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Autism Spectrum Disorder and Family Impact

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AUTISM SPECTRUM DISORDER
AND FAMILY IMPACT

A MASTER'S THESIS

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Abstract

Primary caregivers of children with autism spectrum disorders (ASD) face various specific challenges no matter the severity of their child's ASD. Children with autism experience difficulty with social interaction and communication and experience restricted or repetitive thoughts or patterns of behavior. Parents of children with autism spectrum disorders (ASD) face challenges directly related to their child's diagnosis. Parenting a child with autism exhibits high amounts of stress, and affects mothers and fathers differently. Parents who are able to successfully find coping mechanisms such as increased social support, participation in their child's therapy, and increased optimism can assist them in parenting children with autism and are less susceptible to personal negative mental health conditions.

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CHAPTER I: INTRODUCTION

In the 2018 report, The Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network found that 1 in 59, or 1.7% of 8-year old children were identified with Autism Spectrum Disorder (ASD) (Baio, et al., 2014). According to this research, boys were 4 times more likely to be identified with ASD than girls. ASD was more likely to be diagnosed among white children than black or Hispanic children. Of the children diagnosed with ASD, about 85% showed devlopmental concerns by age three, but only about 42% received a comprehensive developmental evaluation by age three. Amongst children identified with ASD who had intelligence quotient (IQ) scores available, 31% also demonstrated an intellectual disability (IQ score ≤70) (Baio, et al., 2014). From this research, the Minnesota-Autism and Developmental Monitoring Network (MN-ADDM) reported one in 42 eight-year old children were found to have ASD in 2014.

A diagnosis of ASD is based on the results of a comprehensive evaluation completed by a pediatrician, child neurologist, child psychiatrist, or child psychologist. The comprehensive evaluation includes a thorough review of the behavior and development of the child, including parental reports, health history, clinical observation, psychological testing, and assessments of speech and language. Developmental and ASD screenings are the first methods used to determine a child's acquisition of cognitive, language, motor, and social skills. The American Academy of Pediatrics advises screening for children for ASD between 18 and 24 months of age (Baio, et al., 2014).

The reason ASD is significantly more common in males is still unknown, but it is thought to be related to the differences in brain structure (Baron-Cohen et al., 2011). The extreme male brain (EMB) theory, is a continuation of the Empathizing-Systemizing (E-S) theory of sex differences that asserts that females on average have a greater ability to empathize, and males on average have a greater ability to systemize. A possible biological reason for these sex differences in brain structure is the presence of fetal testosterone (fT) (Baron-Cohen, et al., 2011).

Despite ASD being more common in males, the females affected by ASD face different challenges than males with ASD. A study by Mademtzi et al. (2017), explained that females experienced issues similar to those that males with ASD experienced, including difficulty navigating social situations, vocational concerns, and academic delays. Females, however, faced other challenges such as difficulty forming relationships with other girls, barriers in accessing intervention related to a missed early diagnosis; sexual vulnerability due to social naivety, and sex-specific puberty issues. The ability to keep up with a fast-paced female conversation was especially challenging for a female with ASD who might need more response and processing time to comprehend and appropriately respond to the information being presented (Mademtzi et al. 2017).

The challenge of raising an individual with ASD face also greatly affects parents and caregivers. Parents experience high levels of stress beginning with the initial diagnosis continuing throughout the lifetime of the child.

My work in a Federal Setting IV high school special education program for the past four years with students with primarily moderate to severe autism has allowed me to witness a glimpse of the challenges facing parents of children with ASD. Though I consider myself new to the field, I have interacted with several challenging students, and have seen the heartbreaking and overwhelming impact these challenges have on families. Many of our students no longer live at home, and live in group homes due to the severe nature of their behaviors and need for one-to-one round the clock care. Parents are unable to care for them by themselves, and need support through the use of Personal Care Attendants (PCA's), or use an alternative full-time living situation such as a group home.

The staff at our school have also experienced tremendous amounts of stress due to the intense needs required of our students, including communication barriers, emotional behaviors, and physically aggressive behaviors that accompany their autism or other diagnosis. This year alone our school has seen 11 staff injured from students. Retaining staff in this setting has proven a challenge. We have seen nine staff quit in the first eight weeks of school, and started the year with eight vacancies. Finding subs to cover our vacancies, and staff who are out on medical leave, is also challenging. On any given day we have at least eight-15 positions left unfilled by substitutes. Most of our classrooms have anywhere from six to eight students, and should have five to seven adult staff in the room at all times to maintain safety. Keeping a positive attitude, in the midst of the challenging work environment of students with challenging behaviors and staffing shortages/ turnover is difficult at times, but necessary in order to remain optimistic. I have found that I need to be mindful of my own mental health and fill my life outside of work with things that I am passionate about and that keep me positive. My faith in God is also a major reason I am able to continue to remain at peace throughout my days working as a special education teacher in a setting with students with severe behaviors.

The stress we face as staff in charge of teaching these challenging students is only a glimpse into the lives of what the parents of these children face on a constant basis. I have been a part of multiple IEP meetings where I listened to the concerns of parents of children with severe autism and/or related disabilities. One of these students had a diagnosis of severe autism, a hearing impairment, and a slight vision impairment. I attended this particular meeting as an observer during my student teaching. The student's mother came to the IEP meeting and immediately spewed out concern after concern about her son's condition. Her fears questioned the daunting unknowns about her son's future. The student was 16 years old, and nonverbal. His mom was hysterical during the IEP meeting sharing her concerns about his eloping and physical aggression. She screamed at our administration and his teacher, declaring the school was not teaching him the skills he needed to stay safe. His mother cried and blamed the school for not teaching her son to stay with staff. She expressed her frustration with him running from her in public, constantly pinching and scratching, biting, and making regular loud vocalizations. She lost her husband to suicide two years ago and cares for another child at home. She said she is not sure what her son's future holds, and feels hopeless. In just the short time I observed, I knew that her son's disability impacted her life sifnificantly. The incredible constant stress placed on her as a mother was palpable.

Another student at our school has autism along with co-morbid mental health conditions. He requires two male staff with him at all times because he targets females physically. The multiple behavioral episodes per week require locked seclusion or physical holds. This student lives at home with his mother and grandmother, though they are looking for an alternate living situation because they can no longer manage these behaviors safely. This student's mother shared with the school team, an incdient where her son became extremely frustrated, and subsequently attacked her and his Grandma, breaking three of his mother's ribs. The mother and Grandma locked themselves in a closet while they called the police and waited for them to respond. She continues to be extremely frightened of her son and is at a loss for what to do. This is an extreme example. This situation exhibits trauma and stress beyond what most parents of children with autism have experienced. However, parents of children with mild autism arguably face just as many challenges and stress on a daily basis.

I also participated in a meeting with a mom where I immediately recognized she was in distress. I learned that she had two children with moderate-severe autism, one child with mild-moderate autism, and one typically developing child in her care. She was open about her divorce and the children's father not being involved in their lives. This mother came to the meeting and looked visibly distraught. Her hair was messy, clothes were messy and baggy, and she had dark circles under her eyes. She came to the meeting with a handful of forms she was supposed to fill out and cried and apologized that she did not have the time to do them. This mother commented that the forms and paper work for her to fill out seem never ending among her four kids. The IEP team was understanding and assisted her in completing the required paper work. Our school social worker also helped connect her with services to receive some respite care from her children.

These experiences describe only a few of the many I have witnessed with the children and parents at my school. I have learned that every child with autism is unique and all have specific challenges. However, the effects of this disorder on primary caregivers is unmistakably visable.

CHAPTER II: LITERATURE REVIEW

The challenges faced by parents raising a child with autism are numerous. Parents face distress, confusion and feelings of hopelessness, which contribute to effects on mental and physical health. Caregivers of children with autism experience higher levels of stress and depression when compared with parents and caregivers of typically developing children and children with developmental disabilities (Taylor & Warren, 2011). It is important to understand caregiver depression and distress to better support and contribute to the development of the child.

A study completed by Taylor and Warren (2011) looked at the degree to which caregivers experienced symptoms of depression around the time their child's autism diagnosis, and the factors that continued to lead to long-term depression. This study included 75 mothers of recently diagnosed children with ASD. These participants were 91% Caucasian, 89% married, 88% boys with ASD, with had a median household income between $50,000 and $60,000. Quantitative data was based on several standardized measures including the child's diagnostic evaluation, Composite IQ Index, the Autism Diagnostic Observation Schedule (ADOS), follow-up survey, and the Center for Epidemiological Studies- Depression Scale (CES-D). These tools were used to measure caregiver depression symptoms related to having a child with ASD. Results of this study concluded that mothers experienced significant depression and distress following their child's diagnosis of autism. These depression symptoms also contributed to future chronic or recurring depression. Mothers of recently diagnosed children with ASD also reported less depression than mothers who had a child diagnosed prior to 1990. Furthermore, mothers of children presenting with internalized symptoms of ASD including social withdrawl, anxiety, etc, reported more depression than children who displayed less obvious signs of ASD.

No correlation was found between family income and services related to depression at the time of diagnosis. However, current depression symptoms correlated with higher family income in children who were more self-internalizing. The results of this study supported the authors' hypothesis that depression rates among parents were significant following their child's diagnosis of autism. Furthermore, depression that began after the time of ASD diagnosis likely resulted in chronic depression symptoms (Taylor & Warren, 2011).

Behavior problems associated with children who have ASD also contribute to increased parental depression and anxiety. A study by Rezendes and Scarpa (2011) aimed to examine parental symptoms of anxiety and depression in relation to behavior problems associated with ASD. It also considered potential factors that contributed to these feelings including parental stress and self-efficacy. This study sampled 134 mothers of children with autism and examined the relationship between self-efficacy, child behavior, and parental depression/ anxiety. The authors' hypotheses supported in the study indicated that stress on parents contributed to feelings of decreased self-efficacy when dealing with behavior problems. The decreased self-efficacy contributed to the relationship between parental stress and increased depression/ anxiety.

Parents of children with autism experience stress throughout the child's life, beginning at the onset of diagnosis, as explained in a study completed by Davis and Carter (2008). This study sampled 54 toddlers with ASD and connected child behavior with parenting stress. The mothers and fathers of these toddlers stated feelings of elevated stress due to various behavioral symptoms displayed by their children. The biggest factor that contributed to parental stress was delays or deficits in children's social functioning. Children who had difficulties with self-regulation (ability to calm down independently in a behavioral incident) contributed to an increase in maternal stress. Paternal stress in this study was found to be most closely related to a child's externalizing behaviors.

Parents of children with ASD who already had underlying mental health problems also were more prone to experiencing increased stress, leading to more emotional difficulties (Davis & Carter, 2008). This increased stress was sometimes caused by parents with their own underlying mental health problems who had few coping strategies and resources. Cohen and Tsiouris (2006) explained the majority of parents (64%) reported their first bout of depression before the birth of their child with ASD. This study included parents of 122 children with autism. Parents were given a structured clinical interview of their lifetime history of mood and anxiety disorders. The interview included 122 mothers and 105 fathers. Parents were videotaped during the interview. Of those in the study, 36% of mothers and 17% of fathers were found to have a lifetime history of major mood disorder. 34% of mothers and 14% of fathers had Major Depressive Disorder, and 2% of mothers, and 3% of fathers had Bipolar I and Bipolar II) (Cohen & Tsiouris, 2006). Recurrent Major Depressive Disorder was more common and was found in 67% of mothers. Single Episode Major Depressive Disorder was most common in fathers and found to be 67%. All of the mothers were found to have recurrent Major Depressive Disorder (MDD) or Bipolar Disorder had their first diagnosis prior to the birth of their child with autism. In contrast, only 36% of mothers with Single Episode MDD had their first episode of depression before the birth of their child with autism. Of the fathers who reported having some form of MDD, all except two reported having their first episode of depression prior to the birth of their child with autism. Furthermore, mood and anxiety disorders were highly co-morbid in mothers. Anxiety disorders were found in 62% of mothers who reported Single-Episode MDD, and 83%

of those with Recurrent MDD (Cohen & Tsiouris, 2006). The study found that increased behavior problems in children affected with autism were associated with mothers with recurrent mood disorders. The researchers, however pointed out that mothers with recurrent mood disorders may be more sensitive to behavioral issues. The study concluded that both depression and autism share common genetic alleles (risk alleles). The sharing of these alleles can interact and modify how either depression or autism is expressed. This illustrated how autism and depression are thought to co-occur in families (Cohen & Tsiouris, 2006).

A large national claims database examined the likelihood of depression in parents of children with ASD compared to parents of children without disabilities (Cohrs & Leslie, 2017). This data was attained using the MarketScan Commercial Claims and Encounters database and found a sample of 42,649 children with ASD, and an equal number of children without ASD, totaling 85,298 families. Demographics of each of these families was obtained, as well as parental depression reports. The average age of the children in the study was 9.3 years, and 81.8% of the children were male. Of the 42,649 families, 1533 (3.6%) had more than one child with ASD. Out of the families that had a child with ASD, 8618 (20.2%) had at least one parent with a diagnosis of depression. In contrast, 3616 (8.5%) of families that had at least one parent with depression did not have a child with ASD. As the child's age increased, the percentage of families that had at least one parent with a diagnosis of depression increased as well in both the ASD group and the control group. According to the researchers, the results showed that having a child with ASD nearly tripled the odds of depression in parents (Cohrs & Leslie, 2017). The sex of the child with ASD did not significantly impact parental depression. The results of this large, recent, national study showed that parents of children with ASD were far more likely to have clinical depression than parents of children without ASD.

A study completed by Bitsika and Sharpley (2004) revealed that parents with children with autism are often unsure how to deal with their child's behavior. Their study took place in Gold Coast, Australia and was composed of 107 parents with children with autism. These parents completed a questionnaire that examined their demographics, anxiety and depression scores, and other aspects that contributed to their wellbeing. The most common difficulties parents reported in having a child with autism included behavioral difficulties, cognitive/ learning difficulties, poor communication skills, and lack of independent functioning. The direct result of trying to navigate and manage these difficulties resulted in high levels of stress on parents. 91% of the parents in this study stated they were unable to deal successfully with their child's behavior which resulted in feeling stretched beyond their individual limits. The parents who reported feeling this way said they felt stretched beyond their limits more than 10 times per month. Of those surveyed, 47.6% of parents scored in the severely anxious category on the assessment tool used. For depression, 27.6% had high levels of depression, and 11.4% scored in the severely depressed range. In total, 60% of the parents experienced depression of some kind. This study showed the difficulties parents face in dealing with problematic behaviors and how the effects of autism directly contributed to parental negative well-being.

Mothers of children with ASD reported higher levels of depression than fathers (Davis & Carter, 2008). In another study, mothers were significantly more anxious, more depressed, and described being stretched being their limits more times per month than fathers of children with autism (Bitsika & Sharpley, 2004).

Depression and anxiety among parents can be largely dependent on the severity of which the child displays symptoms of autism. Benson (2006) conducted a study to address how stress proliferation (the effect of stress that produces additional stressors in other areas of life) in parents of children with autism was related to the severity of autism symptoms. The parent sample from this study included 60 mothers and 8 fathers of children with autism. Of the students, 22% of them were nonverbal, 71% attended a fully special needs program separate from general education, and 29% attended a partial or full-day inclusion school. Parents were given an index to score their child's autism symptoms, a stress proliferation scale, a family support scale, and a parent depression scale.

Results from this study showed that nearly half of the parent sample group reported depression symptoms which coincided with being clinically depressed. The severity of child symptoms was positively and significantly related to parent depression and stress proliferation. It was also found that child symptom severity and stress proliferation were strong predictors of parental depression. It was also noted that informal parent support played a role in reducing stress proliferation and depression. However, parent's perceptions of the usefulness and helpfulness of professional support services was not found to reduce either depression or stress (Benson, 2006).

For parents who did have children with severe symptomatic episodes of autism as mentioned in the previous article, different coping mechanisms were used, including both positive, and negative. Altiere and Kluge (2008) conducted a study examining the relationships between family members and looked at cohesion, adaptability and social support to measure the coping abilities of families. Former research has shown that cohesion and adaptability of a family were tied to positive coping methods which increased family satisfaction and functioning within the family (Altiere & Kluge, 2008). In their study, Altiere and Kluge (2008) collected data from 26 pairs of parents who had children with an autism diagnosis, Asperger's disorder, or Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). Of the families, all had two biological parents living in the home and both parents took part in the study. They used a measurement called the Family Adaptability and Cohesion Evaluation Scales-III (FACES-III) to measure the family member's perceived and desired family cohesiveness and their ability to adapt to changes (Altiere & Kluge, 2008). The researchers wanted to compare mothers and fathers scores on cohesion, adaptability, satisfaction with the functioning of their family, coping mechanisms, and their perception of social support. They also wanted to discover the relationship between cohesion and the coping strategies used by the parents. The results showed that mothers believed their family sought out social support in times of crisis more often than fathers believed they did. Mothers also believed they received more social support from family and friends in comparison with the fathers. The results also indicated that more structured and adaptable families had more social support than those with low levels of adaptability. The cohesion levels included disengaged, separated, connected and enmeshed. Participants who rated their family as enmeshed or connected were found to be significantly more likely to utilize coping mechanisms than those who rated their families as disengaged (Altiere & Kluge, 2008). This study showed the vital role that cohesion and adaptability played in coping with the responsibility of raising a child with autism. Families who were more cohesive utilized stronger tactics to cope with the stress.

Coping with stress could also be mediated with help from a supportive extended family. According to Bitsika and Sharpley (2004), parents who had extended family who understood the child's difficulties displayed lower levels of anxiety and depression. In their study, more than half of parents (56%) who obtained assistance from other family members reported that these family members did not clearly understand their child's individual needs. Furthermore, 76.4% of the parents in this study reported not having access to services intended to offer direct support. The reasons for not accessing these services included lack of knowledge that these services existed, financial limitations, no time, no need for them, and unsure these services would help them. Parents reported they found some services helpful including behavior management, stress management, parent support groups, personal counseling, health and exercise training, communication training, assertiveness training, and marital counseling.

A further study examined the coping mechanisms of parents with children with autism was done by Lai, Goh, Oei, and Sung (2015). Their study examined psychological well-being and coping in parents of children with autism and parents of typically developing children. 73 parents of children with autism and 63 parents of typically developing children completed a survey. Parents and children in this study were primarily Chinese (81.6%). Participants completed a demographics screening form, the Parenting Stress Index: Short Form (PSI-SF), Depression Anxiety Stress Scales (DASS-21), and the Brief COPE, which is a self-report measure that shows the maladaptive and adaptive coping strategies of parents. The researchers hypothesized the following: 1) Parents of children with ASD would report more parenting stress, depression, and anxiety symptoms than parents of children with no disability. The study also wanted to determine the amount of parenting stress of varying degrees based on the child's specific diagnosis (comparing parents of children diagnosed with Autism, Asperger's Syndrome, PDD-NOS and of typical development) (Lai et al., 2015). The main areas measured for parents were parenting stress, parental psychological well-being, and coping. In the area of parenting stress, the results showed that parents of children with ASD faced higher parenting stress in general, and more symptoms of subcategories of stress including more negative views of themselves as parents, poorer relationships with their children, and more child-related parenting stress. In the area of parent psychological well-being results suggested that parents with children with ASD have higher levels of depression symptoms than parents with typically developing children. In the area of parental coping, the results revealed parents with children with ASD engaged in active avoidance behaviors more often than parents with typically developing children. Parents of children with autism did not differ significantly in psychological well-being and coping when compared as according to child's specific diagnosis (Lai et al., 2015). Overall, this study maintained the reality that providing for the needs of a child with ASD produces negative psychological effects on parents and caretakers. Study results strengthened the importance of concentrating on well-being and coping needs of parents of children with ASD.

Another study compared the differences in coping strategies in parents with children with High Functioning Autism Spectrum Disorders (HFASDs) and parents with children without any disabilities. From their previous research about this topic, the researchers found limited studies that included a control group. This study included 48 parents of children with HFASDs and 26 parents of children without any disability (Lee, 2009). The purpose of this study was to look at the differences of coping and marital adjustment in parents with children with HFASDs compared with parents of children without any disability. The researchers' hypotheses included the following: 1. Parents with children with HFASDs will display higher scores of depression and anxiety and lower marriage adjustment scores, 2. In the group of parents with HFASDs, mothers will report higher depression and anxiety and have a lower marital adjustment score than the fathers in that group, and 3. In the group of parents with HFASDs, mothers and fathers will show different scores in the coping tests given (Lee, 2009). To measure these hypotheses, participants were given two packets of surveys to complete and two weeks to complete them. Of the participants in the control group and the HFASDs group, 97% were Caucasian, and 90% were married. Among the children in the HFASDs group 79.1% were males. The tools used in this study included the *Family Crisis Oriented Personal Evaluation Scale* (FCOPE) and the *Coping Health Inventory for Parents* (CHIP) to measure coping. It included the *Beck Anxiety Inventory* (BAI) and the *Center for Epidemiological Study- Depression* scale (CESD) to measure anxiety and depression. Finally, the *Dyadic Adjustment Scale* (DAS) was used to examine agreement and disagreement in an individual regarding relationship struggles. The results showed that parents in the HFASD group demonstrated a higher rate of clinical depression (35%) than the control group (15.4%). Additionally, marital adjustment scores were lower in the HFASD group than those in the control group which indicated increased marital distress in those with children with HFASDs. Coping skills such as family integration, cooperation and optimism were lower in the HFASD group than the control group. Within the HFASDs group, mothers showed a higher rate of clinical depression (28%) than fathers (17%). In conclusion, this study found that parents with children with HFASDs had higher levels of stress, more depression and anxiety, and lower marital satisfaction than parents without children with HFASDs.

Additionally, parents with children with HFASDs were less optimistic, had less self-esteem, and less stability psychologically (Lee, 2009).

This study was limited by its small sample size and the unequal number of participants in the control group compared to the HFASDs group. However, the study included a control group, which increased the strength of the study.

An additional study that included a control group was completed by Padden and James (2017) and examined actual physiological indicators of stress on parents with and without children with autism. The physiological factors examined included measuring cortisol, alpha-amylase, ambulatory blood pressure and heart rate to indicate stress among parents with and without children with autism. These participants consisted of 38 parents with children with autism, and 38 parents without children with autism. All participants completed questionnaires, gave saliva samples, and wore blood pressure monitors for 24 hours. The results revealed that parents who have children with autism displayed much higher levels of distress, anxiety, and depression than those parents who had typically developing children. Mothers in both the control group and the autism group reported feeling greater parenting responsibility compared to fathers. Parents of children with autism were also found to have lower levels of cortisol than parents without children with autism. Parents with children with autism reported a greater use of coping strategies such as finding emotional support, planning, acceptance, humor, and religion (Padden & James, 2017).

As mentioned in the previous study, religion and spirituality can be a common way for parents to cope with having a child with autism spectrum disorder. A study focused on religious beliefs and the relationship between emotional functioning in mothers with children with autism was conducted by Ekas, Whitman and Shivers (2008). Their study examined using religious beliefs, activities, and spirituality as a means for mothers to cope with their child's autism, and the effect they have on the socioemotional functioning of mothers. A total of 119 mothers in this study completed questionnaires examining religiosity, spirituality, and factors including stress, depression, anxiety, life satisfaction, self-esteem, a sense of control, and positivity. The religiousness spirituality measure included three subscales that each included 27 questions. The first subscale looked at religious beliefs, which assessed the participants' relationship with God. One sample question given from this subscale included "I work together with God, as partners (on a scale of one to four)" (Ekas, Whitman, & Shivers, 2008). The second subscale included religious activities, which measured the extent of each person's engagement in religious practices (attending church services, reading the Bible, etc). The third subscale, the spirituality subscale, examined the general feelings of intimacy with God and creation. An example question from the subscale included, "I feel God's presence" (Ekas, Whitman & Shivers, 2008). Measurements of parenting stress, affect, depression, self-esteem, child enjoyment, life satisfaction, psychological well-being, and sense of control were taken using various scales for each participant. Results of this study concluded that religious beliefs and spirituality demonstrated positive outcomes on the variables measured (stress, depression, satisfaction, self-esteem, control, etc). Between spirituality, and religious activities, spirituality correlated with greater positive outcomes, and religious activities associated with more negative outcomes. Thus, according to the present study, those who felt a personal connection and intimacy with God were more likely to show positive outcomes in the areas related to stress, anxiety, depression, self-esteem, etc (Ekas, Whitman & Shivers, 2008).

Optimism and well-being in mothers with children with autism has also been linked to having a strong social support network. Ekas, Lickenbrock, and Whitman (2010) studied the relationship between social support as a mediator and moderator of well-being and optimism in mothers with children with autism. The types of social support that were examined were spousal, family, and friends of mothers of children with autism. Negative outcomes such as maternal depression, negative affect, and parenting stress were studied, as well as positive outcomes including life satisfaction, positive affect, and overall psychological well-being. The authors hypothesized that social support would be positively correlated with optimism among mothers, which would lead to overall higher well-being. They also theorized that having strong spousal/ partner support would be more meaningful than friend and family support (Ekas et al., 2010). Participants in this study included 119 mothers of children with ASD. Most of the mothers (83%) were married, Caucasian (95%), and considered middle class. The children with autism were between the ages of two and 18 and were mostly males (83%). Measures used to collect data and test the hypotheses included the Life Orientation Test (LOT) to measure optimism, Informal Social Support scales, Parental Stress Items scale, The Positive and Negative Affect Schedule (PANAS), the Center for Epidemiologic Studies Depression inventory (CES-D), the Satisfaction with Life Scale (SWLS), the Psychological Well-Being Scale (PWB), and Structural equation modeling (SEM) was used to test hypotheses of this study. Results of the study concluded that mothers who had more than one child with autism reported less support from their friends, partner, and family compared to mothers of one child with autism. Mothers with more than one child with autism also reported higher negative affect levels, higher depression, and lower levels of life satisfaction. In line with the authors’ hypotheses, mothers who reported high levels of optimism and informal social support also reported higher levels of life satisfaction. Each type of social support was connected with lower levels of depression, maternal stress, and negative affect. One suggestion for application of these findings was to focus on increasing optimism while partaking in autism interventions such as cognitive-behavior therapy (CBT). If these CBT programs were adapted and implemented for use with families of children with ASD, it would be beneficial in increasing optimism and well-being (Ekas et al., 2010).

As seen in the previous study, spousal support plays a crucial role in improving life satisfaction among parents of children with autism. Keeping a strong marriage can be challenging among these parents raising children with autism. A study by Ramisch, Onaga, and Oh (2013) examined the factors that contributed to success of marriages among parents with and without children with autism. They wanted to see specifically what couples who have children with autism do to keep their marriages strong compared to parents raising typically developing children. In their study, eleven couples with children with autism participated, and twelve couples of children without autism participated. In order to participate, the couples had to have been married for at least one year, live together, and parenting either children with autism, or children without any disability. Many measures were used to obtain results. The main methodology utilized was concept mapping. Concept mapping is a structured procedure that starts with the participants answering a question. The answers were then converted into pictures that represented relationships and patterns. This method was used to obtain information from husbands and wives regarding the elements they viewed as helpful in keeping their marriages whole. The Kansas Marital Satisfaction Scale (KMSS) was used to assess marriage satisfaction. A score of 17 and above indicated a perception of marriage not in distress. A score of 16 or below shows distress in the marriage. Of the 20 parents of typically developing children, only one mother reported a score below 17. Of the 22 parents with children with autism, six parents reported scores below 17. The statements from the concept maps were grouped together in clusters. The clusters for husbands with children with autism included (1) We communicate, (2) We work out our differences, (3) We care for and love each other, (4) We have foundational expectations. The clusters for wives with children with autism included (1) We communicate, (2) We spend time to be a couple, (3) We do things for ourselves, (4) We have foundational expectations, (5) We encourage positive qualities for the marriage (Ramisch, Onaga, & Oh, 2013). From this study, the researchers concluded that the two factors that helped to maintain marriages among parents raising children with autism were communication, and sharing common foundational expectations.

Another factor found to be integral to coping with having a child with autism was an individual's own self-compassion. A study completed by Neff and Faso (2014) assessed the association between one's self-compassion and well-being in parents with children with autism. The study included 51 parents of a child with autism. The participants included 40 mothers, and 11 fathers of children with autism. The sample represented 80% Caucasian, primarily in the middle to upper class. Parents used self-reporting to inform the study results. Measures included the Gillian Autism Rating Scale 2nd edition to measure autism symptom severity, the Self-Compassion Scale (SCS), the Satisfaction with Life Scale (SWLS), the Adult Hope Scale, Goal Reengagement Scale, the Center for Epidemiologic Studies Depression Scale (CES-D), and The Parenting Stress Index-Short Form (PSI-SF). The findings included self-compassion as positively correlated with life satisfaction, goal reengagement, and hope, and negatively correlated with depression and parental stress levels. The study recognized child symptom severity as the strongest indicator of negative parental stress, however, self-compassion collectively led to positive well-being in parents' control over the child's symptoms (Neff & Faso, 2014).

Parents who have processed and accepted the diagnosis of their child's autism may or may not have an advantage compared with parents who are coping with the initial diagnosis of their child having autism. A study by Poslawsky, Naber, Van Daalen and Van Engeland (2013) examined the initial parent reactions directly following their child's diagnosis of autism. In this study 77 parents of children recently diagnosed with autism took part in the Reaction to Diagnosis Interview. A majority (96%) of the participants were in the moderate to high socioeconomic status level. 82% of the participants were married, 8% were divorced, and 10% were single mothers. The children of the parents who participated in the study ranged from 16 to 61 months in age and were diagnosed with ASD by a board certified child psychiatrist as having ASD. The instruments used to collect data included the Autism Diagnostic Observation Schedule-Generic (ADOS-G) Mullen Scales of Early Learning (MSEL), the Reynell test for Dutch language comprehension, Aberrant Behavior Checklist (ABC), Socio-Economic status (SES), Parental Efficacy Questionnaire (PEQ), Parental Daily Hassles (PDH), Symptom Checklist (SCL-90), Autism Quotient (AQ), and the Reaction to Diagnosis Interview (RDI). The results indicated that eight percent of the primary caregivers and eight percent of parents overall showed an above average or high level of autistic traits themselves. The connections between parental reaction to diagnosis, parental and child characteristics, and pre-diagnostic circumstances were investigated (Poslawsky et al., 2013). Most of the parents (75%) were considered ‘resolved’ with regard to their child’s diagnosis. However, parents who had children with more severe symptoms of ASD were found to be ‘unresolved’. These parents were classified as neutralizing, emotionally overwhelmed, and angrily preoccupied (Poslawsky et al., 2013). According to the present study, child symptom severity and parental nationality played significant roles in parental reactions to their child’s initial diagnosis of autism.

The previous study included a small number of single mothers, however another study examined the effects of autism on single mothers and their utilization of respite care, and the stressors they faced. Dyches, Christensen, Harper, Mandleco, and Roper (2015). Respite care provides temporary care for individuals with disabilities to give the primary caregiver relief from caring for the individual(s) (Dyches et al., 2015). This study consisted of 122 single mothers with children with autism. The average age of these mothers was 36.6. Most of the women (76.2%) were divorced, separated, or widowed, but 23.8% never married. Of these participants, 21 mothers reported having more than one child with autism. Out of the 142 children with autism, 112 were males. Mothers completed measures including the Center for Epidemiological Studies Depression Scale (CES-D), The Caregiver Burden Instrument, The Hassles and Uplifts Scale (HUS), The Respite Care Questionnaire, and a demographic questionnaire. Results showed that more than half of the mothers (59.8%) used some type of respite care which was given for one hour/ day by various sources including agencies, grandparents, etc. Most of the mothers in this study were at risk for clinical depression (77%) (Dyches et al., 2015). Uplifts (satisfaction, gladness), were negatively connected with depression, and positively connected to respite care, and resulted in decreased levels of depression. The study suggested that mothers who received larger amounts of respite care experienced more daily uplifts and were able to get a break from their daily stressors providing time to restore themselves. The researchers gave suggestions for policymakers and practitioners. They suggested campaigns (similar to campaigns run to raise awareness about autism symptoms) to raise awareness about respite care and other services for parents with children with disabilities. Additionally, the authors believe more policies to help single parents financially should be enforced. The study pointed out that while almost 88% of the mothers in this study had some type of college education, about one-third of them were living below the poverty level and raising an average of two children. Only 58% of the mothers in this study received child support, compared to 74% of single parents without children with disabilities who received partial or full child support payments. If mothers were to receive these payments, the researchers mentioned the mothers of children with autism would be better equipped to receive high quality respite care (Dyches et al., 2015).

Respite care, as seen in the previous study, as well as parental participation in a child's therapy can benefit both the child with autism and the parents. A study completed by Maughan and Weiss (2017) examined the impact of having parents involved with their autistic child's cognitive behavior therapy. The researchers looked at parental mental health, parenting skills, and expressed emotion after cognitive behavior therapy. Cognitive behavior therapy (CBT) has proved as a successful popular treatment for children with autism (Maughan & Weiss, 2017). The current study hypothesized that parents who were a part of their child's CBT would show increased measures of mental health, parenting, and expressed emotion (a parent's feelings and attitudes expressed for their child), compared to parents in the control group. Participants in this study included 57 parents of children with autism. Each child had one parent who attended their therapy sessions and that parent completed the questionnaire. Children with autism ranged from ages eight-12 years old and were 91.2% male. Of the children with autism, 91.2% also met criteria for one or more mental health problems on the Anxiety Disorders Interview Schedule for DSM-IV. Measures for the study included the following: The Autism-Specific Five-Minute Speech Sample (AFMSS) measured the expressed emotion and involved the parent speaking for five minutes about their child without the child there. Negative parenting practices were measured using the Parenting Scale (PS), which included a 30 question parent-report questionnaire that measured the likelihood of a parent using a particular strategy during discipline situations. Parent's ability to cope was measured using Cognitive Emotion Regulation Questionnaire-Short Version (CERQ). The child's mental health was measured using the Behavior Assessment Scale for Children- 2nd Edition (BASC-2), and the Clinical Global Impression Scale (CGI-S). The procedure included assigning half of the participants to the treatment immediate group, or the waitlist control group. The intervention included 10 sessions of individual CBT intervention for children with autism. The therapy was child-focused, but a parent was involved in each session the entire duration, learning strategies to transfer skills to home, providing support to the therapist and child during the session, and following along in a parent workbook. The results showed that depression decreased in parents after participating in treatment. This was thought to be because participating in their child's therapy increased hopefulness in parents with children with autism (Maughan & Weiss, 2017). There were no significant differences found in parent anxiety or stress following the intervention. Parents improved in their ability to emotionally regulate themselves after treatment and were better able to use positive parental coping strategies. This was thought to be due to parents helping their kids practice emotional regulation that led to parents learning their own strategies to better cope. This study showed that parents participating in CBT with their child with autism was highly beneficial to not only the child, but the parents as well (Maughan & Weiss, 2017).

In addition to parents, other caregivers, such as teachers and personal care attendants (PCA's) experience high levels of stress when working with children with autism. Lecavalier, Leone and Wiltz (2006) completed a study to examine the link of caregiver stress for those caring for children with ASD. The authors' main objectives were to: (1) Sort out the effects of behavior problems and level of functioning on caregiver stress; and (2) measure the permanence of behavior problems and caregiver stress. In this study, parents or teachers of 293 young people with ASDs completed various measures of stress, behavior problems and social competence. Parents completed the Parental Stress Index-Short Form (PSI-SF) to identify parental distress, dysfunctional interaction, and difficulty of the child. Teachers completed the Index of Teaching Stress (ITS) which assessed the level of teacher distress in relation to a specific child. Both parents and teachers completed the Nisonger Child Behavior Rating Form (NCBRF) which measured social competence and behavior problems in adolescents with disabilities. Parents and teachers also completed the Scales of Independent Behavior (SIB-R) which evaluates adaptive behavior among children with ASD. Results showed that parents and teachers did not completely agree on the nature and severity of behavior problems. However, both sets of ratings indicated that behavior problems strongly correlated with stress. Behavior problems were more connected with stress among caregivers than any other characteristic of children or caregivers. Children who displayed conduct problems in particular were significant predictors of stress. These included characteristics in the child such as defiance, persistent disobedience, easily frustrated, explosive temper tantrums, and physically attacking people. Adaptive skills were not significantly associated with caregiver stress. Parent ratings showed that behavior problems and stress aggravated one another over time. The researchers concluded that external behaviors were most deeply related to both teacher and parent stress (Lecavalier, Leone & Wiltz, 2006).

Parents and teachers both experienced the stress resulting from externalized behaviors from children with autism as noted in the previous study. Recognizing the differences between males and females with autism can help parents and teachers deal with specific gender related challenges. A study completed by Mademtzi, Singh, Shic, and Koenig (2018) explored the specific challenges related to being a female with autism. The perspectives were taken from parents who had daughters with autism. Many previous studies have focused on males with autism due to the increased prevalence of autism in male children. This study included 40 parents of 40 females ranging in age from four-29 with autism. The parents were put into groups of seven-10 and had a discussion that lasted about two hours per group. A series of questions were asked during discussion which included the following: What are the greatest challenges you have faced with regard to raising your child? What unique challenges have you faced as a parent of a girl with an ASD? Has your daughter suffered from a co-occurring psychiatric or other illnesses? What resources have been most helpful in addressing your daughter’s needs? What kinds of services do you wish were available for support? What barriers to existing services have you faced? Have you found needed services that are affordable? How have you or the school system addressed the need for developing socialization skills? (Mademtzi et al., 2018). This data was qualitative and involved processes such as coding, categorizing, and making sense of the essential meanings of the topic. Themes were identified including Impairment in Social Skills, Difficulty with Building Relationships, Rejection from Others, Rigidity and Solitary Activities, Sensory-Related Issues, Self-Care Skills, Sexual Related Education, Co-occurring Difficulties, Independence and Vocational Concerns, Academic Related Skills, Need of Services, Helpful Programs and Activities, and Barriers to Accessing Services. Some of the topics examined by parents with daughters with ASD were similar to challenges experienced by parents with sons with ASD including poor quality of social interactions, limited group participation skills, inappropriate sexual behaviors, comorbid psychopathology including anxiety and depression, and vocational concerns. There were also concerns related only to females with ASD including their longing for friendships with typically developing girls but having difficulty maintaining them, fear of exploitation in romantic relationships, barriers to accessing services due to a missed diagnosis, and puberty issues that are female-specific (Mademtzi et al., 2017).

Parents of children with ASD also face unique challenges when they may display autistic traits themselves. An article completed by Maxwell, Parish-Morris, Hsin, Bush and Schultz (2013) looked at the Broad autism phenotype (BAP) in parents and its' relationship in order to predict child functioning in those affected with ASD. Broad autism phenotype (BAP) refers to the social and communication deficiencies seen in autism spectrum disorders. This study sought to understand the connection between parental BAP traits and the connection between their children being affected by ASD. This study used the Broad Autism Phenotype Questionnaire (BAPQ) in parents and the Social Responsiveness Scale (SRS) in children to assess the link. The researchers hypothesized that families affected by ASD would show that increased maternal and paternal BAPQ scores were associated with greater symptoms of autism in children who had been diagnosed. In this study, 245 children with ASD and their parents, along with 129 typically developing children and their parents took part in the study. The Autism Diagnostic Observation

Schedule (ADOS) was completed as well as the Autism Diagnostic Interview-Revised (ADI-R) in order to confirm the diagnosis of autism in these children. The Broad Autism Phenotype Questionnaire (BAPQ) was completed by parents about themselves and their child’s other biological parent. It included 36 questions regarding social aloofness, rigidity, and pragmatic language in themselves as well as the child’s other biological parent. Parents also completed the Social Responsiveness Scale (SRS) about their child which included a 65 question inquiry concerning the child’s current and past social behaviors. The children were administered the Differential Ability Scales (DAS-II) by clinicians to further confirm their diagnosis of ASD. The Child and Adolescent Symptom Inventory (CASI) was used to determine if any comorbid conditions were present. 66% of participants with ASD showed elevated scores on the CASI for attention deficit hyperactive disorder (ADHD), oppositional defiant disorder (ODD), and generalized anxiety disorder (GAD). Results from the study concluded a strong link between child SRS score and BAPQ scores in both mother and father in all diagnostic groups. More parents scored above BAPQ cutoffs in the ASD group than in the typically developing children group. In particular, 21% of fathers and 10% of mothers met criteria in the ASD group, compared to 7% of fathers and 1% of mothers in the typically developing children group. The researchers also found that the higher the scores of the parents BAPQ, the poorer and more severe the symptoms were for children with ASD. The study concluded that the father’s characteristics were more strongly related to the child’s ASD phenotype than characteristics of the mother (Maxwell et al., 2013).

Another study examining the BAP was completed by Ingersoll, Meyer and Becker (2010). This study considered the relationship between the broader autism phenotype (BAP) and depression in mothers of children with and without ASD. The study focused on mothers of children with ASD instead of fathers. The researchers hypothesized that mothers of children with ASD would show more symptoms of depression, stress, and characteristics of the BAP than mothers of children without ASD. They also predicted that in mothers of children with ASD, the BAP would correlate with maternal depression despite the autism symptom severity in the child and parenting stress. One hundred and sixty-five mothers (71 with an ASD child and 94 with a non-ASD child) completed a survey of child autism severity (ASD mothers only) using the Autism Behavior Checklist (ABC), The Autism Spectrum Quotient (AQ) to measure maternal BAP, the Family Impact Questionnaire (FIQ) to measure parenting stress, the Center for Epidemiological Studies-Depression Scales to measure maternal depressed mood, and a survey regarding sociodemographic characteristics. Results showed that mothers of children with ASD reported greater depressed mood than mothers without children with ASD. Mothers with children with ASD also reported higher parenting stress. They also displayed more characteristics connected with the BAP than mothers of children without ASD. For mothers of children with ASD, the BAP alone predicted a number of depressive symptoms despite controlling for child autism severity and parenting stress. The results implied that the higher rate of depression found in mothers of children with ASD was related to both the larger number of autistic traits found in mothers, and elevated stress levels from raising a child with ASD, which put these mothers at a much greater risk for developing or increasing depression (Ingersoll, Meyer & Becker, 2010).

Another study that focused on parent factors being predictors of parental mental health problems was completed by Falk, Norris, and Quinn (2014). This study sought to understand the exact factors that predicted stress, anxiety and depression in parents of children with autism. The researchers hypothesized that parental stress, anxiety and depression would be associated with conduct problems in the child, social support, and child's autism symptom severity, and would be substantial predictors of mental health problems in parents. They also predicted that parental mental health problems would be explained by other variables and that it would differ between parental genders. Participants in this study included parents with children between the ages of four and 17 with a diagnosis of ASD. The sample included 250 mothers and 229 fathers with children with ASD. All participants completed an online questionnaire with questions related to their child with autism. These participants also answered questions about their perceived social and economic support. The children's autism symptom severity was measured using the Social Communication Questionnaire (SCQ). The Strengths and Difficulties Questionnaire (SDQ) was used to assess maladaptive behavior problems such as physical aggression, conduct problems, etc. Parental opinion of their own parent-child attachment was measured using the Parent-Child Relationship Inventory (PCRI). There was data collected for 17 different variables that could be seen as potentially leading to mental health problems in parents with autism. The variables were sex of the child, marital status, number of children with autism, age of parent, age of child, social support, economic support, hyperactive behavior, conduct problems, aggressive behavior, autism symptom severity, developmental age, perceived limit setting ability, satisfaction with parenting, perceived parental involvement, and parent locus of control (Falk, Norris & Quinn, 2014). Results showed that variables such as decreased social support, decreased parent locus of control and increased aggressive behavior led to depression in mothers. Paternal depression identified the following contributing variables: decreased social support, perceived limit setting ability, and satisfaction with parenting. Anxiety in mothers was seen in the areas of autism symptom severity, perceived limit setting ability, and mother's age (younger mothers were more susceptible). Anxiety in fathers was linked to perceived limit setting ability, social support, and aggressive behavior. Variables shown to cause stress in mothers included perceived limit setting availability, mother's age (younger mothers were more susceptible), autism symptom severity, social support, parental locus of control, and economic support. Paternal stress was caused by perceived limit setting ability, social support, and father's age. A final key finding from the study was that autism symptom severity was revealed to be a significant factor in contributing to mental health problems in parents of children with autism. More severe autism symptoms led to increased mental health problems (Falk, Norris, & Quinn, 2014).

The previous study noted that increased mental health conditions were aggravated sometimes due to the severity of autism in a child. Another study with this focus area in mind was completed by Zablotsky, Anderson, and Law (2013). These researchers investigated the connection between autism symptoms in children, quality of life in mothers, and the risk of depression for mothers raising children with autism. The researchers presented two different hypotheses. First, they predicted that children with greater symptoms of autism and comorbid psychiatric disorders would be more prone to have a mother who was being treated for depression. They also predicted that children with greater autism symptoms and comorbid psychiatric disorders would have mothers who reported a lower quality of life (Zablotsky, Anderson & Law, 2013). The study included 1100 mother-child pairings, with 540 mothers of children with ASD who had a diagnosed case of depression from a medical professional, and 570 mothers of children with ASD who reported having no diagnosis or self-diagnosis of depression.

Measures used in this study included the Child with ASD Questionnaire (ASDQ), The Social Responsiveness Scale (SRS), the Parental Depression History Questionnaire (PDHQ), a basic medical history questionnaire for mothers, and a questionnaire regarding quality of life and the impact of raising a child with ASD in five different areas of life including relationship with spouse, relationship with extended family, friendships and social networks, career or continuing education, and financial situation (Zablotsky, Anderson & Law, 2013). Results showed that Hispanic children were less prone to having a mother with depression. They also found children with more symptoms of autism had a greater chance of having a mother with depression. Additionally, children with one or more diagnosed psychiatric conditions were highly likely to have a mother who was depressed compared to children without psychiatric conditions. The study also found that regardless of having depression, mothers who reported greater symptoms of autism in their child had a higher likelihood of reporting negative life effects on the relationship with their spouse, extended family, friends, career or education, and financial situation. This study provided a clear relationship between child and mother traits including the severity of symptoms in the child with autism, the occurrence of mother's depression, and mother's quality of life (Zablotsky, Anderson & Law, 2013).

The severity of autism symptoms can also affect mothers and fathers in different ways. A study that compared gender differences when parenting children with autism was done by Jones, Totskika, Hastings & Petalas (2013). This study looked into gender differences between mothers and fathers regarding parenting children with autism. There were 161 couples who participated in this study. Measures used in this study included the Hospital Anxiety and Depression Scale (HADS) to examine parent's mental health, The Parent and Family Problems Subscale of the

Questionnaire on Resources and Stress (QRS-F) was used to measure stress in parents, The Positive Gain Scale (PGS) measured parental positive experiences, The Social Communication Questionnaire (SCQ) measured the severity of the child's autism symptoms, the Vineland Adaptive Behavior Scales- 2nd Edition (VABS II) was used to look at the child's adaptive functioning, and the Strengths and Difficulties Questionnaire (SDQ) measured the child's behavioral and emotional adjustment (Jones et al., 2013). The results showed that mothers of children with ASD reported higher levels of overall psychological stress, including stress, anxiety and depression, compared to fathers. The research also showed that increased behavioral problems led to higher levels of psychological stress among both genders of parents. The researchers pointed to the fact that mothers typically were more involved in the care of their children, therefore leaving them more susceptible to psychological distress. These researchers pointed out the need for awareness surrounding the increase in psychological stress among mothers with autism, and pointed out the need for clinical interventions available to assist mothers' well-being (Jones et al., 2013).

As the previous research indicated, both parents experienced psychological stress as a result of parenting a child with autism. A different study by Foody, James and Leader (2015) investigated the physiological stress symptoms in parents of children with autism. The study had a goal of inspecting the differences of physiological stress symptoms of stress between mothers and fathers of children with autism, and wanted to understand the health consequences of stress. The study utilized the Parenting Stress Index- Short Form (PSI-SF) as a self-report stress measure, the Hospital Anxiety and Depression Scale (HADS) to measure anxiety and depression, the Parental Responsibility Scale (PRS) to measure responsibility among parents, a demographic and health questionnaire for parents, a saliva sample to measure salivary cortisol, a cardiovascular assessment using an Oscar 2 ABP monitor with an Orbit cuff, and a diary given to each participant used to report their location, activity, and mood each time the BP cuff was inflated (Foody, James, & Leader, 2015). This study included 19 mother-father pairs of children with autism. The findings from the study showed that mothers reported greater parenting responsibility than fathers. Mothers also reported greater distress, anxiety, and depression than fathers. Fathers in this study showed higher levels of heart rate variability, and had higher blood pressure than mothers in this study. It was interesting to note that both mothers and fathers had lower than average morning cortisol levels, which the researchers suggested as an effect of stress on the hypothalamic-pituitary-adrenal-axis (Foody, James, & Leader, 2015). The research showed that parents of children with autism had high levels of stress, and could benefit from regular health screenings, as well as partaking in stress reducing activities and interventions.

The previous studies illustrated the high levels of stress that parents faced when parenting a child with autism. Sibling relationships in families with children with autism are also affected. A study done by Rivers and Stoneman (2003) looked at sibling relationships when one child had autism, and how those relationships affected marital stress. It also looked at the effects of higher marriage stress and the impact on sibling relationships. The study took information about the sibling relationships directly from the siblings, as well as from parent reports. These researchers hypothesized that typically developing siblings of children with autism, would report more negative sibling relationships if they were living in a family with more marital stress. Participants included 50 families each with a parent, typically developing sibling, and a sibling with autism. Data was collected through self-reported measures that included the following questionnaires: A family information form (demographics), the Sibling Inventory of Behavior (SIB), the Satisfaction with the Sibling Relationship Scale, The Marital Strains subscale of the Family Inventory of Life Events and Changes to measure marital stress, and the Family Crisis Oriented Personal Evaluation Scales (F-COPES) to evaluate ways families deal with stress. The results showed that typically developing siblings had positive overall ratings of their relationship with their siblings with autism. Siblings, in general rated their sibling relationships more positively than their parents rated it. Furthermore, as hypothesized, the sibling relationship was negatively affected by marital stress. Families that sought social support reported typically developing siblings with increased satisfaction with sibling relationships. The researchers believed these children were emotionally affected by the marital stress, therefore negatively reacted in a way that affected their relationship with siblings (Rivers & Stoneman, 2003).

Families in the previous study that sought social support, reported greater sibling relationships and better family dynamics. Another study looked at what factors helped families remain positive when a child in their family had autism. Whitehead, Dorstyn and Ward (2015) looked at the psychological adjustment in families affected by autism. Researchers wanted to identify the levels of psychological distress, and resilience among families affected by ASD. They also wanted to understand the individual and community influences on caregiver adjustment. The researchers hypothesized that caregiver stress would increase as a result of having poor cognitive behavioral coping strategies in response to a child’s behavioral challenges, and having restricted access to social and community resources. The study included 438 female caregivers of children with autism. The following self-report measures were used to collect data for this study. The Depression Anxiety Stress Scales- 21 Item (DASS-21) measured depression, anxiety and stress. The Connor Davidson Resilience Scale (CD-RISC) measured individual resilience and ability to adapt to adversity. The Development Behavior Checklist (DBC) evaluated negative behaviors in children. The Locus of Control of Behavior Scale (LCB) measured an individual's perception of their behavior being determined by events within their control. The Brief (COPE) measured an individual's differences in coping. The Social Support Index (SSI) measured the caregiver's perceived community support and the Service Obstacles Scale (SOS) measured accessibility of community resources. The results included 18% of caregivers who reported severe to extremely severe depressed mood, 23% with severe to extremely severe levels of anxiety, and 22% reported severe tension and stress. Factors that contributed to the highest levels of distress included avoidance coping strategies, dissatisfaction with social supports and externality. Caregivers who believed their stress was situational and outside of their control, and who showed avoidant coping showed greater psychological distress. In contrast, caregivers that took active steps to pinpoint and solve their problems, as well as those who took part social support opportunities showed greater resilience (Whitehead, Dorstyn & Ward, 2015).

Another study examined the mental health interventions that may benefit parents of children with autism. A study by Fung, Lake, Steel, Bryce and Lunsky (2018) inspected the impact of Acceptance and Commitment Therapy (ACT) group intervention, led by parents. The researchers focused on three psychological processes targeted through ACT: psychological flexibility, fusion, and values (Fung et al., 2018). Participants in this study included 33 mothers of children with autism. These participants completed questionnaires one week prior to ACT intervention, and three months post-intervention. Measures to evaluate the effectiveness of the

ACT intervention included the Acceptance and Action Questionnaire Version II (AAQ-II) that measured overall psychological flexibility, Cognitive Fusion Questionnaire (CFQ) which assessed cognitive fusion, the Values Living Questionnaire (VLQ) assessed perceived importance of values across 10 different areas of life, and the Depression Anxiety Stress Scales (DASS-21). Results showed that following the ACT intervention, mothers showed improvements in psychological flexibility, cognitive fusion, and values. These researchers maintained that improved psychological flexibility contributed to better well-being, and enhanced parenting skills. Mothers in this study also reported engaging in behaviors that were more consistent with their personal values following intervention. Mothers also reported fewer depressive symptoms and less perceived stress following ACT intervention. The researchers explained that this was due to increased self-care activities, as well as improved parenting consistent with their own personal values (Fung et al., 2018).

CHAPTER III: DISCUSSION AND CONCLUSION

Primary caregivers of children with autism are under large amounts of stress on a daily basis as demonstrated by research. Parents need to learn positive coping strategies when engaging with these challenging children. Parents need access to support and resources outside the home to provide relief. In the study by Bitsika and Sharpley (2004), 91% of the parents in their study stated they were unable to deal successfully with their child's behavior which resulted in them feeling stretched beyond their individual limits. The article by Altiere and Kluge (2008) showed that increased cohesion and adaptability of a family were tied to positive coping methods which increased family satisfaction and functioning. Participants who rated their family as enmeshed or connected were found to be significantly more likely to utilize coping mechanisms than those who rated their families as disengaged. The study by Ekas et al. (2010) showed the positive effects of social support from spouses, friends, and family of parents of children with autism. Each type of social support was connected with lower levels of depression, maternal stress, and negative affect. Maughan and Weiss (2017) looked into the impact of Cognitive Behavior Therapy (CBT) and the positive impacts this therapy had on children with autism, especially when parents participated in the therapy with them. The therapy was child-focused, with a parent involved in each session the entire duration. Parents learned strategies that enabled a transfer of skills to home. They provided support to the therapist and child during the session, and followed along in a parent workbook. The results proved that depression decreased in parents after participating in this type of treatment.

Another coping strategy found to increase positivity and decrease depression for parents of children with autism was spirituality. The study completed by Ekas, Whitman & Shivers

(2008) showed that those who felt a personal connection and intimacy with God were more likely to show positive outcomes in the areas related to stress, anxiety, depression, and self-esteem.

The research also showed the importance of early screening for autism. As mentioned in the Baio et al. study (2014), 85% of children found to have ASD had concerns regarding development by three years of age, but only 42% received a comprehensive evaluation. It is crucial that doctors and parents have their children screened when there are concerns, especially since autism can be diagnosed as early as age two. With earlier diagnosis, interventions can start earlier. Early intensive intervention demonstrates statistically significant improvements in cognitive and communication outcomes. There is also a need to educate medical professionals to closer examine children suspected to have autism and not assume the child will “grow out of it.” Parents should not have to fight hard to receive a thorough evaluation if they suspect their child has autism.

Another common finding among the research was the increased amount of stress felt by mothers compared to fathers of children with autism. Davis & Carter (2008) found that mothers of children with autism reported significantly higher levels of depression. The reason for this was not entirely clear, but the researchers thought it could be because mothers take on more of the burden of caring for their child compared to fathers.

The studies also showed that increased symptoms in a child with autism was directly related to the stress parents feel. Children found to have more severe symptoms of autism had parents with higher levels of stress, depression, and anxiety. From experience, I have seen the effects children with severe symptoms of autism have on caregivers including parents and teachers who work regularly with them. Children who display especially difficult behaviors such as physical aggression and self-injurious behaviors are specificially draining for adults who care for them. The article written by Zablotsky, Anderson & Law (2013) also looked at the relationship between children's autism symptom, and depression rates in mothers. This study found that children with more symptoms of autism had a greater chance of having a mother with depression. They also further analyzed the data and examined the prevalence of children with autism who also had comorbid conditions. They found that children with one or more diagnosed psychiatric conditions were significantly more likely to have a mother who was depressed compared to children without psychiatric conditions.

Limitations of the research included small sample sizes in some of the studies. The research completed by Foody, James and Leader (2015) included only 19 mother-father pairs of children with autism. Altiere and Kluge (2008) collected data from 26 pairs of parents of children with autism. The research, though significant, could have shown different and more accurate results with larger sample sizes.

Another limitation of the research included the limited demographics represented in the studies. A majority of the studies found included primarily white families in the middle to upper class. I found limited studies including families of varying races and socioeconomic status. This could be because autism has been found to be more common among Caucasian people compared to any other race. However, more studies should be done that focus on families of minorities, as well as people with a lower socioeconomic status in order to compare the similarities and differences on the effects of parents of children with autism.

An area of future research in this subject area could include more studies on the effects of females with autism and the specific challenges related to families of females with autism. I found only a few studies that focused specifically on females with autism, but most of the studies I found included primarily male children with autism.

Another area of further research could include the challenges faced by parents who have older adult children with autism and the continued effects of autism on the family. All of the studies I found focused on children under 18, and some mentioned the stress parents feel about their child's future, but none studied the familial effects of an adult child with autism. The research showed that depression and mental health conditions are found in parents of children with autism at the onset of their diagnosis, throughout their childhood. Parents who continue to care for their children into adulthood might face similar or more severe symptoms of mental health related conditions. This is especially potentially true as the parents age.

Implications of this research include needing resources to help extended family members understand how to better support parents/ primary caretakers of children with autism. The research shows how valuable a strong support network is for parents of children with disabilities, but sometimes, loved ones are unaware of how to support them. Many extended family members or friends may want to help out the family, but are unsure what they can do, especially if they don't understand autism. Parents of children with autism might be apprehensive to reach out for help and feel they want to try to do it all themselves, but providing help and respite care is critical to these parents who are under constant stress.

The information gained from this research will help me deal with the families at my school so that I can approach my interactions with greater knowledge of the challenges they face on a daily basis. The research opened my eyes to the constant struggle faced by most families of children with autism. It is evident that caregivers of children with autism undergo tremendous amounts of stress and face personal mental health issues as a direct result of caring for these children. As an educator I want to do my best to care for these children and teach them valuable skills they can generalize to home. Educators could take responsibility to support parents by doing a variety of things. Schools could provide a safe space for support groups for parents. Educators could also provide parents a list of specific instrution they are providing students at school, or having them participate in community-based outsings. Another way to support parents could be to provide a list of resources or guest speakers in the community or at school. The autism resource specialist at our school sends our teachers a newsletter with upcoming events from the Autism Society of Minnesota (AUSM). I typically print it off or forward the information along to parents to attempt to keep them informed.

Furthermore, I have a student in my class with intense self-injuious behaviors (SIBs), and her family recently reached out to inquire about specific strategies we use at school to calm her down. They expressed that she recently has increased her behaviors at home. We made copies of all of the visual symbols used, and the calming sequence strategy used with her. If parents follow the same strategies at home as we do at school, it will hopefully alleviate stress, and provide consistency to the student and family. All parents of children with autism need to feel supported and need increased resources to help them provide for these precious children.

References

Altiere, M.J., & Kluge, S.V. (2008). Family functioning and coping behaviors in parents of children with autism. *Journal of Child and Family Studies, 18,* 83-92. doi: 10.1007/s10826-008-9209-y

Baio J., Wiggins L., Christensen D.L., et al. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years. *Autism and Developmental Disabilities Monitoring Network*, *MMWR Surveill Summ 2018;67* 1–23

Baron-Cohen, S., Lombardo, M.V., Augyeung, B., Ashwin, E., Chakrabarti, B., & Knickmeyer, R. (2011). Why are autism spectrum conditions more prevalent in males? *PLOS Biology 9* (6)

Benson, P.R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism and Developmental Disorders, 36*, 685-695. doi: 10.1007/s10803-006-0112-3

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

Cohen, I.L., & Tsiouris, J.A. (2006). Maternal recurrent mood disorders and high-functioning autism. *Journal of Autism and Developmental Disorders, 36,* 1077-1088. doi: 10.1007/s10803-006-0145-7

Cohrs, A.C., & Leslie, D.L. (2017). Depression in parents of children diagnosed with autism spectrum disorder: a claims-based analysis. *Journal of Autism and Developmental Disorders, 47,* 1416-1422. doi: 10.1077/s10803-017-3063-y

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. doi: 10.1007/s10803-007-0512-z

Dyches, T.T., Christensen, R., Harper, J.M., Mandleco, B., & Roper, S.O. (2015). Respite care for single mothers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 46,* 812-824. doi: 10.1007/s10803-015-2618-z

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,* 1274-1284. doi: 10.1007/s10803-010-0986-y

Ekas, N.V., Whitman, T.L., & Shivers, C. (2008). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 39,* 706-719. doi: 10.1007/s10803-008-0673-4

Falk, N.H., Norris, K., & Quinn, M.G. (2014). The factors predicting stress, anxiety, and depression in the parents of children with autism. *Journal of Autism and Developmental Disorders, 44,* 3185-3203. doi: 10.1007/s10803-014-2189-4

Foody, C., James, J.E., & Leader, G. (2015). Parenting stress, salivary biomarkers, and ambulatory blood pressure: a comparison between mothers and fathers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 45,* 1084-1095. doi: 10.1007/s10803-014-2263-y

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

Ingersoll, B., Meyer, K., & Becker, M.W. (2010). Increased rates of depressed mood in mothers of children with ASD associated with the presence of the broader autism phenotype. *International Society for Autism Research, 4,* 143-148. doi: 10.1002/aur.170

Jones, L., Totsiksa, V., Hastings, R.P., & Petalas, M.A. (2013). Gender differences when parenting children with autism spectrum disorders: a multilevel modeling approach. *Journal of Autism and Developmental Disorders, 43,* 2090-2098. doi: 10.1007/s10803-012-1756-9

Lai, W.W., Goh, T.J., Oei, T.P., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders, 45,* 2582-2593. doi: 10.1007/s10803-015-2430-9

Lecavalier, 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*, 172-183. doi: 10.1111/j.1365-2788.2005.00732.x

Lee, G.K. (2009). Parents of children with high functioning autism: how well do they cope and adjust? *Journal of Developmental and Physical Disabilities. 21,* 93-114. doi: 10.1007/s10882-008-9128-2

Mademtzi, M., Singh, P., Shic, F., & Koenig, K. (2018). Challenges of females with autism: a parental perspective. *Journal of Autism and Developmental Disorders, 48,* 1301-1310. doi: 10.1007/s10803-017-3341-8

Maughan, A.L., & Weiss, J.A. (2017). Parental outcomes following participation in cognitive behavior therapy for children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 47,* 3166-3179. doi: 10.1007/s10803-017-3224-z

Maxwell, C.R., Parish-Morris, J., Hsin, O., Bush, J.C., & Schultz, R.T. (2013). The broad autism phenotype predicts child functioning in autism spectrum disorders. *Journal of Neurodevelopmental Disorders, 5*

Neff, K.D., & Faso, D.J. (2015). Self-compassion and well-being in parents of children with autism. *Mindfulness, 6,* 938-947. doi: 10.1007/s12671-014-0359-2

Padden, C., & James, J.E. (2017). Stress among parents of children with and without autism spectrum disorder: a comparison involving physiological indicators and parent self-reports. *Journal of Developmental and Physical Disabilities, 29,* 567-586. doi: 10.1007/s10882-017-9547-z

Rezendes, D.L., & Scarpa, A. (2011). Associations between parental anxiety/depression and child behavior problems related to autism spectrum disorders: The roles of parenting stress and parenting self-efficacy. *Autism Research and Treatment.* doi: 10.1155/2011/395190

Poslawsky, I,E., Naber, F.B.A., Van Daalen, E., & Van Engeland, H. (2014). Parental reaction to early diagnosis of their children’s autism spectrum disorder: an exploratory study. *Child Psychiatry and Human Development, 45,* 294-305. doi: 10.1007/s10578-013-0400-z

Ramisch, J.L., Onaga, E., & Oh, S.M. (2014). Keeping a sound marriage: how couples with children with autism spectrum disorders maintain their marriages. *Journal of Child and Family Studies, 23,* 975-988. doi: 10.1007/s10826-013-9753-y

Rezendes, D.L., & Scarpa, A. (2011). Associations between parental anxiety/depression and child behavior problems related to autism spectrum disorders: the roles of parenting stress and parenting self-efficacy. *Autism Research and Treatement.* doi: 10.1155/2011/395190

Rivers, J.W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: marital stress and support coping. *Journal of Autism and Developmental disorders, 33*(4), 383-394

Taylor, J. L., & Warren, Z. E., (2012). Maternal depressive symptoms following autism spectrum diagnosis. *Journal of Autism and Developmental Disorders, 42*, 1411-1418. doi: 10.1007/s10803-011-1375-x

Whitehead, K., Dorstyn, D., & Ward, L. (2015). Psychological adjustment in families affected by autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 27,* 703-717. doi: 10.1007/s10882-015-9446-0

Zablotsky, B., Anderson, C., & Law, P. (2013). The association between child autism symptomology, maternal quality of life, and risk for depression. *Journal of Autism and Developmental Disorders, 43,* 1946-1955. doi: 10.1007/s10803-012-1745-z