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Being Whole Together: A Study of Blended Family Life on the Spectrum

A dissertation submitted in partial satisfaction of the
requirements for the degree Doctor of Philosophy in Education

by

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Being Whole Together: A Study of Blended Family Life on the Spectrum

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by

Angela P. Ente

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I would like to dedicate this manuscript to the families who participated in this study. First, this dissertation was a collaboration of effort and I owe a huge debt of gratitude to my advisor, Dr. George Singer, without your countless emails and telephone conversations this would never have been completed. Thank you Besty Brenner for the unbelievable time you spent assisting me with this project, your dedication as an educator far exceeds most. This project would definitely not be polished without the amazing assistance of my editor, Katharyn, your time and energy devoted to these families stories speaks volumes about your character, thank you! Thank you to my mother for her countless words of encouragement and wisdom during times of stress. Lastly, thank you to my husband, Philip, who made me a stepmother to his children and who brought his son, William into my life. I love you.

Abstract

Almost nothing was known about the process of family formation among remarried families of children with autism. In this qualitative interview study, a cohort of five remarried couples, three stepparents, one biological parent, and one grandparent were interviewed to determine what adaptations occur during the process of family formation and maintenance in remarried families of children with autism. Variables assessing family stress and adaptation were used to determine what sustainable accommodations were made by families to fit the unique needs of their children all while dealing with the usual difficulties of being a blended family. Interviews were audio recorded and transcribed. Using grounded theory methods, the author analyzed the transcriptions to determine common themes, which were found to be: (a) development of parenting roles; (b) adjusting to problem behavior; (c) developing family routines; (d) services and community resources; and (e) resilience in parenting. Remarried families coordinate their parenting efforts by how they manage the nonnormative demands of parenting a child with autism and work together to produce sustainable accommodations for the child.

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August 2019

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Table of Contents

I. Introduction	1
Statement of problem.....	3
Purpose.....	9
Research questions.....	9
Overview of the theoretical framework.....	12
II. Literature Review	20
Family Systems Theory.....	20
Blended Families.....	21
Defining Roles.....	23
Coparenting.....	30
Parenting Children on the Autism spectrum.....	31
Parenting Stress and Autism.....	36
Optimism.....	43
Coparenting a child with autism.....	44
Interview Based Research on Coparenting.....	45
Service needs across a lifespan.....	48
Chapter Summary.....	51
III. Research Design and Methodology	53
Overview.....	53
Participants.....	55
Procedures.....	59
Data Analysis.....	61
Trustworthiness.....	66
Researcher Background.....	69
IV. Results	71
Developing Parenting Roles.....	74
Adjustment to Problem Behavior.....	81
Communication.....	89
Development of Family Routines.....	97
Families in Crisis.....	103
Worries About the Future.....	107
Services and Community Resources.....	113
Resilience in Parenting: The Story of Us.....	121
V. Discussion	130
Outcomes.....	155
Future Research.....	156
Limitations.....	161
Directions for Further Research.....	161
Conclusion.....	163
References	164
Appendices	178

List of Tables

Table 1: Definition of Educational Terms.....7

Table 2: Demographics of Participant Families.....57

I. Introduction

Divorce and remarriage have been on the rise for the past few decades in the United States and many other industrialized countries. This means that restructured families are on the rise as well. The divorce rate for remarriages is higher than that of first marriages, with 46% of cohabitating relationships coming to an end within 5 years of formation. This means that a considerable number of stepfamilies end in dissolution and many individuals experience redivorce (Coleman, Ganong, Russell, & Frye-Cox, 2015). As the rates of divorce among blended families continue to increase, this makes adequate support for these families even more important.

Adults encounter additional challenges in their repartnering efforts when children are present, such as deciding how much influence the child has on the process of selecting the new partner or deciding when to introduce said partner to their children. Understanding how children change the stages of relationship development is vital, as the negotiation of these family transitions may have significant effects on both adult and child adjustment as well as parental functioning. Cherlin (1978) had predicted that remarriage after divorce would see the norms eventually set in regarding behavior in stepfamilies, e.g. “what kind of relationship stepfather has with his stepchildren” (p. 848). The opposite occurred, according to Cherlin (1978): first marriage became more like remarriage in that it was no longer stable and people were cohabitating instead of marrying. Cherlin (1978) found that a lack of guidelines and norms for role performance and a scarcity of culturally established, socially acceptable techniques for resolving problems for remarried adults contributed to increased stress,

inappropriate solutions to problems, and increased divorce rates for stepfamilies (Ganong & Coleman, 2017). Cherlin (1978) used the term deinstitutionalization as a way of describing the weakening of social norms surrounding marriage.

Cherlin's (1978) incomplete institutionalization hypothesis proposes that there is a lack of proper resources for negotiating changes in family roles and relationships in divorced families and stepfamilies. Issues like these are just the tip of the iceberg for these newly restructured families.

Stepfamilies are known to be more complex and fragile than first marriages because the struggles they face tend to be more complicated, and often they must strive to shape a functional family system despite present and past emotional baggage (Ganong & Coleman, 2017). Recent data taken from the Pew Research Center's work on social and demographic trends suggests that in 2010, more than 4 in 10 U.S. adults had at least one step-relative in their family (Zelevnikow & Zelevnikow, 2015).

Stepfamily life has been well documented, and it is a subject that has continued to remain of interest for researchers. By contrast, there is little known about remarried families of children with autism. Rates of divorce among parents of children with disabilities are higher than those of typically developing children (Carroll, 2013). When children with disabilities are involved in repartnering after divorce, they bring a host of issues with them due to the additional complexities presented by their diagnoses. An example of such complexities is potential conflict with a new sibling who may not know how to communicate with them or understand their need for

routines (Rigles, 2017). Children with some developmental disabilities may also be prone to jealousy when they see the biologic parent treating the new sibling like their own child. Another possible issue is the loss of residence the child has to deal with when they move to a new home. Although such changes are not unique to families with children on the spectrum, the behavioral challenges that go along with them certainly can be. Children with autism are routine oriented and when that routine is changed, either by a move, a new sibling, and or a new spouse living under the same roof, life with the child with autism can become more difficult until the new routines become memorized to a point of mastery for the individual (Rigles, 2017). The establishment of parenting roles is another area of the stepfamily experience that is of particular importance when there is a child with autism present.

Atypical stepfamilies such as those of children with autism are understudied and there is still much to be learned about them.

Statement of Problem

It is estimated that 1 in 59 children have been diagnosed with autism spectrum disorder in the United States (The Centers for Disease Control and Prevention, 2018). Autism is a lifelong neurodevelopmental disorder involving deficiencies in communication and social reciprocity, as well as increases in repetitive/restrictive interests and behaviors (Timmons, Willis, Pruitt, & Ekas, 2016). Parenting a son or daughter with autism presents several exceptional challenges, some of which may be harmful to marriage stability (Saini et al., 2015).

Research on divorce among families of children with autism is incomplete at best, with the divorce rate most commonly reported at 23.5% for the past decade (Baeza-Velasco, Michelon, Rattz, Pernon, & Bagdadli 2013; Freedman, Kalb, Zablotzky, & Stuart, 2012; Hartley et al., 2010). This divorce rate of 23.5% was significantly higher than the divorce rate of parents of typically developing children (13.81 %). The divorce rate among these families has commonly been overstated in the popular literature, with an oft quoted figure of 80% that is an extreme exaggeration (Freedman, 2012). An increase from 14% to 23% is in itself substantial. One possible reason for this difference in divorce rates is that parenting a child with autism has been shown to increase psychological distress in parents (Sanders & Morgan, 1997) and thus increases stress within the family system. Factors that contribute to this stress are the diverse behavioral challenges and other struggles linked with social and communication deficits that are characteristic of autism (Freedman et al., 2012; Hartley et al. 2010; Sikora et al., 2013). Burdens such as these could become overwhelming for families of a child with autism, possibly leading many family relationships to become severely stressed and to then dissolve.

Due to the complexities involved in family functioning when there is a child with autism present, an increase in stress across the family unit is no surprise. Research on family systems theory suggests that the well being of children and adults within the family unit is linked (Cridland, Jones, Magee, & Caputi, 2014; Hastings, Petalas, Jones & Totsika, 2014; Saini et al., 2015; Vasilopoulou & Nisbet, 2016), and

thus the quality of family life is so intertwined that what affects one member will affect the balance of the entire family.

One general definition of stepfamilies is the “result from the union of two adults where at least one partner has a child from a previous relationship” (Sweeny, 2010, p. 671). Stepfamilies with typically developing children are complex, and their dynamics differ from those of nuclear families. For example, parenting roles among biological and stepparents have to be determined, former partners affect the decision making that takes place within the household, and stepparent-stepchild relationships have to be developed (Adler-Baeder & Higginbotham, 2004). These issues do not occur for couples entering first marriages without children. Due to this added difficulty, researchers and clinicians disagree as to what the most beneficial interventions should be in order to promote satisfying stepfamily and couple relationships (Adler-Baeder & Higginbotham, 2004; Ganong, Coleman, & Jamison, 2011; Ganong, Coleman, Jamison, & Feistman, 2015; Sweeny, 2010).

The dynamics between the parental roles of the biological parents and the new partner can be difficult to establish in a new stepfamily, and often the children find themselves caught in the middle of challenging situations between their parents and stepparents (Coleman & Ganong, 2017). A smooth transition will allow for a healthier emotional environment for both children and parents.

Some of the main challenges that remarried couples face early in their relationship relate specifically to relationship satisfaction and stability (Slattery,

Bruce, & Halford, 2011). One particular example of these challenges is the question of when the biological parent should introduce their children to their new partner. These issues are the same in families of children with autism, with the added worry that such an introduction could spark an outburst by the child with autism or other problem behavior. Much is known about parenting a child with autism in a nuclear family (Wang & Singer, 2016), and yet almost nothing is known about remarried families of children with autism. These families are almost entirely absent from the literature, yet they have some of the highest potential levels of stress and thus a greater need for relevant research to be conducted.

When I began searching for remarried families of children with autism in the literature, I searched PsychInfo, ERIC, PubMed and only found 2 articles. When I searched for divorce and separation of families of children with autism I found 70 results. I then broadened my search to families of children with disabilities and remarriage which brought me 7 articles. As a result I had to reach into the literature on nuclear families to find more information on remarriage and blended families.

Research on remarriage by Amato (2005) examined the effects of family structure on children through meta-analysis and found the differences between single parent households and households with both parents, and how these factors affect child outcomes. Within the same article Amato (2005) described that a child's overall well-being has many modifiers and that parental influence is only a snapshot of the whole picture. The section on stepfamily formation that I found to be of the utmost

interest stated that: “stepfamily formation is stressful for many children because it often involves moving (generally to a different neighborhood or town), adapting to new people in the household, and learning new rules and routines” (Amato, 2005, p.80). This added stress is unavoidable, and with all of these new changes it comes as no surprise that stepfamily life can be so stressful in the early stages. Amato (2005) stated that if a stepfamily can persevere through this stressful time, in the end their relationships may become more close and supportive. Children with autism require much more support in learning to navigate new environments and the idea of meeting new people, which lends credibility to the overwhelming need for this understudied stepfamily subject to be researched.

Due to the growing numbers of autism diagnoses and the increasing divorce rates associated with the condition, it is unwise to ignore the fact that these families will indeed remarry. And yet, research on remarried families of a child with autism continues to be absent from the literature. How they come together, what occurs when the child with autism is introduced to the new spouse, and how they persevere despite obstacles are all important events that must be researched. These concepts could help future blended families in their repartnering efforts while also filling in the gaps in the existing literature.

Table 1

Definition of Terms

Educational Terms	Definition
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Blended Families	"A family system in which a new couple partnership is formed, either through remarriage or cohabitation, that includes children from previous relationships" (Kumar, 2017, p.110).
Co-Parenting	"An enterprise involving the coordination among adults responsible for the care and upbringing of children" (McHale, Kuersten-Hogan, & Rao, 2004, p.222).
Residential (Custodial)Mother/Father	"A parent that has the sole physical custody of the child or whom the child resides with the majority of the time"(Svare, Jay, & Mason, 2004, p. 83).
Family Centered Approach	"The U.S. Maternal and Child Health Bureau defines Family Centered Care (FCC) as an approach to care that assures the health and well-being of children and their families through a respectful family-professional partnership"(Gabovitch & Curtin, 2009, pp. 470-471).
Family Support	"Anything that a family says it needs for the development of its children and the functioning of a family unit as a whole" (Zuna, Brown, & Roy, 2014, p.164).
Family	"Two or more people who regard themselves as a family and who carry out the functions that families typically perform; these two people may or may not be related by blood or marriage" (Zuna, Brown, & Roy, 2014, p. 164).

Purpose

The purpose of this study was to query blended families of children with autism by surveying and interviewing them in order to determine what adaptations adequately describe their process of family formation and maintenance. What occurs when the formation of relationships takes place? What adjustments do these families have to make when they restructure their households? This was an important research topic because for the first time these families would be asked to speak for themselves on what it has been like to remarry and adapt when there is a child with autism is present.

Research Questions

There were three original research questions for this study: (1) How do new blended families form when there is a child with autism present? (2) What are additional, if any, adjustment factors in the formation of new blended families due to a child's autism? (3) What support do parents believe might be helpful for problems in family formation of a child with autism? These questions guided the design of the interview protocol in this study. However, the focus of the analysis shifted after the interviews were collected and transcribed. A two stage process of questioning and analyzing the data emerged in the process. After the data was collected, analyzed, and the themes established based on this first set of questions, a second set of questions evolved that were driven by two theories that helped to illuminate the data. Because

this was the first study of this kind, it was important that these stepfamilies be given the opportunity to provide a baseline of information so that more research could be accomplished.

The second set of questions emerged as part of the analytic process. They were derived from two theories of family adaptation that appeared to offer important insights into these families' experiences of family formation and maintenance.

1. In what way does the use of the Family Adjustment Adaptation Response (FAAR) model of family stress and adaptation adequately describe the process of family formation and maintenance in remarried families of children with autism?

A. Demands: If Patterson's (2002) concept of demands fit the data, how so?

(i) To what extent do these families face demands that are normative for any remarried family and to what extent are they nonnormative due to the child with autism?

(ii) Similarly, do these families experience daily hassles, or not?

B. Capabilities: If Patterson's (2002) concept of capabilities fit the data, how so?

(i) What coping behaviors do family members utilize?

(ii) What psychosocial resources function as capabilities in these families?

(iii) What tangible resources do these families utilize?

C. Outcomes: If Patterson's (2002) concept of outcomes fit the data, how so?

(i) Do families show relatively stable patterns of interacting as they balance the demands they face with existing capabilities?

(ii) Explain how some families experience crisis, or periods of significantly disequilibrium.

(a) If so, how do they restore balance?

(b) If they do not restore balance, do they show poor adaptation?

2. How does the use of Gallimore, Weisner, Kaufman, & Bernheimer (1989) ecocultural niche theory help explain what capabilities are used in these families?

Does it help to explain response to crises?

A. How do families develop sustainable accommodations to family routines to meet the needs of their children with autism?

(i) What do they do to develop these accommodations? Do they rely on pre-existing normative knowledge and skills or do they invent or acquire new skills?

(ii) To what extent do they need to invent or acquire new ways of thinking and acting in order to deal with novel problems posed by children with autism?

Overview of the Theoretical Framework

For the theoretical framework two theories are being utilized. The FAAR model (Patterson, 1989, 2002) and Ecocultural niche theory (Gallimore et al., 1989). The theoretical reasoning of the FAAR model came about through the study of the effects of economic depression on families (Patterson, 1988). The early investigators of this theory studied families who faced a variety of stressful experiences, such as “bereavement, alcoholism, and war” (Patterson, 1988, p. 207). The researchers were investigating the conditions that caused families to be adversely affected by stressful experiences (Patterson, 1988). The ABCX model was created from the work done in this early time. This model consisted of “A (stressor event) interacting with B (The families crisis – meeting resources) interacting with C (The definition the family makes of the event) produce X (the crisis)” (Patterson, 1988, p. 207-208). This theoretical framework regulated family stress studies for the following three decades.

The FAAR model came from a longitudinal study that examined families “of a husband/father who was missing in action or a prisoner of war in Vietnam” (Patterson, 1988, p. 208). What they found was that these families “appeared to have a pileup of family demands in addition to or as a result of the stressor of separation; employ various coping strategies in an effort to manage the demands; and modify their perceptions of their total situation in an effort to adjust and eventually adapt” (Patterson, 1988, p. 208). These studies resulted in an advanced ABCX Model of Family Behavior, with additional post crisis criteria in an effort to explain how

families can recover from crisis and achieve adaptation (Patterson, 1988). It was then integrated into a model called Family Adjustment and Adaptation Response (FAAR).

All families want to maintain balance. In the FAAR model, maintaining balance requires families to utilize their capabilities (resources and coping behaviors) to meet the demands of the family. The demands are the stressors and strains. For example, a stressor in a family of a child with autism might be an externalizing behavior, like the self stimulatory behavior of hand flapping. When a family is at home the demand is low because they are not out in public and the behavior does not look odd. However, when the family ventures out into a public place and the child exhibits this behavior, the demand goes up because potential judgment from other people increases the stress of the behavior. When the demands increase and the family does not have the capabilities or the coping behaviors to maintain balance, the family becomes unbalanced. In my example of the child with the hand flapping, if the family was out in public when this occurred and the parents did not have a coping strategy, this would be a real stressor for this family. If they employed a coping strategy, such as using a code word like “chill” to prompt the child to put his hands into his pockets when out in the public, this would decrease the demand and keep balance in place, thus maintaining family functioning.

There are two phases of the FAAR model: adjustment and adaptation. In the adjustment phase a family is relatively stable with only minor changes as the family is trying to meet the demands with their existing capabilities. However, a crisis or state of disequilibrium can occur in a family when the number of demands exceeds the

families capabilities thus forcing an imbalance (Patterson, 1988). The adaptation phase is where the restoration attempt by the family is made “by acquiring new resources and coping behaviors; reducing the demands they must deal with; and/or changing the way they view their situation”(Patterson, 1988, p. 209). In this adaptation phase families have the opportunity to develop new skills in order to meet the demands of the child.

Family demands are broken down into these characteristics: normative and nonnormative stressors; ongoing family strains; and daily hassles. Normative demands are those that any family will encounter. For example, getting a child back into the routine of going to school is a normative routine for any family as all families have to do this when the school year begins. A nonnormative demand is different in that it is a demand that does not affect every family. For example, not being able to eat in a restaurant that has ceiling fans because their child with autism throws tantrums whenever the child encounters the ceiling fan, so the family just eats at home. Ongoing family strains are those that cause tension on families, such as marital conflict or a prolonged illness of a child. Lastly, daily hassles were described as minor disruptions to daily life, like the car breaking down.

Family capabilities are: tangible and psychosocial resources, and coping behaviors. A tangible resource can be something that a family gets with money, or it can be intangible, such as self-esteem. A psychosocial resource is one that a family gains knowledge from, such as family therapy, or a community based resource like a support group. Coping behaviors are the behaviors that a family employs from their

own set of skills to assist with the demands of the daily life. An example of a coping behavior taken from my above example of the child hand flapping would be the use of a family code word like “chill”, which would get the child to put his hands into his pockets. This coping behavior could have been taught to the family by a behavioral therapist because it sounds advanced, or they could have naturally come up with it on their own. Coping behaviors are what the family does in response to their demands. The idea behind coping is to restore balance with demands and resources (Patterson, 1988).

Demands and capabilities can come from three levels of the environment: “(a) individual family members, (b) a family unit, and (c) from various community contexts” (Patterson, 2002, p. 350). For example, “the diagnosis of a child’s illness could be of an individual level, marital conflict about how to manage the child’s condition is an example of the family level demand, and community stigma about disability would be a community level demand” (Patterson, 2002, p. 350-351).

Another area of the FAAR model that is rather important is family meaning. “Family meaning is less apparent in individual resilience perspectives but may add understanding to how the resilience process unfolds” (Patterson, 2002, p. 351). There are “three levels of family meanings: (a) families’ definitions of their demands (primary appraisal) and capabilities (secondary appraisal); (b) their identity as a family (how they see themselves internally as a unit); and (c) their world view (how they see their family in relationship systems outside of their family)” (Patterson, 2002, p. 351). A family’s definition of demands is what they actually define their situation as. For

example a family's description of what it would be like to take their child with autism into a restaurant with the ceiling fans and having the family describe the details of the tantrum and how they felt, basically their appraisal of the situation. Then they use their capabilities to handle the situation. Their identity as a family involves how the family members interact with each other. World view is how the family sees themselves in relation to the world around them. In the FAAR model the family meanings are important because this will determine "the process of adapting to major, nonnormative stressors, such as the diagnosis of a child's chronic health condition, often involves changing prior beliefs and values as a way to make sense of the unexplainable and as a way to adapt" (Patterson, 2002, p. 351).

In balancing the daily demands there are two types of outcomes in the FAAR model. Families regularly attempt to maintain balance and stability, however, there are times when the demands exceed the capabilities and thus a crisis occurs (Patterson, 2002). This is known as the first type of outcome in the FAAR model (Patterson, 2002). A crisis can lead to disequilibrium in the family's functioning. For example, if a child with autism has severe self-injurious behavior that it forces the family to remain home out of fear that the child could hurt themselves, this would place the family in a state of continual crisis if they had no capabilities to get them back into a place of improved family functioning. The second outcome in the FAAR model is when the family restores balance by reducing the demands and increasing the capabilities and/or changing the meanings, this can also be viewed as an indicator of resilience (Patterson, 2002). Using the example above with the child with severe self-injurious behaviors, if

the family uses capabilities to obtain behavioral therapy, it helps to reduce the demands and the outcome of the family is improved which would lead this family to a positive adaptation.

Family strengths are characterized in the literature on resilience. Family adaptation is “defined as a process of restoring balance between capabilities and demands at two levels of transaction: (a) between family members and the family unit, and (b) between a family unit and the community” (Patterson, 2002, p. 352).

When the family is successful in this process, “bonadaptation is observed in the family’s (a) continued ability to promote the development of individual family members and (b) willingness to maintain their family unit so it can accomplish life cycle tasks” (Patterson, 2002, p. 352). This is important when thinking about resilience because the family serves as a pathway between the individual and the community. For example, “when one of the parents in a family takes a new job, and the family moves to a new city, adaptation following this crisis may involve: a parent taking on new job demands and making his or her capabilities fit the new workplace; children fitting into a new school with different expectations; fitting into the neighborhood in terms of property maintenance, socializing etc.; finding new resources in the community for meeting family needs, like medical care, food, clothing etc.; and possibly trying to find a fit for the family’s schema with the new environment’s social, political, and economical values and beliefs” (Patterson, 1988, p. 230).

According to Patterson (1988) the FAAR model is the appropriate family stress model for research because its “concepts bridge physiological, psychological, and social domains”(p.234). The FAAR model also includes the individual, the family, and the community.

Ecocultural niche theory is “derived from the psychocultural model developed by Whiting and Whiting and their colleagues” (Gallimore et al., 1989, p.217). The premise behind this theory is that ecological effects are moderated through the activities of daily routines (Gallimore et al., 1989). These activities provide opportunities for children to learn and develop skills within the context of the family. An example of this is teaching the child how to prepare a meal, which is a useful everyday skill that will be useful throughout the child’s life. These are opportunities where families engage in promoting cognitive and linguistic development (Gallimore et al., 1989). Another example might be reading a story before bedtime. According to activity settings there are five components: “who is present; their values and goals; what tasks are being performed; why are they being performed; and what scripts govern interactions, including those that shape and constrain the child’s participation” (Gallimore et al., 1989, p.217). The ecology and culture borne out of the components reflect who is present with the child and what they are doing (Gallimore et al., 1989).

A family’s econiche reflects material ecology as defined by, “public health conditions, housing and space, transportation, and distance from relatives or services” (Gallimore et al., 1989, p.217-218). The niche is also influenced by cultural traits that human beings employ to understand and organize their everyday lives (Gallimore et

al., 1989). The term “accommodation refers to the proactive social construction actions of the family to adapt, exploit, counterbalance, and react to many competing, and sometimes contradictory, forces: income needs, health and mortality threats, resource allocation choices, domestic workload, marital role attitudes and relationships, parental assessments of a child’s developmental future, emergent child development goals, and parental aspirations” (Gallimore et al., 1989, p.218). For example, a family of a child with autism may make an accommodation to a bedtime routine by playing a game before bed to ease the transition of going to bed. According to Gallimore et al. (1989) “ecocultural theory suggests that one of the predictors of child and family outcome will be sustainability of activity settings across times and multiple situations, rather than more conventional measures such as stimulation level or quality of home environments” (p.225). This means that if the family can maintain consistency with the routine in multiple settings across time then the child will sustain those accommodations. For example, using the previous bedtime routine example, if the parents were divorced and each parent did this routine with the child before bedtime in their respective home, the routine of going to bed would become sustainable according to this theory. Children with autism are routine-oriented and when that routine is changed, either by a move, a new sibling, and or a new spouse living under the same roof, life with the child with autism can become more difficult until the new routines become memorized to the point of mastery for the individual (Rigles, 2017).

II. Literature Review

The following chapter contains a literature review of issues surrounding blended families. Given the lack of research on blended families of children with autism, this chapter will instead report on nuclear families of children with autism. This chapter will also present the results of two pilot interview studies of blended families of typically developing children that expose the greater need for adequate research on blended families of children with autism.

Family Systems Theory

Family systems theory suggests that individuals within the family context cannot be viewed in isolation from one another. The theory is based on the interdependency of family members where each member reacts to the emotional response of the other. This emotional reciprocity strengthens the relationships between each of the family members and deepens their connection to one another (Kerr, 2000; Pace, Shafer, Jensen, & Larson, 2015). Tension can modify these units in either direction, and anxiety in one family member can induce similar emotions in others. This means that the emotional link between family members can become more stressful than comforting as anxiety increases, eventually causing one or more members to feel overpowered, lonely, or unmanageable (Kerr, 2000). For example, a problem with one family member can add stress onto those who tend to be the people pleasers since they feel responsible for decreasing the tension in others. According to

Kerr (2000), they “absorb” system anxiety and thus become the family member who is most susceptible to difficulties such as depression, alcoholism, affairs, or physical illness. System analysts might gain important insight from combining both the individual and family units in order to examine what parts are related among those relationships between the self and the family (Golish, 2003).

The interaction between the individual and the family system depicts the interdependence of the diverse subsystems within a stepfamily. For example, even though a parent might be ready to get married, a child may still be grieving from the divorce, and their feelings of contentment or discontentment with the new stepparent can reverberate throughout the stepfamily. Because family systems theory involves the cyclical interdependency of the family’s ability to function, it comes as no surprise that most of the relevant research on remarriage uses this approach. Blended families are the result of the restructuring and rebuilding of a family and thus their connectedness and reactivity on one another will be intensified.

Blended Families

As stated earlier in this document, there is much research on blended families of typically developing children, especially in the areas of stepfamily development, stepparent-stepchild relationships, and stepfamily cohesion (Cartwright, 2010; Ebersohn & Bouwer, 2015; Ganong & Coleman, 2017; Kumar, 2017; Svare, Jay, & Mason, 2004; Zelenznikow & Zelenznikow, 2015). A blended family is defined as “a family system in which a new couple partnership is formed, either through remarriage

or cohabitation, that includes children from previous relationships” (Kumar, 2017, p.110). Blended families face great challenges associated with creating a shared household of previously unrelated family members, developing new relationships, and dealing with external issues such as ex-spouses or extended step-family (Kumar, 2017). A blended family will have a different structure than that of a nuclear family in that a blended family incorporates children from past relationships, something which often presents unique responsibilities and challenges during the formation of a new family.

Blended families have few resources to gain help from, and societal influences have bestowed many negative stereotypes on stepparents, with step-mothers often being portrayed in the most negative light of all (Ganong & Coleman, 2017; Stratton, 2003). These negative stereotypes can place such individuals in challenging positions, since it can cause a lack of understanding of what their role entails and rob them of appropriate resources with which to clarify their position. There is also the fact that the legal system does not grant the stepparent any authority over stepchildren, which furthers the notion that the stepparents’ position is inferior to biological parents in the life of the child (Ganong & Coleman, 2017; Kumar, 2017). These issues can affect the way the family system operates.

Parenting styles that work for typically developing children, such as authoritative parenting, may not work well for children with disabilities (Carroll, 2013). Baumrind (1991) found that a combination of warmth, firm implementation of

rules, and reason correlated with greater independence and conscious behavior in preschool children (Carroll, 2013). It was found that parents of typically developing children use more authoritative parenting with an older age group of children, but with the parents of children with disabilities it was the opposite. Research showed that for parents of children with disabilities, authoritative parenting was stressful because there was a lot of repetition involved and little success in the end (Carroll, 2013). Another issue for these parents was the time allotted for authoritative parenting, which could cause parents of children with disabilities to use a less demanding parenting style as a “coping response to excessive demands as the child grows older”(Carroll, 2013, p.47).

Defining Roles

All of the individuals within the blended family system play important roles and have different challenges, and they all influence one another. Triadic relationships are defined as the relationships between any three individuals within the family, with examples being “the relationship between the husband, wife, and ex-spouse; among the husband, wife, and stepchild; among the child, nonresidential parent, and stepparent; and among the residential parent, biological child, and stepchild” (Kumar, 2017, p. 112). The unwillingness of biological parents to interact with each other without conflict makes things difficult for children (Kumar, 2017). Unresolved emotional ties or feelings of guilt may lead ex-spouses into areas of conflict as they repartner with new spouses, which can leave the stepparent struggling to find their place in the family unit. Another key is the dyadic relationship between the

stepparents and stepchild, the health of which influences the entire system (Kumar, 2017). Stepparents are often not welcomed as a parental influence by stepchildren, but family cohesion can take place when spouses collaborate to clearly establish parental roles and decrease conflict (Ebersohn & Bouwer, 2015; Kumar, 2017). Generally, stepfamilies have some difficulty in achieving homeostasis due to the reformation of the family and their need for organization, the establishment of new roles, the possibility of life changes (moving, changing in finances etc.), and rearranging of family roles, all of which can test their ability to produce a stable family environment (Pace et al., 2015).

Kumar (2017) proposed a set of guidelines that focus on the unique characteristics of blended family life. These proposed guidelines were the culmination of her graduate work in a review of the literature on blended families in the field of clinical psychology. In her proposed guidelines, Kumar (2017) highlighted blended families and societal expectations such as popular movies depicting negative stereotypes of stepmothers. Also highlighted in this article were the that negative stereotypes could place the individuals in these blended families in challenging positions as they attempt to figure out their role as a stepparent. Blended families were seen as undesirable and incomplete by society (Kumar, 2017). She highlighted the need for support for blended families and pointed out that there were few resources for them to use. Kumar's (2017) solution to these issues surrounding these families is to create a family life cycle for blended families that heightens awareness for their

distinct needs. Her proposed guidelines for families and counselors include the following areas:

“(a) separation, divorce, or death; (b) establishment of parenting agreements; (c) repartnering; (d) preblended family counseling to solidify the couple relationship; (e) defining expectations and roles for the new stepparent; (f) having the stepparent meet the ex-spouse, if appropriate; (g) having the children and stepparent meet; (h) making any necessary changes to parenting agreements to accommodate the new blended family system; (i) meeting with the children to define boundaries and roles; (j) cohabitation or marriage; and (k) preparation for the possible entrance of a new child” (Kumar, 2017, p.122).

Kumar’s (2017) guidelines might be important to families of children with disabilities as well, as they could be useful to them during the repartnering process.

Research suggests that women are often more likely to be the most concerned about the children than men when it comes to forming a union that includes coresidential stepchildren. This is because women generally spend more time taking responsibility for children in the household and may be more involved with coresidential stepchildren than men may be (Goldscheider & Sassler, 2006). Women are more interested in caring for children and less concerned with the biologic component, making selfless social parenthood more acceptable for their partner and easier to form a collaborative partnership (Goldscheider & Sassler, 2006).

Goldscheider & Sassler (2006) used data from the National Surveys of Families and Households (NSFH) to find those who were not living with their partner in 1987-1988. They then used this data to find and re-interview 954 men and 1,640 women from the original NSFH study. They examined the effects of children on partnership reformation. Their results showed that the rates of becoming a coresidential father dramatically increased when forming a union with a woman who had children. The opposite was found for women, thus women's coresidential children reduced her odds of forming unions with men who did not have children, but increased them for unions with men who did (Goldscheider & Sassler, 2006).

The role of stepmother is far different than that of stepfather and far more demanding, as it still involves a lot of stereotypic homemaking (Martin-Uzzi & Duval-Tsioles, 2013; Svare et al., 2004). Stepmothers' roles are frequently portrayed negatively in both media and society, painting a dismal and hopeless picture for blended families and their outcomes. Documented in the literature are the areas in which stepmothers have the most challenges: "ill-defined role expectations, spousal expectations, conflict with the biological mother, and feelings of not being backed up by the spouse"(Kumar, 2017, p. 114). In further research done on the subject, stepmothers reported feeling that their partner was unsupportive, which fed into ideas of irrelevance and the possibility that their partner was putting the children first, as well as feelings of regret and distress about wanting the spouse but not the children due to the added burden (Kumar, 2017).

The role of some stepfathers has been described as asserting their authority because they want to rescue an overwhelmed biological mother, and as transposing their cultural values of fatherhood onto the new family (Svare et al., 2004). However, for the most part stepfathers experience a positive perception of their role within the blended family. Even with the same lack of legal status many stepfathers reported feelings of acceptance and love from their stepchildren, and even held solid relationships with the biological father (Kumar, 2017). Though on the other hand, one frightening report showed that stepfathers were twice as likely as biological fathers to abuse a stepchild (Kumar, 2017). Regardless of some shared characteristics of being stepparents, a stepfather's experience is completely different than that of a stepmother.

The ex-spouse's role can lead to conflict with the biological parent. Parents who repartner tend to perceive their ex-spouse as envious of that new relationship and thus the child and the ex-spouse can have a tough time transitioning within this new blended family. The child often feels torn because they might like the new parent, which could make them pull away from their biological parent (the ex-spouse) and become a source of friction. The roles and how they are managed within the relationships of all the adults involved can impact the development and outcomes of their children.

Research shows that children of blended families are at a greater risk of disadvantage in comparison to those in traditional nuclear families (Ebersohn & Bouwer, 2015; Ganong & Coleman, 2017; Kumar, 2017). Whether because of the

death of a biological parent or due to a divorce, it is a type of loss that causes children to end up in blended families and unsurprisingly, they suffer from feelings of grief regardless of whether their circumstances are improved or not. Research suggests that parents should work toward clearly defined roles and boundaries within the stepfamily so that cohesion can take place, because without this the stepchildren are more likely to exhibit behavioral issues (Ebersohn & Bouwer, 2015; Ganong & Coleman, 2017; Kumar, 2017). For example, the stepparent's role needs to be clearly defined as to what he/she handles for the sake of the child. In order for cohesion within the stepfamily to occur, the roles and boundaries need to be defined so there is no ambiguity regarding the children (Ebersohn & Bouwer, 2015; Ganong & Coleman, 2017; Kumar, 2017). Children are also faced with having access to only one of their biological parents at a time once the blended family has been established, and the type of relationship that the child has with the biological parent significantly impacts the stepparent-stepchild relationship (Ebersohn & Bouwer, 2015; Kumar, 2017).

Disdain between biological parents and stepparents who are involved in the child's life can impede development and foster a negative impression of the blended family, hindering attempts for the blended family unit to bond (Kumar, 2017). Much of this division materializes around stepparents' beliefs of proper family roles and boundaries. For example, stepparents often do not view themselves as "real parents" but as a friend to the child instead. This uncertainty when it comes to the stepparent's family role can be worsened by the absence of clear familial norms in stepfamilies

(Cherlin, 1978) and standards presiding over how parental responsibilities will be managed by stepparents (Ganong & Coleman, 2017). However, well-formed blended families are those that support residential and nonresidential parents by being positive, which can help stepchildren in their relationships with their residential stepparent and other blended family members and replace loyalties to their nonresidential biological parent (Kumar, 2017). It has been documented that positive relationships with a stepparent can be beneficial to a child, extending opportunities to financial and emotional supports and acting as a protective factor for children who are faced with ongoing separation from their biological family (Ganong & Coleman, 2017).

Interestingly, research on preparation for stepfamily living has reported that most divorced adults who repartner do so quickly and without conscious planning for the transition to a new family configuration (Cartwright, 2010). “Men continue to remarry at a higher rate than women—the rate for men is twice that for women” (Ganong & Coleman, 2017, p. 63). This can put the children in a difficult place emotionally, as it often leaves them with little time to adjust to the new family. Ganong and Coleman (2017) proposed several reasons for the lack of purposeful planning among stepfamily couples. These involve the use of avoidant strategies to cope with possible potential uncertainties, with one finding showing that these couples avoid sensitive topics of discussion when compared to nuclear couples and are more likely to withdraw from a conversation should it become too difficult (Ganong & Coleman, 2017). Another explanation for the rush into these second marriages is

simply the notion of an underestimated need for planning and a “what is best for the adult is best for the child” mentality (Ganong & Coleman, 2017). According to Ganong & Coleman (2017) the lack of economic resources is a large contributing factor for this rush into repartnering.

Coparenting

A term that is used quite frequently in the literature on blended families is that of coparenting, which is defined as “an enterprise, one involving the coordination among adults responsible for care and upbringing of children” (McHale, et al., 2004, p.222). This involves far more than just carrying out the usual childcare responsibility. There are three core features of coparenting: consensus and support between the coparental partners, the act of getting along in the adults’ coparental relationship, and the extent to which both partners actively participate in the child’s life (McHale et al., 2004). In a study by Jamison, Coleman, Ganong, and Feistman (2014) 47 divorced mothers and fathers were interviewed in order to examine resilience in post-divorce coparenting. Results from their in-depth interviews revealed that successful transitioning between married and divorced coparenting required interpersonal and behavioral changes in at least one of the parents, meaning that the changes that one of the parents made to adjust their communication with their partner affected the transition (Jamison et al., 2014). The parents with the best results in this study showed that they spent most of their time focused on their children, regulating their emotional

responses, and choosing battles when it came to time and money (Jamison et al., 2014).

From this body of literature it is evident that researchers have begun to establish a baseline for understanding the characteristics of strong stepfamilies. Strong families have some of these characteristics: coparenting, defining roles, family cohesion, and are able to support each residential and nonresidential parents with clear communication. The next step in this line of research would be to build upon this solid foundation by applying these techniques to stepfamilies of children with autism.

Parenting Children on the Autism Spectrum

It has been well-documented that parenting a child with autism puts stress on the marital relationship (Baker, Blacher, Crnic, & Edelbrock, 2002; Davis & Carter 2008; Estes et al., 2013; Falk, Norris, & Quinn, 2014; Hayes & Watson, 2013; Keenan, Newman, Gray, & Rinehart, 2016; Sanders & Morgan, 1997; Schieve, Blumberg, Rice, Visser, & Boyle, 2006; Sikora et al., 2013). A common theme throughout the relevant literature is how behavioral problems contributed to the heightened stress levels of parents: the worse the behavior, the higher the level of stress (Schieve et al., 2006). Similarly there is difficulty in making time for family outings due to lack of available and qualified babysitters (Sanders & Morgan, 1997). This results in the families either remaining at home or, on the rare occasion when they are able to go out, using a family member to watch their children.

Most of the empirical research on coparenting has been on nuclear families, and researchers have only recently begun to examine blended family systems. These features of coparenting are just as relevant to blended families of children with autism, as such families have to maintain homeostasis for the sake of the individual with autism. Whether it be through the IEP goals, behavioral goals, speech, or occupational therapy, blended families of children with autism have many more challenges to face than regular blended families. Coparenting research would be greatly enhanced by including blended families of children with autism.

Another common thread is the overwhelming unknowns when it comes to the child's future (Sanders & Morgan, 1997). Parents of children with autism face a difficult challenge in planning for their child's adulthood, and it is one of the most stressful things these parents can endure. Even for parents of neurotypical children this is a stressful task that often requires putting money aside to plan for college, consulting financial advisors, assisting teenagers in filling out college applications, traveling to look at colleges, and so on. There is also the possibility of typically developing children not planning for college, in which case parents still have the stressful task of assisting their children with shaping their path to adulthood, and whether it will involve going to a trade school or a direct transition into the work market. This is even more difficult when planning for a child with autism, and depending on the skillset of the child the parents must attempt to determine where the child will be 10-15 years down the road while they make these plans. Meanwhile they

must also focus on the here and now with the therapies and education that affect the child and their development. With all this in mind, it comes as no surprise that planning for the future may cause more stress for these parents.

In a recent article Brobst, Clopton, and Hendrick (2009) used survey data to compare parents of children with autism to parents of typically developing children. They found that although couples with a child on the spectrum experienced lower levels of relationship satisfaction as compared with the parents in the control group, there was no difference between the groups when it came to perceived spousal support, respect for their partners, or commitment to their relationship. This study and other research (Falk et al., 2014; Freedman et al, 2012) demonstrates that couples who have children with extra/special needs will be worse off in some ways but about on-par in others. Studies like these are important because they show mixed research findings that could be examined from a resilience viewpoint in that many couples who have children with special needs are able to preserve their emotional, cognitive, and physical balance in the face of stress (Bayat, 2007; Brobst et al., 2009). Parents who face these stressful situations tend to make accommodations in their family lifestyle in response to their children's disorders, causing the needs of their family to change and making them resilient (Bayat, 2007; Brobst et al., 2009).

Parents' marital relationships are not under as much strain as one would expect while raising children with disabilities (Risdal & Singer, 2004), and as parents navigate the road of parenting it becomes clear that they must advocate for their child

(Bayat, 2007). According to Bayat (2007), after some parents are successful at advocating a few times, they develop a sense of pride about having a child with a disability. Some families of children with autism may be regarded as resilient families due to overcoming adversity and thus cultivating a more positive outlook. Resilience is evident in families that make efforts to spend time with each other, balance the needs of the family member with autism with the needs of the other family members, maintain healthy routines, hold shared values, find meaning in tough circumstances, have flexible responsibilities, use support services, openly communicate, and have proactive approaches to challenges (Cridland et al., 2014).

Cridland et al. (2014) aimed to provide a theoretical and methodological approach for the future of family-focused autism spectrum disorder research. In their article they highlight that many studies focus on the challenges for families living with autism and thus these details are important, but they are limited by basic research designs and often overlook the complexity of the family system (Cridland et al., 2014). This research pinpoints that a comprehensive view of families living with a child with autism is necessary in order to understand the coping and support mechanisms within. Cridland et al. (2014) stated that existing research has also shown “positive influences of autism on family functioning, including psychological strength, improved communication skills and higher levels of empathy and patience”(p. 214). This article pinpoints how mothers reported psychological benefits to having a child with autism, including “selflessness, compassion, peace during time of uncertainty and a refocus of energy” (Cridland et al., 2014, p. 214). This fits with research presented

from Bayat (2007) on resilience and the positive effects of having a child with disabilities. The family systems approach “considers families as unique interactive and reactive units, with their own basic social system of rules, values and goals” (Cridland et al., 2014, p. 215). Cridland et al. (2014) proposed using a family systems approach as a theoretical framework for future family-centered autism spectrum disorder research in considering the following concepts: “boundaries, ambiguous loss, resilience and traumatic growth” (p.215-217).

Two more important findings are worth mentioning from Brobst et al. (2009). First, they found an important link between support from one’s spouse and relationship satisfaction. When the mothers of children with autism were faced with more intense behavior problems in their children, they reported less support from their husbands and thus “parent support groups that emphasize sustaining a couples’ relationships during times of stress (rather than just focusing on their roles as parents) might be beneficial for families with children with autism” (Brobst et al., 2009, p. 47). Second, there is the important link between respect and relationship satisfaction that implies that helping couples communicate clearly about their appreciation and respect for each other might pay off in the long run for these parents (Brobst et al., 2009). It is clear from this literature that there is detailed help available for nuclear families of children with autism. For a blended family of a child with autism, this is not the case because to this date there is little empirical research that has been done to show that support exists for these families.

Parenting Stress and Autism

Becoming a parent is stressful in its own right, but when the complexities of raising a child with a disability are added to the usual parenting responsibilities it introduces extra stressors that the typical household just does not face. For example, in a study by Davis and Carter (2008) parents of children with autism were surveyed through questionnaires and it was found that high levels of stress were present in both parents when the children were quite young, and that this occurred in particular around the “time of diagnosis and the initiation of intervention of services” (p. 1288). Given the amount of change that occurs within the household environment post-diagnosis, this is not a surprising find. Due to the combination of intervention services, the initial shock of the diagnosis, and the impact of the “new” schedule that the intervention poses on the family, researchers Davis and Carter (2008) highlighted the need for clinicians to be mindful of the increased stress that these families experience in these early months.

Falk et al. (2014) used questionnaires to survey parents of children with autism on many variables related to predicting stress, anxiety, and depression. Their results suggest that the “relationship between ‘child-centric’ factors and parental mental health problems may be mediated by social/economic support and parental cognitions, with significant implications for support services for this parental group” (Falk et al., 2014, p. 3195). What they allude to here is that too often the clinicians are ‘child centered’ when they are working with the parents, as opposed to checking in on the

parents as well. That is, the parents in their study said they often felt like they did not exist when the clinician was there working with the family, which led to heightened parental stress. These are the sorts of issues that parents raising children with autism face, and which can place a heavy burden on the marital relationship.

There is an overabundance of research reporting that the marital relationship is negatively impacted by raising a child with autism (Freedman et al., 2012; Harper, Dyches, Harper, Roper, & South, 2013; Hartley et al., 2010; Johnson, Frenn, Feetham, & Simpson, 2011; Keenan, Newman, Gray, & Rinehart, 2016; May, Fletcher, Dempsey, & Newman, 2015; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013; Shieve et al., 2006). In a study by Sanders and Morgan (1997) in which family stress and adjustment was examined by comparing families with autism, Down syndrome, and developmentally disabled children, their results showed an overall increase in stress in families with autistic children when compared to the other disorders. This finding was supported by the families in their study, who reported that it took a great deal of time and energy to find babysitters or respite services that would permit them to participate in activities outside the home (Sanders & Morgan, 1997). This research provides insight into the increase in stress that families are facing day in and day out when raising a child with autism, which could easily put strain not only on the marriage, but also on each member of the family itself.

Parenting-related stress was found to be higher in mothers of toddlers with autism in a study by Estes et al. (2013), in which parents of children aged 18-30

months were surveyed and stress-assessed using a 78-item questionnaire and four-point Likert scale measurement. The main data point on their scale came from externalizing behaviors. Externalizing behaviors range from noncompliance and elopement to aggression and property destruction, and are known throughout the literature to cause heightened stress for parents (Carroll, 2013; Estes et al., 2013; Freedman et al., 2012; Johnson et al., 2011; Saini et al., 2015; Sikora et al., 2013). For example, in a study measuring stress in mothers by Estes et al. (2013), the children in question were quite young and showing outward signs such as kicking and verbal outbursts because they were new to treatment, so it was no surprise that this time frame was more stressful for the participating families. Children who struggle with clinically significant externalizing behaviors often require caregivers to be “on alert” to contain disruptive behavior (Sikora et al., 2013). These persistent feelings of attentiveness and the need to dedicate energy and time toward preventing intense behaviors may feed into additional stress that in turn impacts a family’s capacity to function at a healthy level.

Several studies reported on the financial struggles that these families face, whether it is due to therapies, lack of insurance coverage, or cost of services (Falk et al., 2014; Nealy, O’hare, Powers, & Swick, 2012; Saini et al., 2015). Monetary resources may affect access to all other services, and the level of support a child with autism receives comes at a financial cost to families. For example, parents expressed that they often have to resign from a career to give full-time childcare and manage the

child's therapy (Nealy et al., 2012). Based on the severity of the child's autism the costs involved in the therapies can be enormous, as they may not be covered by insurance. For example, the child may need some or all of the following: speech therapy, behavioral therapy, occupational therapy, and adapted therapies. Parents may have to travel for these therapies, which adds an additional burden on top of the cost of travel. These sorts of sacrifices most often affect mothers' careers, so that they can provide the in-home care while the father is left as the sole financial support for the family.

A dominant finding across the research is that mothers of children with autism are more likely to show increased signs of depression and have lower levels of psychological well being (Estes et al., 2013; Freedman et al., 2012; Hastings, 2002; Rodrigue, Morgan, & Geffken, 1990; Saini et al., 2015). A possible reason for this could be that for the most part the literature is 'mother rich'. That is, fathers are under reported. There are a lot of reasons for this. First, fathers are still the ones working out of the home, which leaves mothers as the primary caregiver. Second, because of their willingness to participate and their availability, mothers are easier for researchers to target for their studies (Estes et al., 2013; Freedman et al., 2012; Saini et al., 2015). Lastly, mothers face more depression than fathers because they are typically the primary caregivers and may come to perceive themselves as ineffective parents over time (Falk et al., 2014).

Another important area of research is the care involved for a child with a disability. Such research lends credibility to the notion that mothers of children with autism show consistently higher stress levels than mothers of typically developing children and children with other disorders, such as Down syndrome or developmental delay (Freedman et al., 2012; McStay et al., 2014). Mothers of children with Down syndrome find out about the diagnosis when their child is born, whereas mothers of children with autism obtain the diagnosis years later (McStay et al., 2014). The delay in diagnosis might make a mother assume that their child has nothing wrong with them, whereas with a diagnosis at birth the mother has the stress right from the start and is able to start coping with it early. These two mothers would have perceived stress differently because of the delay in the diagnosis. According to research by Rodrigue et al. (1990) mothers of both autistic and Down syndrome children described more caretaker burden, restrictions on family travel, more last-minute changes in plans, and a greater emphasis on short-term plans versus future-oriented goals. However, the mothers of Down syndrome children are not facing the same scenario when their children are young because Down syndrome children do not have the social deficits that are associated with autism. The lack of social reciprocity in children with autism is difficult for their mothers and can cause stress because the mother of the child with autism is not receiving the small social emotional cues that young children give. Mothers of Down syndrome children are receiving these social emotional cues. For example, a mother of a child with Down syndrome may struggle with a morning

routine of feeding, bathing, and dressing their child, but their child is smiling back at them and hugging them. This emotional reciprocation brings the stress level down. This finding suggests several things. First, it pinpoints how difficult it can be to find a reliable person to care for their child, which then leaves these mothers as the sole caregiver. Second, the daily living skills that the young child with autism requires are quite elaborate (e.g. help with grooming, eating rigidity, potty training, etc.) which points to the difficult demands that mothers face in parenting a child with disabilities (Davis & Carter, 2008; Estes et al., 2013; Rodrigue et al., 1990). Lastly, it does not appear that these parents have enough support, if any, in their everyday lives.

Higher levels of stress were found in the limited research on fathers, and they often reported that they were coping with the demands of parenting a child with autism by becoming less involved and distancing themselves from their families (Freedman et al. 2012; Schindler & Coley, 2012). Fathers of children with autism also reported that their families spend less time doing recreational and cultural/intellectual activities compared to fathers of typically developing children (Sanders & Morgan, 1997). In a survey that questioned both mothers and fathers by Baker et al. (2002), it was found that both mothers and fathers seemed to be viewing their child's behavior the same way and reported similar views on levels of stress. This study is also important because it examines families with children who have dual diagnosis, which produces higher levels of stress due to the unique challenges that come with the extra diagnosis and its corresponding behaviors. It would seem that these fathers lack the

support necessary to assist them in functioning beyond the behaviors that their children are having which hold them back from these activities.

Sibling relationships are another area in family functioning worth mentioning. Zetlin (1986) studied 35 mildly Intellectually Disabled (ID) adults who received services from public agencies over an 18-month period. She observed the relationship between the individual with ID and their sibling over the 18-month period and determined that there were five sorts of sibling relationships identified which were based on a ranking system that was independent among the siblings. The ranking system had three major dimensions: (1) warmth, (2) frequency of contact, and (3) degree of involvement. Zetlin (1986) found that it was rare for the ID individuals to be out of touch with their adult siblings, and that “sisters played a greater role than did brothers in providing support to their retarded siblings, and younger siblings were more likely than older siblings were to act as caretakers” (p.224).

Family systems models view families as complex units that include multiple dyadic relationships. Consistent with family systems theory, it is claimed that children’s behaviors and functioning greatly affect their parents’ behaviors and functioning. Children with problem behaviors or other heightened caregiving needs, for example, may discourage heartfelt and involved parenting and increase parents’ stress and tension, leading to both inadequate parenting behaviors and to a higher likelihood of marital dissolution among parents (Schindler & Coley, 2012).

Optimism

Adequate levels of support increases a family's optimism and is correlated with positive affect and life satisfaction, along with lowered levels of depression and parenting stress (Carroll, 2013). Some families have enough support within and outside their family to manage their children's disorders, which greatly contributes to them maintaining their mental health. The amount of support a family has indicates the level of optimism that the family may have. However, "optimism may be a coping strategy for a parent surrounded by challenges for the foreseeable future" (Carroll, 2013, p. 36). Parenting a child with autism requires a parent to rely on specialized knowledge to use a special set of skills, thus an optimistic outlook may move a stressed family to a resilient status with a change in their perception (Carroll, 2013).

The research shows that the more challenging the behavior exhibited by the child with autism the higher the stress on the family (Gabovitch & Curtin, 2009), with the optimism of the mother appearing to have the strongest mediating effect on the family as a whole. Greenberg, Seltzer, Krauss, Chou, and Hong (2004) interviewed mothers to compare the mediating role of dispositional optimism on maternal well-being between families of children with Down-syndrome, schizophrenia, and autism and found that optimism had the highest mediating effect on the quality of parent-child relationship and psychological well-being for these mothers of children with autism. They chose to investigate these three disorders as all three require coping at different stages of life; early adulthood for a child diagnosed with Down-syndrome or autism,

and midlife for parents of a child diagnosed with schizophrenia. Their hypothesis was that because the mothers in their study were continually blamed in research as “bad parents” to explain their child’s autism, they were not given any hope for future improvement. Faced with an unsympathetic professional climate, these mothers contradicted the blame with their actual positive relationships, which may have given them feelings of optimism (Greenberg et al., 2004).

Coparenting a Child with Autism

One of the most important types of relationship that a divorced couple must maintain is that of coparent to a child with autism. Due to the overwhelming needs of the child with autism, parents are faced with coparenting demands that parents of typically developing children do not have. For example, maintaining the same routine schedule between homes is extremely important for a child with autism, so much so that if something gets missed a meltdown may ensue and cause the parent in that given situation a tremendous amount of stress (May, St George, Fletcher, Dempsey, & Newman, 2017). One example from May et al. (2017) is when some parents provided explicit descriptions of how the demands of parenting a child with autism created pressure to change the way that they worked with their parenting partner, like learning to be more flexible. Coparenting competence was defined as “a parent’s sense of a collective parenting efficacy generated from their coparenting partnership and only existing in association with that relationship” (May et al., 2017, p. 2974). Therefore, the coparenting partnership represents a distinguishable entity within the family

system and this becomes a relationship separate from the one that the child shares with either of the parents individually. This relationship that children have with the parenting partnership directly impacts their social and emotional development (May et al., 2017). For example, in their study May et al. (2017) provided many examples of the shared parental journey, where parents described experiences of compromise and camaraderie that brought them closer to each other.

By sharing the details of their parenting journey these parents gained solidarity and developed a sense of coparenting competence, becoming a better couple in the end. Children with autism are more likely to develop externalized behavior problems than typically developing children. Impaired social development and a restricted ability to partake in reciprocal play can also make coparenting more challenging for parents (May et al., 2017). Coparenting quality has been linked to a collection of developmental concerns that are common in children with autism (May et al., 2017), and how parents cope with the experience of parenting a child with autism could be directly influenced by the quality of their coparenting relationship.

Interview Based Research on Coparenting

In a qualitative study by May et al. (2017) where they interviewed parents of children with autism, three areas of coparenting were explored and a total of eleven couples who were biological, cohabitating mothers and fathers were interviewed for their study. One thing that makes this study remarkable is that they were able to get fathers to participate by offering telephone interviews. For their pilot sample they

conducted three interviews, which then required only minor alterations to their interview protocol. The three areas of coparenting that were viewed were: “adapting to the emergence of autism in the child, the functioning of coparenting relationships, and parents’ expectations of the influence that their parenting relationship would have on their child’s developmental outcomes” (May et al., 2017, p. 2977). The results of this qualitative study showed that the parents placed great value on the importance of their coparenting relationship and that this value made their parenting partnership work; a sense of coparenting competence was found across communication, support, and conflict; and lastly parents reported expectations that their coparenting competence would have a positive effect on their children’s developmental outcomes (May et al., 2017). This study is important because it used the foundation of Bandura’s (1977) theoretical analysis of human motivation, wherein he proposed that perceptions of efficacy are the drivers for human behavior. Efficacy is important to discuss when thinking about coping mechanisms. The questions that they designed for their interviews targeted information regarding the three domains of coparenting a child with autism, and were worded to encourage the parents to provide answers. For example, when examining coparenting quality, the questions asked were about parenting conflict and partner strength (May et al., 2017). The results of this study showed a sense of coparenting competence in both mothers and fathers of children with autism across all three domains of coparenting experience: “adapting to the emergence of autism in the child, the functioning of the coparenting relationships, and

parents' expectations of the influence that their parenting relationship would have on their child's developmental outcomes" (May et al., 2017, p. 2977). This study, therefore, served as a significant stepping stone as it linked the collective sense of efficacy that parents feel in their parenting partnership, their ability to cope with adversity, and potential parenting outcomes. The next phase of this research would be to take this study and replicate it with a blended family of a child with autism to see if the domains are the same. What would the differences between coparenting in a nuclear family of a child with autism versus coparenting in a blended family of a child with autism? Are the coparenting competencies the same?

A qualitative study by Hock, Timm, and Ramisch (2012) interviewed nine couples with children with autism to explore how parenting impacts marriage. Their results used modified grounded theory and showed that parenting a child with autism challenges these couples' relationships by placing inordinate amounts of pressure on partners that forces them to modify their relationship (Hock et al., 2012). The two main relationship phases that emerged from this study were tag team and deeper intimacy and commitment (Hock et al., 2012). The term tag team was defined as a way in which partners had to reorganize their professional and family roles, coordinate their parenting efforts, and attempt to maintain unity as a parenting team (Hock et al., 2012, p.411). Deeper intimacy was defined as when the "couples work harder to find time alone and they also used altered communication to extend greater emotional support and understanding to each other during these times of stress" (Hock et al.,

2012, p. 411). Commitment was defined as when “couples who expressed confidence in the resilience of their marital relationship” (Hock et al., 2012, p. 412). I found a few very important factors from this research. First, in the deeper intimacy and commitment phase, one parent stated, “you have to put your marriage first because if you don’t have marriage, you certainly can’t help the kids the same way” (Hock et al., 2012, p.411). This struck me because it showed an overwhelming dedication to the marriage. The ability to put the marriage first is one way to show resilience in the relationship. Resilience in these families is extremely important because it helps them cope with future extenuating circumstances.

Service Needs Across the Lifespan: Transition to Adulthood

Having a child with autism requires behavioral interventions as well as in-home and early-start programs within the school system, and thus the beginning of service needs for the child are a necessary component in the well-being of the child. These services include but are not limited to: speech therapy, occupational therapy, applied behavioral analysis, adapted physical education, and special education involving an Individualized Education Plan or a 504 plan. Specific treatments may include behavioral parent training, alternative communication systems for some children, social skills training, and individualized instruction on academic and functional living skills. Some of these services (i.e. social skills training, functional living skills, and speech therapy) and treatments are needed lifelong, but as the individual with autism ages out of the school system public provision of most of these

services ends, which leaves these individuals without help at a stage of their life when they possibly need it most (Taylor & Mailick, 2014; Turcotte, Matthew, Shea, Brusilovskiy, & Nonnemacher, 2016). Families of children with autism are faced with extreme challenges as their children age out of school and enter into adulthood because they have fewer resources to draw from. There is also very limited research examining what needs are necessary for these individuals as they age (Howlin, Goode, Hutton, & Rutter, 2004). One of the biggest issues facing the adult population of individuals with autism is the need for a social skills program with a focus on communication that would assist in helping them obtain and maintain employment (Turcotte et al., 2016). The social skills program is key because the workplace environment tends to be very social, and for many individuals with autism this is one of the main reasons that impedes employment. As these challenges grow, so do the stress levels of these families as resources dwindle.

Another area of concern for these families is that of respite services, as these too need to change. The overwhelming needs that some of these children have can drain families, and therefore it is important for families to have access to adequate respite services. In much of the research it was revealed that these families for the most part used extended family, friends, and parishes for respite (Gabovitch & Curtin, 2009; Howlin et al., 2004; Ooi et al., 2016; Turcotte et al., 2016). As children with autism age their respite hours often decrease, leaving families with less support and thus less time away to recharge their emotional energy. It remains evident that these

families are under tremendous stress and as the child ages into adulthood this fact remains the same. Therefore respite service hours should increase rather than decrease. Due to the fact that most adults with autism end up residing at home with their parents, autism is a lifelong parental journey that parents must learn to endure, and in order for them to cope and maintain resilient lifestyles, respite support should be an active component of their lives (Gabovitch & Curtin, 2009).

As the behavioral needs of the child with autism increase so do the stress levels within these families (Scorgie & Wilgosh, 2009). In order to increase quality of life for families of children with autism, access to support cannot end as these children age out of the education system. Instead, these children deserve to have continued education in order to learn the necessary skills for them to gain and maintain employment. Their parents need respite services in order for them to be able to maintain some semblance of balance. All of these suggestions would assist in increasing quality of life for families of children with autism. All the while there is a large gap in the literature when it comes to blended families of children with autism. Among the most potentially useful additions to blended family research is a qualitative study in which blended families of children with autism are queried in order to confirm whether their needs remain the same, are different, or are greater.

There is a great need for research on blended families of children on the spectrum because said research does not exist yet. A lot of the reviewed research had to draw upon blended families of typically developing children in order to come to

general conclusions and apply that to nuclear families of children with autism literature. However, I did find two relevant studies (Hock et al., 2012; May et al., 2017) that were quite distinctive due to the fact that they were qualitative in nature and that they were the sort of research that is needed. However, the next step is to apply what was found within these two studies and fold it into the current proposed model for blended families of children with autism. The aim of the proposed study is to understand what the needs for these families are.

Chapter Summary

This chapter began with the review of family systems theory, then moved into the blended family unit and the challenges that go along with it. The family is a cyclical unit where all parts affect each other. I wrote about defining roles in these new relationships and coparenting. Defining roles within the context of blended families is a complex concept that requires. Throughout this chapter we highlighted the difference between nuclear families and blended families.

The next section moved on to parenting on the autism spectrum and how these parents navigate their parenting road. Parenting a child with autism is quite different than parenting a typically developing child. It has some unique characteristics and comes with a lot of added stress for parents. Something specific mentioned in this chapter is coparenting a child with autism and the demands that it places on these parents. Coparenting involves communication between the biological parents and also the maintenance of a working relationship.

Next was reported a few interview based qualitative studies on parents of children with autism on the area of coparenting. In the May et al. (2017) study they reported findings with father participation, which was something that is hardly found in research and again what was seen was the importance of the coparenting relationship. In the Hock et al. (2012) study they investigated the team approach to marriage when one has a child with autism. This study was important because it highlights the resilience these parents display when they are faced with the challenges of autism.

The last topic that was reviewed in the literature was service needs across the lifespan/transition to adulthood for individuals with autism. In this section I pinpoint the challenges families face as their children age out of the system.

III. Research Design and Methodology

The following chapter is organized into five sections and details the research methodology used to conduct this study. The first four sections describe the organization of the study, the participants, procedures used for data collection, and analysis. The final section provides an account of the techniques used to preserve the trustworthiness of the findings.

Overview

This qualitative research was a groundbreaking study, as it was the first to include blended families of children with autism. Qualitative methods were the most appropriate because it involved interviewing families, which allowed enough time for each family's story to unfold in detail. This study interviewed 15 individuals in ten remarried families of a child with autism. Each interview began with one of the parents sharing their family story. From there the open-ended questions targeted multiple domains of family experience, including the spousal relationship, sibling relationships, relationships with the education system, ways in which families find support, and the child with autism's future. To see a complete list of the interview questions, please see Appendices A and B. During each interview, the spouses were interviewed separately from each other and at a different time, so that each would have a chance to tell their side of the story.

The FAAR model was used to examine stress and how these families adapted to the demands of their children with autism (Patterson, 2002). The strength of the FAAR model (2002) allows the researcher to watch as the "families engage in active

processes to balance family demands with capabilities as these interact with family meanings to arrive at a level of family adjustment or adaptation” (p.350). These interactions occur daily and can influence whether the family is balanced or imbalanced.

The second research question utilized the Gallimore et al. (1989) ecocultural niche theory, which was used to examine if families made sustainable accommodations. Every family has their own ecology of how the activities within the family work. In families where there is a child with autism, the natural ecology of the family is going to take on a different shape because the demands are laid out differently. One of the strengths of using the ecocultural niche theory is the ability to view the “interconnectedness of proximal family and child care features with distal events” (Gallimore et al., 1989, p. 217). When interviewing a family and inquiring about activities within the family, a researcher gains a view of the family’s niche and thus how the family operates. Activity settings help to show how families operate on a daily basis because they provide the researcher with a script for how the child can fit into the family as a whole.

This study added to the two interview studies that were mentioned previously in the literature review, May et al. (2017) and Hock et al. (2012), in that it focused exclusively on blended families of children with autism rather than excluding them. We know from research on remarriage with typically developing children (Hetherington, Bridges, & Insabella, 1998; Hetherington & Stanley-Hagan, 1999; Svare et al., 2004) that when a child is living with only one parent post-divorce there

is a tremendous adjustment period required for that child, and the addition of a potential stepparent in the child's life then kicks off a new adjustment period that the child must endure. What was not known, because it was missing in the research, was how these struggles affected blended families of children with autism. These families are more fragile in many ways and with the increase in the rate of autism diagnosis each year there is a great need for this type of interview study.

Various data collection techniques were used, including qualitative interviewing and field notes. Interviewing the biological parents and stepparents allowed these families to share key features of their lives.

Modified grounded theory strategies were used to identify themes in the data. Data was collected through semi-structured, in-depth interviews by the one researcher. All ten families were interviewed over the telephone and were digitally recorded. Grounded theory is appropriate for analyzing data from qualitative interviews.

Participants

Participants were recruited through a selective strategy. Purposeful sampling is unique to qualitative research. It focuses on in-depth research, which for this study is very important due to the nature of these interviews. I emailed the flyer to every Autism support group in the state of California. I listed the link to the survey on the following websites: AutismSpeaks, Craigslist San Luis Obispo, Craigslist Santa Barbara, and Reddit. Flyers for the study were placed in several local doctor's offices in and around Santa Barbara County. I relied on the families' report of their child's diagnosis of autism. Inclusion criteria for this study were that parents had to have a

child autism and be remarried. They must be able to speak English and be above the age of 18. Exclusion criteria for this study included single parents of children with autism, nuclear (unblended) families of a child with autism, foster parents of a child with autism, nuclear families with adopted children with autism. The first step for selection was participation in the online survey and for the parent to select the option saying that they wished to be interviewed, and the parent must have been remarried and have a child on the autism spectrum.

Table 2

Demographics of Participating Families

Demographics Information for Participating Families										
Pseudonym	Gender	Age	Marital Status	Ethnicity	Education	Annual Family Income	No. of Children	Age of Target Child	Gender of Target Child	Diagnosis of Target Child
Fam001 Stepmother	F	35-44	M	Latino	Post-Graduate	Above 100,000	2	10	F	Autism Mod-Severe
Fam002 Stepfather	M	45-54	S	White	Trade/Technical/Voc. Training	80,000-100,000	7	27	M	Autism Mild-Moderate
Fam003 Biological Mother	F	45-54	M	White	Post-Graduate	Above 100,000	5	12	M	Autism Mild-Moderate
Fam004 Biological Mother	F	55-64	M	White	Bachelor's Degree	60,000-80,000	4	33	M	Autism Moderate-Severe & Epilepsy
Fam004 Stepfather	M	55-64	M	White	High School Graduate	60,000-80,000	4		M	Autism Moderate-Severe & Epilepsy
Fam005 Grand-mother	F	65+	D	White	College Degree	20,000-40,000	3	15	F	Autism Mild-Moderate & Epilepsy
Fam006 Biological Mother	F	35-44	M	White	Post-Graduate	20,000-40,000	3	14	M	Autism Mild-Moderate
Fam006 Stepfather	M	45-54	M	White	Trade/Technical/Voc. Training	20,000-40,000	3		M	Autism Mild-Moderate
Fam007 Biological Mother	F	25-34	M	White	Some College	Above 100,000	1	11	F	Deaf & Autism Mild-Moderate

Fam007 Stepfather	M	25-34	M	White	Some College	Above 100,000	1		F	Deaf & Autism Mild-Moderate
Fam008 Biological Mother/ Stepmother	F	45-54	M	White	Post-Graduate	60,000-80,000	5	25, 22	M, M	Bio: Autism Moderate-Severe Step: Autism Mild-Moderate
Fam008 Stepfather / Biological Father/ Autistic Himself	M	45-54	M	White	Trade/Technical/Voc. Training	60,000-80,000	5	25, 22	M, M	Bio: Autism Mild-Moderate Step: Autism Moderate-Severe
Fam009 Biological Father	M	45-54	M	White	Post-Graduate	Above 100,000	1	21	F	Autism Mild-Moderate
Fam009 Stepmother	F	25-34	M	White	Post-Graduate	Above 100,000	1		F	Autism Mild-Moderate
Fam010 Stepfather	M	45-54	M	Native American	Some College	40,000-60,000	3	15	M	Autism Mild-Moderate

M-married D-divorced S-separated

Members from ten separate families participated in this study. None of the participants were interviewed at the same time. The most common age range of the participants (n=7) was 45-54, with five younger participants and three older. The average age of their children with autism was 18.6 years, with the age range being 10-33 years. For a detailed list of the participants please see Table 2. In four out of the ten families interviewed, the children in the family were stepchildren only; these were in

Fam 001, Fam 002, Fam 005, and Fam 010. Fam 005 was actually the biological grandmother who had adopted the granddaughter. Fam 005 qualified for the study because although she was the paternal grandmother to the child with autism, she had remarried and at the time of the interview she and her spouse had recently divorced. All the other children had a stepparent and a biological parent in their home. Seven of the ten families reported having incomes above \$80,000, with the remaining three families reporting annual earnings of around \$40,000. All participants had at least some college or trade school education, with six participants reporting some post graduate work. Thirteen of the participants identified themselves as white, one as Latino, and one as American Indian. These participants came from across the United States and Australia. Table 2 represents demographic information for each participant. For a list of all demographic questions please see Appendix C. Pseudonyms have been used to protect the identity of participants.

Procedures

Modified grounded theory was used to guide data collection and analysis. Data were collected through semi-structured, in depth interviews by me. Each interview began the same. I contacted the participant prior to the interview, either by text, email or phone call and asked them to provide me with any questions they had about the interview before we were to schedule the interview. Every interview was different in that each family interviewed differently, taking their time to answer each question. Each person was interviewed separately. All interviews were done over the telephone

and recorded digitally, with the exception of one. Fam 001 requested that the interview not be recorded.

1. Field Notes

Field notes were taken during each interview. The use of field notes helped me because I wrote down the child's information on the top of the page and the family code, so I had that information close by when I needed it. The information that was recorded was used during the phase when I made the demographic chart.

2. Interviews

A semi-structured interview guide was developed to provide a general structure for the researcher, ensuring that subtopic areas were adequately addressed (see Appendices A and B). All procedures were reviewed and approved by the university institutional review board. Demographic data on the participants were collected through the use of Qualtrics, a secure online survey software tool used to collect responses to surveys. Informed consent was obtained by clicking the *I accept and wish to participate* option. Once consent was provided, skip logic was used to send the participant ahead to the beginning of the survey. The participant was able to skip any question by selecting 'decline to answer', and once the participant reached the last question of the survey they were asked if they wished to be interviewed. If they selected 'no' then no further action was taken, but when 'yes' was selected, they were then directed to one more question, which allowed them the option of leaving their contact information and also provided them with my own contact information. Participants were then contacted to schedule their individual interviews. Because the

conversations were on the telephone and not face to face, I explained in great detail upon initial contact that should the participant wish to end our interview at any time or decline to answer any question they may do so. An interview guide was used to conduct the interviews, which were recorded and transcribed for analysis. Each interview began with one of the parents sharing their family story. From there the open-ended questions targeted multiple domains of family experience, including the spousal relationship, sibling relationships, relationships with the education system, ways in which families find support, and the child with autism's future. After using a broad topical question, I used probes to further elicit participants' perceptions and experiences. Interviews lasted between 1 hour to 90 minutes. All procedures were reviewed and approved by the university institutional review board.

For example:

- When in your evolving relationship did you meet the children?
- (c.) What were your concerns about _____ when you were first getting to know him/her?
- In thinking about _____ 's future what plans have you, your spouse, and the other biological parent discussed?
- How will _____ 's future impact the family?

Data Analysis

The analytic process involved repeated coding, sorting, and comparisons between codes that characterizes the grounded theory approach (Charmaz, 2006). It helped with the large amount of data I obtained through the interviews and created an

index to the transcript. The first step of the analytic process involved coding, which required close attention to the data so that I could move from description toward categorizing that description. It also assisted me in studying the interview data, discerning the sequences, illuminating the implicit meanings and actions and lastly, making the necessary comparisons between the data.

Charmaz and Belgrave (2012) bring forth important questions to keep in mind while coding: “(a) What, if anything, does the concept illuminate about these data? (b) How, if at all, does the concept specifically apply here? (c) Where does the concept take the analysis?” (p.355). These questions were important for this coding process because it helped me maintain the boundary from which to code. “Grounded theory coding is a two-step coding process: (1) initial or open coding forces the researcher to make beginning analytic decisions about the data and (2) selective or focused coding uses the most frequent and/ or significant initial codes to sort, synthesize, and conceptualize large amounts of data” (Charmaz & Belgrave, 2012, p.356).

Level One Coding

A code by meaning unit was used for level one coding. This was done by taking a string of words and coding it into an idea unit. This was done using track changes, where I would select a unit, and code it.

Level Two Coding

Level two coding involved taking the level one codes and creating intermediate codes by collapsing them into a smaller number. The way I did this was by clustering the level one codes around similar overlapping meanings in order to produce a code

book with definitions. This code book provided a paper trail for this large amount of data.

Level Three Coding

Level three coding is known as thematic coding (Charmaz, 2006). It is an inductive process that allows meaning to emerge from the study of those mid-level codes. The study of those mid-level codes went back to the transcripts to try to clarify what the meanings were behind them. During this inductive process for thematic coding, I took the intermediate codes and put them into groups, and then a theme emerged. This process was repeated many times until different combinations of themes emerged. I then took the intermediate codes and wrote them on index cards. The cards were then grouped into stacks, and once grouped they were each given names. I documented the name given to the group, along with the stacked codes in that grouping. Next I took a look at the data from every possible view point, assembling and disassembling different combinations of the big codes to find the combinations that ended up fitting my understanding of my data. This process highlighted the dominant themes by helping me generate a listing of code combinations. I then went through these combinations of codes and combined them by collapsing them into smaller codes based on similarity and commonalities between them, thus the list of dominant themes occurred.

This analysis yielded seven dominant themes: developing parenting roles; adjustment to problem behavior; development of family routines; families in crisis; worries about the future; services and community resources; and resilience in

parenting. There was one sub theme under the category of adjustment to problem behavior, which was communication.

Deductive Coding

For the deductive coding, the two theories used were the FAAR model and ecocultural niche theory (Patterson, 1989, 2002; Gallimore et al., 1989). Once the third level of coding was completed I took these theories and applied them to the dominant themes. First I will begin with the FAAR model and from there I will move into the ecocultural niche theory.

Patterson's (1989, 2002) model of adjustment and adaptation response worked well with data in that it utilized the notion of normative and nonnormative demands. I applied these codes to my data to find that across all of the themes both codes of normative and nonnormative demands were found. A normative demand is one that every remarried couple would have, like determining parenting roles and a nonnormative demand would be dealing with aggressive behavior in the child. Once these demands were determined I had to find if families were able to utilize coping strategies and or use resources or a combination of both as capabilities to adjust to the child's demands. Once this was applied to the data it was determined if the family was in states of crisis. In a state of crisis, a family would then be determined to see if they were at the turning point for either leading to a major change toward discontinuity in family functioning or improved family functioning. If a family were deemed toward poorer functioning then they were leading toward poor adaptation thus they became vulnerable. If a family were deemed positively adapting by way of reducing demands,

increasing capabilities and changing meanings this was an indicator of resilience (Patterson, 1989, 2002).

Gallimore et al.'s (1989) ecocultural niche theory is comprised of five domains: (1) who is present; (2) what are their values and goals; (3) what tasks are being performed; (4) why are they being performed (the motives and feelings surrounding action); and (5) "what are the scripts that govern the interactions, including those that shape and constrain the child's participation"(p.217). Gallimore et al. (1989) claimed that accommodations are, "the proactive, social construction actions of the family to adapt, exploit, counterbalance, and react to many competing, and sometimes contradictory, forces: income needs, health and morality threats, resource allocation choices, domestic workload, marital role attitudes and relationships, parental assessments of a child's developmental future, emergent child development goals, and parental aspirations" (p.218).

When I looked at the establishment of family routines in this data, ecocultural niche theory became particularly helpful. These domains reflect who is present during the activity setting and this was particularly helpful for the following themes in my data: adjustment to problem behavior, development of family routines, and families in crisis. With regard to adjustment to problem behavior, it is important to determine who is taking part because one or more people involved may be responsible for triggering the problem behavior. Second, the goals that the person had with regards to the activity and the development of family routines became particularly important when a family changed a mealtime routine. Third, when it came to what tasks were being

performed in families in crisis, one family could not travel in only one car because it was too dangerous, so this demand deeply changed the family's niche as it altered the parents' travel routine. Fourth, why are they being performed, for one family teaching the child with autism to knock before entering the parents' bedroom was an interesting lesson and necessary since before this the child would just barge into the room unannounced. The son needed to be taught how to respect the privacy of other family members. Lastly for what scripts govern interactions, one family had a child that was abusing the mother, and in response the stepfather told the stepchild that he would not put up with this behavior whatsoever. This script helped place a boundary on that behavior for the child with autism, thus completely changing the direction of the mothers' niche with her son. These accommodations made by the families in this study were unable to be followed up on, so there was no way to find out if such changes to their niches were sustainable or not.

Trustworthiness

Qualitative researchers have a number of strategies with the goal of demonstrating precise qualitative analysis. "A good qualitative study can help us understand a situation that would otherwise be enigmatic or confusing" (Golafshani, 2003, p.601). Trustworthiness in this qualitative research is based on the following criteria: the ability for the research result to accurately describe the experience studied (i.e. credibility), the ability of the study to be consistent and reliable (i.e. dependability), that the ability for the research to be replicated by another and the process of collecting data and coming to conclusions is clear (i.e. confirmability), and

the probability that the results have significance in other comparable conditions (i.e. transferability) (Golafshani, 2003; Midgley, Danaher, & Baguley, 2013; Shenton, 2004). Strategies to develop trustworthiness in the study included a description of researcher reflexivity and researcher background.

Credibility

Two family members were interviewed in five of ten families. This allowed for trust to develop between the interviewer and the interviewee as it insured honesty by the informants. It also allowed for interactive questioning which the researcher gained a more truthful answer from the participants. The use of probes helped the researcher to “elicit detailed data and iterative questioning, in which the researcher returns to matters previously raised by an informant and extracts related data through rephrased questions” (Shenton, 2004, p.67). For example, when my participants asked questions I rephrased them and added that to my data.

Transferability

Purposeful sampling was used to find participants. Those who participated in this study were located in the United States of America, with one family being from Australia. These participants gave detailed quotes to provide an in-depth description.

Dependability

A digital recording device was used in 14 of the interviews. One participant did not wish to be recorded. The use of the recording device provided reliability in the transcription of the word for word content of each of the 14 interviews.

Confirmability/Researcher Reflexivity

Researcher reflexivity is the ability of the researcher to make aware any biases, self-disclose assumptions, beliefs and values (Shenton, 2004). This necessitates the researcher to prepare and reflect on the social, cultural, and historical perspective and to be aware that they may be taking shape in the interpretation of the data. Each participant in this study was made aware that I am a stepmother to a child with autism, a sister to an intellectually disabled individual, a graduate student working in the field of autism, and behavioral therapist who works with individuals with autism. My great experience as a sibling to an individual with intellectual disability provided me the ability to grow up with superior knowledge of the world of disabilities. My knowledge as a stepparent to a child with autism has afforded me a privileged look into the world of parenting an individual with disabilities. My work as a behavioral therapist allowed me into the world of educating parents and working one on one with children and adults with autism. My work in graduate school is now providing me the authority to stand in leadership on these subjects. However, as a parent educator, I had never worked with stepfamilies of a child with autism prior to this study. This study allowed me the opportunity to, for the first time, interview and converse with others like myself. I felt it was rather easy to build and establish rapport with each of the families that took part in this study.

The study included three distinct ethnic groups, albeit one was dominant, so misunderstandings and misinterpretations can arise. In general, I encountered very few occasions where language was an issue because everyone was fluent in English.

Researcher Background

This study was a personal journey for me as I am a stepparent to an adult son with autism. My journey as a stepmother began over sixteen years ago and I experienced many difficulties with the other biological parent due to her mental health issues and alcoholism. The other struggles I faced involved balancing the needs of my other nondisabled stepchild against the demands of the child with autism. This was a very tough demand for our household because my stepson required a tremendous amount of work. In my newly remarried life I took on a husband that worked nearly 90 hours a week and as a result I quickly became a full time parent. This was easy in one part because I was already a behavioral clinician, so I had the necessary training to work with children on the spectrum, but difficult because I was not a parent. It was like overnight I became a mother to a nine year old with autism.

In my experience neither parent really knew what they were doing with this child, so when we married, both parents at that time looked at me with my autism experience and said, “here fix him” and it was left up to me. I was young and excited. Now it is sixteen years later and he is doing somewhat better, but as an adult we still face issues. Those issues mostly focus around assisting him in gaining meaningful employment. Setting up his housing situation and maintaining his supported living home environment. Supported living is when staff assists individuals with whatever type of support they need for however many hours they require, which for my stepson is 24/7 support. The demands of my stepson have decreased somewhat over the years as we have adapted to his needs, although there are flare ups of issues that sometimes

occur weekly that are unpredictable. I guess that is just the nature of having a child on the spectrum.

IV. Results

Based on my prior research I went into these interviews with a good understanding of what occurs in a typical blended family where there is a nondisabled child and also what occurs in a nuclear family of a child with autism. Through this research I discovered that prior to this study there had not been an interview based study of blended families when there is a child with autism present, and thus this study took shape. There were two primary questions to the body of research: (1) In what way does the use of the FAAR Model of family stress and adaptation adequately describe the process of family formation and maintenance in remarried families of children with autism (Patterson, 2002)? (a) How does Patterson's (2002) concept of demands fit the data? (b) How does Patterson's (2002) concept of capabilities fit the data? (c) If Patterson's (2002) concept of outcomes fit the data, how so? If so, how do they restore balance? Does utilizing community resources apply? If they do not restore balance do they show poor adaptation (at an individual level—physical or mental illness etc., at family level sibling conflict, separation or divorce)? (2) How does the use of Gallimore et al.(1989) ecocultural niche theory help to explain family capabilities in these families? Does it help to explain response to crises? (a) Do the families develop sustainable accommodations to family routines to meet the needs of their children with autism?

The results of this study required that two theories be reviewed and applied. Ecocultural niche theory will be used to take the perspective of family (e.g. family goals, values, and needs) into account and is comprehensive in its view of the family

environment and thus “ecocultural niche theory proposes that with vulnerable persons of aversive circumstances, *families take individual and collective action to modify and counteract them*, and in so doing *construct their ecocultural niches*” (Maul & Singer, 2009, p.2). This study revealed rich stories from stepparents and biological parents that describe how being together and compromising—both for their child with autism and for each other—has brought them closer through the reorganization of their family life. The term ‘accommodations’ when it applies to families of children with disabilities is defined as, “protective efforts of a family to adapt, exploit, counterbalance, and react to the many competing and sometimes contradictory forces in their lives” (Bernheimer, Gallimore, & Weisner, 1990, p. 223). This term was used to describe how families made changes to their lives to adapt to the needs of their children with autism. Ecocultural niche theory extends Family Systems theory by building a deeper view on the comprehensive look of the family. A better analysis can be made by viewing the daily routines and activities of the family. Ecocultural niche theory is also applicable to families in all cultures as it is a theory based on cross-cultural literature (Maul & Singer, 2009). Families in different cultural groups will have distinct “niche profiles”, though many have comparable features (Maul & Singer, 2009). The ecocultural niche theory was used to determine if families were able to sustain the accommodations made to their routine or if they were unsustainable.

The Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 2002) was used to emphasize the balance of family demand with family capabilities. As these interact with family meanings, they produce a level of family adjustment or

adaptation. Family meanings are the way in which a family sees itself. There are three central components of the FAAR model: “(a) normative and nonnormative stressors(discrete events of change), (b) ongoing family strains (unresolved, insidious tensions), and (c) daily hassles (minor disruptions of daily life)” (Patterson, 2002, p. 350). These central components were used to further code the themed data. These components also helped to explain family functioning by determining how families balance the demands of daily life.

In the adjustment phase the families respond to events that do not present major hardships and require only minor changes in family functioning, or it serves as the initial response of the family to a more major event. Responses could consist in any of the following: how a family defines stressors, a family’s existing resources, problem solving and coping abilities. If minor changes in family functioning are not adequate to manage these events then the family moves into the crisis state and the adaptation phase of the model. Families in this study were found to utilize all of these. The stressors that families shared in this study determined if the families were headed toward restoring balance by decreasing the demands or into crisis which led to poor adaptation.

There were two broad outcomes to the adaptation phase: resilience, and vulnerability. The crisis situation itself is not necessarily viewed as pathological or detrimental to the family in and of itself, but indicates that the family needs to make fundamental, structural, or systemic changes in functioning in order to adapt to the situation (Patterson, 2002). This situation is defined by a pile-up of demands,

stressors, transitions, strains, strengths, and capabilities of the family unit (Patterson, 2002). During these interactions families create shared meanings between both parents and each individual. Crisis was found in three families whereas resilience was found in an overwhelming number. This balancing act is a careful process that families engage in because it involves daily life and often high amounts of stress. Family resiliency could be used to describe the capacity of a family system to “successfully manage their life circumstances and could also be used to describe the processes by which families are able to adapt and function competently following exposure to significant adversity or crises” (Patterson, 2002, p.352). In order to classify a family as resilient under the FAAR model, said resilience must arise in the wake of a crisis (Patterson, 2002). The families in this study that were found to be resilient worked hard to balance the demands with increasing their capabilities.

The results of my study revealed intimate details as to how these remarried families of a child with autism coped with setting up new family routines and decided on familial roles. The families also shared details on behavioral problems and how they impacted their lives. Worries about the future and what will come for their children were also areas that were explored. Stories of resilience in parenting were found throughout the interviews. These remarried couples did not hold back so that I, as the researcher, could share these findings.

Developing parenting roles.

It is necessary for parents to work out their parenting roles in any remarried family, with the question of how each will relate to the other’s biological children

taking key prominence. This process is a normative stressor according to Patterson (2002). How the parents adapt to their step children will help determine the outcomes of the family. Sometimes one approach to role division was effective for both disabled and nondisabled children, and sometimes special accommodations had to be worked out for parenting the child with autism.

An example of how parenting role assignments for nondisabled children were also effective for parenting a child with autism comes from Family 004. The biological mother of the child with autism recounted how she first had to learn to deal with her new husband's teenage twins. This stepmother found herself in a normative stressor situation when her husband's teenage twins came to visit for a weekend and instead stayed for three months, bringing all the trappings of teenage drama and attitude along with them. Conflicts arose immediately over sharing the bathroom and the telephone.

Having, you know, two teenagers where one might show up for a weekend and stay for 3 months, and all of a sudden—and this is before cellphones—all of a sudden I can't use my house phone when I need to make phone calls because I've got a teenager on the phone for 4 hours, or I'm having to change my schedule in the morning because I've got a teenager that gets up and taking a 20 minute, 30 minute shower in the morning and then spending 2 hours to blow her hair dry.

This mother laughed and seemed to look back on this episode with good humor. According to Patterson's (2002) notion on resilience, this positive tone in

recalling past challenges seemed to be a consistent feature in the five families I came to view as resilient. In her recollection this mother—stepmother to these twins—mentioned several things. First, she did not tell his children to hurry up and that she needed the bathroom, instead she went to their father and quietly told him to have a few words with his children and as a result they ended up working out a schedule. She stated that “if I have an issue with his kids I talk to him and he talks to his kids and so that’s kind of how we worked that stuff out.” Second, the couple found that this way of dealing with the parenting issues posed by their stepchildren worked for both the nondisabled children and the child with autism. Her husband had done the same about her disabled son and as she put it, they were a team on the same side working together. Being able to adjust her routine—this time to suit her two stepchildren—was another way she accommodated her schedule to meet the needs of her newly blended family. This example provided a general view of how new family formation worked for parenting both nondisabled and disabled children. This family’s ecocultural niche involved mutual respect for each other’s children, which allowed their living environment to have a sustainable stability with regard to each child. A family’s ecology can be defined by the family’s “income, public health conditions, housing and space, transportation, and distance from relatives or services” (Gallimore et al., 1989, p. 218). The family niche is influenced by “cultural features that human beings use to understand and organize everyday lives (e.g., beliefs and goals relating to the good and moral life, the origins and causes of handicaps, and culturally appropriate conduct of marriage and family relationships)” (Gallimore et al., 1989, p. 218).

Parenting roles and the relationships between them are important because the more that adults maintain friendly discourse, the less overall dissention there will be in the household (Kumar, 2017). The establishment of parental roles is a normative process because this is something that needs to be accomplished as soon as possible in any blended family. Three of the interviewed families shared stories that related specifically to parenting roles while others mentioned it throughout the course of their interviews but did not pay special attention to it. Defining said roles requires a great deal of communication between the biological parent and the stepparent, but even then the results can feel unfair. For example, the stepmother's role might be the more demanding of the two if she doesn't work outside of the home and must do more of the caregiving while the father is working (Svare et al., 2004). On the other hand, the role of the stepfather as reflected in the literature is perceived as one of authority, as supposedly rescuing the overwhelmed mother from her plight (Svare et al., 2004). As discussed in my literature review (see page 25) one critical process in the formation of remarried families with children is the deciding of parenting roles.

Some families struggle with the balance of meeting the family's needs and the demands of daily life outside of the family. Patterson (2002) described this as a family's balance of demands and family capabilities and how they interact. For one family in this study, the biological mother was highly educated and the financial needs of her family depended on her. However, this mother still struggled despite her non-traditional role in the family. For Fam 003, working out the familial roles was a

somewhat confusing process because she had been a single mother to three children for nearly ten years prior to remarriage. Here is how she described the situation:

So I was used to being the dominant parent in the initial family, the 3 children, I was making all the decisions for a very long time so when he, when we melded together he wanted to take the stereotypical male role, head of the household and him and I had some transitioning with that. To me it was more about whose role was what. Because even now we don't have traditional stereotypical roles, I am more of the, I'm the professional person, I'm the one that my career has been in the forefront and his has been more secondary. We just have never kind of fit the traditional mold of how a stereotypical family operates. My husband's kinda stepped in and I've kinda stepped out, it was kinda like a tag team thing.

The process of re-establishing parenting roles was challenging to this mother due to her being single for so long, and it meant that she would have to relinquish certain roles to her new spouse in order to share the responsibilities of parenthood with him in the way that he preferred. Even so, the normative roles they filled were not traditional ones. This mother worked in a very professional capacity whereas her husband had a nonprofessional job. An example of this was when she was asked to describe her role in the marriage and her answer was, "I am the breadwinner". Her husband, as she stated, "stepped in as she has stepped out" and thus he became the more dominant parental role because he had taken the lead with the children. Despite this mother's work as an educator in early childhood studies, she was not prepared for

when her son became an adolescent which made this mother incapable of being the lead role of parenting. This placed her in a state of crisis as she dealt with the process of her husband being the one her son would go to for his main needs. She described this shift in roles as a rather difficult change. The shifting of roles accommodated the demands of this family by placing the father in a capacity to better suit the needs of the child with autism. This mother and her spouse also went to a therapist to help them with the transition into marriage, which also allowed their children to adjust better. Utilizing the therapist qualified as accessing a tangible resource. This was one of the ways that this family adapted to the needs of the child with autism. This family's ecocultural niche changed over time as both parenting roles shifted, thus creating good adaptability over time for the family and finding a sustaining accommodation that complemented the natural ecology of the family.

One family that I interviewed for this study had only been married for a year and a half, so they were still in the process of determining their roles and were also seeing a therapist who specialized in families of children with autism. They were yet another example of a family who utilized a tangible resource. Fam 007 had a newly-diagnosed 11 year old daughter, so they were newlyweds who had been abruptly saddled with life-changing news. Here is how this biological mother reported what she wanted her daughter to see in their roles:

I want her to see us, him and I as equal, and not one of us be a stronger (parent than the other), and I don't know if with parents, with moms and dads, if kids

normally see one as a more authoritative figure than the other but I want him and I to be like an equal team.

According to this mother, the homeschooling of her daughter (nonnormative stressor) was the source of all of the behavioral issues they were experiencing at the time of the interview. It was apparent during the interview that she was the more authoritative of the pair and needed him to step in, as she continually sighed throughout the interview and spoke about how tired she was that she had to deal with the daughter's meltdowns every day. This situation placed her in a state of crisis. Appropriate accommodation had not yet been achieved in this family, because despite calling the stepfather "Dad" the daughter was still relying on the biological mother for the most part. Her daughter also interrupted the interview several times by ringing the doorbell, which the mother had had installed due to the long hallway leading to her door. A large point of stress that came as a result of the daughter being homeschooled was because of the arguments that the daughter would start whenever there were errors on her work. This placed additional strain on the mother because her ability to teach her daughter was inadequate, and such crisis will likely lead the family into "discontinuity in the family's trajectory of functioning" over time should this continue (Patterson, 2002, p. 351). She explained that the homeschooling was her role because her spouse was enrolled in full time aeronautical school, and she stated repeatedly how she understood that her spouse attending this school was a good thing for the future of their family. This family's ecocultural niche is under stress due to the homeschooling and the husband being enrolled in full time schooling. This level of crisis showed that

the family's ability to function and cope was under duress. The demands of the daughter's schooling and the imbalance of parental responsibility were disrupting the family and might eventually lead them to a poor adaptation outcome. Since I was unable to follow up with them, their present status is unknown.

Parenting roles, whether in the process of being established or properly worked out, at times require careful planning and modifications when the spouses are not yet on the same page. The normative components in defining roles for a nuclear family cannot be applied to remarried families of children with autism because in these families there is more than just the management of the adults who interact with the child. Remarried families of children with autism must deal with the nonnormative management and adaptation of schedules, routines within the household, discipline, and how the remarried couple adapts to the needs of the child with autism. Families in this study shared how their level of functioning either worked to complement or to disrupt the ecology of the family roles.

Adjustment to problem behavior.

The core symptoms of autism include impairments in social interactions and communication, and the presence of restrictive and repetitive behaviors (Timmons, Willis, Pruitt, & Ekas, 2016). Problem behaviors often occur due to this symptomatology, which then places a tremendous amount of stress on the family (Gabovitch & Curtin, 2009). Due to this nonnormative stressor on a blended family, the parenting skill set required to manage these demands would be different from that

of a regular blended family structure. Such nonnormative stressors may lead these families into states of crisis based on the level of demand that they entail.

In four of the ten families that were interviewed, the children exhibited some sort of problem behavior. While this is not uncommon in the area of autism, it was interesting to hear stepparents with no prior knowledge of autism describe how they handled these demands. In the following scenario, the stepfather of Fam 006 described how he addressed the problem of his stepson hitting his mother while she was driving the car:

When I first met him he would come unglued and hit his mom while she was driving down the road, you know, and it got to the point, she has a big SUV, so, first thing let's move him all the way to the way back, then he can't reach out and get you, you know, 'cause that's just not okay you can't have violent outbursts like that. That's been the biggest issue. My wife was at her wit's end, she was a single mom from the time my stepson was born, you know, all the way up until he was 9 or 10 years old and she was at her wit's end, she didn't know what to do anymore, there was no resources in Georgia for her to help herself, you know. So when I came into the situation and started implementing these different behavior modification techniques, she jumped right onboard.

The stepfather's tone was serious while telling this story. This stepfather used coping behaviors by placing distance between the son and his mother while they were in the car, which modified the son's behavior and prevented further trouble. The stepfather was able to devise and implement the solution easily and while it may seem

like an obvious solution, the biological mother could not come up with this on her own due to how overwhelmed she must have been. In effect, the stepfather saved the stepmother from the state of crisis she was living in. The mother's inability to realize an easy solution suggests that her state of crisis was at a turning point that would lead to poor adaptability (Patterson, 2002). This also relates back to the literature by Svare et al., (2004) that describes stepfathers as asserting their authority because they want to rescue an overwhelmed biological mother and to possibly transpose their cultural values of fatherhood onto the new family. This adjustment made by the stepfather solved the behavioral issue and increased the overall quality of life for the family, thus creating a positive family adaptation. This sustainable accommodation complements the natural ecology of the family.

Another stepfather had similar concerns about his stepson's aggressive behavior. While for the most part the siblings got along, the oldest daughter liked to tease her brother with autism, which eventually caused him to react violently toward her. Here is how the stepfather in Fam 010 described the dilemma:

My most pressing concern is that he could potentially and seriously hurt somebody if he feels that somebody is making fun of him. Actually he's done it with his sister as recently a month and a half ago, he literally body slammed his sister in the kitchen...when he was younger, he threw his principal around like a rag doll, when he was elementary age, like 5 years ago. He's always been a big kid for his age, and ok, well now he's in high school and now the rules that applied when he was younger, they are not allowed.

The relationship between siblings is an important one that can have a direct effect on the behavior of the child with autism, so it is important that they get along. In this family the child with autism was getting bigger and older and could eventually hurt someone, as he has done to his eldest sister when provoked. The only adjustment that was noted by Fam 010 was that the stepfather expected the older stepsister to behave better around her brother and avoid teasing him. This family demand was not unreasonable given the situation and the fact that the stepdaughter being older means she should know better. This family had an increased amount of stress because they also had a small child of 2 years old; however the stepfather asserted that the son with autism was a “gentle giant” when he did anything with his youngest sibling. The stepfather also shared a story about a flashlight that demonstrated how careful the son was with his two-year-old sibling. The son brought the heavy maglight flashlight to his stepfather and asked if he could use it to play with his little sister. The stepfather explained to the son that it was too heavy and expensive and that he needed to find a plastic one and that would be safer to play with her with. So the son went off and found a safer flashlight. The stepfather said that the point of this story was to show how his son was able to understand these directions and apply them. This was the stepfather’s way of finding a coping behavior because he was able to manage these tougher situations with his stepson. The stepson was easily redirected to change to the lighter-weight flashlight with no behavioral outburst. The previous aggression that the boy experienced was brought on by his sibling teasing him. The stepfather was also able to balance the demands of the stressful situation with the siblings by defining a

new set of rules for the eldest sibling to follow. The stepfather expressed to the eldest sibling that teasing (defining the circumstance) was what caused the behavior and the eldest daughter needed to change her approach (family adjustment), thus this stepfather used his capabilities to create a better and more stable environment for his son and avoid a family crisis.

Sometimes aggressive behaviors are harder for families to understand, especially when there is no clear antecedent for the behavior. Here the grandmother from Fam 005 provides another example of physical aggression where her granddaughter would physically lash out at her. Here is how she put it:

Well all of a sudden she'll just come out and hit me or I'll walk by and she'll just grab my arm and pinch and give me black and blues. Scream at the top of her lungs and just, rant and rave. I don't understand it, I don't understand the um, I don't understand why it happens at times.

As previously stated, the grandmother had just recently moved, so no behavioral intervention services had been set up. The grandmother did not understand why the granddaughter's behaviors seemed to escalate from nothing to a full-blown outburst. This unawareness could be due to lack of parent education on the antecedents of aggressive behavior, which could be a risk factor for this family. The grandmother not being able to use this capability to reduce the demand of the aggressive behavior is an indicator of poor adaptation. The grandmother's tone sounded depleted as she shared her experiences, and in one statement she said that the only family that lived close was her daughter who visited once a week for a short time.

The grandmother had no peer group that was raising a child around the granddaughter's age, which could explain some of her isolation. This is another risk factor for this family as there is no outside community context for them, which would increase the stress level along with the isolation. This is also known as ongoing family strain because the grandmother was alone in a new state, with no friends, and was completely isolated. The daughter had limited knowledge of autism, so the burden of caregiving remained with the grandmother. This ongoing family strain of caregiving could lead to even worse adaptation and would make the grandmother more vulnerable.

Sometimes the problem behaviors can become too much for a family and can take over their lives. For Fam 001 the difficult behavioral challenges of the child with autism seemed to run every aspect of the household. The stepmother and her husband also had a baby, which further complicated the home life and increased the level of stress. Here is how the stepmother in Fam 001 put it:

All outings are basically dependent by stepchild's behavior. Where we can go-how long we can stay etc. Something always happens behaviorally. We cannot travel. The stepchild and the baby cannot travel in the same car because the stepchild kicks and throws things, it is unsafe, so we travel in two cars. Every aspect of our life is dictated by the behavior. The stepchild wakes between 4-5 AM every day makes loud banging noise. Elopes, is aggressive, self-injurious behavior, hits herself and others, inappropriate kissing, loud shrieks. It's like having a machine that doesn't shut off.

This stepmother sounded strained as she spoke, sighing with nearly every statement she made. The stepchild was a 10-year old female, and the stepmother stated that they had 50/50 custody and that the other biological parent was considering giving up her custody due to the stress of raising the child. The stepmother stated that none of the family could travel in the same car because it was unsafe. In this family's case, their socio economic resources allowed them the tangible resource of two cars and allowed them to travel despite the danger posed by the stepdaughter. This stepmother's statement of, "The stepchild wakes between 4-5 AM every day makes loud banging noise. Elopes, is aggressive, self-injurious behavior, hits herself and others, inappropriate kissing, loud shrieks" fall directly in line with Lucyshyn et al. (2004), "parents of children and youths with autism or mental retardation reported that their son or daughter's problem behavior injected stress into family routines and that they need more support to effectively manage routines in the home" (p.116). Despite the adjustments that had been made, the state of crisis that this family existed in seemed to be pushing them toward poor adaptation, making them vulnerable. The other aspect of this family was that virtually every domain of the family's econiche was affected by the child's behavioral outbursts, creating a very stressful living environment. These nonnormative demands that the child with autism placed on this family created an imbalance and placed them at a greater risk of vulnerability.

Sometimes a child's behavioral outbursts can be something that deters a parent from dating, which can be a normative demand as well as a nonnormative demand. However, when the behavior moves beyond an outburst and into destruction,

the demand becomes nonnormative. In this next quote a mother expressed her concerns about her son's destructive behavior. In Fam 006 the biological mother had been single for her son's entire life and her son had destructive behaviors, so she was quite nervous about introducing her prospective spouse for fear that her son might become violent and hit her during the initial meeting. Physical abuse by her son as a behavior is a nonnormative stressor. For their first meeting they took the son to a long movie and afterwards the son had one of his meltdowns, which confirmed the mother's fear. This is how she put it:

My son flipped his shit and started beating the hell out of me. And I just knew then that was the end of the relationship, um, but my husband handled it calmly, and, and said "look, there's a lot of things I'm gonna put up with, son, but abusing your mother's not one of them", and my son has not abused me since. Sometimes I don't always agree with, with the boundaries or the things that my husband says or what he's trying to do but I try to step back and not have a hand in everything, and let them do their own relationship, and if I think that my husband's done or doing something wrong I'll tell him in private, definitely not in front of my son. I don't protest too much because honestly, if I think that he's wrong and he is wrong it's gonna be pretty apparent pretty quickly that it's wrong. So I don't have to harp on it, my husband's gonna learn for himself that that was not the way to go.

As this biological mother recalled the first meeting of her son and future stepfather and the boundary he quickly set in place, she gave away something about

their relationship: that her son's behavioral outbursts were solely about her. That is, her son would only abuse her, and by establishing this new rule with her son, the stepfather had immediately taken the lead role as a result. Right from the beginning, the two had a shared meaning in the way this situation should be handled in their family. As she stated in this quote, "I don't always agree with the boundaries...but I try to step back and not have a hand in everything." This was her way of adapting to having a stepfather for her son. Her son had no relationship with his biological father, so he had no male figure in his life, but with this stepfather he got one and on the very first meeting the stepfather put important new rules in place. This psychosocial resource that the stepfather placed on the son was beneficial for this family and quickly became family practice and worked well for them. In a way these two parents helped each other with the stepfather placing the boundary on the child with autism and the mother going along with it, leading to a beneficial adaptation in family roles and behavior. These new adjustments lead to positive adaptation for this family.

The nonnormative demands of problem behavior placed additional stress on the families in this study. However, some families were able to use coping skills and creativity to increase balance during these unstable times. Their ability to balance the nonnormative stressor of problem behavior speaks to how well a family has adapted to the diagnosis of autism.

Communication.

The core definition of autism spectrum disorder involves areas of deficiency in communication and social behavior. Communication is one of the most common

issues associated with autism, and families often have to find special ways to communicate with their child with autism.

Several families involved in this study discussed how their children on the spectrum had verbal ability but were unable to carry out normal social communication, and four out of ten families who were interviewed shared stories relating directly to communication. When there is a child who cannot communicate or has difficulty communicating his or her wants and needs, it places extreme burdens on families and increases their level of stress which qualifies it as a nonnormative stressor. This increased stress in a reformed family—where there are already so many situations that may cause stress in place—could cause a decline in quality of life for the family overall. I chose a collection of quotes that clearly demonstrate what these issues look like.

Limitations of expressive language are often associated with problems that children with autism have in identifying and expressing their emotions. This limitation of expressive language is a nonnormative stressor for this family because it is not a normal demand for any family. Goals are set in place for children on the spectrum from a young age that focus on trying to teach them to communicate their feelings. The stepfather of Fam 006 has this to say about his stepson, age 14:

There are still issues with communications. My stepson does not know how to express his feelings very well, so I have to put myself in his shoes and really think about what's going on in his head to get him to see what I'm trying to talk about here, what message I'm trying to convey to him because, you know,

he knows he feels angry but he doesn't exactly know why he's angry, you know or happy's easy, that's no problem, but angry or jealous, things like that he just doesn't understand it and, that is a constant battle.

In telling this story, this stepfather recounted how difficult it is for his stepson to understand emotions, and he even seems to believe that the stepson does not understand his emotions. The stepfather seemed to be saying that there were times when the stepson did not understand what he, the father, was trying to communicate. The stepfather also seemed to believe that the stepson did not understand because his emotions are getting in the way. The stepfather had to try to imagine what the boy was feeling and he assumed that often it had to do with anger or jealousy. Notice that this seems to be a problem of both receptive and expressive communication. The boy could not receive the father's message because his anger or jealousy was blocking the reception. This stepfather was utilizing his coping behaviors to place himself in an understanding role for the son's emotions. In doing this the stepfather used his coping behavior as a family adaptation thus attempted to balance the demands of the receptive and expressive communication of his stepson.

The type of communication challenges that children with autism have are extremely varied. Some may be nonverbal while others may be hyper verbal. Echolalia is defined as "the repetition of phrases, words or parts of words" (The Centers for Disease Control and Prevention, 2018). These types of communication issues are considered nonnormative as they do not appear in typically developing children. In the next quote the biological mother of Fam 006 explains how her son

went from totally silent before turning three, to being extremely verbal but unable to really communicate:

So he didn't speak until he was 3, I mean he didn't even babble or coo, he did not utter one sound. But since he was 3 he has talked nonstop and it's hard to explain to people that even though he talks nonstop he still isn't very good at communicating, cause he basically is just repeating things he's heard.

This mother had a serious tone as she recalled her son's early verbal ability, and went on to express her deep concerns about his inability to communicate about what went on at school or throughout his daily activities. She also shared what they were attempting to remedy this issue by getting him to use his smartphone to text, which seemed to be helping him with this hurdle. The use of the tangible resource (smartphone) was a great idea because most children her son's age have phones and use them a great deal. They even set up his smartphone to read his text messages to him, which allowed him to better understand since he was not an avid reader. She explained that the use of a cell phone was helping them bridge his communication gap, which made this one way that the family was accommodating the son's communication needs. The coping behavior that this mother incorporated within the family seemed to be working out well for both the son and for the family. The mother explained that through the use of the smartphone reading the text messages to him the son was able to understand the message and thus have better and clearer communication. This adaptation to the family helped the son and reduced the overall family stress. The activity setting of the mother teaching the son to use the cell phone

to read the text messages is a change in the econiche of the family. Through this change in the niche of social learning the mother has helped the son and thus added to the ecology of the family's well-being.

Another example of how communication challenges in autism can affect children is whether a child recognizes illness in themselves. This communication challenge is not one that affects a typically developing child and thus is a nonnormative demand. Here is how Fam 003's biological mother explained her son's communication issues:

Yeah, so he was professor talking when he was 1 year old, he would say full sentences, perhaps 6 word sentences. And he amazed everybody, everybody in his program in childcare was like "oh my gosh". But what we noticed was that it was extensive scripting. We also noticed about him is that he has all these great things he can tell you about, but he couldn't say "I have to go to the bathroom."

The verbal ability of this child was advanced from an early age, but the mother reported that her son could not communicate simple things such as when he needed to go to the bathroom. "Scripting" is something that individuals with autism do, and is officially defined as when they recite lines from movies, commercials, books, etc (CDC, 2018). Some theorize that this is used as a "coping mechanism" by individuals with autism, but ultimately the reasons are still unknown. The concept of "scripting" is when an individual with autism will replace normal conversation with lines from a movie/commercial/book etc. The mother in Fam 003 reported that their son scripted

everything, and she then went on to say that even when her son was talking with a friend, the “talk” was not reciprocal and that while the friend may have moved on from the topic of trucks to rats, her son would still be on the topic of trucks and was unaware that the topic of conversation topic had changed. This level of “communication/social skills” is common in the field of autism, but can be taught if the awareness and education begin when the child is relatively young (Falk et al., 2014). The mother stated later on that using the bathroom was always something that had to be prompted or asked, he never once offered to go and still does not. The family modified their lifestyle by taking “bathroom breaks” every 90 minutes or so, just to make sure that their son would not have an accident. Through the use of this coping behavior, e.g. “bathroom breaks” the child has not had any further bathroom-related accidents. This accommodation, according to this mother, worked for them and minimized bathroom-related accidents, which further increased their quality of life and decreased their stress. This is an example of a positive family adaptation. Although this is a positive family adaptation it is also a burden to the family as it is a change to the family’s niche. By stopping every 90 minutes to take someone to the bathroom this family made enormous adjustments to their daily routines to fit this in wherever they go. The extremeness of changing the overall family routine to fit in these bathroom breaks shows a deep level of commitment by each member of the family and is a great sustainable outcome for this family.

The topic of emotional regulation was discussed previously, but requires further development. Emotional regulation in the field of autism is an area that is

defined as, “the automatic or intentional modification of a person’s emotional state that promotes adaptive or goal-directed behavior” (CDC, 2018). This is a core condition of autism and one that most families face on a day to day basis. Regulating emotions is a nonnormative stressor for remarried families of children with autism. In the quote below, Fam 005’s grandmother explained how her adopted granddaughter communicates:

She, well now she talks, I mean she can communicate “I’m hungry, I’m thirsty” or, now, but as far as letting you know how, what’s going on with her, she doesn’t know how. She can’t explain how she’s feeling, she doesn’t ever say “I’m sad” and I know that I can tell just by her physical actions something’s wrong, and she has a really high tolerance for pain so it’s hard to tell if it’s a physical thing or a mental thing. And I know that it bothers her that she’s not with her father, but she doesn’t ever express it. That’s, I think that’s the hardest thing to deal with is learning how to read her, and trying to help her get through this. And I feel that’s part of her meltdowns lately have been because she doesn’t know how to say “mom why aren’t we with daddy anymore, why aren’t”, you know, although she always says “I like Maryland, we live in Maryland now, I’m a Maryland girl”, that’s how she talks. But, and she doesn’t say “how come daddy isn’t here”, which a normal kid would.

There were many issues that this grandmother had to deal with in trying to learn the communication style that her granddaughter used. In the first example shared above, the grandmother stated that “She can’t explain how she’s feeling, she doesn’t

ever say “I’m sad”, however the granddaughter’s physical actions seemed to communicate to the grandmother that this was the case. This was a nonnormative demand placed on this grandmother. This grandmother has recently gone through a divorce, which she believed the granddaughter was sad about and must miss her grandfather, but instead of communicating with, “mom why aren’t we with daddy anymore”, the granddaughter said, “I like Maryland, we live in Maryland now, I’m a Maryland girl”, which communicated to the grandmother that the granddaughter understood the move. This recent divorce and separation from the step-grandfather and move placed this family in a state of crisis thus leading them to a potential place of vulnerability. However, on the topic of the divorce, this grandmother still seemed troubled as she stated, “she doesn’t say “how come daddy isn’t here”, which a normal kid would”. This statement showed the interaction between the granddaughter and the grandmother and that the grandmother has a high level of understanding in this case. The grandmother was trying to use coping behaviors to understand her granddaughter and make adaptations, but she also stated that the “hardest thing was learning how to read her and trying to help her get through” and that her meltdowns were caused because the grandfather was no longer present. According to the FAAR model, the grandmother’s lack of proper coping behaviors for this situation maintained this level of crisis (Patterson, 2002). The grandmother said that there had been an increase in meltdowns ever since they moved. The grandfather did not visit, and he only spoke to the granddaughter every other week on the phone. The communication between this grandmother and granddaughter was rather unique as they spent a lot of time with one

another. For this family, balancing the communication needs of the granddaughter seemed to be situational in that the granddaughter was still trying to make sense of the entire situation herself. The grandmother's lack of capabilities for coping with the recent changes in their family life placed them in a crisis situation.

Communication needs of children with autism vary greatly. Learning the necessary strategies to adapt to the communication demands of their children seems to be at the forefront of these families' minds. For many of them the use of shared meanings, coping behaviors, and capabilities assisted them in strategizing ways to help cope with the way in which their children communicate. These niches are unique and fragile. Some of the ecology represented here predicts vulnerability and others predict outcomes of greatness. Learning what helps each family in the process of communicating with their children and how each child can be understood is something each parent wants.

Development of family routines.

Newly remarried couples must establish boundaries early and with consistency for the sake of family stability, which makes the creation of new routines a mandatory undertaking. The process of working out routines is normative for any newly blended family, however there were nonnormative demands that came into play for these families. They shared some of the issues that arose as they worked to accommodate the needs of their child with autism and the rest of the family, with four out of the ten families that were interviewed sharing stories that related specifically to routines. Some of the solutions to these nonnormative demands came naturally while others

required creativity to formulate. The development of new familial routines is known as a nonnormative stressor in these blended families because these particular routines are not a regular family demand. Although this can be an area of conflict, many of these families found adequate solutions and worked together in order to establish continuity for the sake of their child with autism and for the rest of the family as a whole.

Routines centered around meals are different in families where there is a child with autism, as there is a need to balance the demands of said child with the rest of the family unit. This means they are demands that Patterson (2002) referenced as being nonnormative. When families remarry there can be a new family mealtime routine which would apply normative stressors, but who determines the routine is not always the same from family to family. For the biological father in fam 009, the topic of mealtime routines was quite stressful. His daughter was 21-years old, and for most of his daughter's life it had been just the two of them as a family and he didn't want to be the "bad guy" by telling her what to do, so he never made demands like turning the television off during dinner or telling her she could only have so much ice cream. He was a very easy going dad. However, once he got remarried, mealtime routines changed:

How do we do things here? Like okay we eat together as a family at night at such a time, and that's kinda, the way my wife is gonna do things, and then it's a little different when it was just me and my daughter cause I'd basically you know, "okay, go grab your plate of food and watch TV" and with my new wife it's "okay no TV, it's just family time".

In this case the stepmother established a new dinnertime routine that was basically the opposite of what had been in place before. This was a difficult change for the daughter but according to the father, it was necessary to aid in the new family unity. This biological father decided to go along with what his new wife had established as the routine in her previous family and in the end they all successfully adapted to it. Making this accommodation to the family changed their ecocultural niche and provided them a mealtime routine that favored the stepmother's tradition, thus changing the family's mealtime routine. This sustainable accommodation of the new mealtime routine complemented this family by providing them with a positive adaptation to their family ecology.

In some cases unique problems were posed by the child with autism. Patterson (2002) described how these nonnormative demands can either engage families in balance or send them into a stage of crisis. In Fam 005 the grandmother had adopted the granddaughter as a baby, but when the child was 15 the grandmother divorced her husband and they moved out of state. Just a few months after the move, the car broke down which meant that the only other means for getting to school was the bus, which arrived much earlier than the granddaughter's usual school departure time. These issues—such as the car breaking down—are known as daily hassles. Due to this daily hassle the nonnormative stressor of establishing the new morning routine to accommodate this change in schedule—getting up, grooming, eating breakfast, and catching the school bus—became very difficult because the child had a pre-existing pattern of refusing to eat when told it was breakfast time. As a result of this behavioral

pattern coupled with the change in routine, the granddaughter ended up going to school hungry. This daily hassle sent the family into a state of heightened stress because of a major change that the child with autism was not ready for. I interviewed this grandmother just after she had sent her granddaughter to school on the bus for the first time. That morning the teenager had been noncompliant, refusing to eat prior to catching the school bus. The main problem was that the bus arrived very early and her 15 year old granddaughter needed a lot of time in the morning to get ready for her day. Here is how the grandmother put it:

School starts at 10 to 8. But, 6:25 is godawful early, so of course, you have to give her time to get up and then she'll eat. So she had no breakfast, she went off to school. Yeah, she's waiting at the bus, we were waiting in front of the door for the bus, and she goes "I wanna eat now", I said " You can't eat now, the bus is coming, you had to eat earlier, you can't say 'no' and then mean 'yes'", that's our biggest issue: she'll say 'no' when she means 'yes' but if you try to give in to her, she gets mad, I call it the loop, she gets in a loop and then she can't get out of it. And ah so, there went my girl on the bus, no food. I felt so bad but I could not not let her get on the bus cause she needs to get into the routine, once she's into the routine, she will start eating breakfast, I know that but, it's hard, it breaks your heart.

The first issue at play was that at the time of the interview it was the first day back after the Christmas and New Years holiday and because of this, the task of getting the granddaughter up early for the bus had been a challenge. Second, though

the granddaughter eats well she needs time to adjust upon waking up in the morning. Given that it was the first bus ride at this early hour, the granddaughter had not had time to adjust to this new schedule and routine. The resulting situation presented a difficult choice: either miss breakfast and get to school or miss the bus and give her breakfast. This daily hassle added more stress to the grandmother because the granddaughter ended up missing breakfast and went to school hungry that day. After this answer the grandmother went on to say she did not know if the school would provide her granddaughter breakfast as communication with the school system in Pennsylvania was quite poor. It should be noted that it is not at all unusual for children with autism to have difficulties with food refusal and noncompliance with the kinds of daily requests that are necessary components of parenting (Gabovitch & Curtin, 2009). The disruption to the morning routine placed an enormous strain on both the child and the grandmother, adding to their overall stress. This family's response to the nonnormative routine of the bus changes for the morning niche thus disturbed the natural ecology of the family.

Children with autism often have trouble learning social norms that are usually picked up incidentally through common daily experience in family life. These difficulties in learning are nonnormative stressors for families as typically developing children do not exhibit these same issues. Norms around interpersonal privacy are an example of this. In Fam 006 a rather different nonnormative routine needed to be established from what the stepson was already used to. This stepfather expressed his

views on privacy and how he helped his stepson to get a better grasp on the concept.

He described what he had done about the problem as follows:

Privacy, oh my goodness, when we first got together he would just bust into the room. If mom and I are having alone time leave us alone, learn how to knock on the doors and say “come in” or “don’t come in”. That was, that was a big one. And then also modesty issues he had no qualms about running around naked. He would just go full Monty anytime he felt like it.

This stepfather’s recollection of this event was joyful and playful, and he was clearly proud to take part in teaching his stepson how to respect boundaries. He said that he would practice how to enter the room with his stepson by playing the “knock before entering game”. The element of the new game he created taught some replacement skills because as a result the son would knock on the door before he entered, thus creating new routines for his stepson. This nonnormative parenting skill drew together this stepfather’s coping skills and allowed him to teach an area of sociability to his autistic stepson. The entire time the stepfather was recalling this tidbit he was laughing and joyful, which I believed was quite telling of how this family perceived this and other challenges. The manner in which this parent responded to these sorts of challenges also shows a positive cognitive adaptation and thus the relationship between the parent and the child was a positive learning experience (Turnbull, Patterson, Behr, Murphy, Marquis, & Blue-Banning, 1993). This adaptation remains a sustainable accommodation because the stepfather stated that the son no longer walks into their bedroom unannounced, thus this intervention complemented

the natural ecology of the family. The sustainability of this family was high due to the accommodation fitting this family's need, which means this family sustained the ecological niche.

To summarize, the ecocultural niche of the newly blended family evolves over time. With the establishment of the daily routines, whether they require normative or nonnormative parenting skills, makes up the daily life in a household. In a nuclear family, each spouse brings living patterns based on their family of origin to the new home. Many of these families shared experiences where their families were building sustainable routines that would continue to impact the ecology of the family, thus deepening their commitment to each other.

Families in crisis.

On a daily basis, most families function in a relatively stable pattern of living as they attempt to balance the needs and demands of their family. In this study there were three families that were in unstable situations and they had shifted to an imbalance, thus these families were faced with changes that led toward crisis. Some families in crisis can stabilize, and others can move toward vulnerability which places them in greater risk. Some families lack the capabilities and coping behaviors required to elevate themselves out of these crisis areas.

Fam 001 had an 11 year old daughter with moderate to severe autism as well as a small baby. The nonnormative demands for this 11 year old sounded overwhelming for this stepmother. Here is how she put it:

All outings are basically dependent by stepchild's behavior. Where we can go-how long we can stay etc. Something always happens behaviorally. We cannot travel. The stepchild and the baby cannot travel in the same car because the stepchild kicks and throws things, it is unsafe, so we travel in two cars. Every aspect of our life is dictated by the behavior. The stepchild wakes between 4-5 AM every day makes loud banging noise. Elopes, is aggressive, self-injurious behavior, hits herself and others, inappropriate kissing, loud shrieks. It's like having a machine that doesn't shut off.

As stated by this stepmother, the step daughter's behavior dictated the family's functional ability, thus placing this family in a state of crisis. The imbalance of this family is apparent by the stepmother's statement, "every aspect of our life is dictated by the behavior". Based on the FAAR model, these statements made by the stepmother, lean the family's trajectory of functioning toward poor at this point. Without the capabilities to assist this family they are leading to poor adaptation.

Sometimes remarriages come together with their inherent complexities, but not everything is explained up front. For this next family, the diagnosis was something that no one in the family knew, including the individual himself, until the wife finally explained it to the husband. The diagnosis made sense to the other family members once it was explained, but the enabling of the biological mother continued, which seemed to upset the stepfather. The stepfather of Fam 002 put it like this:

So as we go through this he lives with us for another year, no improvement on money, he won't—you can't get the kid to shovel the walks, to mow the lawn,

his mom has done everything for him. You can't even get him to clear his dishes. So, we move again. Our lease is up, we move again, because her other daughter has actually broken up with her boyfriend cause he's tried to kill her. She moves in with us so we and at the time my middle son had come to live. Throughout this process my kids, my middle one came to live with me and her son, and my youngest who was caught in this divorce between his mom and me and his soccer coach. He doesn't wanna come over to my house and he doesn't wanna stay with me because her daughter's a real challenge, her son's incredibly... Odd and throws temper tantrums and loses his shit all the time.

First, the stepfather explained how the stepson doesn't lift a finger to help out around the house despite being 27 years old, and this caused the stepfather to become upset. This built up anger, which he never expressed to his wife, was one of the major stressors that led to this crisis. According to the FAAR model, the multiple adult family members residing under the roof of the newly remarried couple was an imbalance which helped cause the major crisis of separation. This family was on the downhill trajectory of functioning that would lead to poor adaptation.

Balancing the needs of a teenager with autism is not easy for any parent, let alone one who is in their 60's. Fam 005's grandmother adopted her granddaughter when she was an infant because her son and daughter-in-law were drug abusers and unable to care for her. However, as this grandmother aged she realized she was not going to remain here forever and wanted to find placement for her granddaughter while she was still alive. This nonnormative demand of finding a place for her

granddaughter to live was a logical and resilient move toward the future for her granddaughter. However, when the partner disagrees with this choice, therein lies a potential crisis. Here is how Fam 005's grandmother put it:

...part of the reason my husband and I started going apart. I wanted to start planning for when my granddaughter was an adult, and since I'm 68 I had to think of like a group home or something, for her to live on her own with peers, with people that she liked and got along with. He was adamantly against it and didn't even want to look into it—not that I wanted to put her now when, but I don't know if I'm gonna see next year. I just wanted to find a safe place for her to go to and that was a really big issue with him.

This grandmother was clear and concise as she laid out the family crisis of how she and her partner began their separation. When parents do not agree on how to parent the child, dissention in the household can easily happen (Kumar, 2017). For this family the crisis of the husband moving out, them getting divorced, and moving out of state led to a major change, leaving them more vulnerable to poor adaptability.

According to the FAAR model balancing the daily nonnormative demands of having a child on the spectrum was too much for these families. Sometimes the family demands significantly exceed the capabilities that a family has (Patterson, 2002). The disequilibrium of the crisis for the families represented in this study was only a snapshot, however. I had no opportunity to reconnect with anyone and find out if there was a turning point in their crisis.

Worries about the future.

One of the largest normative stressors for all parents regardless of whether their child has a disability or not is where their child will end up in the future. When a diagnosis of autism enters the family picture, that future will often change drastically. Concerns for lifelong caregiving needs, planning for housing, basically anything that the child will need for the rest of their life remains on the minds of these parents while the child is still growing, which this turns into a nonnormative demand. Here is how the biological father from Fam 009 put it:

Here we are today, she's 21, almost 22. You know, we just keep going along and I'm always concerns about what the future holds, what happens if I die? I feel like you know, I just can't die and that's really a concern but, just focus on one day at a time, as long as we're alive and well, she'll live with one of us and then eventually in my will I'm researching now, we'll have set up a special needs trust for her so when we're all gone, passed, no longer on this blue dot called Earth she'll be in some kind of home there's plenty of different types but some kind supervised home because I don't have faith that she'll be able to live alone.

This biological father was very concerned about his own death and what would happen to his daughter afterward. His voice shook at times and he sounded deeply worried, even asking me for advice on such plans throughout the interview. This father and the biological mother communicated through the daughter on her needs for the future, and given that the daughter was fairly high-functioning they were able to ask

what she wanted directly and attempt to fulfill her requests. The biological parents did not have shared meanings for their daughter's future. At the time of the interview the daughter was living at home with the biological mother, but worked part time in a job that the father said the daughter was bored with. He stated that his biggest concern regarding his daughter was that when he is no longer living she should live in a supervised home so that someone can watch out for her. This nonnormative demand caused the father a great amount of stress as he spoke. This father was in his early forties, but stated that he thinks of his death often and is trying to balance having an adult child with autism with his own mortality. This father's inability to draw on his own capabilities and find the necessary assistance for his daughter was what plagued him. The daily demand of realizing that his impending death was out of his own hands but not knowing how to utilize the resources available to him to assist his daughter now while he is alive was increasing his stress as well. Although this father had great intentions of finding help he was not able to do so, thus the interconnectedness of the niche seemed disconnected.

Not all families agree on how future plans should unfold. The grandmother of Fam 005 planned to find a group home for her daughter to live in at some point in the near future. However, her spouse was totally resistant to the idea. Here is how she described the situation:

... part of the reason my husband and I started going apart. I wanted to start planning for when my granddaughter was an adult, and since I'm 68 I had to think of like a group home or something, for her to live on her own with peers,

with people that she liked and got along with. He was adamantly against it and didn't even want to look into it—not that I wanted to put her now when, but I don't know if I'm gonna see next year... I'm 68, I will be 69 in July, my granddaughter is 15. So I want her to be with people that she likes, and that she can have fun with and relate with. And she likes, much as she has autism she is social.

This grandmother stated that part of the reason she and her ex-husband split up was because she wanted to begin the process of looking for group homes for their granddaughter and he was adamantly opposed to the idea. This immediately placed them in a state of crisis because their shared meanings were not the same. The grandmother stated that she did not know if she would live to see her next birthday, and her granddaughter was only 15 years old. The grandmother's desire for the near future was to begin looking for a group home with like minded individuals to her granddaughter, so she could "have fun and relate with" them. This family then went through crisis when the grandfather decided to leave due in part to the two of them not being on the same parenting page. The grandfather deciding to leave sent the family off-balance and into crisis because they had to move out of state to be closer to another family member. The entire family identity changed course when this crisis occurred. This could lead them to poor adaptation and make them vulnerable if they remain in this state of crisis.

For some families their children with autism were still relatively young, but this conversation about the future had become something that they were already

discussing in depth. Fam 003's son was only 12 years old, and here is how this biological mother laid out potential plans for his future:

So as he's gotten older my husband and I have started saying things like, well you know, we might have to sell the house and get another house that has a little house on the property, so there's a house like a granny unit. So I think we, what we're having conversations about, is there gonna be independence outside of ourselves, with him.

This mother shared that she and her husband would potentially sell their existing home in order to support the future needs of their son with autism, since she and her husband were unsure that he could live independently from them. Although the idea of selling one's home to support a child could be viewed as normative, in this circumstance it is nonnormative based on the fact that the family would be looking for a home with a "granny unit". This family went on to state that they were uncertain if the son would ever truly be independent, which furthers the nonnormative qualification. The tangible resource of selling the existing home to purchase another is a family adjustment. It also speaks to the family's shared meaning as they both came to the agreement that they should do this in the future if they need to. This unity is a defining circumstance of how they see themselves. They were at the beginning stages of discussing this step since the child was so young.

Fam 006 had a son of similar age to Fam 003, but had recently moved to California and had already thought about possible future employment for him. In the quote below, the biological mother shared her thoughts on what she believed would be

an ideal employment situation for her son in the near future. Here is how Fam 006's mother described their plans for their 14 year old son:

We thought that maybe working in a cannabis field or on a farm is a skill that we might be able to teach my son to try get him some employment one day. We would love for him to live independently but I don't know that that's very realistic. More like a semi-independently. I'm very happy that we're in California because he's at least hooked up with the regional center and from what I understand California's the best place to be with developmental disabilities.

Given the recent growth in the marijuana industry and her son's love of the outdoors, this mother stated that she could potentially teach him the necessary skills for this line of employment and give him some financial stability for the future. The ecology of teaching this activity to her son shows how this mother is adapting to the needs of her son's future employment situation. In teaching this pre-employment skill to her son, this mother would be increasing his opportunity for future employment, thus deepening the work ethic niche. This mother did not know if residing independently would be an option for her son, but a semi-independent living arrangement was a possibility that she was open to with the help of their regional center. This nonnormative demand of unknown independence was something that this mother was already aware of, and she had utilized the outside resource of the local regional center to deal with it. The idea that this mother was already beginning to think about future employment and pre-teaching skills revealed her family identity and

how she had adapted to her son's developmental needs. This mother's ecocultural niche showed how she would be able to sustain accommodations for her son's future. This would lead to positive family adaptation because the family was already making plans for the future.

One family in this study had just received the autism diagnosis in the past 9 months before the interview, and thus questions about the future of their 11 year old daughter were still new and challenging. The mother of Fam 007 described it like this:

You know, this is new, we, we haven't discussed—we've wondered is she gonna be able to live on her own, we worry about her being kind of taken advantage of, because she just, for the most part believes people, and we worry about that.

While sharing this answer, this mother revealed that most of her worry stemmed from the fact that her daughter is easy to take advantage of. While this may be a normative concern for most parents with daughters, the added layer of the daughter's deafness places this in the nonnormative stressor category. She also stated that she and her spouse had not discussed the topic of the future, only that they were wondering if their daughter would indeed be able to reside on her own some day. Such situations are common for newly-diagnosed families, and this process of adapting to "major, nonnormative stressors, such as the diagnosis of a child's chronic health condition, often involves changing prior beliefs and values as a way to make sense of the unexplainable and as a way to adapt" (Patterson, 2002, p.351). This quote reveals something common among families of children with autism, because when a parent

receives the diagnosis of autism the future of the child is what the parent often thinks about. According to the FAAR model, the family did not have the capabilities to cope with this nonnormative stressor. Without these capabilities they cannot be in balance.

For most of these families, whether or not their children will be able to live independently was one of the big unknown variables. Another area of concern for these parents was that of employment, of what their adult children will do for a living. Parents who adapt and accommodate the family demands of worry by putting plans in place will begin the process of adaptation and thus have a better outlook for their own future. In summary, future worries are very real for these families and are things that they think about daily, often requiring accommodations to their lifestyle to account for future plans.

Services and community resources.

Many families of a child with autism can gain access to extra services, but certain situations may make them inaccessible. Some services are only available if the family has the available socio-economic means to support such help. The families in this study accessed services through respite care, private therapy, in-home behavioral support, and speech therapy. Though this list of services provides families with adequate support from the title of services that they each provide, some families reported that they were unhappy with inconsistencies among these services.

For behavioral intervention services to run well they must maintain consistency with the schedule. For Fam 010 a lack of consistency in this care was what caused trouble for the son. Here is how the stepfather shared his experience:

They were doing that for a while, but they run into the problem of having a lack of staff, it's not a stable thing, when they ran out of people we had people come and then they stop coming, one got injured, yeah, you know I mean, there's this big change-over in that field. It's almost like they get people in that field, and they have to use that as a stepping stone to moving on to other things. And so people, like my son, they sort of end up getting caught in the middle, that thing where there they don't have transition.. And he needs structure and stability, he needs a regimen, like a set rule. He responds very well to that, to having that, that structure and so when they establish a structure, and they do it for a little while, and they pull it away, well it destabilizes every time they do that. And it also sends a message, that um to him, that he can't really depend on them. And then it goes to an issue of him trying to, even the things they are trying..... They are trying to teach him about stability and structure and yet they are not living it and he's not seeing it being exhibited on their part. What kind of example are they setting him up to look at?

This stepfather clearly laid out a rather insightful viewpoint on what the inconsistencies of behavioral therapy have done to his stepson. The resource of behavioral therapy was supposed to provide this family with interventions to help the son and instead have done the opposite. The stepfather seemed to draw his knowledge on the subject of behavioral therapists from their direct work in the house with his stepson and how his son responds, which shows a level of parent education. This

stepfather's comment regarding the high turnover rate with the behavioral clinicians and their effect on the stepson is important as it could spark more behaviors when the job of clinicians is to assist the family in decreasing them. This inconsistency in the stepson's behavioral therapy was an additional nonnormative stressor for this family as it causes additional stress within the family unit. This family also received respite services, but the stepfather reported that they received it from his mother-in-law who lives 90 minutes away and visits twice per week to help them for 3 hours. The stepfather stated that the respite service was not as helpful as the behavioral support when they came consistently. The added stress of the inconsistent therapy could lead to this family becoming vulnerable to more stress due to the son not receiving the needed behavioral help. This family utilized the resources available to them, but unfortunately the system providing those behavioral resources failed this family.

Some families experienced nonexistent services or absolutely terrible services. This was the case for Fam 006 when they were living in Georgia. The biological mother explains the situation she experienced prior to remarrying:

We spent a lot of time in south Georgia, services were terrible, he had a lot of weird medical things go on for quite a number of years like in 2012 he had 12 hospital visits, 4 of which were stays.

This mother dealt with lack of services for her son, which is a situation that places a tremendous amount of stress on a family. She needed services that just did not exist in the state she was living in, creating a nonnormative stressor. This stress was made even worse by the fact that she was a single mother at the time. This mother

went on to explain that the medical field placed her son on medications that did him harm instead of helping to reduce his anxiety. The hospital visits that she mentioned in her quote placed her family in a state of crisis because the physicians had prescribed medication that simply did not work for her son and even made his condition worse. This was yet another source of stress as the son's behavior and health worsened as a result of the medication. The heightened stress and lack of adequate medical help put this family at greater risk of vulnerability at the time.

Sometimes, like in Fam 006, states are not set up to support children on the spectrum. Despite this, there are sometimes small respite services that families can obtain. Respite services are services that allow the family time away from the child while a qualified caregiver takes their place for a while. This was the case for Fam 005, with minimal services available to them while they were living in Pennsylvania. Here is how the grandmother described it:

We didn't really have a support system in PA, his family was nonexistent and my family was really, lived far away so, I did get, finally get help through um, SWAN, I don't know if you have that in PA—, California, it's called State-Wide Adoption Services, they have like a respite, and I was getting, we were getting, I think it was 6 hours maybe once a month where someone would come to the house and watch my granddaughter so we could go out. That didn't start until maybe 3 years ago, but before that no, we never went anywhere without her.

This grandmother stated that support from her family was nonexistent, and that the only respite services available to them were minimal. The need for respite services in order to do something as simple as grocery shopping makes this a nonnormative demand. Most families just place their children in the car and travel to the grocery store, hence a regular normative demand. However, for a child with autism who experiences extreme behaviors, the ordeal of taking them to the grocery store where there are a lot of unknown variables can place extreme burdens on families. This was the case for this grandmother, thus the need for respite. During those 6 hours away, this grandmother was able to go grocery shopping and get things done for the house that qualify as normative tasks for any parental role. This grandmother never had any time for herself, and what little respite she received only started when her granddaughter turned 12. This grandmother was the main caregiver for the granddaughter and so it would seem that without adequate support for this family, their outlook is vulnerable. The overall niche was impacted by the needs of the child.

Patterson (2002) wrote about families using tangible resources as a way to benefit them. Fam 007's 11-year old daughter was recently diagnosed, and they were doing just that by seeing a therapist who specializes in newly-diagnosed families. Here is how the biological mother put it:

So what he grew up with is not something that would work on her, and he's aware of that. What I grew up with is not something that would work on her. So that's something that we're both working through now, and you know, part of the reason we go and see the therapist is because we want to be able to

communicate with her, we want to be able to communicate with each other about her, and we want to be able to discipline her and not have her shut down, and we want to be able to teach her and have teachable moments.

This young family's ability to seek out parent education on this level suggests that they possessed effective coping skills. This mother stated that their natural way of parenting was not going to work for this child, therefore they both needed education to teach them a way to effectively communicate with their daughter. The shared meaning between these two parents shows that they both want this adjustment with their family. The mother spoke about wanting to have "teachable moments", which shows the ecology of the family is strong because she is willing to learn in order to be better able to teach in the future. This family is showing signs of positive adaptability through the use of therapy.

Sometimes families struggle with finding services because they are difficult to obtain. This is exactly what occurred for Fam 004. Here is how this biological mother explained the situation:

The hardest part is when you don't have services and you don't know what to do, when your kid's having a meltdown and you don't know why this is happening and I don't know how to help, your child and you're, having difficulty finding answers or even finding somebody to ask for help, you know, I think that is the hardest time.

This mother expressed how difficult it was to go through behavioral challenges with these children when you simply do not know what to do and you need help. She

went on to describe a scenario of being in the grocery store with her 33 year old son when he threw himself down on the floor in a meltdown situation. This sort of meltdown situation is normative when the child is between the ages of 1-4, but any age above that is nonnormative. She stated that she had no idea how to handle it, so she called her husband who had to leave work early to come and help her. Such situations are not easy for parents and they require professional services to aid them in understanding how to assist their children. According to the FAAR model, families require adequate support to reduce the demands; and thus if this family continues to not receive services then they may become vulnerable and this may eventually place them in an extreme crisis situation.

There are rare occasions when families' niches are challenged by more than just their children with autism. The biological/stepmother of Fam 008 shared how she found outside support when she was struggling with her husband's autism. Here is how she put it:

Outside support, yeah things got to a point where I did wanna leave, more than one occasion, and I did actually take a break from my marriage, and the longest break I took, I took 3, which was, 2 of those was 1 was a weekend, 1 was a bit longer than a weekend, and the last break I took a few years ago was a, a month, and that wasn't a break, I, I was gonna leave, and that, then he went and seeked help. But I really believe it was autism-focused, but it's very, hard to be dealing with autism with all the other stepfamily, issues that come with that, you know. Um, sometimes you're feeling like a mum to the kids,

sometimes you're not, and, you know, sometimes you feel you're the inside of the, you know, you're a part of the family and other days, you know, when my stepdaughter had her first baby and I was led to believe all along that I would uh, be let up by the door with my husband while she was giving birth and I was told not to come that broke my heart, you know. Um, so things like that on, on top of dealing with autism issues are very overwhelming, so I found faith, and he didn't really, basically kept coming around each evening and checking in on me, you know. And I, I said "you have to, you know, give me a much better reason than the other reason", so he said "right, I'm going, going to a doctor."

This biological/stepmother shared an intimate view of what she went through when her stepdaughter gave birth and how she was left out when she thought she was invited to be part of the experience. This normative experience of becoming a grandparent turned into a nonnormative experience for this stepmother as she was left out. According to the FAAR model, this mother's appraisal of family identity was way off and this could be one reason she felt so bad in this situation. She saw herself in a normative view when really she was not. When it came to the relationship with her husband, the breaks that she took were in response to him being angry and frustrated and taking that out on her, so she decided to take time away. The husband received the diagnosis of Aspergers, which did not seem to help him because he had a lot of anxiety due to the diagnosis. This was almost a state of crisis for them, but because she took herself out of the house and he explained he was seeking help, I felt they were not in the state of crisis because they were using their coping behaviors to get

through this time period. The capabilities of this family were rather balanced as they used their skill set to increase their family cohesiveness and adapt. The mother also spoke about finding faith. Bayat (2007) discussed this concept of spirituality and how this is one of the final resilience processes, and in this mother's case faith helped save her marriage.

The demands of raising a child with autism require families to seek support. For the families in this study, some struggled to find support, others shared inconsistencies with behavioral support, and a few found their own coping mechanisms in family therapy. According to the FAAR model, with the use of community resources families can learn to make adaptations and decrease the demands thus increasing their chance at a better life outcome.

Resilience in parenting: the story of us.

These couples tended to form a new joint identity through shared experiences, to be able to think of themselves as "us". In many of the interviews I was able to gain a sense for how these couples remain unified based on their shared journey and their ability to work together. Much of the work that these parents needed to do centered on how they responded to the core characteristics of autism in their biological or step-children. Autism is a spectrum of disorders that presents itself differently in each child, meaning that accommodations can vary widely from one child to the next. However, there are several traits that represent common features of the condition. Consequently these pose common challenges that most (how many for each problem)

of these families had to address: communication, problem behavior, isolation, and the child's future.

Patterson (2002) defined resilience as “the phenomenon of doing well in the face of adversity” (p. 350). The parents in this study described this journey of parenting a child with autism in unique ways, whether they were searching for the answer to why they were chosen to be the parent of an exceptional child or using the experience of parenting to assist them in reaching sustainable accommodations for their children. Each family's unique story sees them facing the trials and challenges associated with parenting a child with autism on top of adjusting to their status as a remarried family, and many of them emerged in a more resilient state.

Some parents seemed to search for a reason as to why they were cast in the role of exceptional parenting. It is not something that most people expect will happen in their lives or something that is commonly discussed. In this research, resolution of the ‘why me?’ question is associated with research on resilience (Bayat, 2007). The literature on exceptional parenting indicates that some parents rely on spiritual or religious beliefs as sources of support. In the following quote both the existential question and its resolution are illustrated:

When I started this journey I didn't know why God picked me for this, I wouldn't have picked me for this, but at some point I realized God had greater faith in me than I have in myself. I feel like I learned a whole bunch on this journey with my son. I feel like he's taught me a lot about unconditional love, uh cause he's just, you know about forgiveness, if I have a bad day and don't

do well as a mom with him, he still loves me just as much the next day as if I never messed up and, you know, it's a new day or it's a new afternoon or whatever. It was really hard when he was young because, you know, people are a lot less judgmental today than they were 30 years ago, I can remember going out with him in public 30 years ago and have these people tell me "can't you keep him quiet" and giving me really rude looks and rude comments and that was uh, difficult, and then at some point when he was younger I decided that when we go out I want people to see that he is loved and valued by his family, as every special needs kid is. And so, it became I guess kind of a goal of mine, and it's almost like somebody flipped a switch, all of a sudden I stopped seeing the judgmental looks and comments and I had more people come up and say, you know, "you're so patient with him" or "his sister is so loving with him" or, you know, it's like people were getting what I was hoping that they'd get, that he is loved and valued by his family. I do feel like I'm a much better person cause the son in my life. The hardest part is when you don't have services and you don't know what to do, when your kid's having a meltdown and you don't know why this is happening and you don't know how to help, your child and you're having difficulty finding answers or even finding somebody to ask for help, you know, I think that is the hardest time.

This mother's journey was filled with the sense of understanding as she stated her fundamental question, "I didn't know why God chose me for this?" She learned unconditional love from her son and also learned to balance the demands of daily life

as she stated, “I can remember going out with him in public 30 years ago and have these people tell me “can’t you keep him quiet” and giving me really rude looks....that was difficult”. Patterson (2002) wrote that parents of children with autism who are experiencing extreme stress or having poor adaptability were vulnerable, however in this example, this mother adapted by changing her thought process. She stated, “it became I guess kind of a goal of mine, and it’s almost like somebody flipped a switch, all of a sudden I stopped seeing the judgmental looks and comments ...more people come up and say “you’re so patient with him”, which would make this mother resilient by Patterson’s (2002) definition. “Family resilience implies the capacity of a family to successfully manage challenging life circumstances” (Patterson, 2002, p. 352). This mother was able to manage the challenging situation of her son acting out in public through a change in mindset, which I believe qualifies her as a resilient mother according to this concept. Another important comment that this mother shared was that the “hardest part is when you don’t have services and you don’t know what to do”. This statement was followed up with, “when your kid’s having a meltdown and you don’t know why this is happening and you don’t know how to help, your child”. Her son had extreme problem behaviors and she had no idea what the cause was because they had no services to provide them with answers, but this mother struggled through regardless and became resilient as a result.

Some children with autism are particularly sensitive to stress and distress in other family members. If a child is reactive to conflict between a couple, in some families this amplifies the stress because an argument between any two family

members can provoke problem behavior in the child with autism. This kind of amplification of conflict is a perfect example of family systems theory, which states that what happens in one subunit of the family can radiate out and impact all of the other parts of the system. In Fam 006 the parents reported making use of the child's sensitivity to parental conflict as a reason to be extra careful when they work out problems. Here is how the mother put it:

I wouldn't trade him for anything, he has taught me how to be human. He challenges us to be more open-minded and more empathetic to the world in general. Um, and it's really helped me and my husband just to, I don't know, when we fight or when one of us is having a bad day like, my son feels everything and he acts, he acts out. And so when we try to handle things in a healthy way it really, it just keeps the house running beautifully, and the marriage as well.

This mother's statement of "I wouldn't trade him for anything, he has taught me how to be human" has a resilient quality to it because of its pure humility. This mother reported that when her son senses a fight or is having a bad day, he "acts out" and thus they (husband and wife) "try to handle things in a healthy way". In a way, the son's autism pushed this couple toward a more healthy relationship since the resulting environment forced them to avoid getting heated when they disagreed on things, and their ability to adapt to this challenge made them more resilient. The way in which this family sees itself is defined by how the son responds to their relationship thus their family identity is almost solely centered on handling situations in a calm way. This

family's shared meaning, by handling this situation together and in the same way, shows how they have adopted the same meaning and thus a positive adaptation has occurred.

Choosing your battles is normative, as it occurs in most families with children and is not something that is unique to remarried families of children with autism. However, this concept was entirely new for the stepfather in Fam 007 because he had never had a child. His stepdaughter was diagnosed only 9 months ago at the time of the interview, so choosing battles for him had taken on a new meaning. He and his wife of less than two years were learning what choosing battles meant from their newly-diagnosed child. Here was how he described it:

You know, it definitely has its ups and downs, you sorta have to pick your battles, like you just, and, the, you know, take your time when dealing with her, you know, so like when she does something you can't just always go with your first initial reaction to whatever it is that she's doing, you sorta just have to step back a second and just analyze the situation, even to the point of telling her just like time out, like I need to walk away for a second so I can sorta think about what's happening here, what's going on, and find a good way to deal with this, and come back and I'll deal with her then instead of initially just impulsively reacting to whatever she's doing, cause a lot of times that first initial reaction, will just, you know, set her off even more, so, we just sorta have to be aware of how to handle these situations and [sighs] but as difficult as it can be, I mean, it's great too. I love her to death, I think she's a great kid

and she brings a lot of joy to my life and I wouldn't change her for the world

But... It, it definitely takes a lot of patience a lot of teamwork from the both of us.

This stepfather shared how he had to “walk away for a second...find a good way to deal with this” when faced with a behavioral situation because sometimes his first impulse might just be reacting to whatever she was doing at the time. His coping behavior was walking away for a second and it showed that he was “adapting” to her diagnosis. As he stated, “a lot of times that first initial reaction, will just, you know, set her off even more”, which was an area that he and his wife were just beginning to learn through the help of their therapist. This therapist often worked with newly-diagnosed families and was helping them learn how to communicate better as a family and with their daughter, making her an important tangible resource. This shows a tremendous capability on the part of these parents who were trying to balance the needs of their daughter with the needs of the family. The use of a therapist is one tangible resource that this family is utilizing. On the topic of parenting his stepdaughter he stated, “it’s great too. I love her to death, I think she’s a great kid and she brings a lot of joy to my life and I wouldn’t change her for the world...it definitely takes a lot of patience a lot of teamwork from the both of us”. This stepfather’s statement speaks to the shared family identity that is in part created by teamwork. I chose this quote for this section on family resilience because of the statement, “we just sorta have to be aware of how to handle these situations and [sighs] but as difficult as it can be, I mean, it’s great too.” This family was making some positive adaptations.

Sometimes family comes together when it is least expected, as was the case in Fam 006. Here is how the stepfather of this family explained what raising his stepson was like:

I'm a dad that I didn't have to be. Every day's a new challenge, that's for sure. Um, all in all it's been an extremely rewarding experience. Because I've seen him go from a mean, violent little kid to a, a young adult who's now learning how to make decisions for himself and, you know we're, we're continually coaching him on "hey you're gonna be on your own one day, you know, you can't live with us forever, we, we love you and you can come visit but, you're gonna have to be able to do these things for yourself like fold clothes, and wash clothes, and maybe even cook a meal", you know. So it, it is rewarding, you know, sometimes you feel like you're taking 2 steps forward and 3 steps backwards, but all in all we're making progress so, it's, it's, it's nice. And I never, I never thought that I could feel this way, you know, I'm, I was 40... 43 before I had my first kid of my own so, you know, uh, it's been fun. It's a fun adventure.

This stepfather began with, "I'm the dad that I didn't have to be". However, this stepfather was a resilient one because of his viewpoint. He stated, "all in all it's been an extremely rewarding experience...I've seen him go from a mean, violent little kid to a, a young adult who's now learning how to make decisions for himself." Being able to direct the child from his behaviorally challenged time to now is something to marvel at. This stepfather went on to state, "it is rewarding, you know, sometimes you

feel like you're taking 2 steps forward and 3 steps backwards, but all in all we're making progress" again he continued to make these resilient statements about his experience with his family. The risk and the demands of the family show how this resilience has come about. This stepfather's view of his family shows that the demands within the family have been worked out and are balanced. His statements show positive adaptation.

These families shared intimate details of how they used a crisis situation as a turning point to lead them to a positive adaptation for their child. Within each story shared here, the nonnormative demands of daily life, when mixed with the shared meanings of parents, created resilience in the ways the parents had to change. These positive adaptations created balance which greatly reduced the overall demands and assisted these families in successfully managing challenging life circumstances. Because these families were able to show how they successfully managed their life circumstances, I deemed them resilient.

Chapter V. Discussion

This study was a qualitative investigation into the experience of remarried families of a child with autism. The aim of this study was to discover what takes place during the formation of a blended family when there is a child with autism present from the perspective of both biological and stepparents. The study reports firsthand accounts from both biological parents and stepparents in the areas of family stress and adaptation, with the use modified grounded theory to organize the interview data followed up a theoretical analysis based on the Family Adjustment and Adaptation Response (FAAR) model (Patterson, 2002) and using Gallimore et al.'s (1989) ecocultural niche theory as a guiding framework. As described in my Methods section, I began this research study with a set of questions about family formation in remarried families with at least one child with autism. My original questions were: (1) How do new blended families form when there is a child with autism present? (2) What are additional, if any, adjustment factors in the formation of new blended families due to a child's autism? (3) What support do parents believe might be helpful for problems in family formation of a child with autism? After using these questions to create my interview protocol and to guide a first round of inductive analysis, I subsequently developed a second set of questions that were driven by a theoretical framework. The first set of open ended questions allowed me to reduce my data to the five major themes. The themes generated in this way were: (a) development of parenting roles; (b) adjusting to problem behavior; (c) developing family routines; (d) services and community resources; and (e) resilience in parenting. The results of this analysis

revealed how these remarried families of a child with autism coped with setting up new family routines and deciding family roles.

My theory driven research questions centered around the FAAR model (Patterson, 2002) and parts of the ecocultural niche theory (Gallimore et al., 1989) and sought to further reveal the processes of family formation in a remarriage when there is a child with autism present. Patterson's theory pointed to the way these families faced both normative and nonnormative demands. The nonnormative demands were directly caused by the child with autism due to the social and behavioral symptoms associated with the disorder. These families had to make accommodations to fit the unique needs of their children, all while dealing with the usual normative difficulties of creating a blended family. In my second theory driven question Gallimore et al.'s (1989) ecocultural niche theory was used to examine how these families responded to crisis and if their everyday activities were sustainable while accommodating the needs of their children with autism. The following sections will discuss the first level of dominant themes and then use the theoretical frameworks to further make sense of the data. I will also briefly discuss the state of the available literature on remarried families of children with developmental disabilities that existed before this study and conclude by explaining what my study adds to that literature.

Families in this study shared how they established family roles and routines in order to create a livable ecology in the face of the challenges posed by remarriage and parenting a child with exceptional needs. These families also shared details on how the unique behavioral challenges associated with their autistic children impacted their

lives. Some families in this study were able to use coping skills and creativity to increase balance during unstable times. Worries about the future and what will come for their children are also areas that were explored. For most of these families, whether or not their children will be able to live independently was one of the big unknown variables. It appeared from their accounts that parents who were adapting and accommodating the family demands of worry about the future by putting plans in place were beginning the process of adaptation and thus seem to have a better outlook for their own future. Stories of resilience in parenting were also found throughout the interviews. These families shared examples of how they used crisis situations as turning points to lead them to a positive adaptation for their child.

My first theoretical research question was: in what way does the use of the FAAR model of family stress and adaptation adequately describe the process of family formation and maintenance in remarried families of children with autism? This question sought to review the levels of the FAAR model in order to see how well the main concepts of the theory fit with the data. Not only was the FAAR model useful in assisting with the large data in these results, it assisted me in reflecting on the extent these families face demands that are normative for any remarried family and to what extent they addressed nonnormative demands associated with the child with autism. Most remarried families face major normative demands in forming a new family but the nonnormative demands that are placed on families of a child with autism appeared to add considerably to the challenges of normal remarried life. The FAAR model was also useful in pointing out the coping skills and resources families

utilized to become capable at adapting to the difficult additional challenges these newly formed families were facing. The results showed that some families were able to adapt and accommodate to the demands of their children and some remained in states of crisis. Due to the short cycle of the study and the inability of the researcher to follow up with the participants, this brief snapshot provided a glimpse of what adaptations these remarried families of children with autism had made to date.

My second theory driven research question asked, how well Gallimore et al.'s, (1989) ecocultural niche theory helped explain what capabilities were used in these families? Specifically, to what extent did it help to explain response to crises? Gallimore et al. (1989) focused on the way families adjust their activity routines in response to the challenges posed by children with disabilities. In their description of activity routines such as dinner time, family leisure times, and other common daily activities, they had five domains. These domains include personnel (who is present in the activity setting), salient cultural values and beliefs, task demands (how the activity is structured), what scripts for conduct (these govern participants' actions), and the purposes and motives of the participants in the activity context (Gallimore, Goldenberg, & Weisner, 1993). Their analysis of family activity routines was particularly helpful when I examined the data I extracted from the following themes: adjustment to problem behavior, development of family routines, and families in crisis.

For example, I found that some of the families were in a state of crisis at the time of my interviews. Ecocultural niche theory helped to determine the families that

were in crisis by determining that they were not able to make sustainable accommodations. In fam 001, the demands of the child with autism overwhelmed and exhausted the stepmother. Throughout her interview, this stepmother shared the extreme burden that she was facing dealing with the behaviors of her stepdaughter. In fam 002 the stepfather had attempted to make changes to the routine but the biological mother did not adopt them, which prevented them from becoming sustainable for this family.

In fam 005, the grandmother attempted to make revisions to the family lifestyle which caused her husband to leave thus dramatically exhausting her in the process. For fam 005, there were so many revisions to the family lifestyle, e.g. move to a new state, new school for child, new home, etc. that this family remained in crisis. Fam 005 had not made the proper adaptations for the child with autism's needs in this new living environment, and thus had not made sustainable accommodations. The indicators of the unsustainable accommodations for fam 005 were the increased and ongoing behavior problems for the granddaughter, the lack of support for the grandmother, and the inability to reorganize for the new school routine.

A second piece to my second phase of questions was how do families develop sustainable accommodations to family routines to meet the needs of their children with autism? In this question I sought to find if these families were able to make sustainable accommodations to family routines. With the study being as brief as it was, the accommodations that the families shared with me only gave me a brief snapshot as I was unable to follow up with them to know if they have maintained them. What I was

able to find was how these families created these accommodations. Some of the families created accommodations that drew upon pre-existing normative knowledge, for example, putting a child that is hitting his mother in the rear of the car so he can no longer reach her. Other families created accommodations that were invented or acquired new skills, for example, one family incorporated bathroom breaks every 90 minutes and each member of the family (siblings included) took him to use the restroom, so that the child with autism did not have accidents. This idea originally came from their behavioral therapist, but they incorporated it into a family routine and at the time of the interview it appeared to be sustainable as this was introduced a few years previously. .

Prior to this qualitative study, there had never been a study of remarried families of a child with autism thus this is the first one including both the biological and stepparent. However, there were two qualitative studies that included families of children with autism. The Hock et al. (2012) study used modified grounded theory and interviewed nuclear couples from first marriages of children with autism. Their study explored the ways in which parenting a child impacts marriage. Their findings did assist me in that, they found three main phases they labeled *the ASD crucible*, *tagteam*, and *deeper intimacy and commitment*. The term, *tagteam* approach was used to describe how one partner was working with the child and the other was taking a break. One of the families in my study used this same phrase, *tagteam* and when asked to describe it, she nearly described it the exact same way. Hock et al. (2012) study was a good first start, but it did not go far enough because they only scratch the surface of

the marital ground of couple adaptation, there was no mention of the family in this paper. These researchers go through the strains of the relationship and yet they leave out the most important component, the rest of the family and how they fit into the equation. In my study, I took the remarried family, not just the couple, I asked questions regarding the entire family in order to grasp the balance of the family equation in the blended family where there is a child with autism. When doing family research on a child with autism and how that child impacts the family, I think it is quite important to include the entire family unit.

In another qualitative study by May et al. (2017) they too queried nuclear families of a child with autism and explored domains of coparenting. In this study May et al. (2017) interviewed both parents separate from one another, but with the interviews conducted back to back. I found this to be interesting because I did not do this. I suppose they felt it could change the outcome of their results if they separated the interviews more. They explored three domains: adaptation to the emergence of their child's autism, parenting their child with autism, and expectations for other child's developmental outcomes. May et al. (2017) main goal was to appraise coparenting quality, especially in times where there is conflict. The questions in their interview protocol were far different from mine too, since they were asking questions related to parenting. For example, "How important has your parenting relationship with (insert your partners name) been in helping you to cope with a child with ASD?" (May et al., 2017, p.2971). What was good about this question was that they chose to view the positive side of parenting and ask how the parents were coping and how they

support one another. Some of their themes overlapped with what I found in my interviews. In their first domain, *adaptation of the coparenting relationship to the emergence of a child with autism*, May et al. (2017) found that some parents due to the demands of the child with autism had to alter the way that they worked with the parenting partner. I found this to be true in fam 006, in the way in which both parents described how the child with autism had changed the way in which these parents communicate with one another if they are having a disagreement. For fam 006 the child with autism taught the parents to communicate with each other in a calmer way so as to not disrupt his emotional state of mind. May et al.'s (2017) second domain, parenting in partnership, a sense of solidarity, the parents in this study spoke of being on a 'shared journey' which involved "appreciation, camaraderie and compromise" (p.2974). I found this also to be true in my findings in that the parents in my study reported how they accommodated to the demands of the child by making changes together and jointly creating environments that met the needs of the children.

The literature was full of articles relating to stress in families of children with autism (Davis & Carter, 2008; Falk et al., 2014; Freedman et al., 2012; Hartley et al., 2010; Shieve et al., 2006). In light of the negativity toward autism in family literature, May et al. (2017) reported about parents' coparenting journey and highlighted how the parents found support in one another. Though not all of their domains overlapped with my study, their findings suggested that parents became businesslike when making decisions about parenting post autism diagnosis, which suggests that in order for these parents to make their relationship work they had to be very orderly about distribution

of parenting roles and responsibilities. This helped them cope with parenting a child with autism (May et al. 2017). However, my own findings did not support this as the participants in my study did not state that they needed to be businesslike with their children.

Parental roles have to be established in any remarried family and therefore qualifies as a normative demand for the couple. However, when there is a child with autism present in a newly remarried family this development of parental roles required more in-depth insight due to the child's needs. This means that the demands placed on these families are greater as well. One example of this is that individuals with autism often have multiple important therapies to attend, which requires a lot of juggling when it comes to family schedule. The decision of who will transport the child to therapy has to be determined, as well as the decision of who attends sessions, pays for sessions, and who implements new therapies for the child. These are all nonnormative stressors for remarried families of children with autism, adding an extra layer of potential conflict onto the normal clutter of a family's schedule.

The stepparent may or may not play a large part in parenting the stepchildren, but when it comes to parenting a child with autism both parents need to be onboard in order to ensure the best outcomes. When both the stepparent and biological parent are actively involved, the child with autism may fair better because the stressors may be spread between both parents and allow them to create a more stable environment overall. In the FAAR model when meanings are shared between parents it limits the nature and extent of the risk, which adds a layer of protection for the family

(Patterson, 2002). Patterson (2002) also explained that this is “what accounts for why some stay healthy and well in the face of risk and adversity and others do not” (p.350).

This notion of doing well in the face of adversity is known as resilience (Patterson, 2002). However, there are three basic conditions to considering resilience: (1) *family level outcome*; (2) *risk*; and (3) *protective mechanisms* (Patterson, 2002).

Family-level outcomes is used to assess the degree in which the family can accomplish the necessary accommodations. Negative family outcomes when negative include separations, out of home placements, and in remarried families can include a second divorce. According to Patterson, “there is always some *risk* associated with the expectation that a family will not be successful” (p.350). The *protective mechanisms* are understood as factors that prevent poor outcomes. Shared meanings by both parents is rather important because it can help parents adjust to “major, nonnormative demands” (Patterson, 2002, p. 351).

Of the three families that were reported in the parental roles section of the results, I shared about fam 003 and the biological mother who struggled when her son hit adolescent age despite her high degree of education in human and family development. Therefore the roles had to change in their family. The change in the parenting role activity was a shift for this biological mother as her professional training had not provided her the capabilities to manage adolescence.

Another interesting family was Fam 007, who were recently married with a newly diagnosed 11-year old daughter. This family was young in age and were trying so desperately to understand how to communicate well with their daughter and with one

another so that their marriage would last. The mother's teaching activity with the daughter brought her a lot of stress. The ecological and cultural effects of the homework activity are greatly impacting this family, and because the mother and daughter's daily routine of schooling is under duress they should make modifications to the activity.

Gallimore et al. (1993) stated, "what activities children engage in as an ordinary part of their daily lives have profound impact on the cognitive and communicative functions they develop" (p.539). This means that if changes to the homework activity do not occur, there may be an impact on this family that is greater than they realize.

It is not uncommon for problem behaviors to arise in the stepchildren of any remarried family (Ganong & Coleman, 2017), which would make this a normative stressor. However, for remarried couples of children with autism the process of adjusting to problem behaviors can be complicated by the child's condition. For these remarried families the problem behaviors are unique to the child's condition because they are unlike behaviors that neurotypical children exhibit.

Four out of the ten families interviewed for this study shared problems relating to adjustment to problem behavior, and their ability to find solutions varied from family to family. An example of a family that found a solution to their problem behavior was Fam 006. This was an interesting interview process because independent of one another each of these parents gave me this same example. When the stepfather was interviewed, he was rather jovial, but stern, as he shared how he

came up with the idea of the son sitting in the rear of the car as a solution to abusing the mother while she was driving. When the mother was sharing the story, she was quite serious in tone. The father introduced an essential change to the important activity routine of driving by changing its physical setup, which made a potentially dangerous situation much safer as a result. Over time the way the mother was driving with the child in reach of her would have been increasingly unsustainable whereas it seems reasonable to assume that the change the stepfather introduced would be a sustainable accommodation although longitudinal research would be necessary to verify this assumption.

In another family, the son was growing larger in size and at times became aggressive when he was picked on by others. In Fam 010, the eldest sibling sometimes picked on her brother, a source of growing stress for the family. The step father believed this problem was preventable. He was rather disturbed by his stepdaughter teasing her younger brother, which explains in part how the interaction caused an increase in family stress. The eldest daughter was turning 18 soon and leaving the home to join the army, according to the stepfather, and he hoped this would teach her to become more mature.

This particular sibling relationship aligns with previous findings in the literature. Zetlin (1986) studied adult sibling to sibling relationships in which one of the two experienced intellectual disability. In her retrospective study she found that poor adaptation for the relationship with the eldest sibling was more common (Zetlin, 1986) while relationships with younger siblings tended to be stronger long term

relationships due possibly to a closeness they developed during their childhood. This same stepfather shared a story about how careful his stepson was around his two-year old sister and that the only time that aggressive behavior came out was when it was provoked. This aligns well with Zetlin's findings. Based on Zetlin's findings, there's a possibility that this positive relationship between the child with autism and his younger sister at a relatively early age may remain positive throughout their lives. Again, longitudinal research would be needed to test this hopeful assumption.

The subject of problem behaviors is not limited to violent outbursts, as difficulties with communication can also result in stressful situations. Communication deficits are part of the core definition of autism, and therefore the main communication issues that were brought up by the families in this study qualified as nonnormative stressors. Four out of the ten families represented in this study noted difficulties that resulted from deficits in communication. Some parents described limitations in expressive communication skills where their children were quite verbal, but unable to express their feelings or regulate their emotions. These challenges are nonnormative stressors for these remarried parents because they are common in autism and other developmental disorders (CDC, 2018).

Fam 006 had ideas that were outside the box. They dealt with their child's inability to express his feelings by giving him a smartphone and setting it up to read the text messages to him. This way he would be able to understand the message despite the fact that reading was not his strong suit. This accommodation showed that this family was able to adapt to the needs of their child and change common activity

routines for the child, making a stable change that accommodated the needs of the child and helped him grow. Gallimore et al., (1993) described this notion as “pronatural”, which reflects a parent's ability to accommodate “ecocultural niche presses to create and sustain activity settings reflecting their values and child development goals” (p.546). Children with autism present with nonconventional needs, sometimes requiring parents to come to heroic ideas, that is major changes, in order for their children to succeed.

Fam 005, consisting of a grandmother raising her granddaughter with autism had many examples of interesting ways the granddaughter communicated. They had just moved to a new state on the East Coast and this was a new transition for her, so she still getting used to the new environment. Gallimore et al. (1989) would define this experience as “defining her econiche” because the granddaughter was using her own expressive language to explain to the grandmother that she was happy in Maryland with her. In the granddaughter’s statement, “I like Maryland, we live in Maryland now, I’m a Maryland girl” I believe this was the granddaughter’s way of transitioning herself to the new living environment. However, according to the grandmother, these statements were directly related to missing the step-grandfather. While there was no way to find out, there was truth to both concepts in that the grandmother was recently divorced and this caused the move, so the granddaughter could be missing the grandfather; and according to the FAAR model the grandmother lacked the appropriate coping skills to adequately cope with the situation (Patterson, 1989, 2002). Since the move the granddaughter had experienced a number of meltdowns and the

grandmother reported that she did not know how to handle them. This placed the family in crisis.

Regarding the nonnormative stressor of adjusting to the demands of problem behaviors, these families did their best to describe their circumstances and face the situations. Those demands that these parents were facing were difficult and time consuming. The problem behaviors without adequate coping skills in the parents were causing instability in the family ecology. A variety of exceptional parenting skills were reported throughout this study, whether the resulting solutions came naturally or required creativity to come up with.

The FAAR model posits that families seek to maintain an effective balance of demands and resources as mediated by their ongoing meaning making processes. In her conceptualization of demands, Patterson (2002) distinguishes between normative and nonnormative pressures on families. This way of thinking about demands fit my data well because it outlines a framework for how to view families behaviors and evaluate them. This notion of normative and nonnormative demands is another way of viewing distinct events of changes within the family.

The implementation of family routines in any remarried couple is a normative demand, but when a child with autism is present this can make things much more difficult. There were three families out of the ten represented in developing family routines. One clear example of both a normative and a nonnormative demand that emerged from the data was that of mealtime routines. Newly formed families have to establish how they will design mealtime routines unless they already share cultural

assumptions about these regular parts of domestic life. The establishment of these mealtime routines is a normative requirement for any remarried family. However, the challenges posed by the child with autism added a nonnormative element that required these families to develop ways of designing mealtimes that required conscious decision making. Change in mealtime routines can be difficult for individuals with autism because food rigidity is often associated with the disorder, which makes such situations an additional stressor for families. However, for a few families in this study a change in mealtime routine ended up as a sustainable accommodation and benefited the families despite the initial stress.

The biological father in fam 009 had been a very easy-going dad regarding meals with his daughter, but when he remarried the mealtime routine changed dramatically due to the stepmother's input. Using the cultural input from the stepmother's background to completely modify the mealtime routine was a difficult change for this family, and the father stated that the daughter protested at first. The change to the mealtime activity created a new routine for this family. Now that they have been married a few years, this routine has been in place for some time and the accommodations to the new routine have been sustained over time. The newness of the marriage and the newness of the routine were a lot for the daughter to take in. In the end the accommodation that the new spouse made to the mealtime routine complemented this family by providing them with a positive adaptation to their family ecology.

Fam 006 had some interesting stories about routines. The example shared about the 'knock' game is something that needed to be highlighted in this section. First it showed how the stepfather used creativity to invent an activity to teach a new routine. The stepfather was able to use humor and create privacy by changing the activity surrounding it. He created a new game for the child with autism as a teaching device and created a new routine, knocking at the door prior to entry, that preserved the privacy of family members.

The positive cognitive adaptation that this father created here explained that the relationship he had with his stepson was a positive one (Turnbull et al., 1993). The use of positive expressions is important for remarried families because it may be something that determines the longevity of the marriage so for remarried families of a child with autism, this could be something for future studies to look into.

Some of the routine-related demands that surfaced in these families were more difficult to deal with than others. Facing daily hassles was another way in which nonnormative demands caused changes in a daily routine for these families. Forming new mealtime routines for a family is a nonnormative stressor as it can add a tremendous amount of stress for newly remarried families. Changes to an activity can help a family adapt and adjust to new routines over time thus making them sustainable. The way that step-parents, in my sample mostly step-fathers, dealt with this form of stressor was an important part of the process of new family formation.

In the FAAR model there are two types of family outcomes: resilience and vulnerability. Families work to achieve a balance of demands every day by using

“their existing capabilities to achieve a level of family adaptation” (Patterson, 2002, p.351). Sometimes a family’s demands are too great and exceed their capabilities, which shifts the balance to an imbalance. When an imbalance persists it causes a family to become disorganized and thus the equilibrium of the family turns into disequilibrium. The persistence of the imbalance that these families experience is called crisis. Crisis can be a turning point for a family wherein a family can change their structure and achieve improved functioning for the family. However, in this study the three families that were in states of crisis were leaning toward poorer functioning levels.

Fam 001 was the family that the interview was not recorded and was one of the families found to be in crisis. This was caused by the fact that they had a small baby living under the same roof as a child with extreme behaviors. The literature on parenting a child with autism who exhibits extreme behaviors shows that maternal stress is greatly increased over paternal stress due to the caregiving involved (Davis & Carter, 2008; Estes et al., 2013; Rodrigue et al., 1990; Sanders & Morgan, 1997). When externalizing behaviors are so severe that they can cause harm to a family member the stress level in the home increases to extreme levels (Falk et al., 2014; Hartley et al., 2010).. The demands that this child placed on the family far exceeded this stepmother’s coping behaviors, as there was nothing in the interview to indicate that she was using any strategies to help the child with autism. Gallimore et al. (1993) pinpointed that “activity settings which are introduced by interventionists had to be sustainable and meaningful within the full range of what the family was trying to

accomplish” (p.554). I was only given a brief amount of time to talk with this family and did not find the opportunity to follow up with another interview, so I have no idea if this family was able to find behavioral help for the child. The father would not be interviewed for the study, according to the stepmother. The stepmother stated that the biological mother was about to give up on her custody, which would give them full custody of the child with autism. With that information, I placed this family in a state of crisis.

Fam 002 had several issues they were dealing with. First, at the time of the interview the stepfather claimed that the increased stress he was under was because of the biological mother, continued to financially support her adult son with autism. This family was in a constant state of imbalance, and this breakdown in communication between the two parents was a large source of stress for both of them. According the FAAR model, the mother had no capabilities to help her son with autism and in fact refused to even try to do so, meanwhile the stepfather had good intentions and attempted to provide boundaries for his stepson (Patterson, 1989, 2002). However, without the support from the other parent the boundaries for the child have no meaning (Kumar, 2017). This family was unable to change their activity settings. The mother appeared to be extremely reluctant to promote normal age appropriate independent behavior in her son. This relationship between this parent and child in this family did not seem to include usual boundaries which, in the end, helped to keep the family in a state of crisis. For this family, the mother’s inability to allow the son to

make decisions on his own contributed to the family crisis because it caused the son to remain in a constant state of dependent behavior.

Families in crisis can move in two different directions. Through the use of a family's capabilities and adaptation to family demands each family could have moved toward balance which would shape their outcomes in the direction of positive adaptation. Through "a stable daily routine, parents can socially construct the ecocultural niche of their family" (Gallimore et al., 1989, p.218). Instead these three families remained in states of crisis and vulnerability due to their inability to overcome the challenges they were faced with.

According to the FAAR model, demands and capabilities develop from three levels of the ecosystem: "(a) individual family members, (b) a family unit, and (c) from various community contexts" (Patterson, 2002, p.350). By utilizing the capabilities of these different levels, families can overcome obstacles and become resilient. Parent education, family cohesiveness, and good health and education services are examples of capabilities at each of the three levels and are ways in which families can increase their ability to become resilient (Patterson, 2002).

Families of children with autism can utilize tangible resources and services that are offered to them (Patterson, 2002), as did some of the families in this study. Six families were represented in this category. Utilizing outside family members as respite workers is one example of this. Respite care is a service that provides families with a time away from caregiving, and is sometimes one of the only services that these families can obtain. Often families do not receive many hours of respite, and in this

study families reported that they received on average around 10 hours per week. Another type of community support that was mentioned was that of special needs support groups, where groups of like minded folks get together and share time with their children on the spectrum. Utilizing these sorts of tangible resources provides families with outlets for stress and assists with their ability to cope, but they are far from the only resources available. Other resources that were mentioned by the participants in this study include: respite, therapy, special needs support group, grandparents, and friends.

Although several families mentioned the use of friends for respite hours, I need to clarify that not all of those interviewed stated that their friends understood the life situation, and the amount of information that families had shared with friends was limited. Examples of this include: not sharing about a child's behavioral outbursts, only sharing positive accomplishments, and a lack of understanding on the part of the friend that left the person feeling worse. This corresponds with what Carroll (2013) stated, "social isolation is exacerbated by the responses of other people" (p. 97). This quote is in reference to how many parents of children with disabilities feel about the stigma associated with having a child with a disability. The carryover into community resources and finding them outside the family can be challenging for these families.

Another tangible resource that was used by families in this study was that of psychotherapy. Several families stated that they either had used a therapist in the past or were currently using a therapist in order to improve their relationship with their child with autism and also with their spouse. The use of the therapeutic environment is

a tangible resource that, when effective, may have multiple positive effects throughout the household (Kerr, 2000). The family system would potentially work better by utilizing this resource since it is a source of professional help for the parents. The therapeutic environment was one place where they could discuss the behavior of the child with autism as well as any other issues that affected the family without it carrying over to the home environment. This made the therapist's office a safe space for these parents. Through the use of this tangible resource these families showed success in coping because it helped them to better understand the child with autism and each other, which increased the likelihood of marital success by reducing stress.

Whether a family turns to faith or to respite, outside services for families of children with autism are a requirement. Receiving services to help a family is something that can aid in the adaptation and adjustment of family functioning. It can also reduce family stress. Making respite services easier for families to receive and increasing the hours per family would be one place to start in aiding these families' overall quality of life and helping them on their quest toward balance. Social supports for these families promote parental well-being and improve the quality of parenting, which in turn provide more favorable outcomes.

Patterson (2002) defined resilience as "the phenomenon of doing well in the face of adversity" (p. 350). Family resilience is similar to how families restore balance among the family and what Patterson (2002) refers to as restoring regenerative power. Families are faced with nonnormative demands that place them in phases where they adjust and this leads to positive adaptation. Some of the families that I have

highlighted in this study were able to balance the demands of daily life with their capabilities in order to achieve a degree of family adjustment (Patterson, 2002). The families that were interviewed for this study shared intimate details that revealed the layers of the relationship that both parents shared with the child with autism. Resilience emerged as a theme throughout the sequence of stories. Four of the ten families interviewed were represented in this category.

Patterson (2002) discussed the concept of family identity, which is defined as how a family sees itself. Many of the families represented in these results described challenging situations not as a hopeless struggle but as an opportunity, an act that shifted their thought process regarding said situations. Patterson (2002) refers to meaning making and the use of capabilities to explain how this occurs. This is shown in the results when parents attempted to find positive meaning by asking and answering the question of why they were chosen to parent a child on the spectrum.

Throughout this study these families shared both struggles and joys in parenting their children. When faced with nonnormative demands these parents also demonstrated the ability to use natural skills and creativity in setting new sustainable routines for their families, sometimes coming up with solutions for situations where relying on personal experience was not enough. When faced with situations that would seem daunting for some, there were parents who chose to view these situations as opportunities and to set boundaries. This created a sense of confidence in the way they viewed the family situation, and as a result they achieved balance rather than going into a state of crisis. For many of these families the difficulty involved in learning and

sustaining strategies that help accommodate nonnormative stressors made them positively adapt.

Every family stated that they had concerns about their child's future, with six of the ten families interviewed shared that they thought about their child's future often. The nonnormative stressor of the future and what it holds for children with Intellectual Disability (ID) is different than that of a typically developing child in most cases due to the variation in caregiving needs of the child with autism (Murphy et al., 2006).

For the father in fam 009 he reported that he was fearful about his death and what would happen to his daughter afterward nearly every day. His stress is common among others who took part in this study. The activity of a trust is ensuring that those family members who need the most assistance will be taken care of once we are gone. This activity was not sustained for this father hence the stress he was under daily. The accommodation that he could make for himself is to get the trust scheduled with his attorney.

Interesting, for fam 006, the biological mother was thinking about her son's future chances at employment. She was already thinking about teaching the pre-employment activity that her son would need to increase his chance at future employment. This mother was improving the outcome of the son's niche by teaching the activity thus she had chosen to "deliberately construct an econiche that will influence their child's development towards...the cultural norm" (Gallimore et al., 1998, p.226). This means that by teaching her son the cultural norm of what it takes to

obtain the future employment, this mother will increase the likelihood of her son obtaining a job in the future. This is not only beneficial but could be a long term sustainable proactive accommodation. Another benefit would be the strong work ethic that comes with teaching him such skills early. Again, the concept of exceptional parenting comes into play here because this is what parenting a child with ID and autism seems to instill as a skill set. Some of the ideas that these parents had were creative and completely outside the box while others came naturally, the natural ideas were more normative.

Concern for a child's future might be on the mind of any remarried family and thus be a normative stressor, however what makes this particular worry a nonnormative one is the additional unknowns present in the future for a child with autism. The variability of the spectrum of autism is one component of this, since a child's position on the spectrum will determine how much help they will need even as adults and whether or not they can live on their own. Fiscal resources do make a difference, as seen for some of these families: seven of the ten families had incomes of above \$60,000 and most had higher levels of education, which would allow them to utilize resources that poorer families just do not have or would not know how to find. Regardless of this, employment opportunities are absent for many individuals with disabilities (Carroll, 2013). These findings directly relate back to previous research by Sanders and Morgan (1997) where they pinpointed how parents of children with autism face a difficult challenge when planning for the unknown future.

Outcomes

Many of these families surprised me with the way they approached each situation. Although this study was unique because it was the first one that involved blended families of children with autism, it sheds light on where families are balancing and adapting to the needs of their children. As a researcher I remain concerned about blended families of a child with autism due to the overwhelming needs these children require throughout their lifespan and due to the inherent instability involved with creating a new blended family. I believe these families deserve support to assist them in learning to adapt and make sense of the unexplainable in their life.

There were some families that struck me with how isolated they were. The stepmother of Fam 001 would not allow me to record her, and I fear that this family's outcome will not be a positive one given the behavioral struggle of the child with autism and the lack of positive adaptations by the family. Although the Fam 005's grandmother was doing her best to adapt to the needs of the granddaughter, she was 68, alone, and as she put it, isolated. This grandmother had no outside support and I fear that her situation could derail very quickly.

Fam 003 was adapting to having an adolescent-aged son. The stepfather had stepped in and taken the lead parenting role, thus making the necessary family adjustments which could lead to more positive family adaptations in the future. Fam 004 made the necessary adjustments with their son and were looking for a place for him to move into. The son was 33, and although he had a high frequency of seizures,

the mother said recently that she is ready for this next stage. This is a positive family adaptation. As Fam 006 continued to look forward toward their son's future employment, they were making positive family adaptations within the family. I see the outlook for this family to be quite positive. Since fam 007 was utilizing the tangible resource of a therapist, I see them continuing to adapt to their situation and make more positive steps should they continue with the therapy. The father of fam 009 was very concerned about his death throughout the interview, but he was going to put together a special needs trust in place for his daughter. He was also going to look at supported living options in the state of New York, which means that he took the information provided to him, from me, and was hopefully going to put it into place, thus making positive adaptations for his family which would decrease some of his stress. Lastly, maintaining sibling relationships in Fam 010 will eventually work out for them because the eldest daughter was leaving this summer for the army. This was a natural adaptation as the eldest daughter was turning 18.

Future Research

This study added to the previous research on blended families by opening a door into the world of blended families with a child on the spectrum who were otherwise left out of the literature. The research on parental roles discussed sets of triadic relationships and their effect on one another (Kumar, 2017). In accordance with this, I examined the relationship between biological parent, stepparent, the child with autism, and how the family balanced the demands of parenting the child. In the Hock et al. (2012) study the term "tag team parenting" was defined as "a way in which

partners had to reorganize their professional and family roles, coordinate their parenting efforts and attempt to maintain unity as a parenting team” (p.411). This definition relates to my study in that tag teaming was exactly what many of these families were doing when it came to dealing with the demands of having a child with autism. This strategy in particular made the reorganization of roles as well as routines and who would be responsible for setting them easier for both parents. Remarried families coordinate their parenting efforts by how they take the nonnormative demands of parenting a child with autism and work together to produce sustainable accommodations for the child.

In the Hock et al. (2012) grounded theory study they interviewed ten couples of children with autism, similar to my study except they were nuclear families rather than blended families. However their interview protocol basically looked at general areas of family functioning. They did find three main phases of relationship procedures: ASD crucible; tag team; and deeper intimacy (Hock et al. (2012). The tag team area involved parents sharing the responsibility of raising their child with autism. In their definition, it was a way to, “see your partner as the tag team partner, where the sole interaction, is okay, your turn, now you’re on” (Hock et al., 2012, p. 411). This relates to my study and how Fam 003 used this exact term when the biological mother was explaining how she and her spouse parent their son. This concept of taking turns is a way of maintaining order because it strengthens parenting by allowing the parent who is out to have a break and the one who is in to take the role of lead. I do not know

if this is how many parents felt, but for my study and for Fam 003, that was how they spoke about it.

In the section on the *ASD crucible*, Hock et al. (2012) found that parents described a situation where “demands associated with ASD exerted immense pressure on their relationship” (p.409). This section on the *ASD crucible* relates to my findings for fam 007 in that because this family was dealing with the diagnosis of autism for the first time. Hock et al. (2012) also stated that the entrance of a child with autism introduces a “range of contextual demands such as physical and emotional exhaustion, financial strain and social isolation” (p.409). These contextual demands were also seen in my findings. For example, in all three of the families in crisis these contextual demands were found. However, it is important to note that most of the families in my study were not suffering from emotional exhaustion, financial strain, and social isolation. The participants in my study showed a much wider range of responses to the challenges of parenting children with autism even though they simultaneously were dealing with the demands raised by forming new step families.

The interview study by May et al. (2017) was another qualitative study with families of children with autism that examined parental relationships. They too found three dominant themes: “parents’ adaptation of the coparenting relationship to the emergence of a child with ASD, the sense of partnership that they were experiencing in parenting their child with ASD, and their expectations of how the quality of their parenting partnership would influence their child’s ability to reach the developmental potential” (May et al., 2017, p. 2973). Their first domain had the most overlap with

my study in that it showed how parents adapted to their child's diagnosis and how their roles, routines, and parenting expectations changed (May et al., 2017). This is exactly what the FAAR model showed when I applied it to my data for most of the families.

The results of this study greatly impact the field of psychotherapeutic support for these remarried families in that it provides insight into their day to day functioning. Interventions that include psychotherapeutic support for families of children with autism would be a great benefit for all parents as it could help reduce stress and provide strategies to help manage externalizing behaviors (Falk et al., 2012). The family in my study that had the newly diagnosed daughter was involved in psychotherapy and spoke in great detail of how beneficial the therapy was for them. Not only did the therapy assist them in dealing with the recent diagnosis and how to manage their daughter's behaviors, it also gave them a safe place to discuss matters relating to their daughter where they could not be interrupted or overheard by her.

Another factor that is impacted by this study is how these families were affected by inconsistencies in behavioral therapy. As a behavioral clinician, I pride myself on consistency in my therapeutic practice. However, this standard is not consistent across the field of behavioral therapy. Due to the family in my study that was impacted by the inconsistency in this therapy, I will change how I practice in the future with regard to hiring employees who will work with me. Reliability and consistency will be key. Also, now that I know how missed appointments affect the family and potentially the child's behavior I will make provisions with the family

ahead of time, so I will not miss future appointments. I believe that maintaining clear communication with the family is one way to alleviate the stress of a rescheduled session. Another fact of particular note is that families of children with autism often have siblings, which is an added stressor that could increase the need for behavioral services. Incorporating the whole family in the session is one way to involve the ecology of the family and teach family activities to increase family adaptation for better outcomes.

Another article to review is that of Jamison et al. (2014), where they utilized grounded theory to examine the resilience processes that take place after divorce with regard to coparenting. They too conducted interviews, and their study focused on families of nondisabled children. Their measure was looking at the direct relationship of the ex-spouse. Although I did have a question or two related to this, my study was completely different in that I asked questions relating to the child and the family as it all relates to autism. A few of my participants did comment on their ex-spouses, but did not give enough information for it to be relevant to the study, so this remains a topic of interest for future research on remarried families of children with autism. However, in their findings they found that the language parents used provided insight into how they thought parents coparented, thus the resilient parents spoke about their children more. In my study, the resilient parents were deemed as such because of their perception of their situation. For example in Fam 004 there was the biological mother's statement about not understanding why God chose her to parent her son, and when she gave me that answer she had such joy in her voice as she spoke. I know this

family fairly well and the son has epilepsy and moderate to severe autism, so this mother's journey has not been an easy one, yet her joyful expressions said so much. This is why her answer was resilient, it was selfless.

Limitations

There were some limitations to this study. The first family that participated refused to be recorded, which made the data difficult to use. The second and fifth families were in the process of a divorce and I had no established way of following up with them in order to find out what the results were. The overall sample size was very small and predominantly upper middle class, Caucasian families. None of the interviews were done in person, which removed potential data that could be gleaned from gestures and facial expressions. This study was a one time, brief snapshot of what is a long term process of adjustment, which meant that I could not follow up later and discover what outcomes these families arrived at.

Practical Implications

Despite these limitations, the present study was the first of its kind and therefore contributes to the body of research regarding remarried families of a child with autism and blended families in general. Autism diagnoses seem to be on the rise with the current rate of 1 in 59 children being diagnosed (CDC, 2018). With this increase in diagnosis come more families who have to deal with the unusual lifelong challenges posed by autism. Given secular rates of divorce and remarriage, large numbers of step families will be addressing these challenges. As such, there is a need for more information about how they do and do not manage.

Future research should consider a longitudinal design where the recruitment for participation in the study is partnered with Kaiser or a larger medical group in order to obtain a larger pool of families. Along with this recruitment would be the addition of support services for these families that include psychoeducation and behavioral management training as mentioned in Falk et al. (2012), in conjunction with respite care for the child. I believe that such additions would not only enhance what has begun in this study, but move beyond it by acquiring key data on how such services benefit these families over a longer period of time. The addition of the educational courses and the respite would also allow for families to attend without having to worry that their child with autism would not receive appropriate care, thus increasing the likelihood of parental attendance. In this study parents shared that without services they did not know what to do when their child was acting out, so providing direct behavioral education that focuses on specific areas of behavioral interventions would provide a great deal of help for these families and many more. In providing more directed support to families of children with autism, the focus is shifted from child-centered to family-centered, thus increasing the likelihood of enriching the family niche.

Other things to consider are the implications for practical use of the FAAR model in clinical practice. Regarding clinical family work, the use of the FAAR model could be helpful in explaining to families what they are dealing with daily when it comes to their children with autism. Some of these nonnormative demands are lifelong and with this realization comes additional stress, but if families learn

strategies to cope and modify how they deal with these lifelong stressors their marriages may remain intact and families will have better life outcomes. Another conclusion to take away by applying a model like this is that positive family adaptation has been known to help families (Turnbull et al., 1993). When the family is adapting to the demands and making changes a positive shift occurs within the family unit. It would be great to see more positive literature on families of children with autism.

Conclusion

This study was the first of its kind and although there were only ten families represented, there is a lot of great information that these families shared about the nonnormative demands placed on remarried parents of children with autism. The adoption of new activity settings for some parents in this study dramatically changed their lives for the better thus making those activities sustainable accommodations to the family unit. When families of children with autism adapt to the needs of the child, the demands associated with autism are reduced thus reducing the overall stress of the family. It was truly remarkable to witness how families adapt to the unique needs of their children.

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Interview Questions for Stepparent

Appendix A

Interview Questions:

- 1) Tell me the story of your family since _____ was born.
- 2) Let's go back to the beginning when you first started to get together.
 - (a.) Tell me about how you met.
 - (b.) When in your evolving relationship did you meet the children?
 - (c.) What were your concerns about _____ when you were first getting to know him/her?
 - (d) What seemed to you in the beginning to be the most challenging component _____ to building a bond with the children? And why do you think it was so?
 - (e.) What's your relationship with the children like now? How do they get along.
 - (f.) What was the role of the biologic parent while your new family was developing?
- 3) Were there any other issues you had to work out in your new family?
 - (a.) Can you give me an example/ tell me more about that...?
- 4) Tell me what social outings are like for the family?
 - (a.) Can you give me an example? Tell me more about that....
 - (b.) Are there any other challenges?
- 5) Tell me what it's like parenting a child with Autism?
 - (a.) Tell me what activities does _____ enjoy?
 - (b.) How did you learn to get around _____ communication style?
 - (c.) Were there any concerns about disruptive behavior? Can you share some with me? How does that work for you as a couple?
 - (d.) Are there any academic areas _____ likes?
 - (e.) Tell me how the siblings adjusted to having a brother/sister with autism? What was that like? How did that or did that impact you as a couple? What sort of ways were you able to help the children learn to manage? Can you give me an example? What sort of things do they all enjoy doing together now? Can you give me some examples?
 - (f.) In thinking about _____'s future what plans have you, your spouse and the other biologic parent discussed?
 - (g.) How will _____ future impact the family?
- 6) Tell me about dealing with _____ school? Who deals with it? How do you, your spouse and the other biological parent manage issues with school?
 - (a.) Can you share with me some things you recall. Examples.
- 7) Describe your role in the marriage?
- 8) Tell me about the good things that have happened in your marriage because of _____.
- 9) Tell me about a time when you were able to go out without the children?
 - (a.) How do you and your spouse make time for one another?
 - (b.) Can you give me an example?
- 10) Is there anything else you would like to share?
- 11) Is there anything you would like to ask me?

Interview Questions for Biological Parent

Appendix B

- 1) Tell me the story of your family since _____ was born.

- 2) Let's go back to the beginning when you first started to get together.
 - (a.) Tell me about how you met.
 - (b.) Tell me what it was like when the children first met _____.
 - (c.) What were your concerns about introducing your future wife/husband to your children?
 - (d.) What seemed to be the most challenging for your children in building the bond with your new spouse? Or Tell me about the experience of the children building the bond with your new spouse, what was that like for them? Examples?
 - (e.) Tell me about your relationship with the children today. How do they get along.
 - (f.) What was the role of the other biological parent (your ex) while your new family was developing?
- 3) Were there any other issues you had to work out in your new family?
 - (a.) Can you give me an example/ Tell me more about that.

- 4) Tell me what social outings are like for the family?
 - (a.) Can you give me an example? Tell me more about that.
 - (b.) Are there any other challenges?

- 5) Tell me what it's been like parenting a child with Autism?
 - (a.) Tell me what activities does _____ enjoy?
 - (b.) Were there any challenges with _____ communication style when he/she was getting to know your spouse? What was this like?
 - (c.) Did you have any concerns about disruptive behavior? How does that work for you as a couple?
 - (d.) Are there any academic areas _____ likes?
 - (e.) In thinking about _____'s future what plans have you, your spouse and the other biologic parent discussed?
 - (f.) How do you think this will impact the family?

- 6) Tell me about dealing with _____ school? Who deals with it? How do you, your spouse and the other biological parent manage issues with school?
 - (a.) Can you share with me some things you recall.

- 7) Describe your role in the marriage.

- 8) Tell me about good things that have happened in your marriage because of _____.

- 9) Tell me about a time when you were able to go out without the children?
 - (a.) How do you and your spouse make time for one another?
 - (b.) Can you give me an example?
- 10) Is there anything else you would like to share?
- 11) Is there anything you would like to ask me?

Demographic Survey
Appendix C

1. What is your gender?
 - Female
 - Male
 - Decline to answer
2. What is your age?
 - 18-24
 - 25-34
 - 35-44
 - 45-54
 - 55-64
 - 65-74
 - 75 or Older
 - Decline to answer
3. What is your ethnicity?
 - White
 - Hispanic or Latino
 - Black or African American
 - Native American or American Indian
 - Asian/ Pacific Islander
 - Other
 - Decline to answer
4. What is the highest level of education you have completed?
 - Some high school
 - High school graduate
 - Some college
 - Trade/Technical/Vocational training
 - College graduate
 - Some postgraduate work
 - Post graduate degree
 - Decline to answer
5. What is your yearly household income?
 - Less than \$20,000
 - \$20,000 to \$40,000
 - \$40,001 to \$60,000
 - \$60,001 to \$80,000
 - \$80,001 to \$100,000
 - Above \$100,000

- Decline to answer
6. What are the gender and corresponding ages of your children? (Leave blank if you decline to answer)
-

7. What is your current custody agreement? Please explain. (Leave blank if you decline to answer)

8. Would you be willing to share your child with autism psychological testing results with us?

- Yes
- No
- Decline to answer

9. What is the level of functioning of your child with autism?

- Mild to Moderate
- Moderate to Severe
- Non-Verbal
- Decline to answer

10. Are you the biologic parent of the child with autism?

- Yes
- No

11. Do you wish to participate in an interview?

- Yes
- No
- If they answer yes, they are given my contact and the skip logic option will direct them to leave a contact for them.