, and social skills groups. Parents begin engaging with formal support during the diagnostic process and continue as they seek formal social support to aid in caring for the child: enlisting the support of medical doctors, psychologists, social workers and special education teachers (Altiere & Von Kluge 2009). These individuals who provide assistance and understand the child's difficulties make a significant difference for parents (Sharpley, Bitskia & Efremidis, 1997).

The literature has found that parents of children with ASD were more than twice as likely to have problems with referrals, appointments, and finding appropriate providers, and coordinated care than parents of children with other special healthcare needs (Krauss et. al., 2003). Additionally, research reveals the need for parents to be better informed by professionals about their child's disorder and to receive appropriate support, especially when the diagnosis is disclosed (Hahaut, Castagna & Vervier, 2002; Whitaker, 2002). Often, parents are not provided with sufficient information on how to access services or information about the disorder. This can be attributed to a lack of an effective and cohesive system providing accurate information about ASD (Jacobsen & Mulick, 2000). Pain (1999) found that information helped parents to adjust emotionally, to access services and benefits, and to improve overall management of their child's behavior, while a lack of information and support may leave them with a sense of hopelessness.

In terms of direct services for the child with ASD, parents often report satisfaction with services, especially behavioral therapy or ABA services; ABA is an effective and evidence-based treatment of ASD (Granpeesheh, Tarbox & Dixon, 2009). Service delivery of ABA varies from in-home programming to clinic-based programs, depending on the parents' preferences and the child's needs. Children with ASD are responsive to treatment; ABA has overwhelmingly positive impacts on the child's social skills, challenging behaviors, language and communication, gross and fine motor skills, independence and overall quality of life (McPhilemy & Dillenburger, 2013). Parents often report an increased feeling of hope for the child's future as they progress through direct services, however, these treatment programs are often child-focused and child-centered. Overall, parents report satisfaction with their child's progress and outcomes from direct services, but children with ASD often do not generalize treatment gains outside of the therapy session (Gould & Redmond, 2014). Thus, there is a need to consider the contexts and behavior-change agents outside of the therapy context. As a result, parent training has become a necessary component of the child's treatment package (National Autism Center, 2009; National Research Council, 2001) and typically focuses on teaching parents to effectively modify their child's behavior; parent training for parents of children with ASD will be explored and discussed at length later. However, it is important to note that parents do report dissatisfaction with parent training programs as well as a lack of focus on the parents and families' needs.

Despite parent satisfaction with direct services and parent training, parental involvement for children with ASD requires careful consideration as these parents are already at increased risk of negative outcomes, such as high levels of stress and depression (Hastings et. al., 2005). Although the research findings imply that children with ASD have better outcomes if their parents become highly involved in the treatment programs, researchers have found that parental participation can place a heavy burden upon parents who may feel that they have to take considerable responsibility for their child's treatment. This may have financial implications for a family as a parent may have to give up work to care for their child and undertake any training that is necessary. Additionally, parents may feel the added pressure of being responsible for the treatment outcomes, which could negatively impact emotional well-being if progress is not as expected. Implementing their own child's treatment could affect a parent's social life or relationship with their partner or other children as they take on the sole responsibility for their child's care. Parents face a situation where the most successful interventions appear to be those with significant parental involvement, which may result in parents making substantial changes to their lives (Evans, 2010). However, researchers have found that participation in a parent training resulted in parents being less likely to believe that their child's problem behavior was caused by intrinsic factors and more likely capable of change in the future (Whittingham et. al., 2009); thus, it may be possible to change the possible negative outcomes of parental involvement if support for parents is provided. The high levels of parental stress after a child's diagnosis of ASD are associated with factors relating to the child (concerns about their education, health and future well-being), but also a lack of help or support for the family (Kasari & Sigman, 1997). Parental stress has been found to be alleviated if training gives parents coping strategies together with social support (Dunn et. al., 2001) and if training reduces management problems, bringing about change in the child's behavior (Koegel et. al., 1992).

Perceptions of Treatment Outcomes & the Future. The process of acquiring and processing a diagnosis such as ASD is often linked to bereavement (Dale, Jahoda & Knott, 2006). With the loss of hopes and dreams they had for their child, parents often experience grief when their child receives a diagnosis of ASD (Ariel & Naseef, 2006; Blacher, 1984). Waisbren (1980) revealed that receiving a diagnosis for their child is a crisis for parents as they enter a period of mourning for the loss of the "hoped for" child. Accepting a diagnosis and resolving themselves to the implications and possible outcomes is a difficult process for most parents; however, it is a necessary process in which resolution involves parents coming to terms with and accepting their child's diagnosis (Milshtein et. al., 2010). It is particularly important for parents of children with a disability to come to terms with their child's diagnosis in order to avoid documented parenting difficulties and to ensure the well-being of the parent, child and family as a whole.

Milshtein et. al. (2010) found that 57% of parents were unresolved to a diagnosis of ASD for their child and this was associated with negative perceptions about their child, the influence the disability has on family functioning, and the child's future outcomes. Parents of children with ASD appear to find it more difficult to come to terms with their child's diagnosis than parents of children with other disabilities because of the ambiguity and uncertainty of the child's prognosis following the diagnosis. For other disorders, parents may lower their expectations about their child's potential or the impact that experts may have on changing outcomes for their child, but ASD provides some home for improvement; this creates a different climate for parents of children with ASD as there may be significant discrepancies between their expectations and outcomes (Dale et al., 2006). A review of the literature has revealed that there does appear to be some plasticity of ASD in the early developmental years, but any question of a full recovery needs further research (Rogers, 1998; Rogers & Vismara, 2008). Furthermore, there is uncertainty surrounding how much change can be brought about through effective treatment. Dale and colleagues (2006) found that parents who hold the belief that their child's condition can be partly or completely overcome may be more likely to engage in interventions. However, the possibilities that remain about the potential for positive outcomes amongst children with ASD and the uncertainties that surround the likelihood of this make parenting particularly difficult.

Research suggests that parental distress results from such factors as the intensity, magnitude, duration, and unpredictability of ASD (Noh et. al., 1989).

In addition, parents often have concerns regarding their child's well-being and quality of life. Early studies reveal that when parents first learn about their child's diagnosis, they react with feelings of loss and mourning for the "hoped-for-child," similar to bereavement associated with the death of a family member or friend (Blacher, 1984). A number of factors have been found to moderate parents' responses to their child's diagnosis of ASD: level of impairment and presence, or lack thereof, maladaptive behaviors. According to research conducted by Evans (2010), parents largely fell into three main categories in regard to perceptions of their child's future: optimism, pessimism and uncertainty. An important factor in identifying parents' stance on their views about the future was the severity of their child's ASD; the nature of their child's ASD clearly influenced parent's perceptions of the future. Parents of children with considerable maladaptive behavior, speech impairment or severe learning difficulties usually had a bleaker view of the future in terms of what their child may be able to achieve. Their fears were largely associated with the perceived levels of independence their child may achieve and subsequently the level of care they may have to provide in the long term. These findings may be the result of the increased stress experienced by parents of children with extreme maladaptive behavior (Evans, 2010; Tobing & Glenwick, 2002). For parents who were identified as having optimistic views, they tended to express hopeful beliefs about the development of support services for children and families living with ASD. Additionally, hopeful aspirations about the future were expressed in terms of what parents expected their child to achieve in adulthood; more optimistic parents believed that their child would achieve happiness and be able to live an independent life without needing long-term support. For parents who were identified as having pessimistic views of their child's future, they tended to make comparisons to the perceived future of their child and that of a typically developing child; parents tended to use typical development as a benchmark, which proved to be more distressing for those parents who became aware of their child's deficiencies and the reduced potential for future development. The discrepancy between what they perceived their child was capable of achieving and that of the average population was a source of great worry, and thus a factor that influenced parental stress levels. Lastly, Evans (2010) found that some parents perceived their child's diagnosis with uncertainty: recognizing their inability to make accurate predictions about their child's future life. In their descriptions of the future, parents who were uncertain often talked using negative terminology, implying that their doubts about the future were linked to fears and worries. This perception of uncertainty for the future reflects, and adds, to the already uncertain climate parents of children with ASD found themselves navigating. Evans (2010) found that parents' perceptions of ASD and their level of understanding have a large and significant impact on parents' response to a diagnosis and subsequent actions or lack thereof.

This creates a distinctive situation for parents of children with ASD who face many uncertainties about their child's future, and their role in possible treatments and the outcomes of those treatments.

Impact on Family Functioning. Family functioning refers to the extent to which families communicate effectively, manage daily life, and foster positive relationships (Zubrick et al., 2000). A well-functioning family system provides support for family members and is associated with positive child and parent outcomes (Renzaho et al., 2013). The literature suggests that when there is a child with ASD, family functioning is often affected as strain is put on the family system (Gomes et al., 2015; Hutton & Caron, 2005; Jellett et al., 2014). Having a child with ASD presents a distinctive set of challenges that impacts the entire family unit and individual family members' health, well-being, and experiences across the lifespan (Patterson, 2005; Turnbull, Turnbull, Erwin & Soodak, 2006). ASD can put a considerable amount of restrictions on the family, negatively impact the martial relationship, and adversely affect the well-being of siblings, thus putting families at an increased risk of family breakdowns (Fisman et al., 2000). The challenges that families of children with ASD start early and last a lifetime.

The behaviors associated with ASD (i.e., stereotypy, maladaptive behaviors such as aggression, self-injury, food refusal) can often place a considerable amount of restrictions upon a family; they can interfere with normal routines, such as eating out, shopping, or holidays. Furthermore, families with a child with ASD tend to participate less in recreational activities (Myers, Mackintosh & Goin-Kochel, 2009) and are more isolated (Kinnear et al., 2015). Often, family life focuses on the needs of the affected child (Myers et al., 2009), ignoring the needs of other family members. Parents of children with ASD typically report less effective family functioning than parents of typically developing children (Higgins, Bailey & Pearce, 2005). Furthermore, this finding has been replicated across families of children with ASD regardless of cultural and ethnic background (Gau et al., 2012).

Although it has been believed that parents of children with ASD are more likely to get divorced, recent research has debunked the myth that the divorce rate in families of ASD is 80%. Ubrano and Hodapp (2007) found that that about 64% of children with ASD (n=913) lived with both their biological and adoptive parents. Moreover, they found that the severity of the child's ASD symptoms had no effect on the likelihood that parents would get divorced. However, research has found that parents of children with ASD do have a higher divorce rate than comparison groups: 23.5% versus 13.8% (Hartley et al., 2010). For parents of children with

ASD, the rate of divorce remained high throughout the child's lifespan (i.e., into adolescence and early adulthood), whereas, for the comparison group, the divorce rate decreased after the child reached 8 years of age. Parents report that caring for a child with ASD places a "huge strain on [their] marriage" (Myers et al., 2009). Most parents reported that the main source of stress or strain stemmed from one parent's inability to accept or come to terms with the child's diagnosis, especially if one parent is in denial of the diagnosis. If these problems are not resolved, parents reported that they could lead to divorce (Myers et al., 2009). Conversely, some parents reported that having a child with ASD strengthened their marital bond. With one father sharing, "autism does one of two things: it drives families apart or makes them stronger" (Myers et al., 2009). Not all families are negatively impacted by raising a child with ASD, but research does support that having a child with a disability can add stress to a marriage (Bristol, Gallager & Schopler, 1988; Myers et al., 2009), as well as a family (Abbeduto et al., 2004) and individual family members.

In the family context, the child with ASD is often the focal child; attention is typically focused on the affected child (Tsao, Davenport & Schmiege, 2011). However, parents, specialists and researchers have concerns for other children in the family as well (Hastings, 2007). Of particular concern is the impact on the sibling relationship and how-to best support typically developing siblings of children with ASD (Lock, 2009). The research investigating the impact of children with ASD on siblings is mixed (Orsmond & Seltzer, 2007), indicating both positive and negative results that are dependent on the siblings' perceptions and experiences related to their sibling with ASD. Negative sibling relationships were associated with worries about the future of the child with ASD, perceptions of parental favoritism toward the child with ASD, and feelings of rejection toward the child with ASD (McHale, Sloan & Simeonsson, 1986). Often, siblings of children with ASD report feelings of embarrassment or shame toward their sibling with ASD and behaviors related to their diagnosis (Orsmond & Seltzer, 2007), which may result on a lack of social support from friends (Kaminsky & Dewey, 2002). Furthermore, contributing to siblings' feelings of isolation and lack of support, research has found that sibling relationships are characterized by less intimacy and nurturance (Kaminsky & Dewey, 2002). With some researchers finding that child with ASD and their typically developing siblings spend less time together than typically developing sibling dyads (Knott et al., 1995). However, when siblings do interact and engage with one another, 84% of siblings reported that their sibling with ASD exhibited aggressive behavior toward them when trying to engage them during play (Orsmond & Seltzer, 2007). Siblings of children with ASD with negative sibling relationships are at-risk for higher attentional problems, loneliness, and problems with peers (Bagenholm & Gillberg, 1991). In contrast, research has demonstrated that when siblings have a good understanding of their brother or sister's disability and perceive that parents and peers have positive reactions toward the sibling with ASD, they are more likely to have positive sibling relationships (McHale et al., 1986). Positive findings indicate that in some instances, siblings of ASD seem to adjust well to their family situation, and occasionally perform better in some aspects of their social emotional development than normative samples (Mates, 1990). Additionally, siblings with positive perceptions and experiences related to their sibling with ASD are likely to adapt successfully to the impact of having a disability on the family (Taunt & Hastings, 2002). Siblings of children with ASD with positive sibling relationships can develop high self-concepts, healthy academic performance, and healthy behavioral adjustment, as rated by parents and teachers (Mates, 1990). Overall, the impact of having a sibling with ASD may vary among children as the research on sibling relationships is quite contradictory (Stoneman, 2001). It appears that the impact of ASD on the typically developing sibling is dependent on their perceptions and experiences related to their sibling with ASD, which can be mediated by the perceptions of their parents and peers. Additionally, there are certain variables that may directly or indirectly affect the adaption of typically developing siblings of ASD, such as gender, age, information, knowledge about ASD, or the age between difference between siblings (Unal & Baran, 2011). While nothing can really be done about the age of children, their birth order or the severity of ASD, there are strategies that can be implemented to promote and facilitated positive relationships between the typically developing sibling and their sibling with ASD (Beyer, 2009).

The quality of the sibling relationship is especially important for the child with ASD. Sibling relationships are a source of companionship, help, and emotional support. In sibling interactions, siblings may acquire many social and cognitive skills that are central to healthy social development (Furman & Burmester, 1985). For children with ASD, siblings and the sibling relationship are important for two main reasons. First, siblings may provide children with ASD opportunities to socially interact with other children under supportive conditions (Travis & Sigman, 1998; Rivers & Stoneman, 2008). Typically developing siblings have great potential to impact children with ASD, especially in terms of development and acquisition of social competencies (Knott et al., 1995; Tsao & Odom, 2006). Second, siblings often take on the caregiver role as parents age. Research has indicated that siblings of ASD does alter normative life cycle events, specifically, that having a sibling with ASD influences the siblings' vocational, martial, and family planning (Ferraioli & Harris, 2010). Thus, it is necessary to foster positive a relationship between the child with ASD and their typically developing sibling(s).

Raising a child with ASD can be challenging for parents and families. A well-functioning family provides support for family members and is associated with positive child and parent outcomes. However, research indicates that ASD can have negative and adverse effects on family functioning, dynamics, and family members. Research has demonstrated a relationship between parent mental health and poor family functioning in families where there is an individual with ASD (Baker, Seltzer & Greenberg, 2011). Furthermore, parental stress and mental health difficulties are often conceptualized as an outcome of poor family functioning (Baker, Seltzer & Greenberg, 2011). Thus, impaired family functioning can be another potential source of stress for the parents of a child with ASD.

Impact of Parenting Stress

Research clearly demonstrates that parents of children with ASD are at-risk for experiencing high amounts of stress related to the tasks and demands of parenthood. Stress stems from several sources, including the diagnosis and acceptance of their child's ASD, perceived diagnosis of autism, access and satisfaction with both informal and formal support systems, and the impact of ASD on overall family functioning. Given parents unique experiences, it is important to highlight the adverse effects of parental stress on parent-child interactions, child outcomes, and parent outcomes. Thus, highlighting the need to address parental stress.

Parent-child Interactions. The way parents perceive their parenting experience, including parental stress, and their child with ASD aligns with how parents behave toward their child with ASD. The effects of child behavior and parenting stress depend in part on how parents respond to their child's personal attributes (Bates et al., 1998). Not only does the child characteristics play a role, but there are individual differences in parents' own attributes may make it easier or more difficult for them to adapt to the stressors of parenthood (Deater-Deckard, 2004). Parenting behavior and the stress of parenthood influence one another. When parenting stress is high, parental cognitions and behaviors change, and problems in parenting and the parent-child relationship arise or grow (Deater-Deckard, 2004). For parents of children with ASD who are raising children facing minor to very serious challenges, such as challenges with their behaviors and emotions, skills and competencies, and physical and mental health, their stress is likely increased thus contributing to problems within the parent-child relationship. On average, the parent-child relationship in these families show signs of and further contribute to distress and difficulties for parents and children alike (Deater-Deckard, 2004).

McAdoo & DeMeyer (1977) observed that the high levels of stress associated with parenting a child with ASD may actually affect parental personalities and subsequently parenting styles and behaviors. Additionally, the research has found that a change in parenting style can negatively impact the coherence of the family unit (Holroyd & McArthur, 1976). This is particularly relevant for parents of children with ASD as they generally endure higher stress levels in comparison to parents of children with other disabilities, making them more likely to change their parenting behavior and are subsequently susceptible to relational family difficulties, which can only increase parental stress levels (Evans, 2010). Powers (2000) suggests that parents of children with ASD face three common barriers to be successful that are not experienced by parents of other children with disabilities. They are at risk of being overprotective and restrictive, they face increased risk of rejecting the child, and finally they are at risk of becoming over involved or overcompensation their child with ASD at the risk of neglecting other children in the family. The construct of parenting style is an important component of raising a child, especially a child with ASD, as it is the way parents' attempt to control and socialize their children (Baumrind, 1991). In turn, these behaviors (i.e., harsh and reactive parenting, cold and withdrawn parenting) can create more stressors for the family and parent.

Child Outcomes. The way parents feel about themselves, their situation, and their child goes hand in hand with the way parents behave toward their children. According to Deater-

Deckard (2003) parenting stress disrupts some of the psychological mechanisms that link parenting and children's development. In general, parents of children who have more disabling conditions that persist for longer periods of time show more signs of severe, chronic parenting stress. It is well-documented that parents of children with ASD experience chronic and persistent parenting stress across the child's lifespan that not only impacts parent outcomes, but also child outcomes.

As in any transactional process (Sameroff & Chandler, 1975), the stress of raising a child with ASD comes from a variety of factors acting and interacting at the same time; the severity of the child's impairment with social skills and communication can increase parental stress, but parents' own stress and tension can escalate the situation in a bidirectional way and exacerbate the child's characteristics and problem behaviors (Myers et. al., 2009). Osborne (2008) proposed that high levels of parenting stress could lead to subsequent worsening of child behavior problems; parenting stress can have a significant impact on parenting behaviors, which, in turn, have an impact on a child's problem behaviors and outcomes. The presence of the child's disruptive or maladaptive behaviors can further impair the parent-child relationship (Fox et al., 2002). In terms of treatment outcomes, Robbins, Dunlap & Plienis (1991) noted a strong relationship between parenting stress and later child progress in young children undergoing intervention programs; establishing a strong association between parenting stress and child behavior problems. As in any transactional relationship, parenting stress can adversely impact the child with ASD; these adverse effects on the child, their behaviors, and developmental outcomes can further contribute to parental stress.

Parent Outcomes. The challenges and demands of parenting a child with ASD place a significant amount of stress on parents and caregivers. It has been well-documented that parents of children with ASD experience significantly higher stress levels than parents of typically-developing children (Bitsika & Sharpley, 2004; Dumas et al., 1991; Estes et al., 2009), and parents of children with other developmental disabilities (Abbeduto et al., 2004; Dabrowska & Pisula, 2010; Dumas et al., 1991; Hayes & Watson, 2013). And for many parents of children with ASD, parental stress is chronic and persists across the child's lifespan. High parenting stress is an important environmental risk variable (Neece, Green & Baker, 2012). It has been associated with numerous undesirable outcomes, including broader psychological well-being issues, such as reduced quality of life, burnout, feelings of isolation, and other mental health issues, such as depression and anxiety (Cachia et al., 2015; Deater-Deckard et al., 1998; Dumas et al., 1991; Hastings et al., 2006), and poorer physical health (Eisenhower et al., 2009). Chronic stress wears down on the body, particularly the cardiovascular, immune, and gastrointestinal systems Miodrag & Hodapp, 2010). Chronic stress not only impacts the body physically, but parents also experience more mental health problems, such as depression (Hastings, 2003; Zablotsky, Anderson & Law, 2013) and anxiety (Dykens et al., 2014).

While a majority of the research assessing the impact of stress on parental outcomes has used self-report measures, recent research used cortisol levels or the biological marker of stress to assess the impact of stress on parents' physiological and physical health. Seltzer and colleagues (2010) found that mothers of adolescents with ASD have blunted cortisol responses similar to what has been seen among combat soliders, Holocaust survivors, and individuals suffering post-traumatic stress disorder (Heim, Ehlert & Hellhammer, 2000; Yehuda et al., 1995). The researchers assessed mothers of adolescents, rather than young children, to investigate the effects of chronic as well as daily parenting stress. The researchers found that mothers' cortisol levels were extremely low, which is consistent with people experiencing chronic stress (Gunnar

& Vasquez, 2001). This is the physiological residue of daily stress experienced by parents of children with ASD. While the long-term effect of this physiological profile of chronic stress on the mothers' physical health is not known, research has shown that these hormone levels have been associated with chronic health problems and can affect glucose regulation, immune functioning, and mental activity (Flinn, 2006). Additionally, these hormone levels are consistent with individuals who experience clinical burnout (Sonnenschien et al., 2007). Furthermore, the researchers found that a history of elevated behavior problems moderated maternal cortisol levels (Seltzer et al., 2010), or that child's problem behaviors impacted parental stress levels.

Thus, ASD is considered one of the most demanding disorders in terms of threats to parents' well-being and mental health (Seltzer et al., 2001).

Parent Training Programs

To remediate the difficulties that parents of children with ASD experience, parent training programs have become an integral and necessary component in the treatment of ASD (Bearss et al., 2015; Celiberti & Harris, 1993; Keen et al., 2009). *Parent training* (e.g., parent education, parent-mediated/implemented interventions) broadly refers to interventions or programs designed to develop or enhance parent behaviors or knowledge that will promote positive developmental outcomes in their children (Najdowski & Gould, 2013). Research strongly supports the inclusion of parents and family members as key components of successful treatment programs (National Autism Center, 2009; National Research Council, 2001) and positive developmental outcomes for children with ASD. Currently, parent training research with parents of children with ASD encompasses two main, but different approaches: behavioral parent training (BPT) and mindfulness-based parent training (MBPT).

Special attention for parent training programs is necessary as research has demonstrated that without targeting parents' needs, parenting stress can impede the effectiveness of a child's intervention and overall positive developmental outcomes (Deater-Deckard, 2004). While children with ASD exhibit improvements in behaviors and skills through child-centered interventions (i.e., therapy), for long-term positive outcomes, parental involvement is especially important (Burrell & Borrego, 2012).

Behavioral Parent Training (BPT) Programs

The most common type of parent training programs for parents of children with ASD is based on the principles of Applied Behavior Analysis (ABA), which is an effective and evidence-based treatment for ASD (Granpeesheh, Tarbox & Dixon, 2009). These behavioral parent training programs (BPT) are a component of the child's treatment package (National Autism Center, 2009; National Research Council, 2001) and typically focus on teaching parents to effectively modify their child's behavior. More specifically, BPT is focused on skill acquisition related to the core features of ASD (i.e., impairments in social communication and interaction; restricted or repetitive behaviors, interests or activities) and/or the management, reduction, or elimination of maladaptive behaviors (Bearrs et al., 2015; Schultz et al., 2011).

The earliest reports on training parents of children with ASD began in the late 1960s (Wetzel, Baker, Roney & Martin, 1966; Wolf, Risely & Mees, 1964). However, the seminal work of Lovaas, Koegel, Simmons and Stevens-Long (1973) found that parental involvement is a critical and necessary component to producing long-lasting treatment gains, above and beyond gains made in behavioral therapy. Lovaas and colleagues (1973) conducted a four-year follow-up study of 20 children with ASD who had received behavioral treatment for a year, with some parents receiving parent training. Children whose parents did not receive BPT regressed and lost previously acquired skills. Children whose parents received BPT either maintained the gains originally acquired during treatment or continued to improve. Through parent training, parents learned to effectively modify their child's behavior and effectively address their child's skill deficits and challenging behaviors (Lovaas et al., 1973). This landmark study demonstrated that BPT is essential for both immediate and long-term positive developmental outcomes and clinical prognosis.

Since then, a multitude of behavioral parent training (BPT) programs have been designed and implemented with parents of children with ASD with high success (Schultz, Schmidt & Stichter, 2011). In the last several decades, the modalities of effective parent training have developed significantly, however, the content remains heavily the same. Most often, BPT programs use behavioral skills training, which consists of a combination of instructions, modeling, rehearsal, role-playing, and feedback (Ward-Horner & Strumey, 2012), to teach parents the principles and methods of behavior modification, or ABA (Matson, Mahan & Matson, 2009). Because of the range and severity of skill deficits and maladaptive behaviors associated with an ASD diagnosis, parents must learn a curriculum including contingency management and operant training procedures (Schreibman, 1988). Parents are taught a range of basic procedural rules and principles of ABA such that they are able to adapt learned skills to a variety of situations, contexts, and behaviors (Koegel & Schreibman, 1982; Matson et al., 2009; Schreibman, 1988; Schreibman, Koegel, Mills & Burke, 1984). More specifically, BPT focuses on improving behavioral deficits (e.g., increasing speech and language, joint attention, social skills) and decreasing behavioral excesses (e.g., decreasing stereotypy, aggression, sleep disturbance issues). Parents are able to effectively manage, reduce and eliminate their child's maladaptive behaviors, while teaching the acquisition of adaptive skills (Ducharme & Drain, 2004). Often, BPT programs coincide with the child's treatment program with the aim of complementing the child's treatment goals; thus, parents are learning similar procedures to those being limited by professionals in direct treatment sessions. Furthermore, BPT is ongoing throughout the child's treatment program, with the main goal being to successfully transition the child out of receiving services and improving clinical prognosis (Najdowski & Gould, 2013). Thus, the focus of treatment is on the target child: BPT programs typically examine the direct effects on the target child, rather than the parents or broader family.

Since the 1960s, there has been substantial evidence in the BPT literature that parents can effectively modify their child's behavior and address their child's skill deficits and challenging behaviors (Lovaas, Koegel, Simmons & Stevens-Long, 1973; Najdowski & Gould, 2013; Schreibman, 1983). Decades of research support parents as critical participants in treatment and parent training as they increase the success of behavioral treatment (National Autism Center, 2009; National Research Council, 2001) and increase the probability of a good clinical prognosis (Simpson, 1999) for their child. Parent training is highly effective for several reasons. The inclusion of parents immediately increases the number of learning opportunities a child can access throughout their daily routine, ensures the consistency of program implementation, and maximizes the potential for maintenance and generalization of treatment gains outside the therapy setting (Brookman-Frazee et al., 2009; Gould & Redmond, 2014; Harris et al., 1981; Kaiser & Hancock, 2003; Kogel, Koegel & Schreibman, 1991; McConachie & Diggle, 2007; National Research Council, 2001; Schreibman, 1988; Symon, 2001). Lastly, parental involvement results in parents becoming "experts" on their child as they have an intimate knowledge of their child that others lack (Malmberg, 2007). Parents are exposed to and trained to understand their child's treatment package, and to implement intervention procedures that positively impact their child’s development. This is especially important as parents are stable in their child’s life, whereas practitioners and providers are less consistent and stable. Thus, parents are able to apply learned skills consistently throughout the child’s lifespan and development (Mullen & Frea, 1995). Moreover, through effective parent training, parents are able to provide “around the clock intervention” (McConachie & Diggle, 2007; Najdowski & Gould, 2014; Symon, 2001). The parent training model is a cost-efficient method as it reduces the need for parents to seek out longer-term behavioral services (Cordisco, Strain & Depew, 1988; Symon, 2001). Through parent training, parents of children with ASD are taught specialized skills that equip them with methods and tools to address new behaviors or difficulties that occur as their children age. Decades of research support that parents are able to act proactively and implement behavior management programs or skill acquisition programs, without the support of a treatment provider, resulting in positive sustained change and developmental outcomes.

Overall, parents have viewed BPT programs as effective in providing positive benefits for themselves, their child and the broader family (Grindle, Kovshoff, Hastings & Remington, 2009), but for many parents, participation may be more burdensome than beneficial. Despite their advantages, BPT programs can be a significant source of parental stress, which can reduce the effectiveness of treatment overall (Grindle et al., 2009; Osborne et al., 2008; Symon, 2001), reduce parental adherence and motivation to use to the learned skills (Harris, 1984; Koegel, Schreibman, Britten, Burke & O’Neill, 1982; Schreibman, 1983), reduce a parent’s ability to benefit from parent training (Symon, 2001), and impede child development (Dempsey, Keen & Pennell, 2008). For some parents, involvement in BPT is insufficient in increasing a parent’s ability to adapt and adjust to the challenges present in raising a child with ASD.

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High expectations of parental involvement in BPT programs is an additional source of stress for already stressed parents, which further contributes to the complexities of raising a child with ASD. This additional source of stress can be detrimental as high levels of psychological distress can decrease parental involvement in services, significantly impact a parent's ability to manage their child's behaviors, reduce the effectiveness of behavioral interventions, and as a result may impede a parent's ability to benefit from training programs (Osborne et al., 2008; Symon, 2001). Moreover, high parental stress has been linked to less beneficial and positive outcomes for the child, impeded child development, and higher rates of child psychopathology and antisocial behaviors (Brinker, Seifer & Sameroff, 1994; Llewllyn, McConnell, Thompson & Whybrow, 2005; O'Connor, 2002; Dempsey & Keen, 2008). For some parents, involvement in BPT is insufficient in increasing a parent's ability to adapt and adjust to the challenges present in raising a child with ASD.

Mindfulness-based Parent Training (MBPT) Programs

Due to the persistent and chronic stress experienced by parents of children with ASD, there has been an influx of mindfulness-based approaches to parent training (Cachia et al., 2015). Previous research has shown mindfulness training to be effective in reducing stress and enhancing psychological well-being in a wide variety of clinic and non-clinical groups, and more recently has been studied with parents of children with ASD. Although mindfulness-based parent training (MBPT) approaches have not been implemented extensively with parents of children with ASD, there is preliminary evidence to suggest that it could be beneficial for this population and a potential evidence-based intervention (Cachia, 2017; Cachia et al., 2015). These programs are designed to teach parents to mindfully attend to the stressors of raising a child with ASD, while nonjudgmentally accepting associated negative sensations and emotions.

Mindfulness can be simply defined as paying attention in a particular way: on purpose, in the present moment, and nonjudgmentally (Kabat-Zinn, 1990). Mindfulness, as it is used today, is “an acceptance-orientated psychological process and involves relating openly, with curiosity and receptivity to one’s thoughts, sensations and emotions” (Fletcher, 2011, p. 4). A universal characteristic of mindfulness is the idea of nonjudgmental acceptance of negative sensations (Kabat-Zinn & Kabat-Zinn, 1991, 1997). Mindfulness encompasses a body of techniques that emphasizes awareness of thoughts, beliefs, and feelings, the objective of which is to change an individual’s relationship to and experience of distress (Ferraioli & Harris, 2013). With mindfulness training, there is a shift from being preoccupied only with repairing the worst things in life to also building positive qualities (Seligman & Csikszentmihalyi, 2000). This is based on the notion that we can determine our future experiences and emotions by shifting our focus from the negative to the positive, being aware of our emotions, and electing acceptance of our current situation. The goal is not to eliminate or suppress one’s negative or aversive thoughts or experiences, but rather to learn to accept and directly address one’s stress (Duncan, Coatsworth & Greenberg, 2009). Mindful parenting brings the elements of mindfulness to parenting (Kabat-Zinn & Kabat-Zinn, 1997); most importantly, there is a focus on nonjudgmental acceptance of negative sensations (Kabat-Zinn & Kabat-Zinn, 1991) related specifically to the tasks and demands of parenting. More specifically, these programs are designed to teach parents to mindfully attend to the stressors of raising a child with ASD, while nonjudgmentally accepting associated negative sensations and emotions.

MBPT programs are not technique-focused, like BPT programs, but rather are focused on addressing parental stress by teaching parents mindful tactics and practices such that they learn to reframe their experience with and response to their stress and experiences. MBPT programs focus on bringing awareness to the present moment by engaging parents in experiential exercises, such as guided mediation, body scans (i.e., bringing awareness to bodily sensations), and mindful eating. By teaching parents mindfulness exercises focused on the present moment, parents will be able to use these techniques or strategies during stressful times when their child is present. Specifically, parents will be able to change their child's behavior and their experience by changing their own behavior when they interact with their child (Singh et al., 2006).

The literature on mindfulness-based programs for parents of children with ASD is new but growing. Singh and colleagues' (2006) seminal study exploring mindfulness-based programing with parents of ASD provided evidence that parents of children with ASD can benefit from such interventions. Since then, there is preliminary evidence to suggest that MBPT programs could be beneficial for this population. Recent research has found a myriad of positive outcomes when parents utilize mindfulness in their interactions with their children. A systematic review of ten mindfulness interventions for and with parents of children with ASD found that mindfulness training directly benefited parents while positively impacting the child with ASD (Cachia et al., 2015). More specifically, when working with their children, mindfulness interventions have reduced parental stress and depression, enhanced parental perceived mother-child interactions, increased parental satisfaction with these interactions, and reduced the child's aggressive and maladaptive behaviors (Cachia, Anderson & Moore, 2015). Although the delivery of mindfulness content and contact hours varied across the ten studies assessed, results demonstrated that mindfulness training is effective at reducing stress and enhancing the psychological wellbeing of parents of children with ASD, while indirectly benefiting the child with ASD. Overall, Cachia, Anderson and Moore (2015) concluded that mindfulness-based interventions constitute evidence-based procedures for parents of children with ASD.

However, despite the benefits of mindful parenting and evidence of favorable social acceptability for MBPT programs, many parents drop out of these programs because they want to "actually learn something" (Ferraioli & Harris, 2013). MBPT programs are not technique- or skill-focused like BPT programs, which teach parents to effectively parent a child with ASD; for that reason, parents often report that they prefer BPT programs to MBPT programs when given a choice. The research has indicated that parents prefer learning specific strategies to address their child's behavior, rather than learning general techniques (Burrell & Borrego, 2012). In fact, there is evidence that providing parents with hands-on specific training for specific skills is more effective and associated with more positive outcomes than supplying information alone (Bearss et al., 2015; Burrell & Borrego, 2012). For example, when comparing the effects of a skills-based, or BPT program with a MBPT program, Ferraioli and Harris (2013) reported higher attrition rates for the MBPT group than the BPT group; with several parents stating that they had wanted to be placed in the skills-based group. Interestingly, this study reported significant improvements in parental stress and general health within the mindfulness group immediately after the intervention in addition to an increase in general health at 3-month follow-up. Despite these positive outcomes, these parental attitudes are common in the mindfulness literature

(Cachia et al., 2015). The parental attitudes noted by Ferraioli and Harris (2013) represents a common parental concern with MBPT programs. Parents of children with ASD have come to expect that parent training programs will equip them with specific skills and tools to effectively modify their child's behavior (Najdowski & Gould, 2014). These parental attitudes represent a barrier for the broader application of MPBT programs for this population, thus restricting its utility.

Summary & Conclusion

From a developmental systems perspective, a child's development is inherently bidirectional and is the product of constantly changing interactions between the developing child and their environments environments (Lerner, 1991; Lerner, Wertlieb & Jacobs, 2003). Development is a complex process that occurs because of the bidirectional and reciprocal relationships between children and the different layers of their environments; these interactions between the developing child and the stimuli in their environment are the mechanisms that produce development (Bronfbrenner, 2000; Bronfbrenner & Morris, 2006). Children are embedded within a developmental system that is comprised of many variables that not only influence their behavior and development, but also the behavior of those who raise them (e.g., Skinner, 1953; Lerner, 1991). Thus, it is critically important that researchers and practitioners consider the experiences of parents of children with ASD and make informed decisions on how to better meet the needs of this population.

While the detrimental role of stress experienced by parents of children with ASD has been investigated over the last several decades (Cachia et al., 2015; Cachia, 2017), these issues are still prevalent today. Significant strides have been made in terms of the skills that parents can successfully learn and implement with their child with ASD with behavioral parent training programs, and more recently mindfulness-based parent training programs have successfully reduced parental stress. Yet, researchers have consistently demonstrated that parenting a child with ASD is associated with a multitude of challenges and daily stressors beyond typical parenting stress (Evans, 2010). Moreover, researchers have demonstrated that parental involvement in behavioral parent training, despite its advantages, can have aversive effects on the parent, child and family. Because of the additional stress parents experience, they often do not adhere to or drop out of behavioral parent training programming, rendering them ineffective. Although mindfulness-based parent training programs specifically target a reduction in parental stress, many parents opt out of such programs because they do not find them useful.

No matter how effective a parent training program is, if parents do not like it because they find it requires too much effort or is not considered useful, they are less likely to use it (Schreibman, 1983). These programs often do not consider the impact of parent training on parents themselves and the family as a whole. ASD is a pervasive, life-long condition for individuals, but also for their parents, and yet research rarely addresses family needs and concerns, and family dynamics. The need to understand the characteristics of effective interventions for parents and families with ASD is a growing national concern (Lord et al., 2005) as the prevalence rates of ASD continue to rise (Centers for Disease Control [CDC], 2018). There is an alarming number of distraught parents who can benefit, and in many cases need, parent training (DaPaz & Wallander, 2016). Furthermore, parents are important stakeholders in the treatment of their child with ASD, and research has repeatedly demonstrated that interventions are more effective when people such as family members are involved in treatment rather than specialists alone (Buschbacher et al., 2004; Girolametto & Tannock, 1994; Horner et. al., 2002; Ingersoll & Dvortscak, 2006). Parents are critical participants in treatment and parent training as they increase the probability of a good clinical prognosis (Simpson, 1999) and overall positive developmental outcomes. Thus, parent training programs need to be able to address the overwhelming difficulties these parents face on a day-to-day basis, including managing parental stress and the child's behaviors, while not being an additional source of stress or burden.

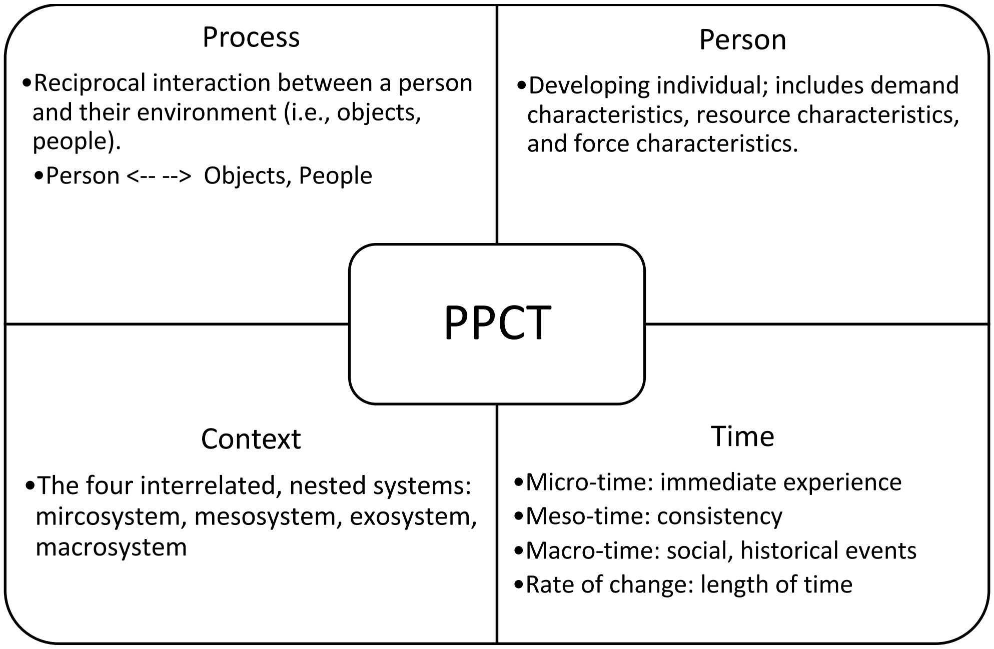
To date, parent training research studies have examined parents' acquisition of skills to improve child behavior or examined parents' use of mindfulness tactics to reduce parenting stress, but few have evaluated parental and contextual factors that promote successful and sustainable interventions (Stahmer & Pellecchia, 2015). According to Matthews and Hudson (2001), parental factors and contextual factors need to be regarded to improve the effectiveness of training programs. This may include parental mental and physical health, family structure, and socioeconomics among other characteristics of family and community systems. There needs to be a shift from expecting parents to become therapists to helping parents succeed at the parenting role. Especially as parenthood constitutes a social role that exists inside and outside of the family (Alexander & Higgins, 1993). Parents must be able to meet their own needs and those of their children, while also meeting the demands placed on them by other family members (i.e., spouses, partners), the community, and broader society (Deater-Deckard, 2004). Parent training programs should look at the parent, the child, and the parent-child relationship in the context of parenting and the broader contexts of family and community.

As developmental science is concerned with the process of human development, there is a focus on the direct and indirect impact of the environment in which the child lives (Lerner, 1991; Moore, 2016). This enduring environment is the ecology in which one develops, including relationships, the home, institutions, community, and geography that influence one another, in a bidirectional manner (Bronfenbrenner, 1974; Moore, 2016). For example, the Bioecological

Model of Human Development BMHD; e.g., Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006) emphasizes interactive relationships among four main elements that influence development: person, process, context, and time (i.e., PPCT model; see Figure 1). The process component overrides the PPCT model, which describes the increasingly complex and reciprocal interactions between a person and the environment (i.e., persons, objects). Proximal processes include those biological, physical, social and cultural experiences that influence the action and development of individuals, while simultaneously considering the influences individuals have on the environment. Parent-child interactions illustrate these proximal processes (Bronfenbrenner, 2005); for example, the reciprocal interaction of parenting styles and infant temperament, which influences the development of attachment styles, is one example of the process component occurring within a microsystem. These increasingly complex and reciprocal interactions between the developing child and the stimuli in their environment are the mechanisms that produce development (Bronfbrenner, 2000; Bronfbrenner & Morris, 2006). While proximal processes direct development, they vary systematically in relation to the three other components of the model: person, context, and time (Bronfenbrenner & Morris, 2006).

Figure 1

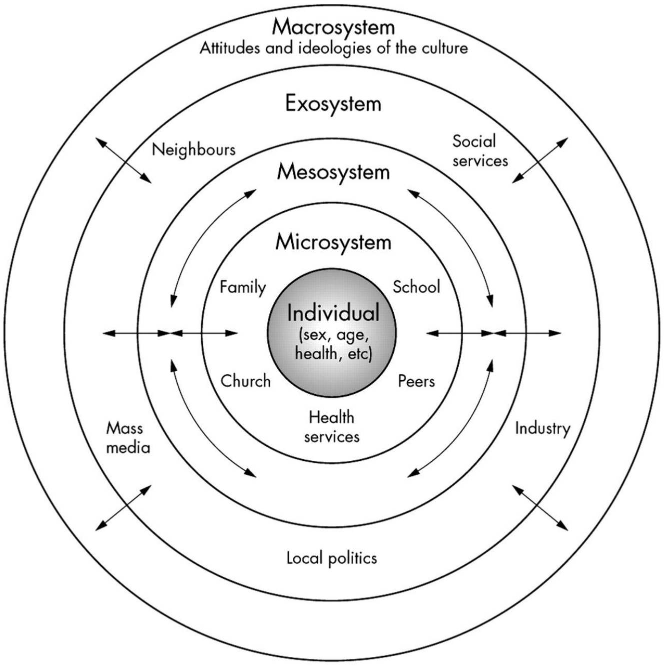
Process, Person, Context, Time (PPCT) Model developed by Bronfenbrenner (2005)



Occurring over time, process interactions differ as a function of the person component; an individual's characteristics (i.e., demand, resource, force) and actions can alter the environment. For children with ASD, their physical and social capabilities may impact the dynamics of their relationships, especially with parents. According to Bronfenbrenner (2005), given two individuals with equal demand (i.e., gender, age, etc.) and resource (i.e., education, intellectual capacity, developed skills) characteristics, their force characteristics (i.e., behavioral disposition, temperament) may alter developmental trajectories. These process and person components of development also occur within socially defined contexts (Bronfenbrenner, 1979). The context component of the PPCT model includes four interrelated, nested systems (see Figure 2). The first is the microsystem, which includes particular contexts of development, such as the home, school, or therapy settings. This is where the developing individual spends a lot of time engaging in face-to-face interactions. As individuals spend time in more than one microsystem context, interrelations among these systems form, which is referred to as mesosystems; an example for the child with ASD and their parent is parent training programs, which are often led by therapists and consist of some overlap between the therapy and home contexts. Outer contexts where individuals may not actually be situated also have important indirect influences on their development; these systems are referred to as the exosystems and macrosystems. In the exosystem, these contexts indirectly influence development through microsystems. For the child with ASD and their parent, exosystems would consist of contexts or environments that the parent spends time in, but the child with ASD does not, such as parent support groups. The outer most system, the macrosystem is comprised of the norms and values of a particular culture usually passed generationally and carried out through institutional systems and resource allocation (Bronfenbrenner, 1979). For example, the lack of awareness or understanding of ASD can result in the stigmatization of children with ASD look like everyone else (i.e., "normal") but may behave differently than expected (Gray, 1993). Lastly, the amount of time individuals spends in a process or context generally increases the magnitude of influence that process or context has on development. The time component of the PPCT model (Bronfenbrenner, 2005) is sorted into macro-time, meso-time, and micro-time. General history represents macro-time, encompassing social, cultural, and political events occurring previous to and throughout the lifespan of a person. For example, in 2012, the state of California signed into effect the Autism Insurance Law (SB946 Steinberg), which requires health plans governed by California to include coverage for autism as a medical benefit. This increased the opportunities for children and adolescents with ASD, and their families by providing ABA services at full or reduced cost (i.e., reduced the financial implications, increased access to services; LeafWing Center, 2019). Meso-time refers to the regularity in which an activity occurs over time. The consistency and frequency that children with ASD receive services would fall into the meso-time category. For instance, children with ASD receiving support and services in the school and other therapy settings, such as clinic-based and in the home, affects the generalizability and maintenance of learned skills across settings. Micro-time is what occurs during some specific interaction or activity, such as therapy sessions or working with their parent. Additionally, the time component incorporates rate of change (Bronfenbrenner, 2005). The temporal aspect is important to consider when conceptualizing development within the context of the parent-child relationship.

Figure 2

Context Component of the Ecological Model



Note. An adapted illustrated model of Bronfenbrenner’s Bioecological Theory of Human Development (1979).

This is a system that is complex and reciprocal in nature; the connection between parent and child is bidirectional, with each partner influencing the other (Bell & Chapman, 1986). The connection between parenting stress and child behaviors has been well-documented for parents of children with ASD, and yet parent training programming and research has not addressed these simultaneously. Instead, behavioral parent training emphasizes child-based outcomes while mindfulness-based parent training addresses parent-based outcomes. There is a need to move toward more ecologically valid models of parent training programs (Stahmer & Pellecchia, 2015), and in order to do so, practitioners and researchers need to understand the ecological systems which they are embedded.

The parent-child relationship occurs across numerous everyday settings (i.e., home, therapy, community outings), involves others (i.e., siblings, therapists, spouses/partners) and occurs across the child's lifespan. Moreover, characteristics of both the parent and child play a role in the development of the parent-child relationship as well as impact the behaviors and biopsychological changes of each. These differences and changes in the child and parent may impact the dynamics of their relationships, home life, institutions, community and so on. The diversity and bidirectional nature of this dynamic and relationship interacts with and contributes to shaping the unique developmental trajectories of the children with ASD. By considering the developmental system of the child, including examining parent-child interactions and the contexts in which they are embedded (i.e., family, community), parent training programming and interventions may be more effective for parents *and* children.

There is a need for a good "contextual fit" between parent training and the family context. Specifically, targets and procedures must be responsive to the values and goals of parents, compatible with the family's typical routines and culture, and optimize the parents' experience, knowledge, and skill sets (Gould & Redmond, 2014). Parent training programs need to equip parents with the skills and strategies to interact with their child on a daily basis as well as teach them to successfully cope with significant stressors and effectively manage mental health issues. Teaching parents effective skills to use with their child helps them manage difficult behaviors, feel more control over their child's symptoms and their daily lives, and decreases stress (Burrell & Borrego, 2012). It is necessary for researchers and practitioners to make parent training programs more acceptable and useful with the real consumers—the parents themselves (Schreibman, 1983).

CHAPTER 2

The Present Study

There is a general consensus that parent involvement is an essential component of effective ASD intervention programs, good clinical progress, and overall positive developmental outcomes for the child with ASD. However, there is a need for parent training programs to better meet the needs of parents while addressing child-focused outcomes through specific training and knowledge development. While behavioral parent training and mindfulness-based parent training each has their merits, they each have limitations. Current parent training programs may be rendered less effective because they are not contextually appropriate and/or useful to the parent.

First, behavioral parent training programs effectively teach parents how to foster change in their child's behavior and promote positive developmental outcomes (Bearss et al., 2015; Schultz et al., 2011). However, these programs can be viewed as restrictive and may even place an additional burden on already stressed parents, which results in low levels of parental participation, parental adherence and reducing the overall effectiveness of treatment and parents' ability to benefit from parent training. Second, mindfulness-based parent training programs can provide parents with the necessary coping skills to improve their family quality of life and reduce parental stress (Cachia, 2017; Cachia et al., 2015). Yet, parents often view them as impractical and unusable, which restricts their utility and the likelihood that parents will participate in such programs. As a consequence, current parent training approaches are insufficiently meeting parents' needs. Parents are the consumers of parent training programs, and it is necessary for practitioners and researchers to better understand parents' experiences in raising a child with ASD and their needs. These findings should inform future parent training programming. Moreover, parents need to be given an opportunity to express what information they want from and/or recommendations they have for parent training programming.

Rationale for Present Study

There is an obligation for parent training programs to shift the focus from being child-centered or parent-centered to being centered on parent-child interactions in the contexts that they occur; this type of programming would look at the parent and child as a whole unit of study. Rather than centering programming only on child-based outcomes (i.e., behavioral parent training) or only on parent-based outcomes (i.e., mindfulness-based parent training programs), programs that center on *both* the parent and child may prove more beneficial. Moreover, parent training programs that consider the parent-child dyad and the contexts in which they are embedded may be the most beneficial for all.

Based on a review of the literature, it is well substantiated that parents of children with ASD experience unique challenges and demands specific to raising a child with ASD. They are considered some of the most at-risk parents of society. The detrimental role of stress experienced by parents of children with ASD has been investigated over decades (Cachia et al., 2015). Researchers have consistently shown that parenting a child with ASD is associated with a multitude of challenges and daily stressors beyond typical parenting stress (Evans, 2010). Psychological distress that arises from the demands of parenting has been shown to be an important risk factor for child developmental outcomes and a particularly important aspect of the development of dysfunctional parent-child relationships (Deater-Deckard, 2006). Although research with parents of children with ASD started as early as the 1970s, these issues are still prevalent today.

Thus, it is critically important that researchers and practitioners consider the experiences of parents of children with ASD and make informed decisions on how to better meet the needs of this population. Not only are parents of children with ASD in want and need of parent training programs, but research strongly supports the inclusion of parents, and other family members, as key components of successful treatment programs (National Autism Center, 2009; National Research Council, 2001) and positive developmental outcomes for children with ASD. Children with ASD respond well to a variety of interventions, and behavioral therapy has been found to be effective in remediating the deficits and impairments associated with an ASD diagnosis, but without the inclusion of family members and a focus on contexts outside of the clinical setting, treatment gains can regress over time. The seminal work of Lovaas, Koegel, Simmons and Stevens-Long (1973) found that not only is behavioral therapy an effective treatment for ASD, but that parental involvement is a critical and necessary component to producing long-lasting treatment gains. For those children whose parents did not receive parent training, they saw a regression and loss of previously acquired skills. While children whose parents received parent training either maintained the gains originally acquired during treatment or continued to improve. Through parent training, parents learned to effectively modify their child’s behavior and effectively address their child’s skill deficits and challenging behaviors (Lovaas et al., 1973). This landmark study demonstrated that parent training is essential for both immediate and long-term positive developmental outcomes and clinical prognosis. The inclusion of parents is critical to promote sustained, positive behavior-change and potentially positive long-term developmental outcomes for the child with ASD.

Although researchers have demonstrated the effectiveness of behavioral parent training, they have also shown that parental involvement in parent training can be detrimental to the parent, the child with ASD, and the family as a whole due to the additional stress that it can cause. Parents have reported that a challenging aspect of behavioral parent training programs is that programming and its therapist typically focus treatment efforts on the child with ASD and are not necessarily mindful of the needs of the parent and family (Grindle et al., 2009). More specifically, these programs do not consider the impact of behavioral parent training on parents themselves and the family as a whole (Schreibman, 1983). These programs can be a significant source of stress, which can result in low levels of parental participation, reduce parental adherence and motivation to use learned skills thus reducing a parents' ability to benefit from parent training, reduce the overall effectiveness of the child's treatment, and impede child development (Dempsey et al., 2008 Grindle et al., 2009; Osborne et al., 2008; Schreibman, 1983; Symon, 2001). In response, mindfulness-based parent training programs have been implemented with parents of children with ASD to combat the negative effects of parental stress associated with parenting and parental involvement in behavioral parent training. The aim of these programs is to reduce parental stress by teaching parents to mindfully attend to the stressors of raising a child with ASD, while nonjudgmentally accepting associated negative sensations and emotions (Kabat-Zinn & Kabat-Zinn, 1991, 1997). This programming has successfully reduced parental stress and increased parental well-being, and has been associated with a positive indirect behavioral response in their children (Singh et al., 2006). However, parents often view these programs as ineffectual; mindfulness-based parent training programs often have high parent attrition rates (Ferraioli & Harris, 2013). Despite being parent-focused, for parents of children with ASD, their concerns and needs are often associated with the day-to-day task of interacting and parenting their child with ASD, which these programs do not address.

It may be that a key part in clinical interventions for parents of children with ASD is addressing parenting stress and parental well-being, while addressing their role and the tasks of parenting a child on the spectrum. Parental well-being is an integral part of a child's long-term healthy outcomes (Deater-Deckard, 2004). While psychological distress is an important risk factor for poor child developmental outcomes and a dysfunctional parent-child relationship, lower stress in the parenting role has been found to be critically important for both positive parent and child outcomes (Deater-Deckard, 2006). While there are obvious immediate benefits to the parent when parenting stress decreases or dissipates, there are also benefits to the child, via improvements in parenting skills, the overall quality of the parent-child relationship, and increased effectiveness of interventions designed to create improvements in the child's developmental outcomes. Reducing parenting stress can have the added benefit of increasing the effectiveness of interventions designed to create improvements in children's developmental outcomes while facilitating positive and effective parenting behaviors, improving the quality of family relationships, and reducing children's behavioral and emotional problems (Deater-Deckard, 2004). Furthermore, just as high levels of parental stress can exacerbate the child's behaviors (Osborne, 2008), the child's challenging behaviors (i.e., behaviors associated with ASD, maladaptive behaviors) contributes to the overall experience of stress (Kasari & Sigman, 1997; Wolf, Noh, Fisman & Speechley, 1989) for parents of ASD. In general, the degree of improvement in children's behaviors is tired to the degree of reduction of parenting stress (Kazdin & Wassell, 2000; Sanders & MacFarland, 2000). Thus, parent training programs need to address the challenges and demands parents experience as parents of children with ASD via behavior management, while addressing the impact those challenges and demands bring by reducing parental stress and increasing parental well-being.

Parents exert significant influence on their children's developmental trajectory and developmental outcomes. They influence their child's life at all times, throughout the child's lifespan (Lerner et al., 2005). However, from a developmental systems perspective, a child's development is inherently bidirectional and is the product of constantly changing interactions between the developing child and their environments (Lerner, 1991; Lerner, Wertlieb & Jacobs, 2003). While relational developmental systems suggest that children's development occurs within changing and interdependent relationships between the child and specific features of his or her physical and social contexts (Lerner, 1991; Moore, 2016). The Bioecological Model of Human Development Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006) emphasizes interactive relationships among four main elements that influence development: person, process, context, and time (i.e., PPCT model; see Figure 1). The PPCT model highlights the roles that the person (i.e., parent, child), proximal processes (i.e., parent-child interactions), contexts (i.e., microsystem, exosystem), and time (i.e., duration and consistency of proximal processes, rate of change) have on development. This interactive, reciprocal and complex ecology has yet to be considered in the design and implementation of parent training programs. Instead, behavioral parent training programs emphasize child-based outcomes while mindfulness-based parent training addresses parent-based outcomes. However, to have long-lasting change that is considerate of parent needs, the parent-child relationship needs to be looked at as a whole.

The parent-child relationship occurs across numerous everyday settings (i.e., home, therapy, community outings), involves others (i.e., siblings, therapists, spouses/partners) and occurs across the child's lifespan. Moreover, characteristics of both the parent and child play a role in the development of the parent-child relationship as well as impact the behaviors and biopsychological changes of each. These differences and changes in the child and parent may impact the dynamics of their relationships, home life, institutions, community and so on. The diversity and bidirectional nature of this dynamic and relationship interacts with and contributes to shaping the unique developmental trajectories of the children with ASD. By considering the developmental system of the child, including examining parent-child interactions and the contexts in which they are embedded (i.e., family, community), parent training programming and interventions may be more effective for parents *and* children.

There is a need to move more toward ecologically valid models of parent training; programming needs to consider parental and contextual factors that promote successful and sustainable interventions (Stahmer & Pellecchia, 2015). According to Matthews and Hudson (2001), parental factors and contextual factors need to be regarded to improve the effectiveness of training programs. This may include parental mental and physical health, family structure, and socioeconomics among other characteristics of family and community systems. There needs to be a shift from expecting parents to become therapists to helping parents succeed at the parenting role. Thus, parent training programs should look at the parent, the child, and the parent-child relationship in the context of parenting and the broader contexts of family and community.

Treatment approaches that focus on the needs of the parents as well as the child, opposed to only focusing on the child or the parent, are more likely to be successful (Deater-Deckard, 2004; Deater-Deckard & Bulkley, 2000). Moreover, interventions that address the needs and concerns of the family unit can produce long-lasting change (Deater-Deckard, 2004). There needs to be a shift toward examining the role of parent-implemented strategies in reducing parental stress, improving family functioning, and facilitating child development. Interventions that reduce parenting stress need not target parenting specifically. Any number of changes in a family’s situation, a parent’s own health and functioning or a child’s behaviors could lead to reductions in parenting stress. This means they are many potential “targets” for intervention efforts (Deater-Deckard, 2004). That being said, the most obvious source of potential change is the parent.

While there is general consensus that parental involvement is an essential component of effective intervention programs, there is significant need for parent training programs to better meet the needs of parents while continuing to aim for child-focused outcomes. Children with ASD are embedded within a developmental system composed of many variables that influence their behavior, as well as the behavior of those who manage their intervention. Therefore, an increased understanding of behavioral supports for family dynamics and factors that influence the effectiveness of interventions for children with ASD is warranted. Parent training programs need to be able to address the overwhelming difficulties associated with the child with ASD without becoming an additional source of stress or a burden to the parent or the family as a whole. Thus, a developmental systems lens may be needed to address and target this area of research and clinical application.

Purpose of Study

The present study focuses on assessing the needs of parents of children with ASD to help in the design of strategies and protocols to be used in parent training programs of children with ASD. This study is different from the current literature in that it provides parents the opportunity to express what information and/or recommendations they would like to have available to them. To answer the research question, the present study uses a phenomenological qualitative approach with a developmental systems lens.

Using phenomenology, this research was focused on the experience of the selected sample; specifically, the goal of this research was to describe the common meaning of a "lived experience" of a phenomenon (Creswell, 2013). The basic purpose of the phenomenological approach is to "reduce individual experiences with a phenomenon to a description of the universal essence" (Creswell, 2013, p. 76); this approach is focused on understanding and describing the "what" of the experience and "how" each individual experienced it. For the purpose of the present study, the phenomenon of interest was the experience of parenting a child with ASD. While phenomenological research typically includes data gathered from participants recounting their experience as the study's primary data, other phenomenological research examines the experience from numerous data sources (Colaizzi, 1973; Moustakas, 1994). Triangulation of data sources was used in the study described to obtain rich and robust information about the parenting experience of parents of children with ASD, as well as to increase the trustworthiness of study findings. These sources included one-on-one interviews with participants, observations of parent-child interactions, and parent-completed self-report measures on parent- and child-based data. Using the literature as a guide, the present study aims to better understand the experiences of parents of children with ASD, specifically with parenting stress, raising a child with ASD, and experiences and interactions with healthcare professionals, in order to address what support parents what and need via direct services and parent training.

This study focuses on assessing the needs of parents by providing parents an opportunity to express what information or recommendations they would like to have available to them. The present study was designed using several assumptions of the researcher conceded by the literature. First, parents experience significant stress related to parenting, and specifically to parenting a child with ASD. Second, the child with ASD may exhibit deficits in social communication and social interaction, restrictive and repetitive behaviors, and potentially maladaptive or problem behaviors. Third, the child with ASD may require significant and ongoing care causing parents to have concerns for the future care of their child. Fourth, parents have had experience and interactions with healthcare professionals as children with ASD receive direct services as well as parents' direct experiences via parent training. Lastly, parents want/need support via direct services and parent training.

In order to obtain a deeper understanding of the perspectives of the participants, the researcher investigated several topics using a semi-structured, open-ended interview protocol. An adapted version of the Ecocultural Family Interview (EFI; Weisner, Coots, Bernheimer & Arzubiaga, 1997) was used. The EFI is meant to be a conversation with parents and caretakes about their children, how they organize their everyday routine; that is, how they plan, create, change and sustain family activities (Weisner et al., 1997). The EFI focuses on family routines because it is daily routines that matter most in children's lives and that serve as the best indicator of family well-being. Furthermore, organizing a family routine is something that all families do. But every family faces the challenge of balancing resources, needs, and skills. More specifically, the EFI aims to expose and capitalize on each family's ecology (i.e., resources and constraints) and culture (i.e., beliefs and values). Thus, the EFI was designed to inform treatment providers about the family context in which intervention would be embedded. The semi-structured, open-ended questions in this interview focus on the family's daily activities, values, and stressors (Weisner, 2002). dimensions expose the adaptions that all families make in constructing their everyday routines. Through a mix of conversation, probing questions by the interviewer, and preplanned structured questions, parents discuss the daily routine from their own perspective, using their own words and categories, and they often share the problems in and successes of the family's everyday life. The format of the EFI of allows the conversation to be guided toward discussing the triumphs and problems of their family's everyday functioning.

The EFI was chosen for the present study as it allowed for a qualitative approach using a developmental systems lens to explore the lived experience of parents of children with ASD. In choosing to use research qualitative, it allows for a complex, detailed understanding of the issue as well as empowers parents to share their stories and hear their voices (Creswell, 2013). by focusing on and asking questions about a family's everyday routine and life, the researcher would be able to gain a deeper understanding of a parent's experience raising a child with ASD as it is happening. As parents of child with a developmental disability, these parents have extensive experience with answering questions about their child with ASD in a healthcare setting; starting early on with the diagnostic assessment process to evaluations by healthcare providers when determining intervention goals to annual IEP (Individualized Education Plan) meetings. Those conversations tend to be child-centered, focused on the child's behaviors and future targets of intervention. But these parents are not necessarily asked questions about their own experiences and feelings, especially as they relate to parenting. Additionally, the conversational format of the EFI, rather than a question-and-answer format, allows for a focused conversation about a familiar topic, while providing parents an opportunity to tell their story.

As recommended by the authors, the EFI was adapted to be used with parents of children with ASD and to address the research questions. Given the unique challenges, demands, and stressors that parents and families of children with ASD encounter and experience, it was important the research protocol was guided by the literature and was specific to the phenomenon of interest. Thus, the adapted protocol aims to obtain a deeper understanding of the perspectives of the participants by asking how each individual experiences the phenomenon of parenting a child with ASD in order to assess what parents need.

The present study used relational developmental systems theory (Lerner, 1991) and the Bioecological Model of Human Development (Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006) as the framework to interpret parental and contextual factors, and the role they play in the caregiving experience. This theoretical foundation fits conceptually with the present study's qualitative phenomenological research design. As individuals with ASD have unique characteristics, interests, deficits, similarly, family systems in which these individuals operate are also distinctive. Quantitative researchers have contributed to understanding the experiences of caregivers, but more investigation is needed to grasp a richer understanding of the demands, needs, and experiences that are grounded in real life stories told about caring for and raising a child with ASD. The open-ended, semi-structured interview aimed to understand parents' experiences as supported by the literature, while also allowing parents an opportunity to share their own personal experience, in their own words. Additionally, this interview asked parents outright what they wanted in and from parent training programs; by exploring their experience with raising a child and interacting with healthcare professionals via direct services and parent training, parents are able to use their own personal experiences to answer this question.

Using a qualitative research design, the purpose of the present study was to examine parents' lived experiences while placing them in a relational, eco-systemic context, assess factors and supports that will influence the effectiveness of parent training programming, and provide recommendations to help future practitioners determine what kind of parent training programs that parents of children with ASD may find useful.

CHAPTER 3

Method

For the purpose of the present study, the phenomenon of interest was the experience of parenting a child with ASD. Using the literature as a guide, the present study aims to better understand the experiences of parents of children with ASD, specifically with parenting stress, raising a child with ASD, and experiences and interactions with healthcare professionals, in order to address what support parents are in need via parent training. Thus, the present study is a needs assessment of parent training programs for parents of children with ASD using a phenomenological approach and developmental systems lens.

Research Design

A qualitative method of inquiry was used to understand the experiences of parents of children with ASD to conduct a needs assessment for parent training programs. Specifically, the present study used a phenomenological research design to discover an essential description of being a parent for a child with ASD. To achieve this level of understanding, the primary researcher studied the meanings related to each significant statement, developed thematic clusters that honored shared meanings, and integrated the essence of the narrative into the phenomenological event's exhaustive description (Creswell, 2013; Moustaka, 1994).

An information letter and a consent form were sent out to participants via email. Each participant was contacted for an interview. This study received approval from Claremont Graduate University's Institutional Review Board prior to data collection (see Appendix A).

Participants

All participating children and parents were recruited from an afterschool research and treatment center for children and adolescents with ASD. During the consent process, parents were told verbally and on their consent forms that all participation in the present study was voluntary, and it would in no way affect their child's participation in other aspects of the center. A sample of 24 parents of children with ASD were selected. Inclusion criteria included parents of children (i.e., 3-18 years of age) diagnosed with ASD according to the criteria in the Diagnostic and Statistical Manual of Mental Disorders-Fifth edition (DSM-5; APA, 2013). A total of 12 parents completed the study, a 50% return rate.

Participants included 12 parents from 9 families of children with ASD. Parents reported on 11 children diagnosed with ASD; however, across the 9 families, there was a total of 15 children and adolescents with ASD represented. Two of the families had children with ASD over 18 years of age, while two other families had children who were diagnosed with ASD in the past, but the diagnosis had been withdrawn. All of the families had multiple children; for two of the families, all of the children were diagnosed with ASD and the remaining 7 families had both children with ASD and neurotypical children. In addition to the children with ASD, 7 neurotypical children and adolescents are represented. All participants were the biological parents. The majority of participants were mothers (n=9, 75%). Parents ranged from 34 to 51 years of age. Parents were from diverse ethnic and cultural backgrounds: 42% Caucasian, 42% Hispanic, 8% Asian, and 8% Middle Eastern/Arab. The children with ASD (n=11) ranged from 4:5 to 14:6 years of age, with the majority being male (n=9, 82%). However, this higher percentage of boys with ASD is unsurprising as males are four times more likely to have a diagnosis of ASD than females (CDC, 2020). The children with ASD were diverse in both their ages and functioning level; 64% presented with severe ASD, 27% with mild/moderate ASD, and 9% with minimal/mild ASD according to their CARS-2 scores. A summary of participants and their characteristics is presented in Table 1.

Table 1

Participant Characteristics

Parent	Age	Gender	Occupation	Ethnicity	Child	Age	Gender	CARS2 Rating
Nina	42	Female	Homemaker	Middle Eastern/Arab	Simon	9:6	Male	Mild/Mod.
Linda	47	Female	Homemaker	Caucasian	Brian	11:4	Male	Mild/Mod.
Sarah	41	Female	School Director	Asian, Pac. Islander	Kevin	13:0	Male	Severe
Reina	41	Female	Homemaker; Self-employed	Hispanic	Justin	13:2	Male	Severe
Maria	51	Female	Teacher	Hispanic	Jessica	14:6	Female	Mild/Mod.
Elizabeth	41	Female	School Director	Caucasian	Michael	8:4	Male	Mild
Lillian[1]	40	Female	Nurse	Caucasian	Zane[1]	7:3	Male	Severe
Cameron[1]	40	Male	Salesman	Hispanic				
Leah[2]	40	Female	Lawyer	Hispanic	Isaiah[2]	12:4	Male	Severe
Caleb[2]	43	Male	Teacher	Hispanic				
Katelyn[3]	34	Female	Homemaker	Caucasian	Jordan[3]	6:5	Male	Severe
					Emma[3]	5:5	Female	Severe
Brandon[3]	35	Male	Engineer	Caucasian	Ryan[3]	4:5	Male	Severe

Note. The [1, 2, 3] denote mother and father respondents

Family 1

The first parent -child dyad was Nina, a 42-year-old Middle Eastern homemaker, and her son, Simon. This middle-class family consists of Nina and her husband, and their children. Simon is one of three children; he has a twin sister, who is 9-years-old and younger brother, who is 7-years-old. His younger brother was previously diagnosed with ASD, but his diagnosis was withdrawn. Simon is a 9-year-6-month-old child with ASD; his Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) score indicates mild/moderate autism. Based on the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983), he has internalizing behaviors and total behaviors in the borderline clinical range. As well as demonstrates moderately low functioning according to his Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores. Nina experiences significant stress related to parenting; according to her Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995) score, she's in the clinical range at the 95th—99th percentile.

Family 2

The second parent-child dyad was Linda, a 47-year-old Caucasian student, and her son, Brian. This middle-class family consists of Linda and her two children; Linda is a widow. Brian is one of two children; he has a younger sister who is 7-years-old. Brian is a 11-year-4-mont-old child with ASD; his Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) score indicates mild/moderate autism. Brian exhibits internalizing, externalizing, and total problem behaviors according to the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983). Additionally, based on his Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores, he demonstrates adequate adaptive functioning. Linda's stress levels are within the normal range falling at the 75th percentile according to her Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995) scores.

Family 3

The third parent-child dyad was Sarah, a 41-year-old Asian health director of a high school, and her son, Kevin. This middle-class family consists of Sarah and her two children; Sarah is divorced and a lone parent. She does have significant support from her parents as well as a caregiver for Kevin. Kevin is one of two children; he has an older brother who is 15-years-old. Kevin is a 13-year-old child with ASD. Based on his Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) scores, Kevin has severe autism. He exhibits internalizing behaviors and total problem behaviors in the borderline clinical range based on the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983). His adaptative functioning is low based on his Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores. His mother, Stephanie's scores on the Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995) indicate that her stress is in the clinical range at the 85th percentile.

Family 4

The fourth parent-child dyad was Reina, a 39-year-old Hispanic homemaker, and her son, Justin. Reina also works part-time from the home. This middle-class family consists of Reina, her husband, and her three children. Justin is one of three children; he has an older brother, who is 23-years-old and a younger brother, who is 10-years-old. His younger brother was previously diagnosed with ASD, but his diagnosis was withdrawn. Justin is a 13-year-4-month adolescent with ASD. He demonstrates severe symptoms of ASD, based on his Childhood Autism Rating

Scale, Second Edition (CARS-2; Schloper et al., 2010) score. Additionally, based on the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983), he exhibits internalizing behaviors, externalizing behaviors, and total problem behaviors in the clinical range. His Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores indicate low adaptive functioning. Based on her Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995) scores, Reina's stress is in the clinical range at the 99+ percentile.

Family 5

The fifth parent-child dyad was Maria, a 51-year-old Hispanic teacher, and her daughter, Jessica. This middle-class family consists of Maria and her daughter; Maria is divorced and her oldest currently lives with his father. Jessica is one of two children; her older brother is a 19-year-old male diagnosed with ASD. Because Maria's oldest son is over 18 years of age, she only completed self-report measures for Jessica. Jessica is a 14-year-6-month-old adolescent with ASD. She exhibits mild/moderate autism symptoms based on her Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) scores. Based on the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983), her internalizing behaviors, externalizing behaviors, and total problem behaviors are within the normal range for youth 6-18. Her adaptive functioning is in the adequate ranged based on her Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores. Miriam's stress levels are within the normal range at the 30th percentile, based on her Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995) scores.

Family 6

The sixth parent-child dyad was Elizabeth, a 41-year-old Caucasian college athletic director, and her son, Michael. This middle-class family consists of Elizabeth, her husband and her two children. Michael is the oldest of two boys; he's younger brother is 6-years-old. Michael is an 8-year-4-month-old with ASD. His Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) scores indicate minimal/mild autism – Michael was diagnosed with ASD at 8-year-2-months and just began receiving services. Based on the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983), he fell within the normal range for internalizing behaviors, externalizing behaviors, and total problem behaviors. His adaptative functioning is moderately high according to his Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores. Based on the Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995), Elizabeth's stress levels fall within the normal range at the 25th percentile.

Family 7

Both mother and father participated. Lillian is a 40-year-old Caucasian nurse and Cameron is a 40-year-old Hispanic salesman. This middle-class family consists of Lillian and Cameron and their four children, two boys and two girls; both of their sons are diagnosed with ASD. Their two daughters are 13-years-old and 4-years-old. Because their eldest son is a 20-year-old college student, Lillian and Cameron only completed self-report measures for Zane. Zane is a 7-year-3-month-old child with ASD. His Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) scores indicate severe autism. He exhibits internalizing behaviors in the borderline clinical range, and externalizing behaviors and total problem behaviors in the normal range, according to the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983). Based on his Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores, Zane has low adaptive functioning. Both parents experience parenting stress in the normal range, with Lillian at the 60th percentile and Cameron at the 50th percentile based on their Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995) scores.

Family 8

Both mother and father participated. Leah is a 40-year-old Hispanic part-time lawyer and Caleb is a 43-year-old Hispanic teacher. This middle-family consists of Leah, Caleb and their two children: a teenage daughter, who is 14-years-old and their son, Isaiah. Isaiah is a 12-year-4-month child with ASD. His Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) scores indicate severe autism. Based on the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983), he exhibits internalizing behaviors, externalizing. behaviors, and total problem behaviors in the clinical range. He has also demonstrated low adaptive functioning based on his Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores. Both parents experience parenting stress levels in the clinical range, with Leah at the 90th-95th percentile and Caleb at the 95-99th percentile based on their Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995) scores.

Family 9

Both mother and father responded, they have three children diagnosed with ASD. Katelyn is a 34-year-old Caucasian homemaker and Brandon is a 35-year-old Caucasian engineer. This middle-class family consists of Katelyn and Brandon, and their three children: Jordan, Emma, and Ryan. Jordan is a 6-year-5-month old child with ASD. Based on his Childhood Autism

Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) scores, he has severe autism. His internalizing behaviors and externalizing behaviors are in the borderline clinical range, while his total problem behaviors are in the clinical range based on the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983). His Vineland Adaptive Behavior Scales-3 Domain-Level Parent/Caregiver Form (VABS-3; Sparrow, Cicchetti, & Saulnier, 2016) scores indicate moderately low adaptive functioning. Emma is a 5-year-5-month old child with ASD. Her CARS-2 scores indicate severe autism. She exhibits internalizing behaviors in the borderline clinical range, and her externalizing behaviors and total problem behaviors are in the normal range based on her CBCL scores. Her VABS-3 scores indicate low adaptive functioning. Ryan is a 4-year-5-month-old child with ASD. Based on his CARS-2 scores, he demonstrates severe autism. Based on the CBCL, his internalizing behaviors, externalizing behaviors, and total problem behaviors are in the clinical range. His VABS-3 scores indicate moderately adaptive functioning. Both parents experience parenting stress levels in the clinical range, with Brandon at the 95th percentile and Katelyn at the 99+ percentile based on their Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995) scores.

Data Collection

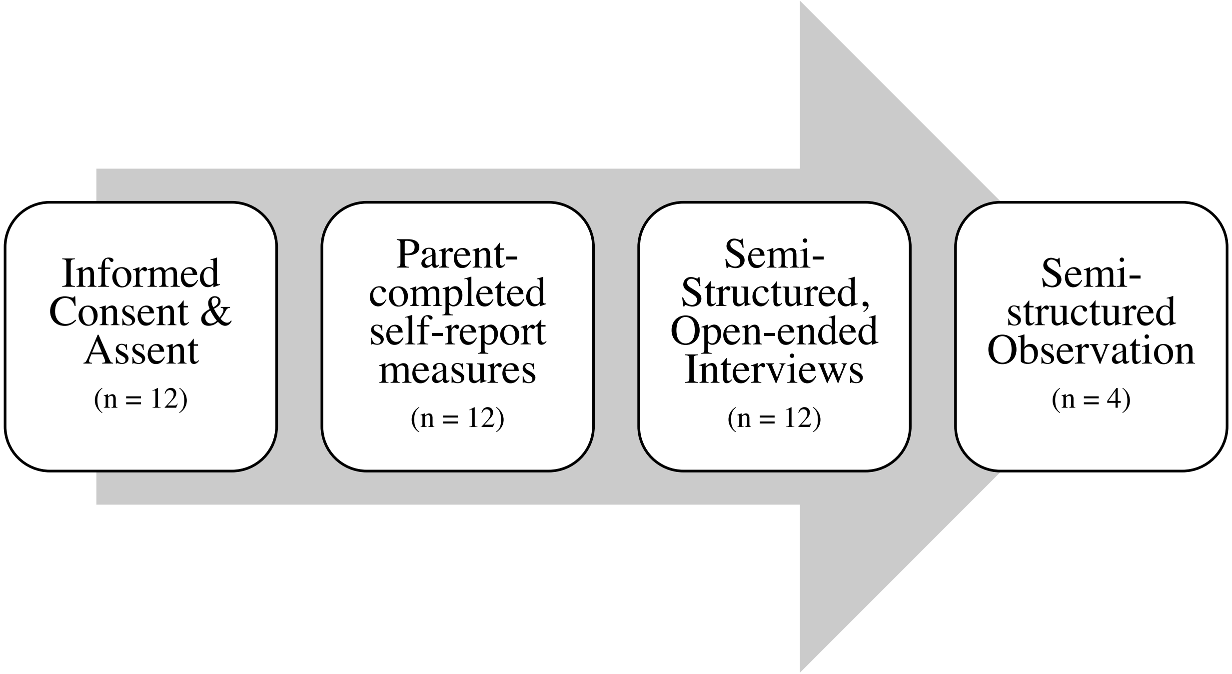
Data collection (see Figure 3) included (1) parent-completed self-report measures on parent and child measures, (2) semi-structured, open-ended interviews with the 12 parents, and (3) semi-structured observations of parent-child interactions in the home and/or community.

Consent was obtained prior to any interviews or observations that were conducted (see Appendix B). In observations of parent-child interactions, child assent was discussed and provided. As the present study included both children with ASD that are capable of understanding assent and those who do not, two assent procedures were used. First, for those children who were capable of understanding assent, a simplified assent form (i.e., using a picture-based system) and process was used (see Appendix C). For those children with ASD who are nonverbal or are unable to give assent, their acted as the custodian of informed consent. Additionally, assent removal was determined if the child refused to participate, cried, exhibited aggressive behavior, became visibly distressed and/or attempted to leave the room. The children with ASD only directly interacted with their parent throughout the duration of the study.

Once consent and assent were obtained, parents completed demographic questionnaires for themselves and the child (see Appendix D) and self-report measures on parent measures (and child measures. Following the completion of the self-report measures, interviews and observations were scheduled. Because data collection began before and occurred during COVID19 and the Stay-at-Home order (CDC, 2020; California Executive Order No. N-33-20, 2020), some interviews and data were collected in-person in the afterschool treatment center or in the parents' home, while some interviews and data were collected virtually (i.e., over the phone, FaceTime or Zoom). Thus, observations of parent-child interactions did not occur for every parent-child dyad; observations were conducted for 4 of the 12 parents. A digital audio-recording device was used to collect all interview data, which were then transferred to an external hard drive and transcribed at a later time. To ensure accurate data collection, notes were taken by hand during the entire interview. A digital video-recording device was used to collect all observational data, which were then transferred to an external hard drive and reviewed at a later time. To ensure accurate data collection, notes were taken by hand during the entire observation.

Figure 3

Data Collection Procedure



The Self-Report Measures

Prior to the interviews or observations, parents completed a packet that included demographic questionnaires about parent and child, and self-report measures: the Parenting Stress Index, Third Edition—Long Form (PSI—3; Abidin, 1995), the Childhood Autism Rating Scale, Second Edition—Questionnaire for Parents or Caregivers (CARS2-QPC; Schloper et al., 2010), and the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983). The descriptions of each of these measures is below.

Demographic Questionnaire. The demographic questionnaire (see Appendix D) was a short form for parents to report parent, child, and family demographics as well as child services received.

Parent Report: Parenting Stress. The Parenting Stress Index, Third Edition—Long Form (PSI-3—LF; Abidin, 1995) was used to examine parental stress levels. The PSI-3 is a standardized measure that identifies the perceived levels of stress related to the tasks of parenting, and the ability to effectively manage that stress. It is a 120-item Likert scale measure that provides a total stress score by measuring factors within both child and parent domains. High scores within the child domain suggest child characteristics that make it difficult for parents to fulfill their parenting role. The child domain rates child-level features including adaptability, demandingness, mood, distractibility/hyperactivity, acceptability of child to the parent, and child's reinforcement of the parent. High scores within the parent domain suggest sources of stress and potential dysfunction of the parent-child system related to dimensions of the parent's functioning. The parent domain assesses parental depression, attachment to the child, social isolation, sense of competence in the parenting role, relationship with spouse/parenting partner, role restrictions, and health.

Scores are calculated by calculating subscale scores in order to identify a total stress score (Abidin, 1995). Raw scores are then converted to percentiles, with the normal range of scores falling within the 15th and 80th percentiles and the clinical range of scores being those identified above the 85th percentile.

Parent Report: Child Measures. Parents completed two self-report measures on their child's ASD characteristics and behaviors. Characteristics of the children were assessed using the Childhood Autism Rating Scale, Second Edition—Questionnaire for Parents or Caregivers (CARS2-QPC; Schloper et al., 2010) and the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983).

The Childhood Autism Rating Scale, Second Edition – Questionnaire for Parents and Caregivers (CARS2-QPC; Schloper et al., 2010) was used to assess the severity of the ASD by parents. The CARS2-QPC is an unscored form completed by the parent of the child with ASD that provides more information when accompanied by the CARS-2. The Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) is designed as a clinical rating scale for the trained clinician to rate item indicative of ASD after direct observation. The CARS2-ST identifies severity of ASD symptoms via direct observation by a clinician.

The Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983) is a parent report measure of their child's maladaptive behaviors. The CBCL provides behavior scores within normal, borderline, or clinical ranges on three domains: internalizing behaviors, externalizing behaviors, and total problem behaviors (Achenbach, 1991; Achenbach & Edelbrock, 1983). For parents of children under 6 years of age, they were given the CBCL for children 1.5 to 5 years of age (100 items); parents of children over the age of 6 were given the CBCL for children 6 to 18 years of age (113 items). Some parents were given the CBCL for children 1.5 to 5 years of age if their child was chronologically older than 6 years of age, but their mental age was under 6 years of age (based on adaptive functioning scores using the Vineland Adaptive Behavior Scales-3; Sparrow, Cicchetti, & Saulnier, 2016).

Semi-structured, Open-ended Interviews. Semi-structured, open-ended interviews were conducted to collect qualitative data on parenting experiences and parental needs. All interviews were performed by the primary researcher (Masters level doctoral student) trained in this technique and were audio-recorded to supplement notetaking and facilitate data collection. Open-ended questions were formulated to generate a conversation about the parents' needs; the primary researcher adapted the Ecocultural Family Interview (EFI; Weisner, 1997). The EFI is a semi-structured interview designed to inform treatment providers about the family context in which intervention will be embedded. Open-ended questions in this interview focus on the family's daily activities, values, and stressors (Weisner, 2002). As recommended by the authors, the EFI was adapted to be used with parents of children with ASD. During the interview, the primary researcher followed cue cards with general questions and follow-up probe questions.

For the purpose of the present study, the EFI was adapted to better understand parents' experiences raising a child with ASD, including stressors, the child's services, the impact of ASD on the parent and family to better assess parents' needs. Moreover, the EFI was adapted to better assess the needs of parents by providing parents an opportunity to express what information or recommendations they would like to have available to them. The present study was designed using several assumptions of the researcher conceded by the literature. First, parents experience significant stress related to parenting, and specifically to parenting a child with ASD. Second, the child with ASD may exhibit deficits in social communication and social interaction, restrictive and repetitive behaviors, and potentially maladaptive or problem behaviors. Third, the child with ASD may require significant and ongoing care causing parents to have concerns for the future care of their child. Fourth, parents have had experience and interactions with healthcare professionals as children with ASD receive direct services as well as parents' direct experiences via parent training. Lastly, parents want/need support via direct services and parent training.

The adapted EFI protocol included nine dimensions: (a) the parent, (b) parenting, (c) parenting stress, (d) parenting success, (e) family context and experience, (f) child with ASD, (g) services for your child with ASD, (h) support system(s) and information, and (i) interventions and parent training programs. For each dimension, the interviewer encouraged parents to speak about their experiences, unmet needs, and their expectations in order to better understand their experiences as parents of children with ASD, and to identify intervention priorities and possible improvements for parent training programs. Parents were asked to provide examples and elaborate or clarify their initial statements when appropriate (e.g., do you have further examples of this? What do you mean by that?). The researcher sought to develop what was said by asking other questions, if necessary. The interviews took between 45 and 120 minutes.

Because data collection began before and occurred during COVID19 (CDC, 2020), some interviews were collected in-person in the afterschool treatment center or in the parents' home, while some interviews and data were collected virtually (i.e., over the phone, FaceTime or Zoom). A digital audio-recording device was used to collect all interview data, which were then transferred to an external hard drive and transcribed at a later time. To ensure accurate data collection, notes were taken by hand during the entire interview.

Semi-structured Observations. Following the completion of interviews, observations were conducted. Semi-structured direct observations were included to triangulate data gathered via self-report measures and parent views. The aim was to provide unbiased and objective data for parent-child interactions as they occur in natural settings such as the home or community. Because data collection began before and occurred during COVID19 (CDC, 2020), some interviews and data were collected in-person in the afterschool treatment center or in the parents' home, while some interviews and data were collected virtually (i.e., over the phone, FaceTime or Zoom). Thus, observations of parent-child interactions did not occur for every parent-child dyad; observations were conducted for 4 of the 12 parents. After the interview, 5-minute observations were conducted of parent-child interactions. These interactions consisted of either the parents playing with their child with ASD, sitting and talking with their child with ASD, or engaging in a daily routine; depending on the child with ASD and typical parent-child interactions. For two parents, the observation consisted of the daily routine of walking their children into school. For one parent, the observation consisted of the parent playing with her child with ASD and his two siblings. And for the last parent, the observation consisted of her and her son talking at the kitchen table.

A digital video-recording device was used to collect all observational data, which were then transferred to an external hard drive and reviewed at a later time. To ensure accurate data collection, notes were taken by hand during the entire observation.

Data Analysis

Analysis of Self-report Measures

The self-report measures for parent and child were administered and scored using the professional manuals and scoring procedures. Scores are presented as recommended (i.e., raw scores, percentiles, t-scores). Pearson's correlation coefficient was run to assess the relationship between parenting stress and child characteristics, including ASD diagnosis and the presence of maladaptive behaviors. Additionally, Person's correlation coefficient was run to assess the relationship between parenting stress and parents' ACT processes measures. Pearson's correlation coefficient (r) is a measure of the strength and direction of the association between two quantitative variables.

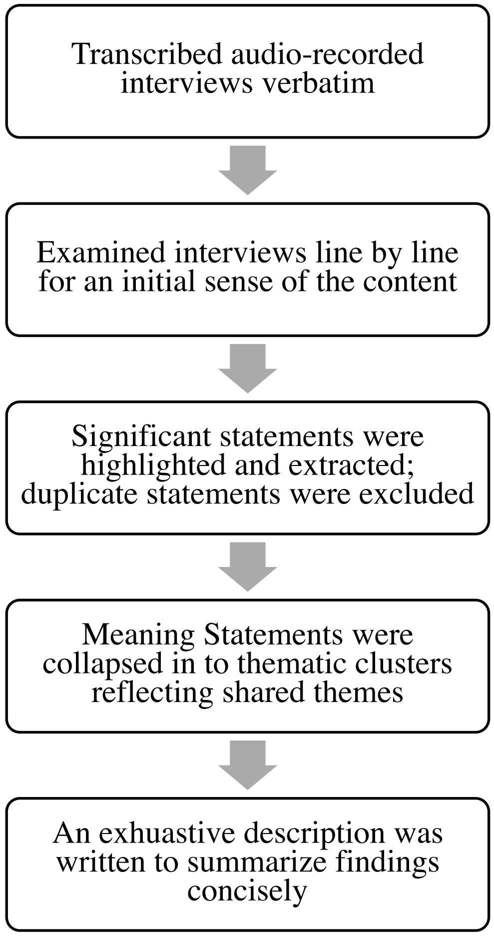
Analysis of Semi-structured, Open-ended Interviews

Prior to data analysis, the primary researcher transcribed each audio-recorded interview verbatim and checked for accuracy. Participants' data were analyzed using Moustakas (1994) method of phenomenological data analysis (see Figure 4). The following steps were used: (1) Researcher read and reviewed the interview transcriptions to acquire an initial sense of the content; (2) Significant statements, or quotes that provide an understanding of how the participants experience the phenomenon, were highlighted and extracted; (3) Meaning statements were created for each significant statement; (4) Meaning statements were collapsed into thematic clusters reflecting shared themes, or clusters of meaning were developed; and (5) An exhaustive description was written to summarize findings concisely, or composite description that presents the “essence” of the phenomenon. Throughout this analytic process, the researcher identified themes consistent with the literature on experiences of parents of children with ASD. In qualitative research, data collection ends when saturation is achieved and no further themes emerge (Rafuls & Moon, 1996). Saturation was achieved with the 12 interviews conducted.

In addition to the development of a strong theoretical framework, elements of triangulation were used to ensure that the data gathered in this research had been adequately analyzed. The issue of validity was addressed through the use of triangulation, employing the use of multiple researchers, methods and sources (Strauss & Corbin, 1998), which included independent reviews of the transcripts by two trained undergraduate psychology students to confirm the themes described in the results of this study. Triangulation was also achieved through the use of parent-completed self-report measures on both parent and child measures and observations of parent-child interactions in the home and/or community.

Figure 4

Flow Diagram of Data Analysis Procedure



Note. Participants' data were analyzed using Moustakas (1994) method of phenomenological data analysis (Creswell, 1998, 2013).

Role of the Researcher. Phenomenology supports the ideology that researchers' preconceived notions, beliefs, and biases may influence their interpretation of data (Creswell, 2013). Thus, it is recommended that researchers write about their own experiences and the context and situations that have influenced their experiences (Moustakas, 1994) and include it in the methods section (Marshall & Rossman, 2010). Because the researcher is the primary instrument of data collection in phenomenology, it is necessary to note the interviewer's characteristics. For this study, the primary researcher is a doctoral student studying positive developmental psychology with an emphasis on autism spectrum disorders and applied behavioral analysis; this study serves as the primary researcher's doctoral dissertation research project. A crucial aspect of the researcher for this study was to ensure her beliefs and experiences, as well as her ethnic and cultural background did not bias the interpretation and presentation of this research. Rogers (1986) strongly argued that clinicians must lay aside their own judgements and values in order to grasp, with delicate accuracy, the exact meaning of what the client is experiencing. Working with children with ASD, their parents and their families has been the focus of the researcher's academic and professional endeavors as clinician for 10 years. As a clinician, it was important to the researcher to understand the perspectives and experiences of parents raising a child with ASD. Through an empathic understanding of their experiences, parent training methods can be developed and individualized, which in turn will contribute to better treatment outcomes for the child, the parent, and the family.

Semi-structured Observations

Given the limitations of the semi-structured observations due to data collection due to COVID19 and the Stay-at-Home order (CDC, 2020; California Executive Order No. N-33-20, 2020), the data from the observations are used for the purposes of triangulation of the qualitative data collected via interviews. Only 4 parents (n =12) were able to observed in the home and/or community.

Scoring/Reliability

Validity

Research data must be considered valid if applied to practice in a useful manner (Morse, Barrett, Mayan, Olson, & Spiers, 2008). The term validation has been defined as the process of evaluating the accuracy of the collected data. For a qualitative study, validation is facilitated through extensive work in the field, meaningful interactions during time spent with the participants, and accurate transcriptions of the collected data (Morse et al., 2008).

Since the present study used a phenomenological qualitative approach to explore the personal perspectives of the study's participants, validity of the findings need to be addressed. Therefore, through an accurate transcription of the collected data, the researcher validated any conclusions and interpretations based on the careful analysis of the perspectives of the participants, which are being considered as honest and trustworthy in order for this study's findings to be valid (Morse et al., 2008). Additionally, issue of validity was addressed through the use of triangulation, employing the use of multiple researchers, methods and sources (Strauss & Corbin, 1998), which included independent reviews of the transcripts by the researcher and external coders to confirm the themes described in the results of this study. Triangulation was also achieved through the parent self-report measures.

Reliability

The researcher ensured the reliability of this study's findings by : (a) preventing errors when accurately transcribing the data; (b) reviewing the data and documenting each step in the review process; and (c) carefully assigning codes that are consistent within and across cases with no deviation from case to case.

Additionally, interrater agreement was obtained for parent interviews. The interview transcriptions were read and coded independently by two external coders. To establish inter-rater reliability, the researcher first coded the transcripts independently and then met with the two external coders, independently to review codes and themes. The independent coders coded independently to guarantee that the codes were consistent in their application and thematic clusters were similarly identified. For the present study, inter-rater reliability was 92% within parent interviews and 89% across parent interviews.

Procedural Validity

Procedural validity was obtained for parent interviews. All parent interviews were audio-recorded and assessed by two independent trained raters for procedural integrity. Thirty-three percent of the recorded sessions were randomly evaluated by the two independent trained coders using a task analysis checklist to score the presence or absence of components of the interview protocol. Additionally, all processes used to collect and analyze data were systematically followed and consistent across all participants. Based on procedural validity coding, the interviews were conducted with 100% procedural integrity.

Transferability

Transferability was supported through a comprehensive description of the perspectives (e.g., thoughts, experiences, feelings) of the participants in the context of their role as a parent of a child with ASD. Each case was described in detailed narrative form using direct quotes and multiple exemplars. Moreover, the diversity of the participants in terms of their ages, genders, and ethnic and cultural backgrounds as well as the children's ages, genders, and functioning levels greatly enhanced the transferability of the study's results to the population of parents of children with ASD.

CHAPTER 4

Results

The results and findings from the present study are presented as the data was collected via multiple sources: parent self-report measures and semi-structured, open-ended interviews with the parents. First, the results from the parent-completed self-report measures is presented; these measures attempted to assess parenting stress using the PSI-3 across (a) child characteristics using the CARS-2 and the CBCL, and (b) parents' psychological flexibility or ACT processes using the AAQ-II, CFQ and VLQ. Additionally, several themes developed during the semi-structured, open-ended interviews with the parents. Using Moustakas' (1994) method of phenomenological data analysis (see Figure 3), five thematic clusters developed: (a) psychological implications, (b) familial implications, (c) social implications, (d) focus on future, and (e) services and support. Lastly, an exhaustive description of the phenomenological experience is presented.

Parenting Stress

The Parenting Stress Index, Third Edition—Long Form (PSI-3—LF; Abidin, 1995) was used to examine and assess parental stress levels in the 12 parents interviewed. The PSI-3 provides a total stress score and three subscale scores: child domain, parent domain, and life stress score. The raw scores across the child and parent domains, and the total stress score are converted into percentiles (see Table 2). Based on the percentiles of converted raw scores, scores within the normal range of scores fall between the 15th and 80th percentiles and the clinical range of scores are identified as being above the 85th percentile or below the 15th percentile.

Table 2

Parenting Stress Measure

Parent	PSI-3 Child Domain Score	Child Domain Percentile	PSI-3 Parent Domain Score	Parent Domain Percentile	PSI-3 Total Raw Score	PSI-3 Total Percentile
Nina	158	99th **	159	90-95th**	317	95-99th**
Linda	123	90-95th**	121	50th	244	75th
Sarah	135	95-99th**	122	50th	257	85th**
Reina	172	99+**	147	80-85th*	319	99+**
Maria	89	30th	112	35th	201	30th
Elizabeth	99	50th	98	10-15th**	197	25th
Lillian[1]	135	95-99th**	93	10th **	228	60th
Cameron[1]	129	90-95th**	92	10th**	221	50th
Leah[2]	173	99+**	109	25-30th	282	90-95th**
Caleb[2]	173	99+**	103	20-25th	276	90-95th**
Katelyn[3]	173	99+**	154	90-95th**	327	99+**
Brandon[3]	150	99+**	151	85-90th**	301	95-99+**

Note. The [1, 2, 3] denote mother and father respondents. The ** denotes clinical ranges for parents' PSI-3 scores: child domain, parent domain, and total score. For the PSI-3, raw scores are converted to percentiles, with the normal range of scores falling in within the 15th and 80th percentile, and scores in the 85th percentile and above are considered in the clinical range. The ^ denotes percentiles that would be considered in the clinical range but due to contextual factors, these parents are not considered at-risk.

The total PSI score is the primary value that identifies parent-child systems that are under stress or at-risk for the development of dysfunctional parenting behaviors or behavior problems in the child (Abidin, 1995). Raw scores of 260 and higher are considered in the clinical range. It is possible for parents to earn a total PSI score in the normal range and earn domain scores that fall in the clinical range or below the normal range. Across the 12 parents, 42% scored within the normal range while 58% scored in the clinical range (see Figure 5). Parental stress levels (*M* = 264.7; SD = 46.4) ranged from the 25th percentile to the 99+ percentile; the mean for parenting stress levels fell in the clinical range of stress between the 85th and 90th percentile. Stress appeared to be lower for parents of children with minimal to moderate ASD, while for the majority of parents of children with severe ASD, their stress index fell in the clinical range. This trend was also present across the two families that consisted only of children diagnosed with ASD.

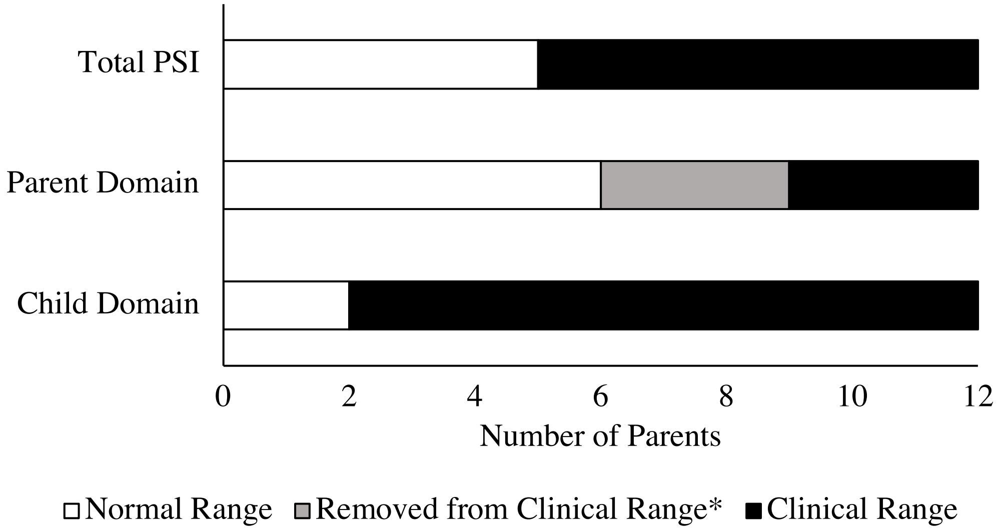
High scores in the child domain may be associated with children who display qualities that make it difficult for parents to fulfill their parenting roles (Abidin, 1995). The child domain rates child-level features including adaptability, demandingness, mood, distractibility/hyperactivity, acceptability of child to the parent, and child's reinforcement of the parent. When this score is elevated, compared to parent and life domains, it may be that the child characteristics are major factors that contribute to overall stress in the parent-child system. Across the 12 parents, which represents a total of 11 children with ASD aged 3-18 years of age, 83% scored in the clinical range for the child domain of the PSI-3 (see Figure 5). Given the unique characteristics and demands of ASD, high scores in the child domain are expected; scores are typically elevated for parents of children with special needs (Abidin, 1995). Moreover, this data demonstrates that even though five parents' overall total PSI fell in the normal range, that three of these five parents are experiencing substantial parenting stress related to the demands and needs of their child with ASD.

High scores in the parent domain suggest that sources of stress and potential dysfunction of the parent-child system may be related to dimensions of the parent's functioning (Abidin, 1995). The parent domain assesses parental depression, attachment to the child, social isolation, sense of competence in the parenting role, relationship with spouse/parenting partner, role restrictions, and health. Across the 12 parents, 58% scored within the clinical range (i.e., greater than 85% and below 15%); three parents scored below the 15th percentile (e.g., Elizabeth; Lillian and Cameron – see Figure 5).

Elizabeth, who scored within the normal range on the Total PSI score and within the clinical range for child domain, also obtained a concerning defensive responding score. The defensive responding score (i.e., 24 or less) indicates that the parent may have been responding in a defensive manner. As for Lillian and Cameron, they both scored within the normal range on the Total PSI score and within the clinical range for child domain and parent domain scores, also obtained a concerning defensive responding score. However, low defensive responding scores with low Total PSI scores can also indicate that the parent is very competent and that the parent-child relationship exists within a supportive social situation that is economically advantaged.

Figure 5

Distribution of Parenting Stress using the PSI-3

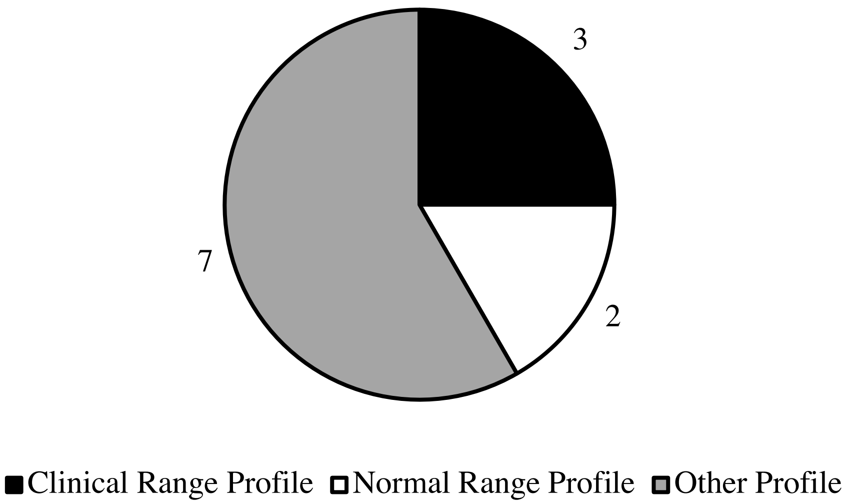


Note. Shows the distribution of parents' scores (n = 12) in the clinical and normal range across the Total PSI score, the parent domain score, and the child domain score. The * denotes data removed from the interpretation of the clinical range under the parent domain. Three parents obtained scores lower than the 15th percentile, but upon further investigation and examination, they are not considered in the clinical range.

The PSI-3 (Abidin, 1995) allows for and the interpretation of parenting stress profiles because this measure not only captures a total parenting stress score, but it provides scores related to both parent and child features of the parent-child system. Across the 12 parents, four distinct parenting stress profiles arose (see Figure 6). The first two domains are parents that obtained clinically high scores across all three domains (n =3) or obtained scores within the normal range across all three domains (n = 2). The third profile, parents obtained scores in the clinical range for the child domain only, while scoring in the normal range for the parent domain and total stress score (n = 3). The last profile, parents obtained scores in the clinical range for the child domain and total score and scored in the normal range for the parent domain (n = 4). These distinct stress profiles are important to consider as they can help to determine what kinds of interventions are necessary and where treatment efforts should be placed: child behaviors, parent behaviors, and/or the parent-child system as a whole. The assumptions of the PSI-3 (Abidin, 1995) are that stress, or sources of stressors is additive, and that stressors are multidimensional. Thus, for parenting stress, the two major source domains of stressors are child characteristics and parent characteristics as both contribute to the overall functioning of the parent-child system. These parenting stress profiles are important to consider when trying to identify and understand parent-child systems; understanding sources of stress on the parent-child system should inform treatment efforts aimed at reducing parental stress. For example, parents who have obtained clinically high scores in both the child and parent domains, as well as their overall total score, may not benefit from intervention efforts that only focus on child characteristics and behaviors, and ignore parent-focused programming. Moreover, if only the total parenting stress is considered and not individual domain scores, parents who have an overall score in the normal range but clinical scores in the child domain may be overlooked.

Figure 6

Distribution of Parenting Stress Profiles



Note. The Clinical Range profile includes parents that obtained clinically high scores across all three domains: Total PSI score, Child Domain, and Parent Domain. The Normal Range profile includes parents that obtained normal scores across all three domains. The Other profile consists of two parenting stress profiles: (1) parents obtained clinically high scores in the Child Domain only, and normal range of scores for Total PSI and the Parent Domain; and (2) parents obtained clinically high scores in the Child Domain and for the Total PSI score, but scores in the normal range for the Parent Domain.

Parenting Stress & Child Characteristics

Parents completed two self-report measures specific to child characteristics. First, parents completed the Childhood Autism Rating Scale, Second Edition—Questionnaire for Parents or Caregivers (CARS2-QPC; Schloper et al., 2010) to rate the severity of ASD symptomology and behavior. The CARS2-QPC was used alongside the Childhood Autism Rating Scale – 2 (CARS-2; Schloper et al., 2010), which had been completed by clinicians at the afterschool treatment program the families attended. The CARS2-QPC is an unscored form for parents to record observations; the two forms were used to ensure consistent reporting from parents. For the CARS-2 total scores can range from a low of 15 to a high of 60; scores below 30 indicate that the child is in the non-autistic range, scores between 30 and 36.5 indicate mild to moderate autism, and scores from 37 to 60 indicate severe autism (Schloper et al., 1988). Second, parents completed the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983), which is a parent report measure of their child's maladaptive behaviors. The CBCL provides behavior scores within normal, borderline, or clinical ranges on three domains: internalizing behaviors, externalizing behaviors, and total problem behaviors (Achenbach, 1991; Achenbach & Edelbrock, 1983). For the CBCL, it uses t-scores; scores under 59 are in the normal range, scores between 60 and 63 are in the borderline clinical range, and scores 64 and above are in the clinical range. The CARS-2 and CBCL are parent measures of child ASD characteristics and maladaptive behaviors.

Table 3

Participant Measures

Parent	PSI-3 Raw Score	PSI-3 Percentile	Child	CARS-2 Raw Score	CARS-2 Rating	CBCL T-score
Nina	317	95-99th**	Simon	31.5	Mild/Mod.	60*
Linda	244	75th	Brian	32	Mild/Mod.	77**
Sarah	257	85th**	Kevin	43.5	Severe	60*
Reina	319	99+**	Justin	52	Severe	71**
Maria	201	30th	Jessica	33	Mild/Mod.	56
Elizabeth	197	25th	Michael	24.5	Minimal/Mild	47
Lillian[1]	228	60th	Zane[1]	49	Severe	58
Cameron[1]	221	50th				
Leah[2]	282	90-95th**	Isaiah[2]	52	Severe	72**
Caleb[2]	276	90-95th**				
Katelyn[3]	327	99+**	Jordan[3] Emma[3] Ryan[3]	41 53 38	Severe Severe Severe	64** 59 68**
Brandon[3]	Engineer	95-99+**				

Note. The [1, 2, 3] denote mother and father respondents. The ** denotes clinical ranges for both parents' PSI-3 scores and children's CBCL scores, and the * denotes borderline clinical ranges for the CBCL. For the PSI-3, raw scores are converted to percentiles, with the normal range of scores falling in within the 15th and 80th percentile, and scores in the 85th percentile and above are considered in the clinical range. For the CBCL, raw scores are converted into T-scores; scores 59 and under are in the normal rang, scores from 60-63 are in the borderline clinical range, and scores 64 and over are in the clinical range.

In the present study, 11 children with ASD are represented in the data (see Table 3). There were a total of 15 children with ASD, however, two individuals were over 18 years of age and two children had previously had their diagnostic label removed. Thus, the children with ASD ranged in age for 4 to 14 years old, and the majority were male. The children with ASD were diverse in both their ages and functioning level; 64% presented with severe ASD, 27% with mild/moderate ASD, and 9% with minimal/mild ASD according to their CARS-2 scores (see Figure 7). The majority of children exhibited maladaptive behaviors; 45% presented with behavior scores in the clinical range for total behavior problems (see Figure 8). Nine of the 12 parents fit the typical profiles of parenting stress as they relate to their child with ASD's characteristics and personal attributes: greater child impairment is accompanied by more parenting stress.

Figure 7

Distribution of ASD Characteristics in Children with ASD using the CARS-2

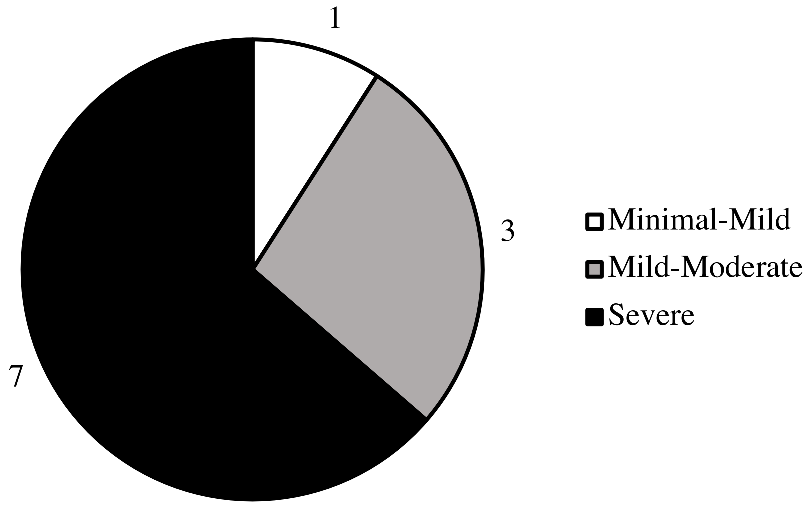
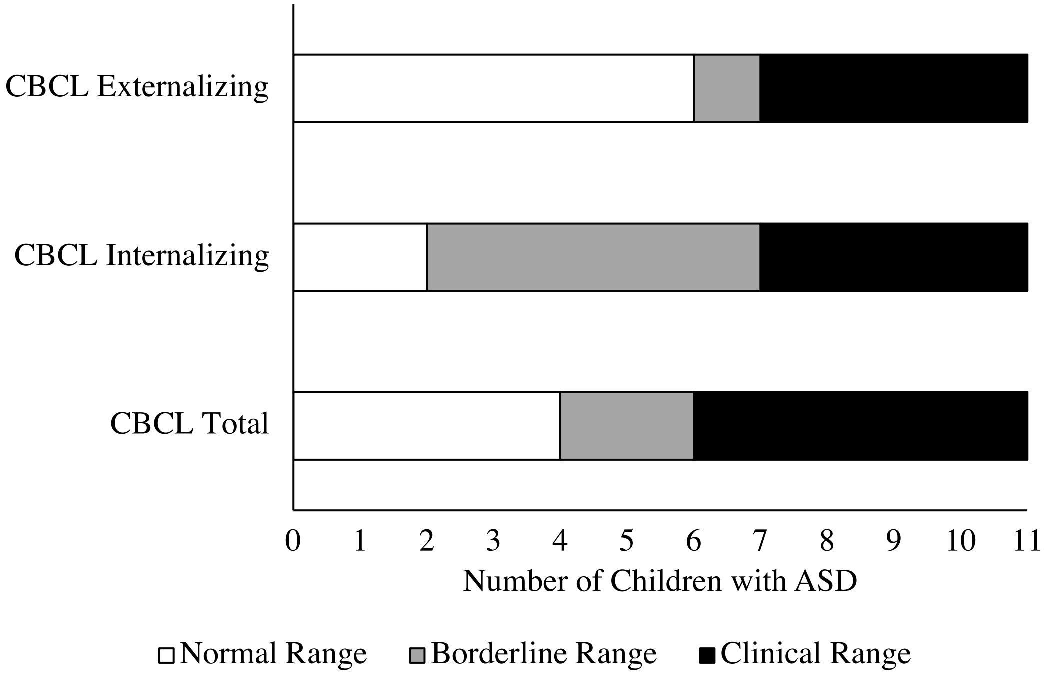


Figure 8

Presence of Maladaptive Behaviors in Children with ASD using the CBCL



While all parents experience stress at some point, it can be intensified by a child's additional needs. In general, parents of children who have more disabling conditions that persist for longer periods of time show more signs of severe, chronic parenting stress. Using the Parenting Stress Index, Third Edition (PSI-3) as a measure of parenting stress, the Childhood Autism Rating Scale, Second Edition (CARS-2) as measure of severity of ASD, and the Child Behavior Checklist (CBCL) as a measure of the presence of problem behaviors, significant positive relationships were found between parent's stress levels and the child's characteristics (see Table 4). More specifically, there is a significant positive relationship between parent's stress levels and the child's ASD severity, $r(10) = .58$, p = .05 as well as between parent's stress levels and the child's problem behaviors, $r(10) = .60$, p = .05. Assessing for total impact of child characteristics on parent stress, a significant positive relationship was found between parent's stress levels and total severity (combination of CARS-2 and CBCL), *r*(10) = .59, p = .05. Furthermore, there is a significantly positive relationship between the child's ASD severity and the presence of problem behaviors (i.e., externalizing, internalizing, and total), *r*(9) = .97, p < .001; children with more severe ASD symptoms tend to exhibit more maladaptive and problem behaviors.

Table 4

Correlations: Parenting Stress & Child Characteristics

Measure	PSI-3 Total Raw Score	CARS-2 Raw Score	CBCL T-score	Total Severity (CARS-2 + CBCL)
PSI-3 Total Raw Score	--	.58*	.59*	.59*
CARS-2 Raw Score	--	--	.97**	--
CBCL T-score	--	--	--	--
Total Severity (CARS-2 + CBCL)	--	--	--	--

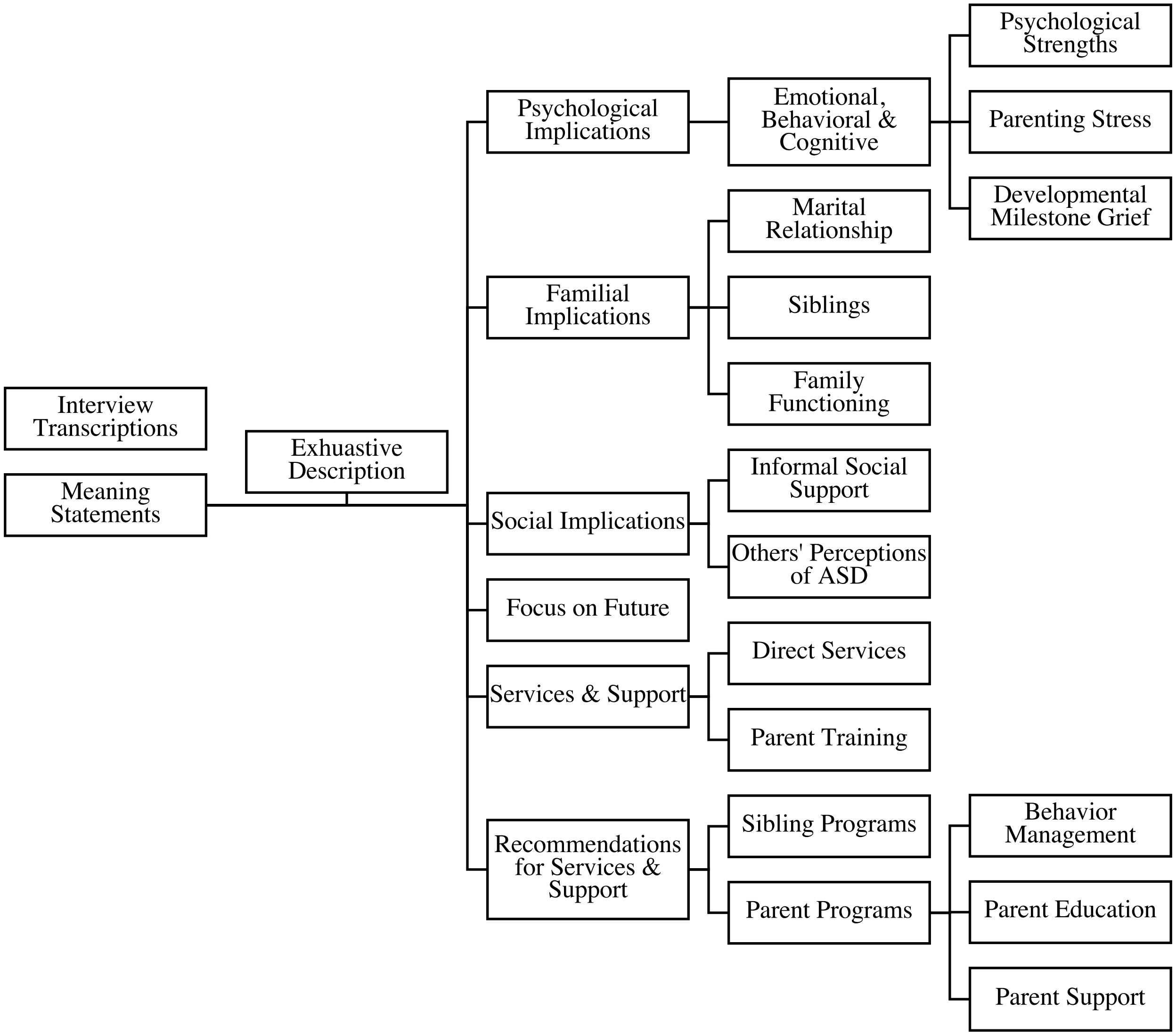
Note. Pearson Correlation (2-tailed). The * denotes correlations are significant at the .05 level (2-tailed) and ** denotes correlations are significant at the .01 level (2-tailed).

Qualitative Findings

The resulting six thematic clusters (see Figure 9) are presented independently. However, given the relational developmental systems lens, it is important to consider each cluster's interconnectedness. Using Moustaka's (1994) method of phenomenological data analysis (see Figure 3), six thematic clusters developed: (a) psychological implications, (b) familial implications, (c) social implications, (d) focus on future, (e) services and support, and (f) recommendations for services and support. Following the six thematic clusters, a summary of the study's findings and all thematic content areas are presented in an exhaustive description.

Figure 9

Development of Thematic Clusters from Meaning Statements

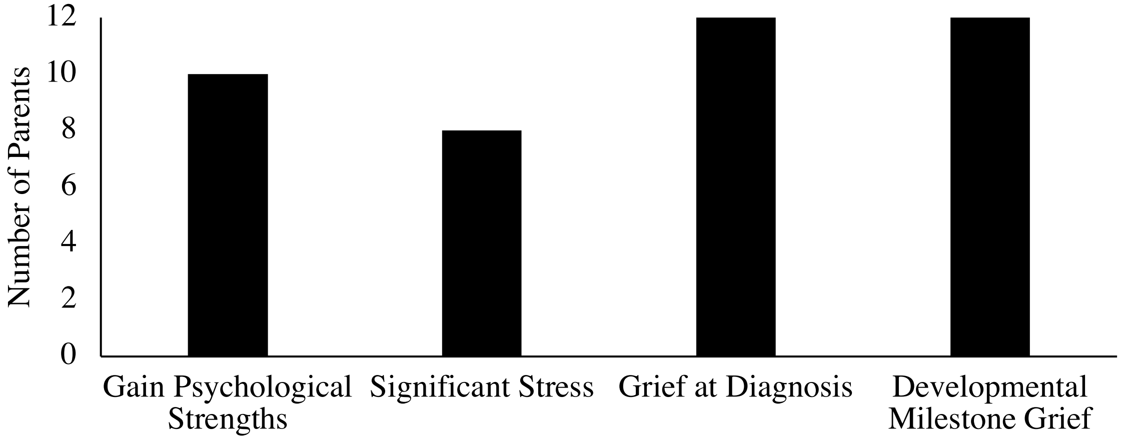


Cluster One: Psychological implications

The first thematic cluster that developed describes the emotional, cognitive, and behavioral implications of raising a child with ASD. More specifically, the benefits and challenges that parents report in their parenting experience; see Figure 10 to see parents' responses to the subthemes found in this thematic cluster.

Figure 10

Psychological Implications



While the present study focused heavily on parenting stress, the challenges and demands parents face, it also asked parents about the positive and beneficial outcomes of their parenting experience. Approximately, ten parents reported that their experience with ASD has several beneficial outcomes. The parenting role has allowed parents to gain several psychological strengths, including higher levels of selflessness, greater compassion and empathy for others, and increased adaptability and resiliency in life. Many parents expressed that they feel that "autism has been their greatest teacher." ASD has taught them so much, not just in respect to parenthood but in life. Some parents shared that their experience with their children with ASD has positively impacted other areas of life, such as the work environment because they have taken those psychological strengths and applied them in their work; one parent shared that the development of compassion and understanding has positively influence his position as a manager. Another parent shared that it positively impacted other relationships in their lives, including their marriage and with other family members and friends, both of which will be explored further in other thematic clusters. Parents also reported seeing these same benefits in other family members, from siblings to relatives; that their child with ASD positively impacts those around them. Moreover, many parents expressed that these psychological strengths translated to their overall outlook on life, often putting life and what is important into perspective. As one parent shared, "Something I've noticed is how much they can teach you. There is so much you learn that you cannot learn any other way but through autism. Not just as a parent, but as a human being."

Another benefit reported was the optimism parents felt as their child progressed, despite their diagnosis. For many parents, they reported that ASD provided them and their families "little victories." Despite the deficits and impairments associated with ASD, through direct intervention services and parental involvement, their child progressed and improved albeit at their own pace. Whereas parents of typically-developing children experience many milestones, for parents of children with ASD, there are many more milestones and breakthroughs. Rather than only celebrating their child's first words or first steps, parents are celebrating all of the developmental breakthroughs that their child makes across their lifespan. Parents explained that these breakthroughs are worth celebrating and keep them motivated to continue doing what is necessary. One parent explained, "I remember every breakthrough, I remember all of his firsts. They are such a big deal and we celebrate them. With autism, you learn that, that you need to celebrate the small victories. It makes it all worth it." For some parents, they believe that ASD gives them those wins and that it teaches them to take nothing for granted.

Additionally, parents reported that another benefit is the optimism they feel when advocating for their child and other children with ASD, especially as they become a resource for other parents. Parents move from new-ASD-parents and overtime learn how to navigate the network of services, insurance, and ASD, and become a resource for new parents of children with ASD. Many of these parents reported feeling overwhelmed when their child was initially diagnosed and that much of what they were able to accomplish was self-taught, but that becoming a resource for other parents gives them a sense of achievement. As one parent shared, "Other parents will tell each other, 'you should talk to [Sarah] and that role reversal, it's so great. It feels an accomplishment and brings me a sense of calm, like I've been successful in this journey." The network of services from ABA programs to support in schools is complex and often convoluted, and it often requires parents to not only learn and understand how the system works, but also requires parents to constantly advocate and fight for what their child needs. This role reversal gives parents hope and reassurance that they successfully meeting the demands and challenges of parenting a child with ASD.

Well parents reported benevolent and personal gains in their parenting role, they also found it difficult to cope with the overall emotional demands they faced daily and over the course of their child's life. Feelings of sadness, hopelessness, isolation, and stress were reported; eight parents reported experiencing significant stress. Moreover, these parents expressed that they expressed stressed specific to the demands, tasks, and challenges of raising a child on the spectrum. Parents described feeling exhausted and overwhelmed by the responsibilities of their parenting role. Parents shared that, "This is crazy hard. Emotionally, it's very tough. It's one of the most challenging parts of my life." Some parents shared that they often to suppress these negative emotions because if they did not, they would not be able to focus their efforts and attention on their children and would not be able to successfully meet the demands of parenthood. Parents explained that "These feelings will just wear on you and eat at you. They'll just sit with you so it's better to ignore them." Several parents reported that they would occasionally breakdown as a result; they would experience emotional breakdowns that often consisted of crying and just letting themselves experience how emotionally difficulty and draining this experience is. Additionally, parents reported that they felt isolated in their emotions and experiences because others do not understand the emotional toll, which further contributed to their negative emotional experience. This often resulted in parents not seeking help or discussing these emotions with others. As one parent expressed, "People are always complimenting me and telling me I make it look so easy, that I have it all together. And I just feel that even though on the outside it looks easy, it's hard on the inside. I feel misunderstood, like I can't share how hard it is, so I don't express it out loud." Many of the mothers shared the same sentiment, even acknowledging that in the interview process it was hard for them to be honest about the negative aspects of their parenting experience. Moreover, these parents admitted that they did not withhold this information purposefully but that it came almost naturally. For example, one parent shared, "I don't think I was super honest with everything. Not that I lied, but just that you kind of get used to saying, 'everything is fine' and even when you're asked to be honest, that's the natural response." It seems that not only are parents experiencing negative emotional experiences, but they may not have access or the tools to successfully cope with the emotional demands of parenthood.

One specific emotional demand associated with being a parent of child with ASD is experiencing grief or mourning during the diagnostic process; parents often report feeling a sense of loss upon receiving their child's ASD diagnosis. Of the 12 parents, only one parent experienced the diagnostic process within the last year; this child was diagnosed at 8-years-old. However, the majority of children with ASD having been diagnosed around two-to-three years of age. Thus, 11 parents had received and processed their child's diagnosis; no parents appeared to be in denial of their child's diagnosis. All parents reported experiencing a period of mourning or grief as well as a period of coming to terms and accepting their child's diagnosis. Interestingly, parents reported that their period of grief was quite short-lived, and it was often accompanied with a sense of a relief and a shift in attitude toward an action-orientated perspective. Parents acknowledged that the diagnosis itself did not change who their child was, but that the diagnostic label, while carrying a stigma, also granted the child access to a myriad of services that are otherwise inaccessible after the age of three. Parents reported that while the diagnostic process was lengthy, once the diagnosis was given, access to services was almost immediate; they were able to request individualized education plans from schools, access ABA programs through insurance, and so on. While the system and network of systems is complex, parents reported that they developed a roll-up-your-sleeves kind of mentality. They may have been feeling a sense of loss at receiving their child's diagnosis, but they knew that with that diagnosis, they as parents needed to learn everything they could about ASD. Actually, parents stated that although they experienced a period of grief and a sense of loss when their child was diagnosed with ASD, they felt that "the blow came later."

The final challenge that parents reported was the presence of grief and loss throughout the child's life, especially when faced with developmental milestones that are not being reached by their children; the primary researcher termed this as *developmental milestone grief* post-hoc. Through interviews, all 12 parents expressed and shared experiences that resemble developmental milestone grief. Three mothers explicitly characterized this grief or sense of loss as “milestone grief.” This experience was common amongst the parents interviewed, and it did not discriminate across the spectrum. Both parents of high-functioning and low-functioning children with ASD experienced this type of grief and acknowledged that they experienced bereavement more frequently as their child aged because the delays and differences become more evident. Parents explained that receiving the diagnosis early on in the child’s life gave them hope, that with the diagnostic label came access to services and thus an opportunity for positive developmental gains. Following the diagnostic process, parents focus on obtaining services and support. As one parent described, “It’s not just the initial diagnosis. Those feelings [of grief, loss] don’t ever really end, they just change. And they are there for every milestone, you know, the ones he’s not reaching.” Another parent explained it, “As he’s aged, I don’t know how to explain it other than, it’s like this milestone grief; it’s like with every missed milestone, you know those moments that typically-developing kids experience, it’s hard. It’s a reminder of what he can’t do. What he’s missing.” From some parents, even seeing neurotypical children of the same age can be a difficult reminder. Parents agreed, that as their children with ASD aged it has become more emotionally challenging as they are reminded that ASD is a pervasive life-long disorder; the stressors and challenges that accompany the diagnosis are present across the child’s lifespan and both directly and indirectly impact the parent. As one parent summed it up: “autistic toddlers become autistic teens that become autistic adults.” Moreover, parents recognized that while they continuously experience this grief and loss, they anticipate that it will continue as their child ages and potentially continues to “miss” other major milestones. The current emotional toll of developmental milestone grief also feeds into parents' concerns and focus on the future, which will be explored in another thematic cluster. But parents expressed concern for future milestones that their child might miss out on due to their diagnosis.

While parents expressed that they are overwhelmed, exhausted, and stressed, they also consistently express that it is "all worth it." As one parent shared,

> "It's very rewarding. Like it's not always negative, it's not. It's very hard, don't get me wrong. It's 80% hard, but that 20%, that will overcome that 80% every time. It's hard work, but that's okay because it's very rewarding."

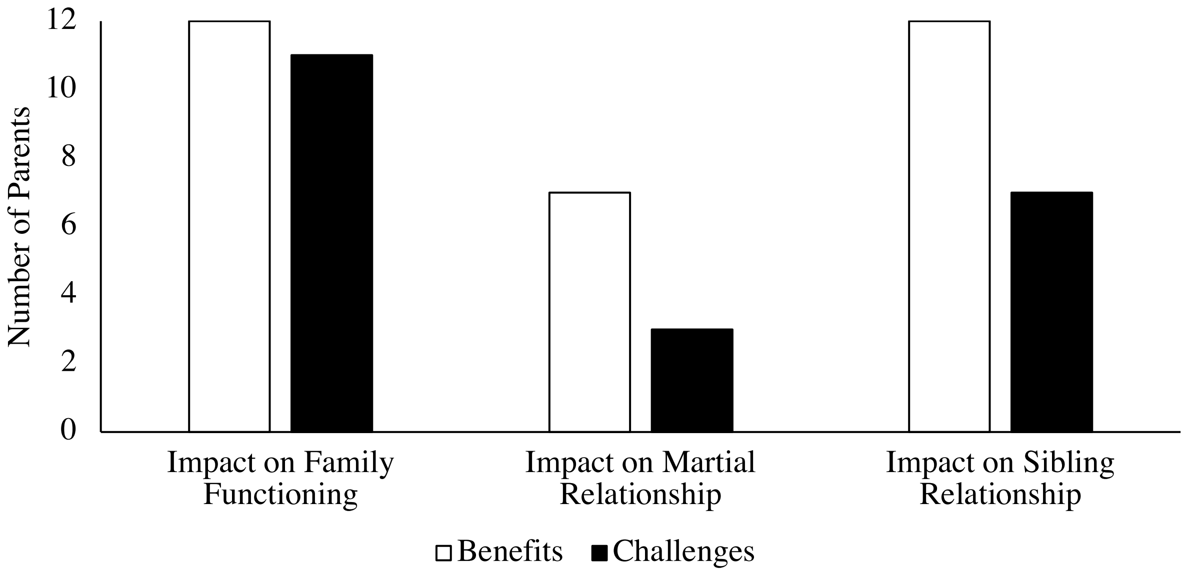
Despite the stress associated with parenthood and parenting a child with ASD, parents report that they are positively impacted by their experience.

Cluster Two: Familial Implications

The second thematic cluster is used to describe the familial implications of having a child diagnosed with ASD. For the present study, family was defined as those relationships within the nuclear family system (i.e., parent-child, sibling dyad, and marital dyad) and limited to those living together; implications of having a child diagnosed with ASD on broader familial relationships (i.e., extended relatives such as grandparents, uncles and aunts, cousins) will be discussed in the next thematic cluster. Parents reported both benefits and challenges of ASD on family functioning and dynamics; see Figure 11 to see parents' responses to the subthemes found in this thematic cluster.

Figure 11

Familial Implications



All 12 parents reported that having a child with ASD built stronger connections among family members, and 11 parents also reported that ASD did put a strain on relationships and overall family functioning. Parents felt that their child with ASD was an integral part of family functioning. Only one parent shared that they had to make significant adjustments to family outings in order to incorporate their child with ASD, while other parents reported that they occasionally made minor adjustments, but it was necessary to ensure that the whole family was included. Many parents shared that they would avoid certain activities or environments that it might be difficult to include their child with ASD, such as movie theatres but instead would pick activities where their children could be themselves, such as trampoline parks. One parent shared that their family was season ticket holders for a local professional sports team, saying that she loved taking her son with ASD because the screaming crowd in the stands was inclusive such that he could engage in high rates of vocal stereotypy without any negative ramifications (i.e., stares, comments). By continuously ensuring that the family found activities to do all together, this mother reported that her oldest son has always been inclusive of his younger brother when planning activities. Parents agreed that it was important that their child with ASD was included and that the child did not keep them from spending time together as a family, instead the types of activities changed to accommodate the needs and challenges of ASD.

Parents unanimously agreed that their children with ASD influenced and impacted their relationship with their spouse. Of the 12 parents, nine were married, two were divorced, and one was widowed. Seven parents acknowledged that while having a child with ASD puts a strain on their martial relationship, they have also found that it has strengthened their marriage. These parents expressed their understanding that either ASD brings you together or how it can drive you apart, as adding children to the relationship "exposes the worst parts, but also brings out the best of your partner." These parents reported that their marriage shifted from a relationship to a partnership, where they are dependent on one another and must work together. Despite overall strengthening their marital relationship, parents were report common stressors that can put strain on their relationship, including differing discipline techniques or opinions on decisions related to therapy and school, limited time for one another, and oftentimes incompatible coping styles when stressed. For the two parents who were divorced, they stated that having a child with ASD was not the cause of their divorce but in a way, it contributed as it exposed flaws and shortcomings in the martial relationship that had been present before the child was born and diagnosed. A significant period of stress that all parents experienced in their martial relationship was during the diagnostic process. Parents shared that they each had their own way of coping and coming to terms with the diagnosis, some parents were quick to accept and move forward with finding and starting services, while other parents experienced denial early on and it took a longer for them to accept the diagnosis. Parents reported that while their relationships have experienced trials and tribulations throughout their child's life, the diagnostic period was extremely difficult.

Another relational benefit reported by parents is that they have a greater sense of value regarding the progress and achievements of all their children. As one parent shared, "I try not to take for granted all the things that all my other kids can do. Like with my youngest, with her being neurotypical, if anything, I almost celebrate her milestones and achievements more." Nine of the parents had both a child with ASD and typically-developing children; three parents only had children with a diagnosis of ASD. Although many parents felt that they are able to successfully juggle the attention needed by a child with ASD and by their typically-developing children, five parents described family life as being a constant struggle. Parents' felt that their availability, in terms of time and attention may play a large role in the adjustment of typically-developing siblings of children with ASD. For example, these parents reported that the child with ASD demanded more attention and care, thereby reducing time spent with the typically-developing sibling, other family members, or familial responsibilities. Parents reported that they do attempt to make time for their typically-developing children, that they try to be intentional in planning one-on-one opportunities but that it does not always happen or often.

One of the most important factors that determines the adjustment of a typically-developing sibling of a child with ASD is their understanding of the diagnosis, according to parents; seven parents reported being concerned about the impact of ASD on their neurotypical children. While parents acknowledge that it's difficult to juggle and balance the needs of all their children, they found that when their neurotypical children understand *what* ASD is and *why* there is an imbalance of parental attention, it improves both family functioning and relationships between siblings. First, if the neurotypical child does not fully understand ASD and the behaviors of their sibling, it can place strain on the sibling relationship, and thus overall family functioning. Parents reported that when their neurotypical children better understand ASD, there is a positive sibling relationship. For example, one parent shared that their eldest daughter is often present when their son with ASD receives behavioral therapy, where she's learned not only what ASD is but how to positively interact with her little brother. This parent reported that by having her daughter involved in her son's therapy, it has improved not only the sibling relationship but also family functioning as there is less of a strain overall. Moreover, their daughter has expressed an interest in working with her children with ASD in the future. Whereas another parent shared that her two neurotypical children do not always understand why their brother with ASD engages in some maladaptive behaviors (e.g., cussing, tantruming) and shows little interest in playing with them. This parent reported that this often causes tension between the siblings, with the neurotypical siblings growing frustrated with their brother with ASD. Sometimes, as this parent reported, the siblings do not actively involve her son with ASD; this strain in the sibling relationship is a major source of stress for parents. Second, if their typically-developing does not fully understand why there may be an imbalance, parents report that their neurotypical children often feel jealous that the parent is spending more time caring for the child with ASD. Parents report concerns and worry that these feelings of jealousy may turn to resentment, and that they are not sure how to always address this dynamic. Overall, parents expressed that sibling relationships between the typically-developing child and the child with ASD are usually positive, with conflict being similar to sibling relationships amongst neurotypical children, but they are concerned with the adjustment of their neurotypical children as being a sibling of child with ASD is hard and lonely.

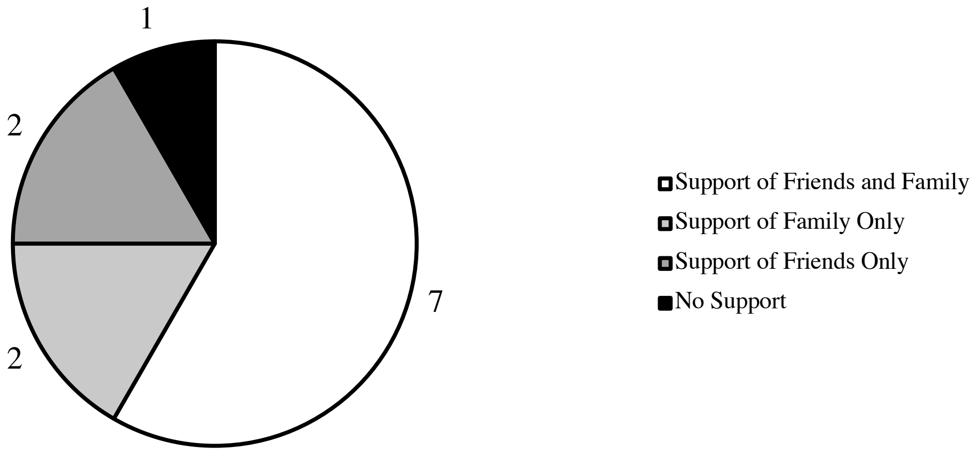
As one parent shared about their typically-developing daughter and her younger son with ASD, “She knows and understands that we are tapped out from raising him so she’s really independent and tries to not to make any waves for us.” This mother added that her daughter tries to be very independent and not require too much time or attention, but that “as a parent, I want her to feel validated. It’s not just her brother’s world, but that’s hard to balance and I don’t always know how to do that.”

Cluster Three: Social Implications

The third thematic cluster is used to illustrated reported social benefits and challenges associated with caring for a child with ASD. Social is defined in this cluster as including those relationships and larger societal interactions occurring outside the immediate family system, such as friends, other parents, church, or extended family; see Figure 12 to see parents’ responses access to informal support systems. Given that the research indicates that the presence of informal social support is a protective factor of parental stress, this study did include broad and open-ended questions regarding the social implications of having a child with ASD.

Figure 12

Forms of Informal Social Support



The majority of parents reported that extended family has been an important source of support, from emotional support to assisting with caregiving responsibilities. Nine parents reported that their extended family members, including grandparents, aunts, uncles, and cousins, have been extremely helpful, welcoming, and inclusive to their child with ASD. Parents felt that the child with ASD positively impacted their extended family members and relatives, as one parent shared about his son with ASD, “I don’t know if he brings people together or what, but he brings something extra. Everybody, I mean cousins, aunts, uncles, everybody is just more understanding, more patient, and more appreciative. It touches everybody.” Additionally, seven parents reported that grandparents were a significant source of support. For these families, grandparents were heavily involved in caregiving responsibilities and often assisted weekly with childcare, transportation, and so on. For the other three parents, only one parent reported that they received little to no support for their child with ASD while the other two parents reported that they feel that their extended family members would be a source of a support in an emergency, but they are not a consistent source of support. Instead, as one parent shared, "Our ideas of support and help were different than their ideas of support and help. I know I can call on them when I really need them, but we are basically on our own when it comes to our families."

Eight parents reported that having a child with ASD has given them opportunities to meet others with shared experiences, or other parents and caregivers of children with ASD and special needs. None of the parents reported participating in official or organized support groups, however. Instead, three parents reported meeting other parents of children with ASD and special needs through their church. Another two parents reported finding support in the other parents of children with ASD that attended their children's school. Two parents reported using Facebook and other social media parenting groups as another source. All eight parents reported that they found the other parents of the afterschool treatment program that all of the children attended to be another resource for informal social support; as one parent shared, "Just talking to the other moms is so helpful. They've been through it and understand what I'm going through." These parents expressed that finding other parents of children with ASD has been extremely beneficial as these parents are both a resource and source of support. Parents commented that it has been helpful to hear the stories of other parents of ASD and share their own experiences, especially as they felt that they can be "open and honest about [their] experiences, without facing judgment because everyone understands." The open nature of this support system allowed parents to access emotional and informational assistance such as sharing information about their child's diagnosis, discussing challenges and strengths, and sharing stories with families in similar situations. This support system provided hope and encouragement for the future. While some parents felt ASD opened avenues to help form friendships, one parent reported that they felt that ASD diminished these opportunities. The three other parents reported that ASD did not help or diminish opportunities for friendship.

Eleven parents reported that the felt that society lacked understanding or care about their situation. These parents held the compliant that society lacks knowledge about ASD and how it manifests in children. All of these parents reported at least one incident in public where people either stared or made comments toward the parent regarding their child with ASD, whether the child was engaging behaviors associated with ASD, such as vocal or motor stereotypy, and/or problem behaviors, such as tantruming or self-injurious behaviors. However, all of these parents also reported that the stares and comments are not a significant source of stress. While it hurts in the moment, parents shared that they have had to learn to not let themselves be burdened by it. Rather, parents are focused on not learning to not be concerned with what others think or say. Moreover, as one parent shared, “When he is having a meltdown, yes there may be people looking at us, but I can’t even let myself be bothered by it because I need to focus on him.” Lastly, parents did express that they wished broader society would be more understanding, aware, and inclusive of ASD. There has been increased awareness and acceptance of ASD; but while there are numerous educational programs for others, parents reported a need for more events and programming for ASD families. For parents, it seems that the focus has been on increasing awareness of ASD, which is important and necessary, but now is the time for more inclusivity. As one parent shared, “People have heard of autism, but they do really know what it is or what we are going through as a family.”

Cluster Four: Focus on the Future

The fourth thematic cluster is used to identify parents' thoughts and feelings about the future. All 12 parent interviews supported the development of this theme, which included the process of acceptance for and uncertainties about the future. For example, one parent shared, "The hardest part is the stress and anxiety over the future. And my brain doesn't shut off. You're lying in bed and thinking about it; you're driving and thinking about it; you don't stop thinking about it." The worry process was constant for parents because they reported facing new challenges and demands each day. As one parent shared, "autistic toddlers become autistic teens that become autistic adults." Many parents expressed that their worries and concerns changed as their child has aged, and that they are concerned that as their child ages they will not be able to raise to the demands of new parenting tasks. Other worries for parents included the decisions they were making for their child's services. As one parent shared, "The biggest in the moment stressor is 'Are you doing it right? 'Are you doing everything you can?' 'Everything possible to set them up for the best possible outcome?' I want to give him everything possible, build the right foundation that way he can thrive. I worry that I'm not doing enough for his future." Other worries for parents included preparing for a future that is unknown, especially in regard to a future where the parent is no longer present; as one parent shared, "I am constantly thinking about who's going to take care of him when we're gone."

Although concerns and worry for the future was a common theme among all participants, several parents reported that they attempt to focus on the present rather than "get sucked into the despair hole of the future." Parents acknowledged that the stress about the future is always going to be present, but when they focus on the present moment and accept their child's condition, it helps to reshape their vision of the future.

Cluster Five: Services & Support

The fifth thematic cluster that developed was focused on the experience and usefulness of formal supports. This cluster is used to describe parents' thoughts about formal supports and gives specific examples of services identified by parents that they found effective or inadequate.

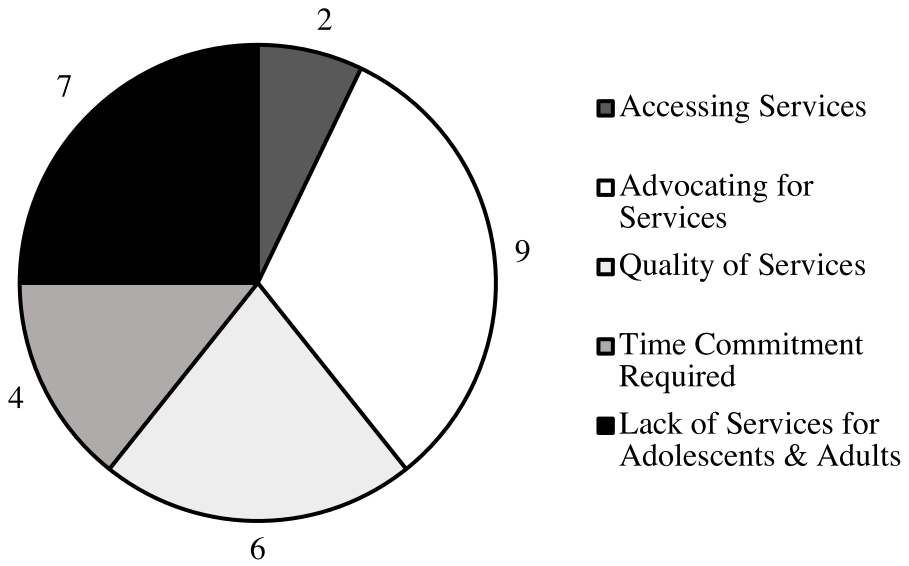
A significant demand of raising a child with ASD is the numerous therapeutic services they receive; in addition to receiving services at school through Individualized Education Plans (IEPs), children with ASD typically receive an array of services outside of school hours, usually on weekdays and sometimes on the weekends. Parents reported that the number of service hours outside of school varied from 2-hours-per-week (i.e., after-school treatment program through which participants were recruited) to 20-hours-per-week. Services provided also range; some children are only receiving behavioral therapy, while others receive behavioral therapy, occupational therapy, speech therapy, and physical therapy. At the time of interviews, only 10 children with ASD (11 parents) were receiving direct services and formal supports, outside of the school setting.

All 12 parents reported that services and formal supports helped them better understand their children, eased stressors placed on the family, and gave them hope for their children with ASD's future. However, parents' satisfaction ranged across the types of services and formal supports their child with ASD received and they as parents participated in. The types of services and formal supports that families included behavioral therapy, social skills programs, speech therapy, occupational therapy, respite care, and the public-school system. Parents reported the most indicative factor of satisfaction and success was dedicated and caring individuals, whether that is their child's teacher or therapist. One parent shared, "You can see it, you can see that they are interested, they understand, and they love what they do. For me, it's the people that make his services and our experience." Another parent added, "Some of them only look at it as a job, they don't connect with him or seem to care beyond that. And that shows too. That's hard to see as a parent." Moreover, parents were pleased when they felt that they and other family members are involved in their child's programming, either in identifying treatment goals and/or being included in direct services. Lastly, parents reportedly were most pleased when they felt well informed about their child's treatment program and progress. While services often require serious time commitments and high parental involvement, parents were reportedly pleased in seeing the gains their child made as result of services and formal supports. For instance, one parent expressed, "It's very hard, all of the different therapies and services. When he first started, he had a full-time 40-hour-a-week program; I couldn't leave the house, I couldn't go to parties. But seeing him doing everything that you've worked for, that's very rewarding. It makes it all worth it. Even now, there's no time because we need to be home for his therapies, but he keeps making progress." Overall, parents reported satisfaction with their child's direct services and formal supports because of their child's progress and developmental gains.

Just as parents reported the helpfulness of formal supports, they also viewed some services and programming to be challenging or unhelpful; see Figure 13 for parents' responses for challenges of direct services and supports. Major areas of dissatisfaction were related to advocating for services, quality of services, the time commitment that is often required, and continuing to access to services as their child ages. A common compliant for ASD services is that the systems in place are extremely confusing and convoluted; parents need to learn how to navigate the public-school system, insurance companies, and the overwhelming number of providers that are available. Parents disclosed that accessing services early on, especially following their child's diagnosis, was difficult. While parents reported that accessing services became easier as their child aged, it was solely based on their learning how to navigate themselves; as one parent shared, “No one hands you a list of resources and service providers, instead it’s you learning how to self-navigate the system. You have to do the research yourself.” But while the network becomes easier to navigate, parents reported that it continues to be difficult because they are constantly fighting and advocating for their child, as both school districts and insurance companies attempt to cut hours and services. It’s one thing to access services, it’s another to maintain them. As one parent shared, “I’m always fighting. Whether it’s the school, whether it’s insurance, it’s always a fight. Either they are cutting hours or not providing services they are required to provide.” Other parents reiterated this sentiment, commenting that parents, who do not know and understand the school system or insurance companies, often get taken advantage of. For example, one parent stated, “You have to know what you’re doing – if not you’ll get the bare minimum to fill the legal requirements.” Nine of the parents reported that they often had to strongly advocate on behalf of their child receive the necessary services and hours. The three other parents reported that they have yet to fight for services, which they attribute to great teachers and therapists that advocate on behalf of the child with ASD and their parent. However, two parents reported having had to take legal action against the public-school system and/or insurance companies; these were under circumstances where legal requirements were not being meant. While other parents reported that they have not had to pursue legal action, they did share that that is something they need to be aware of and be prepared for. Parents understood that they are more than just a parent or a caregiver, but also a life-long advocate for their child with ASD in a system that may not have the child and family’s best interests at heart. For example, one parent shared, “Every other parent tells you that you have to be ready and you have to learn to be demanding. If you won’t advocate, then who will?”

Figure 13

Challenges Regarding Direct Services & Support



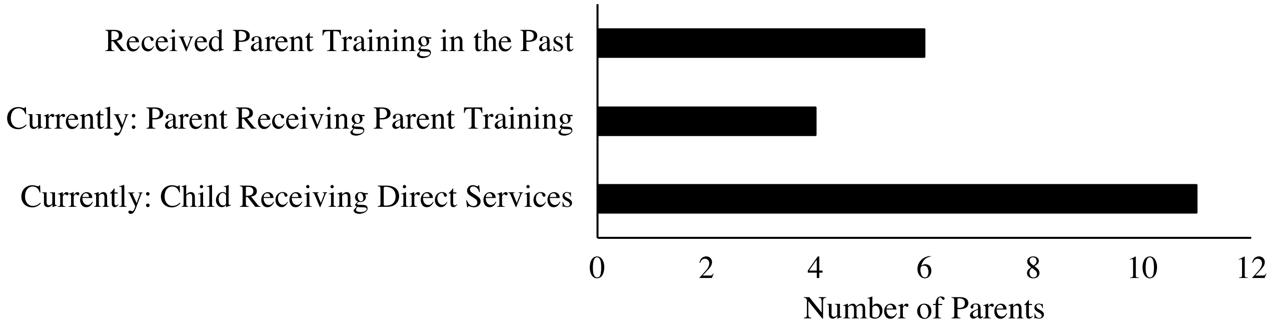
In addition to accessing and advocating for services, parents reported that the quality and time commitments required of direct services and formal supports can also be a challenge. A major challenge is the high turn-over rate in special education and behavioral therapies, especially for direct providers (i.e., aides, behavior therapists). Across the eleven children with ASD in the present study, weekly service hours, outside of school services and hours, ranged from 2-hours to 20-hours. Eight children only received 2-4 hours of direct services, which were often clinic-based programs and did not include school services and supports. Three children received additional hours, often in-home ABA programs during the after-school hours and/or on the weekend. For those families that opted for less hours a week, they did not cite time commitment as a significant stressor or challenge; however, they consciously made the decision to not have their child participate in a significant number of services outside of school hours. The time commitment of direct services varied across families, seemingly due to the child's needs, access to services, and contextual fit. First, the majority of children who presented with minimal to moderate ASD had less weekly service hours outside of school than the children who presented with severe ASD. With the exception of one child, who had more weekly service hours than any other child in the present study. Second, access to services varied by the child's age and functioning level; it is easier to access more in-home service hours if the child is younger and/or requires more one-on-one programming. Third, parents reported that the child's participation in direct services and supports outside of school hours were dependent on what worked for their family. Interestingly, eight of the children with ASD did not receive any in-home ABA direct services, and instead opted for weekly 2-hour clinic-based programming. These parents reported that they made the conscious decision to not have in-home programming and/or significant direct service hours. As one parent shared, "You have to choose what's right for your family, and for us, that wasn't it. We didn't need someone coming in the home." This may be a confound of the present study as all parent participants were recruited from an after-school clinic-based treatment program. Thus, these parents may self-select into clinic-based programming because it is a better contextual fit for their families.

The last main challenge parents reported is the changing landscape of services as children age. Parents reported that accessing services as their child ages and/or progresses in treatment becomes more difficult. There is no shortage of early intervention programs, but as children age becoming adolescents and then adults, the number of services for this segment of the population shrinks. This is especially problematic as each developmental stage brings a new set of challenges, from puberty to becoming more independent. As one parent shared, "There's still this need to focus and anticipate those next stages while you still have access to healthcare professionals that can help you through it, even if it's not happening yet" as she described her worries as her 13-year-old soon enters adolescence. Many parents were concerned with the developmental challenges they will face when they no longer have access to healthcare providers, especially as many direct intervention services are reduced over time and often do not continue into adolescence and adulthood. As one parent shared, “They still have the diagnosis. They still need support to learn how to cope as they grow. Yes, Jessica is doing well in school and has friends, but she still struggles. Yes, my oldest has a job and drives, but he doesn’t always know how to cope and take care of himself. I worry about that.”

In addition to direct services for the child with ASD, parents reported experiences with receiving parent-focused formal supports; see Figure 14 for breakdown of parent responses regarding direct services and parent training. At the time of the present study, only four parents were receiving formal parent training programs through their child’s ABA provider; these programs included meeting with the child’s supervisor, creating and following treatment programs, and were often required as part of the child’s overall treatment programs. These four parents were the same families who’s the three children with ASD were receiving in-home ABA programs. Of the twelve parents, only parent used to receive formal parent training, but no longer does as her child aged out of direct services. The remaining seven parents receive more informal parent support, when needed, at the child’s afterschool treatment center; it is not a requirement of the child’s treatment program. For the seven parents who did not receive formal parent training, it was their choice and not an issue of accessing services. Of these 7 parents, all but one had previously received some kind of parent training; only one parent did not have experience with parent training as her son was only recently diagnosed with ASD two months prior to the interview period. Benefits and challenges of parent training programs will be explored in the next thematic cluster, which discusses recommendations for services and support.

Figure 14

Experience with Services & Support

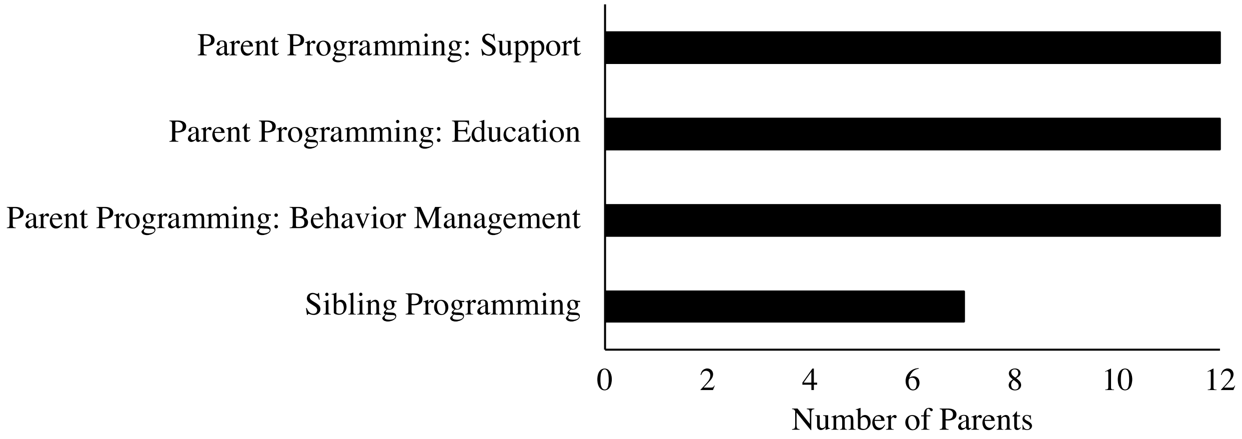


Cluster Six: Recommendations for Services & Support

The final thematic cluster that developed was focused on the experience and usefulness of formal supports and expanded to include recommendations for parent programming. This cluster is used to describe parents' thoughts about formal supports, their experience as parents of children with ASD, and gives clear recommendations for future formal support programming; see Figure 15 to see parents' recommendations for future programming.

Figure 15

Parent Recommendations for Future Programming



Sibling Support & Programs. Although the need for parent training programs is well-documented in the literature, reports of the need for sibling support and programming seems to have been overlooked. Of the nine families included in the present study, seven families consisted of both children with ASD and neurotypical children. Seven of these parents all reported an intense need for more sibling support and programming, where the typically-developing child can connect with other siblings of ASD, learn about and understand ASD, and/or learn how to better interact with their sibling with ASD.

Parents reported that a chief obstacle or challenge of raising a child with ASD is the impact and implications on the broader family, especially on the adjustment of their typically-developing children (see Thematic Cluster Two Familial: Implications). Although parents reported positive relationships between siblings and an overall positive family dynamic amongst the immediate family, they are concerned with the impact of being a sibling with ASD on the neurotypical child's development and the sibling relationship in the future. A major concern is that typically-developing siblings feel a sense of responsibility for their sibling, and often take on the role of "mini-mom" or "mini-dad" instead of "just getting to be a kid." As one parent shared about her neurotypical teenage daughter, "She's a kid herself and I don't feel like she always gets to be. She tries to be independent and keep to herself because she knows we are busy and focused on her brother. And she gets why, she isn't resentful. But this is hard." While parents are grateful for the additional support, they do worry about the long-term implications for their neurotypical children. Additionally, parents reported that they want their neurotypical children to have space to be a kid with other children who understand and share the experience of being a sibling with ASD. Much like parents are in need of emotional and informal support from those who share their experience, so are typically-developing siblings of ASD. For example, one parent shared, “There is this pressure for them to always be kind and understanding, and they are, but as kids, it’s also frustrating to have your brother steals your French fries off your plate or needs mom’s attention when you’re just trying to talk about your school day. They need to share that with other kids who understand that feeling.” By creating a space for these siblings to come together to share an experience that most do not understand, to vent about their feelings, and to just be a kid without being “so-and-so’s sibling.”

Moreover, parents reported that there is a need to create a program and space that is focused on the typically-developing siblings. Often, siblings are not even included in the child with ASD’s programming. In some cases, siblings are highly encouraged to participate in the child with ASD’s programming. Parents reported high satisfaction with the after-school treatment center their child with ASD attends because neurotypical siblings not only attend but are heavily encouraged to participate in social skills and one-on-one programming. But to provide an opportunity for neurotypical siblings to have a program that’s all their own, that supports them as a sibling of ASD, that is an entirely new concept. To give them their own space within the autism world may be beneficial to the neurotypical sibling, the family, and ultimately, the child with ASD.

Parents also reported an intense need for sibling education programs as well. A significant challenge parents reported within sibling dynamics was that their neurotypical did not always understand *what* ASD is and *why* their sibling acted in certain ways and/or need additional support. Parents shared that they believed that if their neurotypical children understood the what’s and why’s, it could improve family functioning, relationships between siblings, and their child’s overall adjustment. While parents have attempted to explain ASD and answer questions, they reported that they as parents feel they need support in promoting and supporting positive sibling interactions and dynamics. Thus, programming that explains ASD to siblings, answers common questions, and shows them how to engage and interact with their sibling with ASD may prove useful. As one parent shared, “There will always be differences in how I treat them, how much support and attention I give them and so on. There are just aspects about autism that make it that way. They have different baselines, different skill sets; they are different. I cannot treat them equally, but I can treat them fairly. And I hope by doing that, I can foster that bond between them. For me, it’s important that his brother understands why he needs additional support, why I treat them differently, because I have to.”

Parents want positive relationships between their children, but often the child with ASD is the focal point. Although the child with ASD would remain somewhat of a focal point as sibling support and programs are specific to siblings of ASD, this would give them their own space within the ASD world that they belong to. These neurotypical children will always be siblings of children with ASD. While the child with ASD may often be the focal point, siblings are the child’s playmates, friends, and protectors. It is important and necessary to foster positive, warm relationships between these siblings while giving typically-developing children space to just be children. Sibling support may prove to have long-lasting positive outcomes for the sibling, the child with ASD, and their families.

Parent Training Programs. As the primary purpose of the present study was to conduct a needs assessment for parent training programs for parents of children with ASD, parents were simply asked if they wanted to receive parent training and if so, what should it include. All parents reported an interest in parent training programs, with varying responses of what should be included or what they needed. As one parent shared, “parent training is necessary, but I don’t always know what it should include, that’s going to change but I would say a mix of practical applications, knowledge and support for parents." Based on parents' responses during the semi-structured, open-ended interviews, three subthemes emerged regarding parent programming: (a) behavior management, (b) parent education, and (c) parent support. These subthemes for parent training programs were separated because parent training is somewhat vague and encompasses various approaches and programs. All three of these themes fall under parent training, and yet, have varying and differing goals.

Behavior Management. The primary concern for parents regarding parent training programs was behavior management across all 12 parents; parents discussed that there are areas they need support with when it comes to their child's behaviors and skills. More specifically, parents expressed that they wanted their behavior management training to be specific and individualized to their child with ASD and their family. They did not want a blanket approach that broadly explains the principles of ABA or that explains that they should spend time playing with their child. Instead, they want specific training and want to be trained in vivo; they want to be shown these techniques and skills with their own child. Although parents reported that parent training and formal services have helped them better understand their children, they also felt that these programs placed unnecessary stress on the family, did not teach them effective parenting skills, and were not considerate of the broader familial context. First, parents reported that high parental involvement was a stressor on themselves and the family. Parents were not only expected to participate in parent training and sometimes during their child's therapy sessions, but parents were also expected to find time outside of therapy sessions to implement learned protocols. This was another challenge as parent training did not necessarily teach parenting skills, but rather taught parents how to implement therapist skills. Additionally, parents reported that parent training was often not individualized and focused on teaching parents the basics of

ABA. Some parents complained that their parent training supervisor would come out with a binder and checklist of goals where they discuss child behaviors and goals without the child being present. Another challenge parents faced was that they felt that therapists and supervisors did not consider the family context. Instead of assessing the family environment

Another challenge was that parent training did not consider the familial context, such as the presence of other family members or the behavior of the child has it naturally occurs; training was conducted in isolation, often with the child not present. As one parent shared,

> "They tried to do parent training, but it was a joke. You know, they would come in and be like we are teaching you the ABCs [antecedents behaviors consequences] versus looking at the household and seeing what we actually need help with. She sat me down one day, and go out her binder and was like, so, every day you need to talk to your children. And it's like, 'oh wow, okay thank you' like it's something I didn't know. It's just stuff like that. Or when you're explain what's happening, and their response is, 'I know it's hard' and then just keep going with the instruction, like they aren't really listening to the situation."

Often, parents are being taught a broader approach to ABA that is not always individualized to the child and the family's needs. For parents, this broad approach does not prepare them or equip them with the skills to engage and manage their child with ASD.

Instead, parents are in need of parent training programs that teach them skills and techniques that they can apply to their child's skill deficits and problem behaviors. The behavioral parent training literature provides an abundance of how skills and techniques that parents can effectively learn. Parents reported that they had been provided the right sources and the right training, they found it be effective for both parent and child behavior. Parents agreed that for parent training to be effective for them, they need to see it and practice these skills and techniques. For many parents, discussing the child's behavior and possible skills parents can employ is very different than seeing these skills in action and practicing them themselves. As a parent shared, "The best 'training' I've experienced is when it's been specific, exact approaches for me and him. Where I'm listened to, I can share exactly what's happening, practice it and then it's adjusted when it doesn't work. I think being listened to, feeling heard, that helps me." Across all 12 parents, there was agreement on the need for specific, individualized training goals and plans for the child, the parent, and the family. Rather than a blanket approach to parent training. Moreover, parents reported that they tended to use learned skills more frequently and broader contexts when programming was individualized to parent and child.

While the argument can be made that teaching parents the broad tenets and principles of ABA would be more beneficial in the long run, practitioners and researchers need to remember that parents are parents, not therapists. As a parent shared,

> "The eye of the ABA therapist is different than the eye of the parent. For instance, one time, Simon was pulling his pants down. And I came freaking out, telling my supervisor and she just like, 'put a belt on.' I put on a belt, and it stopped. It stopped. It was as simple as that. Where like, we let our emotions take over. You guys, you look at like it's behavior. ABC: antecedent, behavior, consequence. And I've learned that too, but we don't look at it like that. As much training as you get, you're still the parent and you just don't see it that way."

Parent Education. Instead, it may be more beneficial in the long-run for parent programming to include parent education on "all the different aspects of ASD." Parent education is more knowledge-focused and provides parents with access to quality information about ASD

(Hamilton, 2008; Whitaker, 2002). By providing parents with up-to-date information about ASD, effective education programs can help parents adjust expectations for the child's future and advocate for appropriate services (Bearss et al., 2015). All twelve parents reported that they are in need of more parent education programs that discuss a variety of topics. As one parent shared, "There are so many aspects of ASD beyond the immediate behaviors, problems, and issues that I feel like I need support on. There was so much that I had to learn to self-navigate, but there are still so many what-ifs." Parents acknowledged that they are not experts and would love to access to experts on an array of topics.

Parents explained that parent education programs need to cover a wide range of topics, but that topics should cover the "next steps" of the ASD journey for the child and parent. For so many parents, from the onset of their child's diagnosis, parents were often left on their own to learn to navigate the never-ending world of ASD. Although they can turn to other parents of children with ASD, they feel that they could greatly benefit from more parent education programs that will prepare them for what's next. As one parent shared,

> "There needs to be programs that educate and prepare parents. Ideally, before a child is diagnosed or even born, but that's ideal. Parents need to be prepared. I think for us, looking back, we had to learn so much on the fly. We can't prepare for everything, but I feel that programs shouldn't just focus on the here and now, I mean that's important. We need that support for behaviors and issues now, but there should be ongoing programs to prepare us for the next stages of life. Education programs specific to toddlers, to school and those transitions, and preparing for the transitions, not just what's in the IEP. Also, adolescence, you know puberty and the like. But also, adulthood, things like

> conservatorships and homes. These are all things we have to think about and aren't quite prepared for. It'll be a lot of self-navigating as he ages."

And while these types of programs exist, parents assert that there are barriers to accessing these programs, such as childcare. Additionally, these programs do not always advertise accurately with many parents leaving feeling that they did not learn what they thought they would.

Parent Support. While not all parents interviewed experienced stress in the clinical ranges, that does not mean they are not in need of support. And not simply parent support groups, although parents do agree these are beneficial. A number of the parents interviewed are actively involved in support groups and/or Facebook groups for parents of children with ASD. Parents asserted that they often turn to these groups because they learn more from other parents of ASD than healthcare providers. However, parents said that they simply did not want parent support groups but programs that provided support and guidance provided by healthcare professionals. There was unanimous agreement for the need for parent training programs across all 12 parents, with parents needing varying levels of support. As one parent shared, "I don't feel a huge need at this point in time, but at some point, I feel that I might. And I know that there are other autism parents, with children with more significant behavioral issues and needs, that need more. But I don't think that means I'll never need support." Thus, programs for parents should consider parents varying levels of need; programs should be tailored to meet the needs of the parents who will use them.

Instead of more informal types of support groups, parents reported that more formal programs created and provided by healthcare professionals could be beneficial to parents. Parents acknowledge that they themselves are not always "experts;" as Sarah expressed, "I know parent training is necessary, but sometimes I don't even realize what I need." Thus, healthcare professionals can help guide parent programs to support parents as they need it. However, these programs should include the parents' voices. Such programs can be organized by healthcare professionals, but they should allow parents to support and share with one another. It is important that parents' voices are heard as they are experts on their own children, while acknowledging the knowledge that healthcare providers bring. Rather than being provider-led and directed, programs should use a collaborative model that ensures programs are individualized to the needs of parents and their families. Parents agreed that parent training programs, support and services "need to be useful." And if parents are providing input and direction, then these programs are likely to be more useful to parents.

Additionally, *other* parents of ASD are an important resource for parents. Parents continuously reported that other parents of children with ASD are informal support systems, but they should also be integrated into more formal support systems. One parent shared, "I learned so much about what to do from other special needs parents, they were major resources for me in the beginning. And in turn, I've become a resource for new parents of special needs parents." By including parents, there is a sense of ownership in the programming. Furthermore, some parents have shared that while they have had positive experiences with parent training programs provided by healthcare professionals, those individuals are not necessarily experts even though it seems that way "on paper" (i.e., education, certified). Often, therapists are experts in their field, but they do not have the experience of parenting a child with ASD. For instance, one parent shared, "Sometimes you get therapists or parent educators who on paper seem knowledgeable, but it's like 'how can *you train me*?" In reality, they don't always know. It's like, what you learn in a classroom or from a textbook doesn't always translate. Sometimes they just don't know or understand." There needs to be recognition that therapists and supervisors are not all-knowing;

they are there to provide support, but they are not necessarily experts in all areas. Instead, there could be a program for parents by parents, that is more legitimate through use of evidence-based practices.

Parents agreed that they have learned from parent training programs, that parent training programs have helped them better understand their children, eased stressors placed on the family, and gave them hope for their children with ASD's future. But parents also stressed that they have learned a significant amount from other parents. Parents agreed that support-based programs should not be only about talking about their parenting experiences, but also be about being a resource for one another. As one parent shared,

> "I love talking to the other moms, you learn so much from one another. But not in a support group kind of way, I don't want a support group where you sit in a circle and just talk about how hard it is. That's not useful and helpful to me. I want to talk to other moms where there is an emphasis on learning about resources and learning from each other. We can share and learn from one another."

Thus, programs should employ a collaborative approach where the healthcare provider is an expert in their area (e.g., behavior management) and parents bring their expertise in parenting a child with ASD.

Lastly, any kind of parent support program should include components that focus parental well-being, specifically reducing parental stress and increasing parental competency. Parents of children with ASD experience significant stressors unique to an ASD diagnosis. Although seven of the parents interviewed experience stress in the clinical range, all parents experience some stress and negative emotions related to parenting. While there should be a heavy focus on addressing parental well-being and parental stress for parents who experience severe and chronic stress, all parents could benefit from programs that provide support, education, and behavior management. The most problematic issue is that parent stress is present across the child's lifespan, especially for parents of children with ASD. Despite the fact that none of the parents interviewed explicitly requested or expressed an interest in parent training programs that addressed parental stress, many of them shared that "being a parent of a child with ASD is hard." More specifically, there are stressors and challenges that they face both short-term and long-term that make the tasks and demands of parenthood more difficult. Many of the parents shared the emotional toll that parenting has on them, from breaking down due to the weight of it all to "shutting off their feelings" so that they can focus on the tasks of parenting. For the majority of the parents, they shared that their child with ASD greatly impacts their day-to-day functioning and emotions; they feel the brunt of the good and bad days. Often, their own worth as parents is inextricably linked to their child. For example, one parent shared, "He's my thermostat. It's like if he's having a bad day, I will have a bad day. It will eat away at me. And if he's having a great day, then I'll feel that too." Although parenthood is an important role, it is important that parents, especially parents of children with ASD and other special needs, are able to separate themselves from the parenting role, separate their parental competency from the unavoidable bad days, and that they learn to manage and deal with the chronic stress that results from parenting.

Parental stress will always be present, and likely will impact the day-to-day demands and challenges of parenting as well as their long-term well-being. Parents are in need of support beyond learning behavior management skills and receiving resources via parent education. Although parental competency moderates parental stress (i.e., reduction in child problem behaviors reduces parental stress, increase in parents' knowledge and access to resources reduces parental stress), parents are in need of programs that directly target parental well-being, including reducing in parental stress and increasing parental competency.

Exhaustive Description of Phenomenon

Finally, an exhaustive description of the phenomenon is presented. This exhaustive description is written to summarize findings concisely by providing a composite description that presents the "essence" of the phenomenon. While this description is a summary, not all parents experienced parenthood exactly the same; Table 5 provides a breakdown of the emergent thematic clusters by parent.

Table 5

Emergent Thematic Clusters by Parent

	Nina	Linda	Sarah	Reina	Maria	Elizabeth	Lillian	Cameron	Leah	Caleb	Katelyn	Brandon
Psychological Strengths		•	•	•	•		•	•	•	•	•	•
Significant Stress	•		•	•			•		•	•	•	•
Grief at Diagnosis	•	•	•	•	•	•	•	•	•	•	•	•
Developmental Milestone Grief	•	•	•	•	•	•	•	•	•	•	•	•
Strain on Family Functioning	•	•	•	•	•		•	•	•	•	•	•
Strengthened Martial Relationship				•			•	•	•	•	•	•
Concerned with Neurotypical Siblings' Adjustment	•	•		•			•	•	•	•		
Informal Support: Family		•	•	•	•	•	•	•	•	•		
Informal Support: Friends			•	•		•	•	•	•	•	•	•
Informal Support: Other Parents of ASD			•	•			•	•	•	•	•	•
Receiving Parent Training	•			•			•	•				
Recommended: Sibling Programming	•	•		•			•	•	•	•		
Recommended: Behavior Management	•	•	•	•	•	•	•	•	•	•	•	•
Recommendation: Education	•	•	•	•	•	•	•	•	•	•	•	•
Recommendation: Support	•	•	•	•	•	•	•	•	•	•	•	•

The parents in this study reported how ASD has impacted their psychological well-being, influenced social and familial contexts, and provided recommendations for future formal support programming. Psychologically, many parents reported gains in knowledge, patience, insight, motivation, and selflessness. However, parents also reported psychological straining occurring simultaneously. These challenges often surfaced in the areas of difficulty in coping with the emotional demands of raising a child with ASD, including feelings of exhaustion, isolation, sadness, hopelessness, grief related to their child's developmental outcomes when compared to neurotypical peers, and worry over the child's future. One challenge that was unexpectedly reported was developmental milestone grief, or the presence of grief and loss throughout the child's life, especially when faced with developmental milestones that are not being reached by their children. Parents reported that they experienced a sense of loss or mourning when their child was diagnosed with ASD, but they also felt that the diagnostic label allowed them access to a myriad of services. However, they continued to experience loss and grief as their child aged and the discrepancies between their child and typically-developing peers become more apparent. This emotional challenge compounded parents' concerns and worries for the future, especially for a future where they are no longer present. Without a doubt, ASD led to some challenges. Challenges included strain on parents' martial relationships, family functioning and dynamics, equal attention to all of their children, and psychological well-being for typically-developing siblings. Socially, it enabled them to meet new people who shared in their struggles and strengthened bonds between family members. However, the lack of understanding surrounding this disorder occasionally led to frustrating social interactions with those without a child with ASD; all parents reported uncomfortable situations in public. They reported that society lacks knowledge of this disorder and how it shapes families. Parents' views of services were also mixed. They identified dedicated therapists, providers, teachers, and the after-school treatment center as offering an enormous amount of support, structure, understanding, and hope for the family. Some areas of reported frustration were the constant need to advocate for services, quality of services, the time commitment that is often required, and the lack of services as their child ages. Parents often questioned their decisions regarding services and their role as a parent; parents were often asking themselves if "am I doing it right and doing enough?" Parents shared several clear recommendations for future formal programming, including the need for sibling support programming and parent programming. Parents called for programs dedicated to siblings of ASD that provide support, education, and coaching. For parent programming, parents reported that healthcare professionals need to provide a mix of programming that emphasizes behavior management, education, and support.

Interestingly, there were several emergent themes that developed that were unexpected. The majority of themes that arose were expected as the adapted interview protocol used in the present study was created using several assumptions of the researcher conceded by the literature. Table 6 provides a list of expected versus unexpected themes that emerged.

Table 6

Expected versus Unexpected Emergent Themes

Expected Emergent Themes	Unexpected Emergent Themes

• Parenting Stress
• Psychological Strengths
• Strain on Family Functioning, Martial Relationship, and Siblings
• Access to Informal Support
• Feelings of Isolation
• Satisfaction and Dissatisfaction with Formal Support Systems
• Focus and Concerns for the Future
	• Developmental Milestone Grief
	• Sibling Support & Programs
	• Need for Parent Training Programs
	  • Behavior Management
	  • Parent Education
	  • Support
	  • Family-focused
	  • Parent-professional collaboration

CHAPTER 5

Discussion

The present study used a qualitative research design to conduct a needs assessment of parent training programs for parents of children with ASD. Specifically, a phenomenological approach was used to highlight the unique experiences and confirm the known ways that parents of children with ASD experience autism and the ways that healthcare providers can better support them. In light of the shortcomings of the current parent training models, the present study examined parents' lived experiences while placing them in an ecological context, assessed factors and supports that influence the effectiveness of parent training programming, and provided recommendations to help future practitioners determine what kind of parent training programs that parents of children with ASD may find useful.

The standardized and objective Parenting Stress Index, Third Edition (PSI-3; Abidin, 1995) was used to assess parent stress levels as they relate to the parent-child relationship, while looking at factors of stress based on both parent and child characteristics (i.e., an overall stress score, parent domain stress score, and child domain stress score). Based on the parent reported data, parents reported high levels of stress related to the tasks and demands of parenthood with seven parents obtaining scores in the clinical range. Five parents obtained stress scores in the clinical range on the parent domain, while ten parents obtained stress scores in the clinical range for the child domain. In addition to domain scores, parenting stress profiles also emerged from the data; four distinct profiles highlighted the varying sources of stress across parents. These distinct stress profiles are important to consider as they can help to determine what kinds of interventions are necessary and where treatment efforts should be placed: child behaviors, parent behaviors, and/or the parent-child system as a whole.

Additional self-report measures completed by parents were used to assess the impact of the child's ASD and maladaptive behaviors on parenting stress. Using the Childhood Autism Rating Scale, Second Edition (CARS-2; Schloper et al., 2010) and the Childhood Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983) to assess a correlational relationship with parents' stress scores using the PSI-3, a significant positive relationship was found between parenting stress levels and the child's total severity (i.e., combination of CARS-2 and CBCL scores). Additionally, there was a significant positive relationship between parenting stress levels and the severity of the child's ASD as well as between parenting stress and the child's maladaptive behaviors. There was also a significantly positive relationship between the child's ASD symptomology and their maladaptive behaviors indicating that for children with more severe ASD, they exhibited more challenging behaviors. Based on the PSI-3 child domain scores and these correlational findings, the data indicates that a major source of stress for parents is child-based characteristics, specifically related to the child's ASD diagnosis.

Semi-structured direct observations were conducted to examine parent-child interactions in naturally-occurring settings, including in the home and community. This data was collected to triangulate the qualitative data collected via interviews. However, due to COVID-19 and the California Safer-at-Home Executive Order (CDC, 2020; California Executive Order No. N-33-20, 2020), the observational data was limited; only four parents were able to be observed, but the data collected did support many of the present study's current findings. First, parents do experience stress related to the sibling relationships between their child with ASD and neurotypical children. One parent-child observation showed that parents must constantly act as facilitators of sibling interactions, especially related to play. Second, parents do have difficulty managing their child with ASD's maladaptive behaviors and often worry about the stigma of these behaviors occurring in public and/or in front of others. In one observation, the child with ASD exhibited tantruming behavior, including yelling, cursing, and throwing toys, and the mother being observed continuously apologized to the researcher for the child's behavior, expressing some embarrassment at the outburst. Overall, the data collected from the observations coincided with the literature and supported the data collected via interviews and self-report measures.

Because of the nature of phenomenological research, the semi-structured, open-ended interviews, using the adapted Ecological Family Interview (EFI; Weisner, 1997), provided a rich narrative of parents' lived experiences in raising a child with ASD and interacting with healthcare providers via direct services and parent training programs. Six main thematic clusters emerged from parent interviews. First, parents described the emotional, cognitive, and behavioral implications of raising a child with ASD. Parents reported both psychological benefits (e.g., psychological strengths, optimism) and challenges (e.g., emotional demands, parenting stress) associated with parenting, including developmental milestone grief. Parents reported experiencing grief and a sense of loss each time they were faced with developmental milestones that are not being reached by their child with ASD, which is a new finding and not consistent with the literature. Second, parents discussed the impact of ASD on family members and overall family functioning; as expected, ASD impacts the martial relationship, neurotypical siblings, and presents limitations and restrictions on the family unit. Third, parents discussed the social implications of having a child with ASD such as issues with informal support systems (i.e., friends, support groups), impact on extended family members, feelings of isolation, and society's lack of knowledge and acceptance of ASD. These social implications often compounded parents' existing psychosocial strain as they often reported feeling alone in their parenting journey.

Fourth, parents reported having concerns regarding their child's future, including worries about the uncertainties of and planning for the future. Fifth, parents addressed their dissatisfaction with accessing and advocating for services, the quality of services, and the lack of services for older children with ASD. Lastly, parents provided recommendations for services and support, which included the need for parent programming, and sibling support and programming. They explicitly communicated their needs for behavioral parent training (i.e., learning how to engage their child and manage the child's more challenging behaviors), parent education (i.e., resources and information related to various aspects of ASD), and support (i.e., talking with other parents, voicing their concerns). Moreover, parents are in need of programming that enhances the contextual fit of intervention by considering the family context and uses a collaborative approach between parent and professional. These findings indicate that an integrated behavioral- and mindfulness-based parent training program that is ecologically-valid may be an appropriate parent program that better meets the needs of this population.

This study offers two unique contributions to the literature regarding support and programming for parents of children with ASD and their families. First, this study found that parents experience grief throughout the child's lifespan, specifically developmental milestone grief. While it's been well-established that parents experience a mourning period following their child's diagnosis followed by a period of acceptance, this finding highlights that parents are potentially in constant contact with negative emotions associated with their child's ASD. Second, parents reported that in addition to parent training programs, they recommend the design and implementation of sibling support and programming. Most often, parents are the only family members that are actively involved in their child's treatment, with siblings often not included purposefully, but these findings shed light on the reality that child with ASD is developing in contexts that consist of many behavior-change agents that are impacted by ASD.

Emergent Themes

The findings, new and old, of the present study reinforce the need to move towards more ecologically-valid models of treatment, including parent training programs and sibling programs. Several findings that emerged through the parent interviews and other data collected are consistent with the literature, however, several unexpected themes emerged.

Expected Themes Consistent with the Literature

Parenting Stress. The detrimental role of stress experience by parents of children with ASD has been investigated over decades (Cachia et al., 2015). Researchers have consistently shown that parenting a child with ASD is associated with a multitude of challenges and daily stressors beyond typical parenting stress (Evans, 2001). Notably, parents reported clinically significant stress levels within the parenting role with stress most strongly associated with child-based outcomes, including the severity of the child's ASD diagnosis and the presence of maladaptive behaviors. This finding is consistent with the literature, which has demonstrated that parents of children with ASD experience significant stress specific to raising a child on the spectrum (Brobst, Clopton & Hendrick, 2009; Ekas & Whitman, 2010; Estes et al., 2009: Lecavalier et al., 2006; Tomanik et al., 2014). However, not all parents experienced such clinically significant levels of stress This may be due in part to the differences in child characteristics (i.e., a child with minimal to moderate ASD), parent characteristics (i.e., coping styles), and/or resources available to parents (i.e., informal support systems).

Although the present study assessed factors that influence parenting stress and supports that may alleviate it, the qualitative nature of the present study does not lend itself to examine these findings but rather provides a description of parents' lived experiences. Further research is warranted to better understand not only the impact of stress on parents but to assess the moderating and mediating effects of such factors that influence stress. Based on the present study, several exploratory findings may be useful, specifically the PSI-3 (Abidin, 1995) data, including parenting stress profiles. Notably, the majority of parents obtained scores in the clinical range for total stress, but not every parent reported clinically significant scores. Interestingly, the majority of parents obtained clinically significant scores on the child domain while more than half of the parents obtained scores in the normal range for the parent domain. Yet, five parents who had normal scores in the parent domain obtained overall stress scores in the clinical range because of their child domain stress score. High scores in the child domain are associated with children who display qualities that make it difficult for parents to fulfill their parenting roles; scores are typically elevated for parents of children with special needs (Abidin, 1995). While high scores in the parent domain suggest that sources of stress and potential dysfunction of the parent-child system may be related to parent's functioning, with parents feeling overwhelmed and inadequate to the task of parenting (Abidin, 1995). Only three parents reported clinically significant scores in the parent domain; two of these parents had three children with ASD under the ages of six-years-old, while the other parent who scored in the clinical range for the parent domain obtained a clinically significant score on the parent subdomain depression, which is suggestive of the presence of significant depression in the parent. These findings together highlight that some parents cope in different ways, and some may cope better than others (Deater-Deckard, 2004). The assumption of the PSI-3 (Abidin, 1995) is that stress, or sources of stressors are additive, and that stressors are multidimensional. Thus, for parenting stress, the two major source domains of stressors are child characteristics and parent characteristics as both contribute to the overall functioning of the parent-child system. But for parents of children with ASD, child characteristics can place an overwhelming demand on parents even when their own characteristics are a potential protective factor.

Additionally, parenting stress profiles emerged in the parent reported data. These parenting stress profiles are important to consider when trying to identify and understand parent-child systems; understanding sources of stress on the parent-child system should inform treatment efforts aimed at reducing parental stress. For example, parents who have obtained clinically high scores in both the child and parent domains, as well as their overall total score, may not benefit from intervention efforts that only focus on child characteristics and behaviors, and ignore parent-focused programming. Moreover, if only the total parenting stress is considered and not individual domain scores, parents that have an overall score in the normal range but clinical scores in the child domain may be overlooked. This data demonstrates that not only do the majority of parents experience substantial parenting stress related to the demands and needs of their child with ASD, but practitioners and researchers need to understand the sources of stress in order to make informed decisions about treatment and parent programming.

Additionally, special attention needs to be focused on the family context when assessing parenting stress profiles. For example, three of the parents (e.g., Elizabeth, Lillian, Cameron) all scored in the clinical range (i.e., below the 15th percentile) in the parent domain. Moreover, these parents obtained concerning defensive responding scores, which indicates that a parent may have been responding in a defensive manner. However, low defensive responding scores with low Total PSI scores can also indicate that the parent is very competent and that the parent-child relationship exists within a supportive social situation that is economically advantaged (Abidin, 1995). Elizbeth obtained a clinically significant score in the parent domain. Given the context of

Elizabeth's family, including that she is middle-class, her husband is the primary caregiver, and her 8-year-old son was only recently diagnosed with ASD, her parent domain score does not seem concerning; especially as she was just at the 15th percentile cutoff. As for Lillian and Cameron, they obtained clinically significant scores in the child domain (e.g., above the 90th percentile) and the parent domain (e.g., below the 15th percentile). However, given the context of their family, including that they are middle-class, have been married for 20+ years, and have an older son with ASD who is attending college, their parent domain score does not seem concerning. Their particular experience of having raised a child with ASD, who presented very similarly to their youngest son, may positively impact their parenting domain score. These findings highlight the need to consider the broader familial context when assessing parenting stress profiles.

Sources of Parenting Stress. Previous research has highlighted that parenting a child with ASD can result in psychological gains and other positive effects, such as strengthening the martial relationship and relationships with other family members, increased compassion and selflessness, and social enrichment. Parents highlighted the importance of informal support via family members and other parents of ASD; these were noted as crucial support systems. Moreover, other parents of children with ASD were significant resources. Conversely, research has highlighted that parents experience significant stress related to their parenting experience, and that ASD impacts many facets of day-to-day life including family functioning, marital relationships, siblings, and social contexts (Patterson, 2005; Turnbull, Turnbull, Erwin & Soodak, 2006). Parents reported significant sources of stress were the child's diagnosis child (Ariel & Naseef, 2006; Blacher, 1984), the severity of the child's ASD behaviors (Bebko et al., 1987; Davis & Carter, 2008; Gabriels et al., 2005), the presence of maladaptive behaviors

(Kasari & Sigman, 1997; Wolf, Noh, Fisman & Speechley, 1989), the stigma of ASD and others' perceptions (Gray, 1993; Papadopoulos et al., 2019), impact of ASD on family functioning and neurotypical siblings (Gomes et al., 2015; Hutton & Caron, 2005; Jellett et al., 2014; Orsmond & Seltzer, 2007), dissatisfaction with informal and formal social support systems (Henderson & Vandenberg, 1992; Sanders & Morgan, 1997), and concerns and uncertainty regarding the future (Milshtein et. al., 2010). These findings are well-supported in the literature and highlight the various areas and contexts that ASD has an impact.

There are findings of the present study, that are consistent with the literature, that require more attention and pertain to recommendations to future parent programming; these findings highlight the emotional experiences of parents that are often ignored in parent training. Due to the psychological situation (i.e., difficult thoughts and feelings) of parents of children with ASD caused by the unique stressors and challenges presented by ASD (Blackledge & Hayes, 2006; Gould et al., 2017)., there is a need for healthcare providers to address these parent-based factors when treating the child with ASD. Parents experience not only experience high and clinically significant levels of stress, but they also reported having difficulty coping with the emotional demands of parenting (Deater-Deckard, 2004); parents continuously reported that parenting a child was ASD is very hard. Parents reported feeling isolated and alone in their parenting experience (Kinnear et al., 2015) due to the unique challenges and demands of ASD. Lastly, parents reported having anxiety concerning their child's future (Dale et al., 2006) because there is the potential for positive outcomes for children with ASD through effective treatment, however, there is a certain amount of ambiguity and uncertainty surrounding the child's prognosis. This creates a climate that may make parenting particularly difficult as they are discrepancies between their expectations and outcomes (Dale et al., 2006).

As a result of the experiences reported, parents are in need of professionals that are sensitive to the divergent experiences of parents of children with ASD and support families in tailoring treatment goals to their unique family dynamics.

Unexpected Themes Gleaned from the Research

Developmental Milestone Grief. Although labels of stress or frustration may be used to reflect the general struggles that parents experience, a specific focus on the emotional demands of parenthood specific to raising a child with ASD may help interventionists to provide targeted interventions and support to this specific risk factor, possibly thwarting greater psychological strain. Parental feelings of disbelief, distress, anxiety or sadness are common at the time of the child's diagnosis (Ariel & Naseef, 2006; Blacher, 1984; Deater-Deckard, 2004) and in the following months as parents come to terms with their child's diagnosis (Milshtein et. al., 2010). Researchers have emphasized that parental stress is likely acute at the time when the assessment and diagnosis is occurring, with many parents experiencing a grief or mourning period for their "hoped for" or "lost child" (Evans, 2001; Fernandez-Alacantara et al., 2016). Although a significant portion of the literature suggests experience significant negative emotions when their child is newly diagnosed, the results from the present study shed some insight on parents' experiences with grief and other negative emotions during and following the diagnostic assessment, as well as throughout the child's lifespan.

While parents reported that they experienced grief and extreme sadness when their child was diagnosed, for the majority of the parents interviewed, they reported that the diagnosis also brought about a sense of relief that comes with understanding their child and being given some kind of direction to move forward in. With the diagnostic label of ASD, parents were able to access a myriad of services for their children that are otherwise inaccessible after the age of three without a diagnosis. Parents reported that they developed a “roll up your sleeves and get to work” kind of mentality; that the outcome of testing and diagnosis resulted in searching out resources and support. Following the diagnosis, the diagnostic label of ASD increased access to resources, ranging from information to social support to effective intervention and therapy (Deater-Deckard, 2004). Though there was brief mourning or grieving period, parents reported with the ASD diagnosis, “the blow came later.”

The results of the present study indicate that parents may experience chronic grief throughout the child’s lifespan, but especially when faced with developmental milestones that are not being reached by their children, or as the researcher termed *developmental milestone grief*. This experience was common amongst the parents interviewed, and it did not discriminate across the spectrum; all the parents reported experiencing this feeling to some extent. Although it was more common and severe in the parents of children who are more impacted by their ASD diagnosis. Furthermore, parents expressed that these feelings of grief increased as their child aged, or as their child’s differences and deficits become more evident. Parents shared that as their child aged, not only did the manifestation of the child’s ASD became more apparent but the gap between the child and their neurotypical peers began to widen. It seems that parents’ increased experiences with developmental milestone grief are more severe when parents are concerned that the “gap” will not close; that there are some developmental milestones that their child may never reach.

The research heavily supports that parents experience grief at the time of the child’s diagnosis, but to date, only one study has found that parents of child with ASD endure intense and continuous grief due to the impact that having and caring for child (Bravo-Benitez, Perez-Marfil, Roman-Alegre and Cruz-Quintana (2019). However, the researchers did not find that parents' experience with grief was related to their child not meeting developmental milestones. Instead, Bravo-Benitez (2019) found that parents experienced persistent grief due to the intense demands that caregiving placed on them, and changes in family dynamics due to the child with ASD being the focus of attention and resources. To date, the present study is the first to identify parents' experiences with developmental milestone grief. While previous researchers have found that parents have compared their child's development and behaviors with neurotypical peers (Evans, 2001), they did not find that parents are experiencing continuous grief. Moreover, Evans (2001) found that parents with a pessimistic view of their child's future tended to make these comparisons. However, in the present study, all parents reported experiencing developmental milestone grief. There are several reasons that can potentially explain parents' experience with developmental milestone grief. While parents experience emotional pain due to the loss of their ideal child and the disruption of their expectations at the time of the child's diagnosis, they may continue to experience this disruption and sense of loss over the course of the child's life. Thus, parents may be experiencing the concept of ambiguous loss. Several factors are related to ambiguous loss, such as uncertain prognoses, variable daily functioning, seemingly normal development of the child during the early years, and the manifestation of only some symptoms (O'Brien, 2007). Parents experience grief over the loss of their "expected child" and find it difficult to accept the reality. Another potential explanation is that parents are experiencing "chronic sorrow" (Olshanky, 1962) or "nonfinite grief (Rarity, 2007); essentially, parents experience persistent and chronic sadness, and that this sadness changes as aspects of life specific to the child with ASD continually falls short of expectations.

As a pervasive, life-long disorder, parental stress is present across the child's lifespan: from infancy to middle childhood to adolescence, and even into adulthood. Notably, parents report not only that parenting stress has been present across the child's lifespan, but that as their child ages, their stress changes and in some cases intensifies. The research does demonstrate that challenges are present throughout a child's lifespan, but certain stressors are specifically associated with distinct developmental stages (White, McMorris, Weiss & Lunksy, 2011). There are the normative stressors of starting school, physical maturation like puberty, relationships with peers and entering the workforce (White, McMorris, Weiss & Lunksy, 2011), but for parents of children with ASD there may be the added stressors of delayed language development, concerns with safety, vocational skills training, and whether the child will be independent. For parents, this stressor is twofold as parents report that not only are there distinct challenges with age but that as their children age, the differences between their child with ASD and their neurotypical peers becomes more apparent.

These findings demonstrate that traditional behavioral parent training may be insufficient in meeting parents' needs. Furthermore, these findings may indicate that mindfulness-based only parent training programs may be inadequate as they do not target child-based outcomes and behaviors, which seem to be the root of developmental milestone grief. An integrated model of behavioral- and mindfulness-based approaches seems particularly applicable to the psychological situation of parents of children with ASD as the difficult thoughts and feelings experienced are not necessarily exaggerated or inaccurate given the unique stressors and challenges presented by an ASD diagnosis (Blackledge & Hayes, 2006; Gould et al., 2017). It is especially applicable as parents are likely to experience these difficult thoughts and feelings throughout the child's lifespan. From a mindfulness-based perspective, individuals do not get to choose which emotions they have, however, they do have the opportunity to choose how they interact with those emotions (Hayes et al., 1999). Simply put, an integrated model can focus on increased behavioral effectiveness (i.e., behavior change), regardless of the presence of unpleasant thoughts and emotions of varying degrees of intensity. It can help parents to cope more effectively with difficult feelings and thoughts, which are likely to persistent and chronic.

Consistent with the literature, parents of children with ASD can experience significant stress beyond typical parenting stress that's specific to the challenges and demands of an ASD diagnosis, parents can experience chronic and severe stress across the child's lifespan, and parents are in need of parent training programming that addresses more parent-based outcomes in addition to child-based outcomes, such as an integrated approach to parent training programming. Furthermore, the present results provide stronger evidence that parents are in need of programs that provide significant support and focus on parent needs. Researchers and practitioners need to understand and know what the emotional state of parents to plan and implement programs adapted to their real needs.

Services & Support. The primary purpose of the present research was to understand parents' needs in regard to services and support based on their experiences parenting a child with ASD. First, parents reported a need for support and programs for typically-developing siblings; parents reported concerns with the adjustment of their neurotypical children. Parents specifically reported a need for sibling programming with groups dedicated to typically-developing siblings to share their experiences, ask questions, and receive guidance on interacting with their sibling with ASD. Parents then provided clear recommendations for future parent programming that could better meet their needs.

Sibling Support & Programs. Having a child with ASD presents a distinctive set of challenges that impacts the entire family unit and individual family members' health, well-being, and experiences across the lifespan (Patterson, 2005; Turnbull, Turnbull, Erwin & Soodak, 2006), including negatively impact siblings (Fisman et al., 2000). In the family context, and within the context of services and intervention, attention is typically focused on the child with ASD (Tsao, Davenport & Schmiege, 2011). However, many parents report concerns for the other children in the family (Hastings, 2007).

For the parents interviewed, their concerns were not focused on the relationship between the child with ASD and their siblings; parents shared that these relationships and the interactions between siblings were usually positive. This is consistent with the literature on sibling relationships of children with ASD (McHale et al., 1986; Stoneman et al., 1987; Bagenholm & Gillberg, 1991; Lobato et al., 1991). Actually, parents reported that they loved how the siblings often interacted with one another; the typically-developing siblings were very patient and understanding with their sibling with ASD. Instead, parents are concerned with the impact that being a sibling with ASD has on the typically-developing child's well-being. Parents observe the difficulty that siblings experienced, with a lot of these problems being very similar to what parents' experience, such as isolation and the ongoing demands of ASD. Parents reported concerns with the emotional difficulties that neurotypical siblings may experience, and that they are in need of programs that provide both education and knowledge development, and support for siblings.

In terms of current approaches to siblings of children with ASD, the research has heavily focused on sibling-mediated interventions; typically, these interventions train and teach siblings how to be behavior change agents and effectively implement behavioral procedures to target an increase the child with ASD's skills or behaviors (Tsao at el., 2011). Essentially, these sibling interventions teach the neurotypical sibling how to be a "mini-therapist." While it's important to acknowledge that the sibling is a successful social agent for the child with ASD, it is equally important that these interventions focus on promoting positive sibling interactions and not simply creating another behavior change agent in the child with ASD's life. Although parents expressed the importance of siblings learning new ways of interacting with the child with ASD, their main concerns were that their neurotypical child had a space to share their experience as well as vent any frustrations they may have in being a sibling of ASD.

Like parents, siblings are likely in need of support and programming that focused on their healthy and adaptive adjustment, and overall well-being. Parents specifically reported a need for sibling programming with groups dedicated to typically-developing siblings to share their experiences, ask questions, and receive guidance on interacting with their sibling with ASD. Parents' strong recommendations for programs for neurotypical siblings is a new finding; although previous research has included sibling-mediated interventions for the child with ASD, programs solely for the sibling of ASD is a new concept.

Parent Programming. Parents asserted their need for parent training, education, and support by healthcare professionals as the experience of parenting a child with ASD is fraught with unique challenges and demands. Parents explicitly communicated their needs for behavioral parent training (i.e., learning how to engage their child and manage the child's more challenging behaviors), parent education (i.e., resources and information related to various aspects of ASD), and support (i.e., talking with other parents, voicing their concerns). Parents are in need of effective behavior management strategies and coping strategies, especially to address parental stress. Parental stress has been found to be alleviated if training gives parents coping strategies together with social support (Dunn et. al., 2001) and if training reduces management problems, bringing about change in the child's behavior (Koegel et. al., 1992). Moreover, to produce long-lasting change and to better meet parents' needs, recommendations for future parent programming include focusing on the family unit, collaboration between parent and professional, and the integration of behavioral and mindfulness approaches. Together, these three recommendations can enhance an intervention's "goodness of fit" thus making it more ecologically valid.

First, parents reported wanting programs that focused on the family unit and family context. Despite research documenting the adverse effects that ASD has on individual family members and overall family functioning, interventions are typically child-focused even to the detriment of parents (i.e., behavioral parent training). Moreover, despite the impact of parental stress on child-based outcomes and family functioning, interventions that have focused on reducing parental stress often only focus on parent-based outcomes (i.e., mindfulness-based parent training). In order to better meet the needs of this population it might be imperative to view the parent-child relationship within the broader familial context, or to create a good "contextual fit" between parent training and the family context. By considering the developmental system of the child, including examining parent-child interactions and the contexts in which they are embedded (i.e., family, community), parent training programming and interventions may be more effective for parents *and* children.

From a developmental perspective, primarily Bronfenbrenner's Bioecological Model of Human Development (BMHD; e.g., Bronfenbrenner, 2005; Bronfenbrenner & Ceci, 1994; Bronfenbrenner & Morris, 2006), this focus on the family context will allow healthcare providers to help parents deal competently and successfully day after day with the challenges and demands encountered in everyday life. The components of the Process-Person-Context-Time Model (Bronfenbrenner & Morris, 2006) are pertinent to future parent programming for parents of children with ASD, especially programming that combines behavioral and mindfulness approaches into an integrated parent training model that emphasizes the ecological contexts of the parent and child. In terms of *processes*, there needs to be a creation of positive proximal processes between the child and their environment, both immediate and remote; specifically, using parents as targets of intervention and components of behavioral parent training, practitioners can intervene and teach parents to effectively manage their child's behaviors and address deficits. Moreover, with mindfulness training, parents are able to contact the present moment nonjudgmentally to promote positive child-interactions. For the *person*, change needs to occur at the characteristics level; both parent-based and child-based outcomes will be addressed. Furthermore, the *person* component also acknowledges parent and child characteristics (i.e., demand, resource, force) that may hinder or facilitate positive outcomes for parent and child. By considering these parent factors, programming can be individualized to better meet parents' needs. For *context*, positive relationships need to occur within the many systems that the parent and child are embedded in, including the home and community. Moreover, parents will be provided with a supportive exosystem (i.e., context that the child is not directly in contact) as they receive formal support. Lastly, in regard to *time*, emphasis can be placed on the duration of these components especially those proximal processes that drive developmental outcomes; because interventions consider the family context and the longevity of the parent-child relationship, this programming can grow with the child within the parent-child relationship. Considering the components of this model within parent programming is necessary for long-term impact.

There is a need for a good "contextual fit" between parent training and the family context. Specifically, targets and procedures must be responsive to the values and goals of parents, compatible with the family's typical routines and culture, and optimize the parents' experience, knowledge, and skill sets (Gould & Redmond, 2014). Teaching parents effective skills to use with their child helps them manage difficult behaviors, feel more control over their child's symptoms and their daily lives, and decreases stress (Burrell & Borrego, 2012). Furthermore, research supports that interventions that address the needs and concerns of the family unit (as opposed to only focusing the child or parent) are likely to be more successful (Deater-Deckard, 2004). The most successful programs involve ongoing contact, or that a lasting relationship between the intervention team and the family is established, and the treatment approach focuses on the needs of the parent and family as well as the child (Deater-Deckard, 2004; Deater-Deckard & Bulkley, 2000).

Second, parents expressed wanting more collaboration within the parent training paradigm. Specifically, they wanted to be involved in the design and implementation of individualized treatment goals and interventions and reported that they wanted access to other parents of children with ASD as a resource in a group setting. Parents reported that they wanted individualized programming rather than a blanket approach to parent training. Thus, parent involvement in programming should consist of parent-professional collaboration in determining the direction of treatment and an intervention's contextual fit (Brookman-Frazee, 2004; Moes & Frea, 2002) as well as the selection of interventions and procedures (Berquist & Charlop, 2014). Parents can and should be important collaborators for designing interventions, from incorporating and prioritizing goals, to determining whether certain goals and teaching procedures will be feasible and contextually appropriate for the family (Baily et al., 1998). Programming needs to recognize that parents are the experts on their child with ASD and family as parents have an intimate knowledge of their child that others lack (Malmberg, 2007), while acknowledging the knowledge that healthcare providers bring. For example, Malmberg (2007) assessed the effectiveness of a collaborative parent program on the management and reduction of rigid behaviors (e.g., stereotypy, preservative interests, routines) exhibited by six children with ASD. Working collaboratively with parents, researchers aimed to strengthen the contextual fit of the intervention by involving parents in its design and implementation. All six children showed a decrease in rigid behavior during targeted activities, and five of the six parents consistently implemented learned skills. Results also showed decreased parental stress levels, high parental satisfaction, and increased parental competence. Overall, parents successfully and effectively modified their child's behavior, thus increasing parenting competence and decreasing parenting stress. In another study, Moes and Frea (2002) compared a contextualize functional communication training (FCT) program developed through parent-professional collaboration with a standard FCT program for three children with ASD; participants experienced both the FCT and the contextualized FCT training. Results indicated that collaborating with parents and considering family context (i.e., contextualized FCT) contributed to more stability and durability of the reduction of problem behavior as well as stronger parent and family adherence to treatment (i.e., families were better able to use functional communication when the contextualized FCT was being implemented). This research strongly demonstrates the success of parent-professional collaboration that increases an intervention's "goodness of fit" with the family context. Parent training programs should be individualized and focus on embedding behavioral skills within family routines, thus creating contextualized behavioral support for the parent while successfully targeting child outcomes. In sum, by considering the family context and working with parents to design and implement an intervention, parent-professional collaboration parent training programs can meet the needs of the child and the parent. These collaborative efforts consider the common factors and variables that tend to hinder the success of behavioral parent training programs for parents of children with ASD.

Additionally, parents repeatedly reported that other parents of children with ASD were a major resource throughout their autism journey. Not only did other parents provide emotional and informal social support, but they also shared their experiences, answered questions, and provided pertinent information related to the challenges that parents face (i.e., accessing services, child behaviors). Research on integrating other parent of children with ASD into formal support systems is limited. Most often, the inclusion of other parents of ASD occurs when parent training programming is offered in a group format, however, this does not mean that parents of ASD are included the development and implementation of such programs. There is evidence to support the use of group format in parent training, and it is beneficial for several reasons. First, research has found that receiving support from other individuals, who share the same difficulties and challenges, may make parents feel supported, understood and accepted, and also facilitate mutual support to normalize the concept of having a child with psychological and behavioral problems (Corti et al., 2018; Scott & Gardner, 2015). Moreover, the group format allows for the reduction of expenses both for parents and the provider (Scott & Gardner, 2015). Lastly, previous research has shown that parents are likely to participate in group-based treatments (Cunningham et al., 1995). Nonetheless, parents of the present study reported that other parents of children with ASD are a vital resource and it may beneficial to have parents co-facilitate parent programming alongside healthcare providers.

While practitioners and clinicians are experts in their field, they do not have the shared experience of parenting a child with ASD. There needs to be recognition that therapists and supervisors are not all-knowing; they are there to provide support, but they are not necessarily experts in all areas. Instead, there could be a program for parents by parents supported by practitioners, thus making it more legitimate through use of evidence-based practices. For example, research by Lunksy and colleagues (2017) and Fung and colleagues (2018) assessed the effectiveness of parent-facilitated mindfulness-based (i.e., Acceptance and Commitment Therapy, ACT; Hayes, Stroshal & Wilson, 1999) group workshops for mothers of children with ASD. Research has supported parent-to-parent models in a support group setting as there are beneficial effects of self-disclosure and sharing of similar experiences (Singer et al., 1999). Lunksy and colleagues (2017) evaluated a co-parent-facilitated 1.5-day workshop with a refresher session for 33 mothers of children with ASD; it was facilitated by a co-author on the study and two mothers of children with ASD. The intervention was delivered in a group format consisting of one evening session followed by a full-day session, and a second "refresher" evening session 1-month later. The intervention consisted of group instruction, group participation, and experiential group exercises. Following the workshop, significant improvements on depression, stress, and physical health outcomes were reported. These improvements were maintained at 3-month follow-up. Extending the work of Lunksy and colleagues (2017), Fung and colleagues (2018) assessed the effectiveness of a parent-facilitated 1.5-day workshop with a refresher evening session 1-month later for 33 mothers of children with ASD. The intervention was group-based workshop facilitated by two mothers of children with ASD, who had previously attended series of workshops as participants. The intervention was adapted for this mothers-only group and the parent facilitators; some modifications included location (i.e., in the community, not a clinical setting; Polk & Schoendorff, 2014). The basic format of the group consisted of group exercises followed by debriefing. Following participation in the workshop, Fung and colleagues (2018) reported significant increases in psychological flexibility and value-consistent behavior as well as significant decreases in cognitive fusion, depression, and stress. These improvements were maintained over time (i.e., at 3-month follow up). In sum, these parent-to-parent models that exist within the parent-professional collaboration model can empower parents and allow them to have ownership over their autism and parenting journey. Several parents in the present study reported the role reversal from a new parent of ASD to a resource for other parents gave them a sense of accomplishment as well as hope and reassurance that they were successfully meeting the demands and challenges of parenting a child with ASD. Moreover, parents of ASD have unique experiences that make them appropriate facilitators of parent programming for other parents. Thus, programs should employ a collaborative approach where the healthcare provider is an expert in their area (e.g., behavior management) and parents bring their expertise in parenting a child with ASD.

Taken together, these two approaches toward the parent-professional collaboration model can allow parents to feel empowered as they take ownership of the treatment goals and plans, use their knowledge and expertise about their child with ASD and family to make informed decisions, and create a supportive community made up of healthcare providers and other parents of ASD. It is likely, however, that parents will need varying levels of support; some parents may require the one-on-one individualized support with a healthcare provider, while others will benefit from the parent-to-parent group format. As with all the recommendations provided for parent programming, clinicians need to consider each parent's needs and their family context on a case-by-case basis when deciding on the type of parent training that may be the most effective.

Parents reported their need for more family-focused or family-orientated parent training programming. The social and familial dimensions of the parenting experience had both favorable and unfavorable implications for parents' psychological well-being. Specifically, parents expressed wanting providers to view the parent-child dyad in their home context and within their family environment, and to create treatment plans and goals that fit the family context. Next, parents reported that their needs in future parent programming should consist of a mix of informal support systems (i.e., other parents of ASD) and formal support systems (i.e., healthcare providers). This recommendation supports the need for more collaborative efforts between practitioners and parents in parent programming.

Methodological Limitations & Strengths

While this study sheds new insight into the parenting experience of parents of children with ASD and implications for parent programming, it is not without its limitations. First, all parents interviewed were sampled from one autism treatment program. Furthermore, the small sample size of 12 parents limits the generalizability of these findings to similar populations. The qualitative methods used in this study served as a tool for exploration and a needs assessment, rather than testing, and this also contributes to limitations for the generalizability of the findings. The observational data collected was limited due to COVID-19 and the California Safer-at-Home Executive Order (CDC, 2020; California Executive Order No. N-33-20, 2020); only four parents were directly observed. These results describe the experience and needs for *some* parents of children with ASD, but they do not predict how prevalent this pattern is among *all* parents. That said, it seems likely that parenting experience and needs of parent training programs is similar across parents of children with ASD.

There were several in the present investigation. First, the use of qualitative research methods allowed for a more detailed account of parents' experiences, feelings, and needs. Second, the sample of parents and children with ASD represents different ethnic and cultural backgrounds, and varying severity of ASD symptomology.

Future Directions and Conclusions

In conclusion, this needs assessment provides recommendations for sibling support programming given the unique experiences of neurotypical siblings of ASD. Additionally, this needs assessment provides recommendations for parent training programs that are ecologically-valid by considering the family context as well as focusing on equipping parents with the skills to cope and manage their stress by incorporating mindfulness-based strategies, teaching behavior management skills, and providing both formal and informal support. To move toward more ecologically-valid models of parent training, programming needs to consider parent and contextual factors, child characteristics, and parent-child interactions while using a parent-professional collaboration approach to ensure that parents are active participants in the development and implementation of treatment goals and plans. Overall, the researcher suggests that a collaborative and integrated behavioral- and mindfulness-based model may be effective in meeting parent, family, and the child with ASD's needs.

Currently, research supports the investigation of how mindfulness may complement and advance current evidence-based parent training programs, such as behavioral parent training programs (Cachia, 2017). Behavioral parent training programs have been widely used in the treatment of children with ASD since the 1960s and have decades of support as an effective and evidence-based treatment of ASD (Dumas, 2005). However, there is also support that parental participation in these programs provides an additional source of stress, which can significantly impact a parent's ability to manage their child's behaviors and can reduce the effectiveness of behavioral interventions, and as a result may impede a parent's ability to benefit from training programs (Osborne et al., 2008; Symon, 2001). This may because behavioral parent training programs are not often considerate of the ecological context in which the parent and child are embedded; these programs are often child-focused with the expectation that parents will make adjustments in their own lives and routines to implement learned skills (Stahmer & Pellecchia, 2015). Based on the needs assessment conducted, parents reported the need for practitioners to look at the child within the context of the home and family unit. Thus, there is a need to look at the family as a unit when designing parent training programs (Bronfenbrenner, 2000; Bronfenbrenner & Morris, 2006). However, mindfulness-based parent training programs have effectively decreased parental stress and increased parental competence (Cachia et all., 2015). An integrated approach that blends behavioral- and mindfulness-based principles is needed to inform parent training programs (Dumas, 2005). Recent research has found that adding mindfulness-based training to existing behavioral knowledge produced clear and measurable positive changes for parents of children with developmental disabilities in addition to decreasing parental stress (Cachia et al., 2015; Myers et al., 2014). Through an integrated behavioral- and mindfulness-based model, parent training can offer parents tools to successfully manage and reduce their child's behaviors as well as target parental stress levels and provide coping strategies to effectively manage the difficulties associated with parenting a child with ASD.

Parents of children with ASD are in need of behavioral approaches to parent training because they experience unique stressors and challenges specific to raising a child with a diagnosis that requires specialized programming and training to manage. Mindfulness-based approaches do not often include specific, programmed contingencies for the child's behavior (Cachia et al., 2015). Research also indicates that parents prefer learning specific strategies to address their child's behaviors, rather than general learning techniques (Burrell & Borrego, 2011). In fact, research indicates that providing parents with hands-on specific training for specific skills is more affective and associated with more positive outcomes than supplying information alone (Bears et al., 2015; Schultz et al., 2011). Ferraioli and Harris (2010) demonstrated this preference and parental attitude towards mindfulness-based parent training programs when they had parents drop out of the mindfulness group because they wanted to "actually learn something." Although they found decreases in parental stress for parents who participated in the mindfulness group, especially when compared to parents who participated in the behavioral group, these findings highlight the practical limitations for the implementation of these programs with this population.

Using an integrated model, parents may benefit from the strengths and merits of both of these approaches. With the behavioral approach, parents are able to expand their repertoire of strategies to manage and address behavioral concerns within the context of their daily lives (Cachia et al., 2015; Deater-Deckard, 2004). In general, improvements in children's behaviors arising from these child-centered approaches is linked to reductions of parenting stress (Kazdin & Wassell, 2000; Sanders & Macfarland, 2000). Interventions that target child's problem behaviors and/or deficits in language and social skills can cause improvements in parents' coping and enjoyment of parenting (Deater-Deckard, 2004). Treatments that involve teaching parents new ways to play and interact with their child promotes satisfaction and reduces distress in the parenting role (Chau & Landreth, 1997; Jang, 2000). Using mindfulness, interventions can teach parents new ways to think about their child's behaviors (i.e., more accepting, in the present moment) that can make it possible to more accurately and effectively manage difficult situations (Deater-Deckard, 2004) while decreasing parental stress (Cachia et al., 2015; Cachia, 2017). In fact, interventions that lead parents to new ways of thinking create a long-lasting change in parents' self-efficacy and the use of effective coping strategies (Matthew & Wells, 1996). Interventions that create permanent improvements in parents' feelings of confidence and effectiveness are more likely to lead to lasting improvements in parental well-being (Deater-Deckard, 2004). In addition to reaping the advantages of each approach, together, an integrated model will be able to target both child behaviors and parental stress simultaneously. More specifically, through the inclusion of mindfulness tactics and practices with behavioral parent training, intervention can target parental stress within the context of addressing their child's challenging behaviors (Cachia et al., 2015). Interventions can combine mindfulness tactics with behavioral management strategies to help parents use the tools to reduce stress in order to alter parent-child interactions that may impact their child's behaviors directly; for example, decreases in parental stress may increase parental adherence to learned behavioral strategies and behaviors.

These findings demonstrate that traditional behavioral parent training may be insufficient in meeting parents' needs. Furthermore, these findings may indicate that mindfulness-based only parent training programs may be inadequate as they do not target child-based outcomes and behaviors, which seem to be the root of developmental milestone grief. An integrated model of behavioral- and mindfulness-based approaches seems particularly applicable to the psychological situation of parents of children with ASD as the difficult thoughts and feelings experienced are not necessarily exaggerated or inaccurate given the unique stressors and challenges presented by an ASD diagnosis (Blackledge & Hayes, 2006; Gould et al., 2017). It is especially applicable as parents are likely to experience these difficult thoughts and feelings throughout the child's lifespan. From a mindfulness-based perspective, individuals do not get to choose which emotions they have, however, they do have the opportunity to choose how they interact with those emotions (Hayes et al., 1999). Simply put, an integrated model can focus on increased behavioral effectiveness (i.e., behavior change), regardless of the presence of unpleasant thoughts and emotions of varying degrees of intensity. It can help parents to cope more effectively with difficult feelings and thoughts, which are likely to persistent and chronic while effectively managing their child.

References

Abbeduto, L., Seltzer, M. M., Shattuck, P., Krauss, M. W., Orsmond, G., Murphy, M. M., & Floyd, F. (2004). Psychological well- being and coping in mothers of youths with autism, down syndrome, or fragile x syndrome. *American Journal on Mental Retardation, 109*, 237–254.

Altiere, M. J., & von Kluge, S. (2009). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies, 18*(1), 83–92. https://doi.org/10.1007/s10826-008-9209-y

American Psychiatric Association (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. Washington, DC: Author.

Ariel, C.N. & Naseef, R.A. (Eds.) (2009). *Voices from the spectrum: Parents, grandparents, siblings, people with autism, and professionals share their wisdom*. London: Jessica Kingsley Publishers.

Bågenholm, A., & Gillberg, C. (1991). Psychosocial effects on siblings of children with autism and mental retardation: A population-based study. *Journal of Mental Deficiency Research, 35*(4), 291–307.

Bailey Jr., D.B., Hatton, D.D., Skinner, M. & Mesibov, G. (2000). Autistic behavior, FMR1 protein, and developmental trajectories in young males with Fragile X Syndrome. *Journal of Autism and Developmental Disabilities, 31*: 165-174.

Baker BL, Blacher J, Crnic KA, & Edelbrock C. (2002). Behavior problems and parenting stress in families of threeyear-old children with and without developmental delays. *American Journal of Mental Retardation*, 107: 433–444

Bearss, K., Burrell, T. L., Stewart, L., & Scahill, L. (2015). Parent Training in Autism Spectrum Disorder: What's in a Name? *Clinical Child and Family Psychology Review*, *18*(2), 170–182. https://doi.org/10.1007/s10567-015-0179-5

Bebko, J.M., Konstantareas, M.M. & Springer, J. (1987). Parent and professional evaluations of family stress associated with characteristics of autism. *Journal of Autism and Developmental Disorders, 17*: 565-576.

Bell, R. Q., & Chapman, M. (1986). Child effects in studies using experimental or brief longitudinal approaches to socialization. *Developmental Psychology, 22*(5), 595–603. https://doi.org/10.1037/0012-1649.22.5.595

Benson, P.R. (2009). Cooping, distress, and well-being in mothers of children with autism. *Research in Autism Spectrum Disorders, 4*(2010), 217-228.

Bibby, P., Eikeseth, S., Martin, N. T., Mudford, O. C., & Reeves, D. (2002). Progress and outcomes for children with autism receiving parent-managed intensive interventions. *Research in Developmental Disabilities*, *23*, 81-104.

Bitsika, V., & Sharpley, C. F. (2004). Stress, anxiety and depression among parents of children with autism spectrum disorder. Australian *Journal of Guidance and Counselling, 14*(2), 151–161.

Blackledge, J. T. (2004). *Using acceptance and commitment therapy in the support of parents of children diagnosed with autism* (Order No. 3164681). Available from ProQuest Dissertations & Theses Global. (305163121).

Blackledge, J. T., & Hayes, S. C. (2006). Using Acceptance and Commitment Training in the Support of Parents of Children Diagnosed with Autism. *Child & Family Behavior Therapy*, *28*, 37–41.

Bluth, K., Roberson, P. N. E., Billen, R. M., & Sams, J. M. (2013). A Stress Model for Couples Parenting Children With Autism Spectrum Disorders and the Introduction of a Mindfulness Intervention. *Journal of Family Theory & Review*, *5*(3), 194–213. https://doi.org/10.1111/jftr.12015

Blacher, J. (1984). Sequential stages of parental adjustment to the birth of a child with handicaps: Fact or artifact? *Mental Retardation, 22*(2), 55–68.

Bonde, E. (2000). Co-morbidity and subgroups in childhood autism. *European Child and Adolescent Psychiatry*, 9, 7-10.

Borthwick-Duffy, S. A. (1996). Evaluation and quality of life: Special considerations for persons with mental retardation. In R. L. Schalock & G. N. Siperstein (Eds.), Quality of life: Vol. 1. Conceptualization and measurement (pp. 105–120). Washington, DC: *American Association on Mental Retardation*.

Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46 (6), 722-730.

Bravo-Benítez, J., Pérez-Marfil, M. N., Román-Alegre, B., & Cruz-Quintana, F. (2019). Grief Experiences in Family Caregivers of Children with Autism Spectrum Disorder (ASD). *International journal of environmental research and public health*, *16*(23), 4821. https://doi.org/10.3390/ijerph16234821

Brinker, R. P., Seifer, R., & Sameroff, A. J. (1994). Relations among maternal stress, cognitive development, and early intervention in middle- and low-SES infants with developmental disabilities. *American Journal of Mental Retardation, 98*, 463–480.

Bristol, M. M., Gallagher, J. J., & Schopler, E. (1988). Mothers and fathers of young developmentally disabled and nondisabled boys: Adaptation and spousal support. *Developmental Psychology, 24*(3), 441–451. https://doi.org/10.1037/0012-1649.24.3.441

Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2009). Parenting children with autism spectrum disorders the couple's relation- ship. *Focus on Autism and Other Developmental Disabilities*, 24, 38–49.

Bronfenbrenner, U. (2000). Ecological systems theory. In A.E. Kazdin (Ed.), *Encyolopedia of psychology, Vol. 3* (pp. 129-133). Washington, DC: American Psychological Association.

Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner & W. Damon (Eds.), *Handbook of child psychology: Theoretical models of human development* (pp. 793-828). Hoboken, NJ, US: John Wiley & Sons Inc.

Brookman-Frazee, L., Vismara, L., Drahota, A., Stahmer, A., & Openden, D. (2009). Parent training interventions for children with autism spectrum disorders. In J. L. Matson (Ed.), *Applied behavior analysis for children with autism spectrum disorders* (pp. 237-257). New York, NY: Springer.

Burrell, T. L., & Borrego, J., Jr. (2012). Parents' involvement in ASD treatment: What is their role? *Cognitive and Behavioral Practice, 19*(3), 423-432. https://doi.org/10.1016/j.cbpra.2011.04.003

Cachia, R.L. (2017). Mindfulness and Autism Spectrum Disorder. *Autism - Paradigms, Recent Research and Clinical Applications*, IntechOpen, DOI: 10.5772/65394. Available from: https://www.intechopen.com/books/autism-paradigms-recent-research-and-clinical-applications/mindfulness-and-autism-spectrum-disorder

Cachia, R. L., Anderson, A., & Moore, D. W. (2015). Mindfulness, Stress and Well-Being in Parents of Children with Autism Spectrum Disorder: A Systematic Review. *Journal of Child and Family Studies*, *25*(1), 1–14.

Celiberti, D. A., & Harris, S. L. (1993). Behavioral intervention for siblings of children with autism: a focus on skills to enhance play. *Behavior Therapy, 24*, 573–599.

Cameron, S.J., & Snowdon, A., Orr, R.R. (1992). Emotions experienced by mothers of children with developmental disabilities. *CHC, 21*(2), 96-102.

Centers for Disease Control and Prevention (CDC), (2016). Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years - Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2012. *Morbidity and Mortality Weekly Report. Surveillance Summaries*, *65*(3), 1–23.

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine, 38*(5), 300–314. https://doi.org/10.1097/00006842-197609000-00003

Cordisco, L. K., Strain, P. S., & Depew, N. (1988). Assessment for generalization of parenting skills in home settings. *Journal of the Association for Persons with Severe Handicaps, 13*, 202-210.

Costa, A. P., Steffgen, G., & Ferring, D. (2017). Contributors to well-being and stress in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 37,* 61–72. https://doi.org/10.1016/j.rasd.2017.01.007

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and down syndrome. *Journal of Intellectual Disability Research*, 54, 266–280.

Dale, E., Jahoda, A., & Knott, F. (2006). Mothers' attributions following their child's diagnosis of autistic spectrum disorder: Exploring links with maternal levels of stress, depression, and expectations about their child's future. *Autism, 10*, 463-479. doi:10.1177/1362361306066600

Davis, N. O, & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*, 1278–1291.

Deater-Deckard, K. (2006). Parenting stress and child adjustment: Some old hypotheses and new questions. *Clinical Psychology: Science and Practice*, 5, 3, 314-332.Deater-Deckard, K. (2004). Parenting Stress. New Haven, CT: Yale University Press. https://doi.org/10.12987/yale/9780300103939.001.0001

de Bruin, E. I., Blom, R., Smit, F. M., van Steensel, F. J., & Bo ̈gels, S. M. (2014). MYmind: Mindfulness training for youngsters with autism spectrum disorders and their parents. *Autism*. doi:10.1177/1362361314553279.

Dempsey, I., & Keen, D. (2008). A Review of Processes and Outcomes in Family-Centered Services for Children with a Disability. *Topics in Early Childhood Special Education*, *28*(1), 42–52. https://doi.org/10.1177/0271121408316699

Dempsey, I., Keen., D., Pennell, D., O'Reilly, J., & Neilands., J. (2009). Parent stress, parenting competence and family-centered support to young children with an intellectual or developmental disability. *Research in Developmental Disabilities, 30*(3), 558-566.

Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, down syndrome, behavior disorders, and normal development. *Exceptionality: A Special Education Journal, 2*, 97–110.

Duncan, L. G., Coatsworth, J. D., & Greenberg, M. T. (2009). A Model of Mindful Parenting: Implications for Parent-Child Relationships and Prevention Research. *Clinical Child and Family Psychology Review*, *12*, 255–270. https://doi.org/10.1007/s10567-009-0046-3

Dunn, M.E., Burbine, T., Bowers, C.A. *et al*. Moderators of Stress in Parents of Children with Autism. *Community Ment Health J* **37,** 39–52 (2001). https://doi.org/10.1023/A:1026592305436

Eisenhower, A. S., Baker, B. L., & Blancher, J. (2005). Preschool children with intellectual disability: Syndrome specificity, behavior problems, and maternal wellbeing. *Journal of Intellectual Disability Research*, 657–671

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(10), 1274-1284. https://doi.org/10.1007/s10803-010-0986

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X. H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism, 13*, 375–387.

Evans, A. (2010). *Parents' responses to their child's diagnosis of Autism Spectrum Disorder (ASD)*. University of Southampton, School of Psychology. Doctoral dissertation.

Farrell, M. P., & Barnes, G. M. (1993). Family systems and social support: A test of the effects of cohesion and adaptability on the functioning of parents and adolescents. *Journal of Marriage and the Family, 55*(1), 119–132. https://doi.org/10.2307/352963

Fernandez-Alcantara, M., Garcia-Caro, M.P., Perez-Marfil, M.A., Montoro, C.H., Laynez-Rubio, C., & Cruz-Quintana, F. (2016). Feelings of loss and grief of children diagnosed with autism spectrum disorder (ASD). *Research in Developmental Disabilities, 55*: 312-321. https://doi.org/10.1016/j.ridd.2016.05.007

Ferraioli, S. J., & Harris, S. L. (2013). Comparative effects of mindfulness and skills-based parent training programs for parents of children with autism: feasibility and preliminary outcome data. *Mindfulness*, *4*(2), 89–101. https://doi.org/10.1007/s12671-012-0099-0

Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *Canadian Journal of Psychiatry*, 45, 369-375.

Fletcher, R. J. (2011). Introduction. Psychotherapy for individuals with intellectual disability (pp. 1-12). Kingston, New York: NADD.

Fung, K., Lake, J., Steel, L., Bryce, K., & Lunksy, Y. (2018). ACT processes in group intervention for mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, (2018)*48, 2740-2747. https://doi.org/10.1007/s10803-018-3525-x

Furman, W., & Buhrmester, D. (1985). Children's perceptions of the personal relationships in their social networks. *Developmental Psychology, 21*(6), 1016–1024. https://doi.org/10.1037/0012-1649.21.6.1016

Gabriels, R.L., Cuccaro, M.L., Hill, D.E., Ivers, B.J., & Goldson, E. (2005). Repeitive behaviors in autism: Relationship with associated clinical features. *Research in Developmental Disabilities, 26*(2): 169-181. doi: 10.1016/j.ridd.2004.05.003

Gau, S.S., Chou, M., Chiang, H., Lee, J., Wong, C., Chour, W., & Wu, Y.(2012). Parental adjustment, marital relationship, and family functioning in families of children with autism. *Research in Autism Spectrum Disorders, 6*:263–270. doi:10.1016/j.rasd.2011.05.007

Gomes, P.T.M, Lima, L.H.L., Bueno, M.K.G., Liubiana, A.A. & Souza, N.M. (2015). Autism in Brazil: a systematic review of family challenges and coping strategies. *Jornal de Pediatria, 91(2): 111-121*. https://doi.org/10.1016/j.jpedp.2015.01.005

Gould, E. R. (2016). *Evaluating the effects of acceptance and commitment training on the behavior of parents of children with autism* (Order No. 10243258). Available from ProQuest Dissertations & Theses Global. (1860875859).

Gould, E.R. & Redmond, V. (2014). Chapter 9 - Parental Involvement. *Evidence-based Treatment for Autism, the CARD Model*. DOI: 10.1016/B978-0-12-411603-0.00009-4

Granpeesheh, D., Tarbox, J. & Dixon, D.R. (2009). Applied behavior analytic interventions for children with autism: A description and review of treatment research. *Annals of Clinical Psychiatry, 21*(3): 162-173.

Gray, D.E. (1993). Perceptions of stigma: The parent of autistic children. *Sociology of Health & Illness*. https://doi.org/10.1111/1467-9566.ep11343802

Gray, D.E. & Holden, W.J. (2009). Psycho-social well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities, 18*(2): 83-93. https://doi.org/10.1080/07263869200034841

Grindle, C. F., Kovshoff, H., Hastings, R. P., & Remington, B. (2009). Parents' experiences of home-based applied behavior analysis programs for young children with autism. *Journal of Autism and Developmental Disorders, 39,* 42-56.

Hahaut, V., Castagna, M., & Vervier, J. F. (2002). Autisme et qualité de vie des familles [Autism and quality of life in families]. *Louvain Medical, 121*, 20–30.

Hall, S., Bobrow, M. & Marteau, T.M. (2000). Psychological consequences for parents of false negative results on prenatal screening for Down's syndrome: Retrospective interview study. *BMJ Clinical Research, 320*: 407-412.

Hall, S., Bobrow, M. & Marteau, T.M. (1997). Parents attributions of blame for the birth of a child with down syndrome: A pilot study. *Journal of Psychology and Health, 4*: 579-587. https://doi.org/10.1080/08870449708406733

Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of family psychology: JFP: Journal of the Division of Family Psychology of the American Psychological Association (Division 43)*, *24*(4), 449–457. https://doi.org/10.1037/a0019847

Hartley, S. L., Sikora, D. M., & McCoy, R. (2008). Prevalence and risk factors of maladaptive behavior in young children with Autistic Disorder. *Journal of Intellectual Disability Research, 52*, 819–829.

Hastings, R.P. (2002). Parental stress and behavior of problems of children with developmental disability. *Journal of Intellectual & Developmental Disability, 27*, 149-160.

Hastings, R. P. (2008). Stress in parents of children with autism. In E. McGregor, M. Nunez, D. Cebula, & J. C. Gomez (Eds.), *Autism: An integrated view from neuroscience, clinical, and intervention research* (pp. 303–324). London: Blackwell.

Hastings, R.P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders, 31*, 327-336.

Hastings, R. P., Kovshoff, H., Ward, N. J., degli Espinosa, F., Brown, T., & Remington, B. (2005). Systems analysis of stress and positive perceptions in mothers and fathers of pre-school children with autism. *Journal of Autism and Developmental Disorders*, 35, 635–644.

Hayes, S.A. & Watson, S.L. (2012). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting stress in parents of children with and without autism spectrum disorder. *Journal of Autism and Developmental Disorders, (2013)*, 43, 629-642. doi: 10.1007/s10803-012-1604-y

Henderson, D., & Vandenberg, B. (1992). Factors influencing adjustment in the families of autistic children. *Psychological Reports, 71*(1): 167–171. https://doi.org/10.2466/PR0.71.5.167-171

Herman, S.E. & Thompson, L. (1995). Families perceptions of their resources for caring for children with developmental disabilities. *Mental Retardation, 33*(2): 73-83.

Higgins, D.J., Bailey, S. & Pearce, J.C. (2005). Factors associated with functioning style and coping strategies with a child with Autism Spectrum Disorder. *Autism, 9*(2): 125-137. DOI: 10.1177/1362361305051403

Horner, R. H., Carr, E. G., Strain, P. S., Todd, A. W., & Reed, H. K. (2002). Problem behavior interventions for young children with autism: A research synthesis. *Journal of Autism and Developmental Disorders, 32*(5), 423–446. https://doi.org/10.1023/A:1020593922901.

Howlin, P. & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 patients in the UK. *National Autistic Society, 1*: 135-162. https://doi.org/10.1177/1362361397012003

Hutton, A. M., & Caron, S. L. (2005). Experiences of families with children with autism in rural New England. *Focus on Autism and Other Developmental Disabilities, 20*(3), 180–189. https://doi.org/10.1177/10883576050200030601

Interactive Autism Network (n.d.) Available at: https://www.ianresearch.org

Ingersoll, B., & Dvortcsak, A. (2006). Including parent training in the early childhood special education curriculum for children with autism spectrum disorders. *Journal of Positive Behavior Interventions*, 8, 79–87.

Jacobson, J.W. & Mulick (200). System and cost research issues in treatments for people with autistic disorders. *Journal of Autism and Developmental Disorders, 30: 585-593.*

Jellett, R., Wood, C.E., Giallo, R. & Seymour, M. (2015). Family functioning and behavior problems in children with Autism Spectrum Disorders: The mediating role of parent mental health. *Clinical Psychologist, 19*: 39-48.

Kabat-Zinn, J. (2003). Mindfulness-based stress reduction (MBSR). *Constructivism in the Human Sciences*, 8(2), 73–107.

Kabat-Zinn, J. (2009). *Full catastrophe living: Using the wisdom of your body and mind to face stress, pain, and illness*. New York: Random House LLC.

Kabat-Zinn, M., & Kabat-Zinn, J. (1997). *Everyday blessings: The inner work of mindful parenting*. New York: Hyperion.

Kaminsky, L. & Dewey, D. (2002). Psychosocial adjustment of siblings in children with autism. *The Journal of Child and Psychology and Psychiatry, 43*(2): 225-232. https://doi.org/10.1111/1469-7610.00015

Kasari, C., & Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders*, 27, 39-57.

Kinnear, S.H., Link, B.G., Ballan, M.S., & *Fischbach, R.L.* (2016). Understanding the Experience of Stigma for Parents of Children with Autism Spectrum Disorder and the Role Stigma Plays in Families' Lives. *Journal of Autism and Developmental Disorders, 46***:** 942–953. https://doi.org/10.1007/s10803-015-2637-9

Koegel, R. L., Koegel, L. K., & Schreibman, L. (1991). Assessing and training parents in teaching pivotal behaviors. *Advances in Behavioral Assessment of Children and Families*, *5*, 65-82.

Koegel, R. L., Schreibman, L., Britten, K. R., Burke, J. C., & O'Neill, R. E. (1982). A comparison of parent training to direct child treatment. In: R. L. Koegel, A. Rincover, & A. L. Egel (Eds.), *Educating and understanding autistic children*, (pp. 260-279). San Diego, CA: College-Hill Press.

Koegel, R. L., Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, R. R., & Plienis, A. J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders, 22*, 205–216.

Koegel, R. L., Symon, J. B., & Koegel, L. K. (2002). Parent education for families of children with autism living in geographically distant areas. *Journal of Positive Behavior Interventions*, 4, 88–104.

Konstantareas, M. M. (1991). Autistic, learning disabled and delayed children's impact on their parents. *Canadian Journal of Behavioural Science / Revue canadienne des sciences du comportement, 23*(3), 358–375. https://doi.org/10.1037/h0079022

Konstantareas, M.M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry*, 30(3), 459-470.

Knott, F., Lewis, C. & Williams, T. (1995). Sibling interaction of children with learning disabilities: A comparison of autism and Down's syndrome. *Journal of Child Psychology and Psychiatry, 36*(6): 965-976.

Law, M., King, S., Stewart, D., & King, G. (2001) The perceived effects of parent-led support groups. *Physical and Occupational Therapy in Pediatrics*, *21*:29–49.

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. NY: Springer.

Lecavlier, L., Leone, S., & Wiltz, J. (2006). The impact of behavior problems on caregiver stress in young people with autism spectrum disorders. Journal of Intellectual Disability Research, 50, 172–183.

Lerner, R. M. (1991). Changing organism-context relations as the basic process of development: A developmental contextual perspective. *Developmental Psychology, 27*, 27-32. doi: 10.1037//0012-1649.27.1.27

Lerner, R.M., Jacobs, F., & Wertlieb, D. (2005). *Applied Developmental Science*: An Advanced Textbook. Thousand Oaks: Sage Publications.

Lord, C., Wagner, A., Rogers, S., Szatmari, P., Aman, M., Char- man, T., . . . Yoder, P. (2005). Challenges in evaluating psycho- social interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, *35*, 695–708.

Lovaas, O. I., Koegel, R. L., Simmons, J. Q., & Long, L. S. (1973). Some generalization and follow-up measure on autistic children in behavior therapy. *Journal of Applied Behavior Analysis, 6,* 131–166.

Lowe, K., Allen, D., Jones, E., Brophy, S, Moore, K., & James, W. (2007). Challenging behaviors: prevalence and topographies. *Journal of Intellectual Disability and Research, 51*: 625-636. doi:10.1111/j.1365-2788.2006.00948.x

Lunksy, Y., Fung, K., Lake, J., Steel, L., & Bryce, K. (2017). Evaluation of Acceptance and Commitment Therapy (ACT) for mothers of children and youth with autism spectrum disorder. *Mindfulness*, *(2018)*9, 1110-1116. https://doi.org/10.1007/s12671-017-0846-3

Mahoney, G., & Perales, F. (2005). Relationship-focused early intervention with children with pervasive developmental disorders and other disabilities: A comparative study. *Developmental and Behavioral Pediatrics 26*(2): 77–85.

Mahoney, G., & Perales, F. (2003). Using relationship-focused intervention to enhance the social-emotional functioning of young children with autism spectrum disorders. *Topics in Early Childhood Special Education*, 23, 77–89.

Malmberg, D. B. (2007). *Assessment of a collaborative parent education program targeting the rigid and ritualistic behaviors of children with autism* (Order No. 3272604). Available from ProQuest Dissertations & Theses Global. (304891194)

Mandell, D. S., Ittenbach, R. F., Levy, S. E., & Pinto-Martin, J. A. (2007). Disparities in diagnoses received prior to a diagnosis of autism spectrum disorder. *Journal of autism and developmental disorders*, *37*(9), 1795–1802. https://doi.org/10.1007/s10803-006-0314-8

Martinez-Pedraza, F.L. & Carter, A.S. (2011). Autism spectrum disorders in young children. *Child and Adolescent Psychiatric Clinics of North America, 18*(3): 645-663. doi: 10.1016/j.chc.2009.02.002

Mates, T.E. (1990). Siblings of autistic children: Their adjustment and performance at home and in school. *Journal of Autism and Developmental Disorders, 20***:** 545–553 https://doi.org/10.1007/BF02216059

McClannahan, L. E., Krantz, P. J., & McGee, G. G. (1982). Parents as therapists for autistic children: A model for effective parent training. *Analysis and Intervention in Developmental Disabilities*, *2*, 223-252.

McConachie, H., & Diggle, T. (2007). Parent implemented early intervention for young children with autism spectrum disorder: A systematic review. Journal of Evaluation and Clinical Practice, 13, 120–129.

McHale, S.M., Sloan, J., & Simeonsson, R.J. (1986). Sibling relationships or children with autistic, mentally retarded, and nonhandicapped brothers and sisters. *Journal of Autism and Developmental Disorders, 16*(4):399–413. doi: 10.1007/s10803-015-2611-6

McPhilemy, C., & Dillenburger, K. (2013). Parents' experiences of applied behaviour analysis (ABA)-based interventions for children diagnosed with autistic spectrum disorder. *British Journal of Special Education, 40*(4), 154-161. https://doi.org/10.1111/1467-8578.12038

Milshtein, S., Yirmiya, N., Oppenheim, D. *et al*. Resolution of the Diagnosis Among Parents of Children with Autism Spectrum Disorder: Associations with Child and Parent Characteristics. *Journal of Autism and Developmental Disorders, 40,* 89–99 (2010). https://doi.org/10.1007/s10803-009-0837-x

Miller, P. H. (2011). *Theories of Developmental Psychology* (5th ed.). New York, NY: Worth Publishers.

Moes, D. R., & Frea, W. D. (2002). Contextualized behavioral support in early intervention for children with autism and their families. *Journal of Autism and Developmental Disorders, 32,* 519-533.

Moore, D. S. (2016). The Developmental Systems Approach and the Analysis of Behavior. *The Behavior Analyst*, *39*, 243-258. doi: 10.1007/s40614-016-0068-3

Myers, B. J., Mackintosh, V. H., & Goin-Kochel, R. P. (2009). “My greatest joy and my greatest heartache:” Parents’ own words on how having a child in the autism spectrum has affected their lives and their families’ lives. *Research in Autism Spectrum Disorders, 3*, 670-684.

Najdowski, A. C., & Gould, E. R. (2014). Behavioral Family Intervention. In *Children and Youth with Autism Spectrum Disorder (ASD)* (pp. 237–254). Oxford University Press. https://doi.org/10.1093/med:psych/9780199941575.003.0016

National Autism Center (2009). National Standard Project, Phase 1. National Autism Center at May Institute.

National Research Council. (2001). *Educating children with autism. Commit- tee on Educational Interventions for Children with Autism. Division of Behavioral and Social Sciences and Education*. Washington, DC: National Academy Press.

Neece, C. L. (2014). Mindfulness-based stress reduction for parents of young children with developmental delays: Implications for parental mental health and child behavior problems. *Journal of Applied Research in Intellectual Disabilities*, 27, 174–186.

Neece, C. L., Green, S. A., & Baker, B. L. (2012). Parenting stress and child behavior problems: A transactional relationship across time. *American Journal on Intellectual and Developmental Disabilities*, 117, 48–66.

Nikmat, A.W, Ahmad, M., Oon, N.L. & Razali, S. (2008). Stress and psychological wellbeing among parents of children with autism spectrum disorder. *ASEAN Journal Of Psychiatry 9*(2): 64-72.

Noh, S., Dumas, J., Wolf, L., & Fisman, S. (1989). Delineating Sources of Stress in Parents of Exceptional Children. *Family Relations, 38*(4), 456-461. doi:10.2307/585753

Osborne, L.A. (2008). A dynamic transactional model of parent-child interactions. In P.Reed (Ed.) *Behavioural theories and interventions for autism*. New York: Nova Publishers.

Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, 38, 1092–1103.

Pain, H. (1999). Coping with a child with disabilities from the parents' perspective: The function of information. *Child: Care, Health and Development, 25*(4), 299-312.

Papadopoulos, C., Lodder, A., Constantinou, G., & Randhawa, G. (2019). Systematic Review of the Relationship Between Autism Stigma and Informal Caregiver Mental Health. *Journal of autism and developmental disorders*, *49*(4), 1665–1685. https://doi.org/10.1007/s10803-018-3835-z

Papageorgiou, V. & Kalyva, E. (2010). Self-reported needs and expectations of parents of children with autism spectrum disorders who participate in support groups. *Research in Autism Spectrum Disorders, 4*(4): 653-660. https://doi.org/10.1016/j.rasd.2010.01.001

Patterson, G. R. (1982). *Coercive family process*. Eugene: Castalia.

Patterson, J.M. (2005). *Weaving gold out of straw: Meaning-making in families who have children with chronic illnesses*. In W.M. Pinsof & J.L. Lebow (Eds.), *Family Psychology: The Art of the Science* (pp. 521-548). New York, NY: Oxford University Press.

Pew Research Center (2015). Parenting in America: Satisfaction, time and support. *Pew Research Center:* Washington, DC. https://www.pewsocialtrends.org/2015/12/17/2-satisfaction-time-and-support/

Rao, P.A. & Beidel, D.C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification, 33*(4): 437-451. https://doi.org/10.1177/0145445509336427

Renzaho, A. M. N., Romios, P., Crock, C., &. Sønderlund, A. L. (2013) The effectiveness of cultural competence programs in ethnic minority patient-centered health care—a systematic review of the literature. *International Journal for Quality in Health Care*, *25*(3): 261-269. https://doi.org/10.1093/intqhc/mzt006

Rogers, S.J. (2010). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology, 27(2): 168-179*. https://doi.org/10.1207/s15374424jccp2702_4

Rogers, S. J., & Vismara, L. A. (2008). Evidence-based comprehensive treatments for early autism. *Journal of clinical child and adolescent psychology: The Official Journal for the Society of Clinical Child and Adolescent Psychology, American Psychological Association, Division 53*, *37*(1), 8–38. https://doi.org/10.1080/15374410701817808

Sameroff, A.J., & Chandler, M.J. (1975). Reproductive risk and the continuum of caretaking casualty. In Horowitz, F.D. (Ed.). *Review of child development research*, vol. 3 (pp. 187-244). Chicago: Univ. of Chicago Press.

Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down Syndrome: Implications for intervention. *Child & Family Behavior Therapy, 19*(4), 15–32. https://doi.org/10.1300/J019v19n04_02

Schopler, E. & Mesibov, G.B. (1984). *The effects of autism on the family.* New York, NY: Springer Science + Business Media

Schultz, T. R., Schmidt, C. T., & Stichter, J. P. (2011). A review of parent education programs for parents of children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, *26*, 96–104. https://doi.org/10.1177/1088357610397346

Schreibman, L. (1983). Are we forgetting the *parent* in parent training? *The Behavior Therapist, 6*, 107-109.

Seltzer, M.M., Krauss, M.W., Orsmond, G.I., & Vestal, C. (2001) Families of adolescents and adults with autism: Uncharted territory. In: Glidden, LM., editor. *International review of research on mental retardation,* 23: 267-294. San Diego, CA: Academic Press.

Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual & Developmental Disability, 22*(1), 19–28.

Sheeran, T., Marvin, R. S., & Pianta, R. C. (1997). Mothers' resolution of their child's diagnosis and self-reported measures of parenting stress, marital relations, and social support. *Journal of Pediatric Psychology, 22*(2), 197–212. https://doi.org/10.1093/jpepsy/22.2.197

Siklos, S., & Kerns, K. A. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of autism and developmental disorders*, *36*(7), 921–933. https://doi.org/10.1007/s10803-006-0129-7

Simpson, R. L. (1999). Early intervention with children with autism: The search for best practices. *Journal of the Association for Persons with Severe Handicaps, 24*, 218–221.

Singh, N., Lancioni, G. E., Winton, A. S. W., Fisher, B., Wahler, R., McAleavey, K., et al. (2006). Mindful parenting decreases aggression, noncompliance, and self injury in children with autism. *Journal of Emotional and Behavioral Disorders*, 14, 169–177.

with developmental disabilities. *Behavior Modification, 31*(*6*), 749–771.

Skinner, B. F. (1953). *Science and human behavior*. Simon and Schuster.

Sloper, P., & Turner, S. (1993). Risk and resistance factors in the adaptation of parents of children with severe physical disability. *Journal of child psychology and psychiatry, and allied disciplines*, *34*(2), 167–188. https://doi.org/10.1111/j.1469-7610.1993.tb00978.x

Solomon, M., Ono, M., Timmer, S., & Goodlin-Jones, B. (2008). The effectiveness of parent-child interaction therapy for families of children on the autism spectrum. *Journal of Autism and Developmental Disorders*, 38, 1767–1776.

Solomon, M., Pistrang, N., & Barker, C. (2001). The benefits of mutual support groups for parents of children with disabilities. *American journal of community psychology*, *29*(1), 113–132. https://doi.org/10.1023/A:1005253514140

Stahmer, A.C. & Pellecchia, M. (2015). Moving towards a more ecologically valid of parent-implemented interventions in autism. *Autism, 19*(3), 259-261.

Stoneman, Z. (2001). Supporting positive sibling relationships during childhood. *Mental Retardations and Developmental Disabilities Research Reviews, 7*(2): 134-142. https://doi.org/10.1002/mrdd.1019

Symon, J. B. (2001). Parent education for autism: Issues in providing services at a distance. *Journal of Positive Behavior Interventions*, 3, 160–174.

Symon, J. B. (2005). Expanding interventions for children with autism: Parents as trainers. *Journal of Positive Behavior Interventions, 7*, 159-173.

Taunt, H. M., & Hastings, R. P. (2002). Positive impact of children with developmental disabilities on their families: A preliminary study. *Education & Training in Mental Retardation & Developmental Disabilities, 37*(4), 410–420.

Tobing, L.E. and Glenwick, D.S. (2002) Relation of the Childhood Autism Rating Scale-Parent Version to Diagnosis, Stress, and Age. Research in Developmental Disabilities, 23, 211-223. http://dx.doi.org/10.1016/S0891-4222(02)00099-9

Tomanik, S., Harris, G. & Hawkins, J. (2009). The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual & Developmental Disability 29*(1): 16-26. doi: 10.1080/13668250410001662892

Totsika, V., Hastings, R. P., Emerson, E., Berridge, D. M., & Lancaster, G. A. (2011). Behavior problems at 5 years of age and maternal mental health in autism and intellectual disability. *Journal of Abnormal Child Psychology*, *39*(8), 1137–1147. https://doi.org/10.1007/s10802-011-9534-2

Tsao, L., Davenport, R. & Schmiege, C. Supporting Siblings of Children with Autism Spectrum Disorders. *Early Childhood Education Journal, 40,* 47–54 (2012). https://doi.org/10.1007/s10643-011-0488-3

Turnbull, A., Turnbull, R., Erwin, E., & Soodak, L. (2006). *Families, Professionals, and Exceptionality: Positive Outcomes Through Partnerships and Trust* (5th ed.). Upper Saddle River, NJ: Pearson/Merrill/Prentice Hall.

Ünal, N., & Baran, G. (2011). Behaviors and attitudes of normally developing children toward their intellectually disabled siblings. *Psychological Reports, 108*(2), 553–562. https://doi.org/10.2466/07.10.21.PR0.108.2.553-562

Urbano, R. C., & Hodapp, R. M. (2007). Divorce in families of children with Down syndrome: a population-based study. *American journal of mental retardation: AJMR*, *112*(4), 261–274. https://doi.org/10.1352/0895-8017(2007)112[261:DIFOCW]2.0.CO;2

US Department of Health and Human Resources, Health Resources and Services Administration, Maternal and Child Health Bureau (2014). *The health and well-being of children: A portrait of states and the nation, 2011-2012*. Rockville, Maryland: US Department of Health and Human Services. https://mchb.hrsa.gov/nsch/2011-12/health/childs-family/parental-stress.html

Van Schalkwyk, G.I., Peluso, F., Qayyum, Z., McPartland, J.C., & Volkmar, F.R. (2014). Varities of misdiagnosis of ASD: An illustrative case series. *Journal of Autism and Developmental Disorders, 45*: 911-918. https://doi.org/10.1007/s10803-014-2239-y

Villanueva, S. (2015). *Angst of adolescence: How to parent your teen and live to laugh about it*. Abingdon, United Kingdom: Routledge.

Vostanis, P., Smith, B., Chung, M.C. & Corbett, J. (1994). Early detection of childhood autism: A review of screening instruments and rating scales. *Child: Care, Health and Development*. https://doi.org/10.1111/j.1365-2214.1994.tb00378.x

Waisbren, S. E. (1980). Parents' reactions after the birth of a developmentally disabled child. *American Journal of Mental Deficiency, 84*(4), 345–351.

Wakschlag, L. S., & Leventhal, B. L. (1996). Consultation with young autistic children and their families. *Journal of the American Academy of Child and Adolescent Psychiatry*, *35*(7), 963–965. https://doi.org/10.1097/00004583-199607000-00025

Weisner, T. (2002). Ecocultural understanding of children's developmental pathways. *Human Development, 45*, 275-281.

Weisner, T. (1997). The Ecocultural Family Interview manual. The Ecocultural Scale Project, UCLA.

White, S.E., McMorris, C., Weiss, J.A., & Lunksy, Y. (2011). The experience of crisis in families of individuals with autism spectrym disorder across the lifespan. *Jounral of Child and Family Studies (21)*3, 457-465.

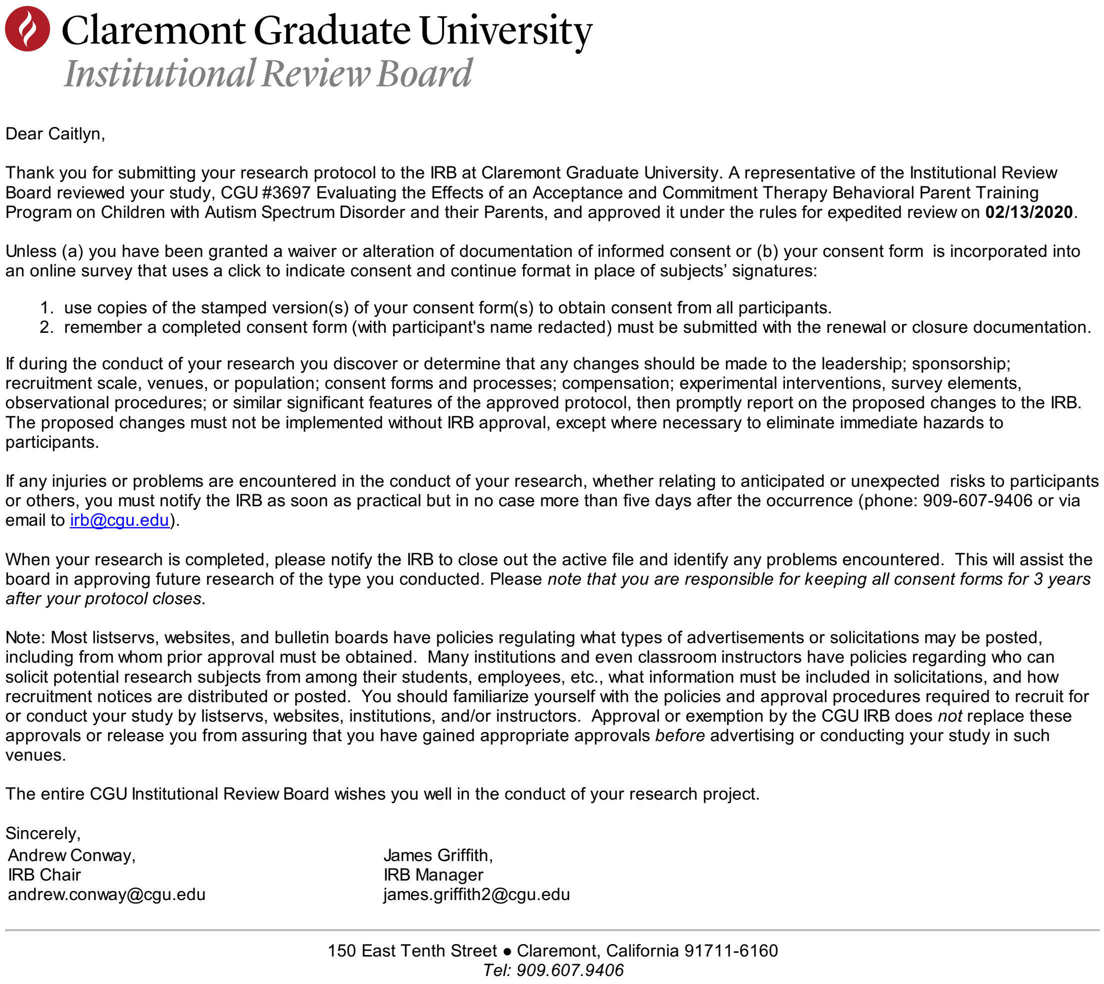
Whitaker, P. (2002). Supporting families of preschool children with autism: What parents want and what helps. *Autism, 6*, 411–426. doi:10.1177/1362361302006004007

Wolf, L. C., Noh, S., Fisman, S. N., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders*, 19, 157–166.

Zubrick, S. R., Williams, A. A., Silburn, S. R., & Vimpani, G. (2000). Indicators of social and family functioning.

Appendix A

IRB Approval Letter



Claremont Graduate University
Institutional Review Board

Dear Caitlyn,

Thank you for submitting your research protocol to the IRB at Claremont Graduate University. A representative of the Institutional Review Board reviewed your study, CGU #3697 Evaluating the Effects of an Acceptance and Commitment Therapy Behavioral Parent Training Program on Children with Autism Spectrum Disorder and their Parents, and approved it under the rules for expedited review on **02/13/2020**.

Unless (a) you have been granted a waiver or alteration of documentation of informed consent or (b) your consent form is incorporated into an online survey that uses a click to indicate consent and continue format in place of subjects' signatures:

1. use copies of the stamped version(s) of your consent form(s) to obtain consent from all participants.
2. remember a completed consent form (with participant's name redacted) must be submitted with the renewal or closure documentation.

If during the conduct of your research you discover or determine that any changes should be made to the leadership; sponsorship; recruitment scale, venues, or population; consent forms and processes; compensation; experimental interventions, survey elements, observational procedures; or similar significant features of the approved protocol, then promptly report on the proposed changes to the IRB. The proposed changes must not be implemented without IRB approval, except where necessary to eliminate immediate hazards to participants.

If any injuries or problems are encountered in the conduct of your research, whether relating to anticipated or unexpected risks to participants or others, you must notify the IRB as soon as practical but in no case more than five days after the occurrence (phone: 909-607-9406 or via email to irb@cgu.edu).

When your research is completed, please notify the IRB to close out the active file and identify any problems encountered. This will assist the board in approving future research of the type you conducted. Please *note that you are responsible for keeping all consent forms for 3 years after your protocol closes*.

Note: Most listservs, websites, and bulletin boards have policies regulating what types of advertisements or solicitations may be posted, including from whom prior approval must be obtained. Many institutions and even classroom instructors have policies regarding who can solicit potential research subjects from among their students, employees, etc., what information must be included in solicitations, and how recruitment notices are distributed or posted. You should familiarize yourself with the policies and approval procedures required to recruit for or conduct your study by listservs, websites, institutions, and/or instructors. Approval or exemption by the CGU IRB does *not* replace these approvals or release you from assuring that you have gained appropriate approvals *before* advertising or conducting your study in such venues.

The entire CGU Institutional Review Board wishes you well in the conduct of your research project.

Sincerely,

Andrew Conway,	James Griffith,
IRB Chair	IRB Manager
andrew.conway@cgu.edu	james.griffith2@cgu.edu

150 East Tenth Street ● Claremont, California 91711-6160
Tel: 909.607.9406

APPENDIX B

Informed Consent Form

Claremont
Graduate
University

Informed Consent for Acceptance and Commitment Therapy Behavioral Parent Training (ACT-B-PT) Program on Children with Autism Spectrum Disorder and their Parents

You and your child are invited to participate in a research project. Volunteering will benefit you and your child directly, and you will be helping investigators to potentially improve parent training programs for parents of children with ASD. This will take about two months of your time. Your involvement is entirely up to you. You may withdraw at any time for any reason. Please continue reading for more information about the study. You and your child are being asked to participate because he or she has received a diagnosis of autism spectrum disorder and you have expressed an interest in receiving parent training programming.

STUDY LEADERSHIP: This research project is led by Caitlyn B. Gumaer, M.A., BCBA, a graduate student at Claremont Graduate University (CGU) and staff member at the Claremont Autism Center. The present project is being supervised by Dr. Marjorie H. Charlop, Director of the Claremont Autism Center at Claremont McKenna College (CMC).

PURPOSE: The purpose of this study is to examine and investigate the effectiveness of an ACT-based behavioral parent training (ACT-B-PT) program on both parent and child outcomes. Acceptance and Commitment Therapy (ACT; Hayes et al., 1999) has successfully been implemented with parents of children with autism spectrum disorder, however, the current literature is limited, and results are inconclusive. The current study aims to assess the overall impact of the 6-week intervention program on parent and child outcomes, including behavioral measures.

ELIGIBILITY: Parents of children (i.e., under 18 years of age) diagnosed with autism spectrum disorder (ASD) are eligible to participate.

PARTICIPATION: If you decide to participate, you will be asked to participate in a 6-week intervention focusing on behavioral skills training and mindfulness practices. Parent training sessions will occur weekly during your child's treatment sessions at the Claremont Autism Center; sessions will be 45 minutes to an hour long. Additionally, training will occur approximately one time per week in the home, depending on your availability to meet outside of your child's regularly scheduled therapy session at the center; sessions will be 45 minutes to an hour long. These sessions will also include home visit probes. These will be conducted during all phases of intervention and will consist of video recorded sessions specific to your individualized treatment programs and goals. Lastly, Generalization probes will be conducted at the center and will consist of five-minute free-play sessions between you and your child. All intervention sessions will be videotaped and analyzed to track you and your child's progress. Although the length of participation will vary, it is estimated that the intervention will last approximately 2-4 months and require 2-3 hours of your time per week.

RISKS & BENEFITS: There are no risks for you or your child, more than in participating in the treatment. It is possible, however, that parent training sessions may be emotionally demanding as the intervention will have you addressing negative emotion and thinking in regard to the parent role and parenting behavior. To minimize this risk, the experimenter will provide breaks when necessary.

Additionally, it is possible for the parent training intervention to fail. There is a chance that the training intervention may not be successful, and that your child's behaviors may not improve beyond baseline levels.

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It is anticipated that you and your child will benefit from participating as the parent training programming and goals are individualized to you and your family. Additionally, this research may benefit Applied Behavior Analysis and behavioral treatment as it may inform future parent training interventions and programming.

COMPENSATION: You will not be directly compensated for participating in this study.

VOLUNTARY PARTICIPATION: Please understand that participation in this study is completely voluntary. Your decision whether or not to allow to participate will in no way affect you or your child's current or future relationship with Claremont Graduate University, Claremont McKenna College, the Claremont Autism Center, or any of their faculty, staff, therapists, or students. You have the right to withdraw from the research at any time without penalty. You also have the right to refuse to participate in any part of the research for any reason without penalty.

CONFIDENTIALITY: The individual privacy of you and your child will be maintained in all publications or presentations resulting from this study. All names will be kept confidential. Only the researchers will have access to the assessment scores, videotapes, and data. All assessment scores, videos, and data sheets will be labeled with a code name and will be stored separately from your informed consent forms. All records will be kept for five years and then destroyed.

ADDITIONAL INFORMATION: If you have any questions or would like additional information about this research, please contact us at (909) 621-8598 or via email at Caitlyn.Gumaer@cgu.edu. You can also contact my research advisor, Dr. Marjorie Charlop, at (909) 607-3879 or Marjorie.Charlop@ClaremontMcKenna.edu. The CGU Institutional Review Board (IRB) has approved this study and its procedures. This Board is responsible for ensuring the protection of research participants. If you have any ethical concerns about this project or your rights as a human subject in research you may contact the CGU IRB at (909) 607-9406.

A signed copy of this consent form will be given to you, if you wish to keep it.

CONSENT: Your signature below means that you understand the information on this form, that someone has answered any and all questions you may have about this study, and you voluntarily agree to participate in this study.

Printed Name of Participant ____

Printed Name of Parent/Guardian ____

Signature of Parent/Guardian ______________________________ Date: __________

The undersigned researcher has reviewed the information in this consent form with the participant and any of his/her/their questions about the study.

Signature of Researcher__________________________________ Date:__________

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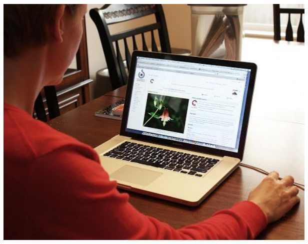
APPENDIX C

Assent Form

When you are at clinic and at home, **you spend time with mom.** We want to know how you and mom spend time together

We want to know how it makes you and mom **feel** when you spend time together.

We want to **record a movie** of you and mom spending time together so we can find out what activities you to do together and how it makes you feel, and what is best for you and other kids and moms.



Can mom help you at home, like when you need her for homework or getting dressed for school or ___*[insert individualized child's targeted behavior]*___? Circle: YES NO

Can we record a movie of you spending time with mom? Circle: YES NO

Can we tell other moms how you spent time with your mom and how it made you feel? This could help kids that you don't know on how they spend time with their mom or dad.
Circle: YES NO

**** If you change your mind and don't want to be recorded later, you can say NO, and we will stop recording and won't tell anyone about how you spend time with mom.**

Sign your Name: ________________________________ Date: _____________

Researcher name, signature, and date: ____

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APPENDIX D

Demographic Questionnaire

1. What gender do you identify with?
    a. Male
    b. Female
    c. Other: __________________
2. What is your age?________
3. What race or ethnicity do you identify yourself as?
    a. White/Caucasian
    b. Hispanic or Latino
    c. Asian or Asian American
    d. Black or African American
    e. Middle Eastern or Arab
    f. Pacific Islander
    g. Native American or American Indian
    h. Other: __________________
4. Are you of Hispanic, Latino or Spanish origin?
    a. No
    b. Yes; Mexican, Mexican-American, Chicano
    c. Yes; Puerto Rican
    d. Yes; Cuban
    e. Yes; another Hispanic, Latino or Spanish Origin: __________________
5. What is your relationship status?
    a. Single
    b. Married/Partner
    c. Separated
    d. Divorced
    e. Widowed
    f. Other: ____________
6. What is your employment status?
    a. Employed for Wages
        i. Full-time
        ii. Part-time
    b. Self-employed
    c. Stay-at-home parent/caregiver
    d. A student
    e. Retired
    f. I am currently not employed
    g. Unable to work
    h. Other: ____________

7. What is the average income per year of your household (including your partner, if applicable)?
    a. Less than 20,000
    b. 20,000-39,999
    c. 40,000-59,999
    d. 60,000-79,999
    e. 80,000-99,999
    f. More than 100,000
8. What is your highest level of education?
    a. Unfinished high school
    b. High school/GED
    c. Associate's Degree
    d. Bachelor's Degree
    e. Advance Degree: ____________
9. What is the composition of your household?
    a. Living with spouse/partner
    b. Lone parent
    c. Family Member other than spouse/partner
        i. Parent
        ii. Sibling
        iii. Cousin
        iv. Other: __________________
10. How many other children live in your household?
    a. None
    b. 1
    c. 2
    d. 3+
11. How many other children in your household have an autism diagnosis?
    a. None
    b. 1
    c. 2
    d. 3+
12. Are you receiving other parent training services for your child with ASD?
    a. Yes
    b. No
    c. Other: __________________
13. If you answered yes to Question 12, what kind of parent training services are you receiving?

Demographics/Background Information for your Child with ASD

1. What is the gender of your child?
    a. Male
    b. Female
    c. Other: ___________________
2. What is the current age of your child? _____
3. What is the race or ethnicity of your child?
    a. White/Caucasian
    b. Hispanic or Latino
    c. Asian or Asian American
    d. Black or African American
    e. Middle Eastern or Arab
    f. Pacific Islander
    g. Native American or American Indian
    h. Other: ___________________
4. Is your child of Hispanic, Latino or Spanish origin?
    a. No
    b. Yes; Mexican, Mexican-American, Chicano
    c. Yes; Puerto Rican
    d. Yes; Cuban
    e. Yes; another Hispanic, Latino or Spanish Origin: ___________________
5. At what age was your child diagnosed? _______
6. What was your child's diagnosis?
    a. Autism Spectrum Disorder
    b. Asperger Syndrome
    c. PDD-NOS
    d. Other: ___________________
7. Type of diagnosis:
    a. Medical
    b. Psychological
    c. Educational
8. If in school, what grade is your child in? _______________
9. What classroom setting is your child in?
    a. Mainstream classroom
    b. Special education classroom
    c. Other: ___________________
10. How many intervention/treatments service(s) does your child currently receive? _______
11. Sources of support or treatment? Circle all that apply.
    a. Speech and language therapy
    b. Special unit or special school
    c. Support at mainstream school
    d. Occupational therapy
    e. Behavior management or parent training
    f. Other: ___________________