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AUSTISM'S AFFECT ON THE FAMILY

by

Jason L. Hicks

A Thesis

Submitted to the
Department of Interdisciplinary and Inclusive Education
College of Education
In partial fulfillment of the requirement
For the degree of
Master of Arts in Special Education
at
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Thesis Advisor: Dr. Amy Accardo

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Dedications

I would like to dedicate this research to my current and former students and every family persevering through their child or sibling's Autism diagnosis.

Acknowledgments

I would like to thank my family. I would also like to thank Dr. Amy Accardo for her guidance and assistance in writing this thesis.

Abstract

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AUSTIM'S AFFECT ON THE FAMILY
2017-2018
Dr. Amy Accardo
Master of Arts in Special Education

Autism Spectrum Disorder (ASD) affects millions of children and families alike and is characterized by impairments in socialization, communication, and restricted and repetitive behaviors. The impairments caused by ASD vary in severity and may negatively impact a child's functioning. The purpose of this exploratory research is to critically examine ASD and how it impacts family units following diagnosis. To that end, this qualitative study provides first-hand accounts of families who have lived through their child's ASD diagnosis. This study provides accounts from four participating families on the topics of their personal feelings of ASD, their knowledge of ASD before and after their child's diagnosis, the impact on their family dynamic, ASD's affect on inter-familial relationships, support systems used to persevere, their acceptance (or non-acceptance) of the diagnosis, and educational supports used to assist in their child's development. The implications of this research provide a deeper knowledge base and insight for affected families, social workers, teachers, therapists and non-affected families alike to understand the wide range of issues that ASD can and does present as well as reinforces the appropriate resources necessary to support and enable affected families to persevere.

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Chapter 1

Introduction

This study examines the social and emotional ways in which Autism Spectrum Disorder (ASD) affects the family dynamic. ASD is characterized by impairments in socialization, communication, and restricted and repetitive behaviors (American Psychiatric Association, 2000). These impairments vary in expression and severity, which in turn, results in a range of cognitive functioning (Jones & Klin, 2009). Such ranges are reflected by a continuum; for example, “low-functioning autism” and “high functioning autism” are often used to describe the two ends of the autism continuum (Jones & Klin, 2009). ASD directly impacts a child’s communication, socialization and daily living skills in ways that are different from children without ASD (Hartmann, 2012). Due to these varying symptoms, many children with ASD experience difficulty relating to peers and creating lasting relationships (Hartmann, 2012).

Children diagnosed with ASD communicate verbally, nonverbally or through a combination of both means (Weiss & Lunsky, 2011). Due to this communicative aspect of ASD, all members of the family are generally required to modify their communication in accordance with what the individual family member with ASD requires. In terms of behavior, families encounter children with ASD who express restricted and repetitive motor mannerisms in order to self-stimulate such as rocking, banging on objects and biting themselves (Mays, Beal-Alvarez, & Jolivette, 2011). This, in turn, may produce feelings of grief, stress and confusion as the family has to transform to effectively respond to and deal with their child’s mannerisms and behavior caused by ASD (Meadan et al., 2010).

The adjustment and transformation required by all family members ultimately leads to a new and learned lifestyle (Meadan et al., 2010). In fact, the initial ASD diagnosis has been reported to leave parents and siblings confused, heartbroken, and sometimes even angry (Hartmann, 2012). Families must quickly accept their new reality, letting go any prior expectations and learning to come to terms with their “new normal.” (Hartmann, 2012). This transformation to the family impacts inter-familial relationships and may result in feelings of fear and worry encompassing the family system (Hooyman & Kramer, 2016).

The transformative effect of ASD, however, goes beyond parents, as siblings, no matter their age, must also quickly and effectively adapt to another sibling’s ASD diagnosis (Rivers & Stoneman, 2008). Although early studies of the effects of a disabled child on siblings almost exclusively report negative psychological effects, research also purports that those negative effects can be overcome by familial support (Rivers & Stoneman, 2008). For example, more recent research suggests little difference in a range of behavioral and social constructs between siblings who do and do not have a sibling with an intellectual disability (Altieri & Kluge, 2009). Consequently, contemporary evidence suggests that it is the overall family functioning that is more likely to determine sibling adjustment (Altieri & Kluge, 2009).

Statement of the Problem

The impetus for this research paper is to examine ASD’s impact on the family unit. ASD is very prevalent in American society. In fact, the Center of Disease Control and Prevention estimates that 1 in 68 children in the United States will be diagnosed with

ASD; including 1 in 42 boys and 1 in 189 girls (Center for Disease Control, 2015). In addition, approximately one third of those diagnosed with ASD remain nonverbal (Hartmann, 2012).

Approximately eleven years ago, the cases of ASD ranged from five per 10,000 to 60 per 10,000 (Altiere & Kluge, 2009). A 2010 study concluded that ASD affects approximately 1 in every 110 children and is growing at a rate of 10% to 17% per year (Meadan, Halle, & Ebata, 2010). Further, as ASD grows in prevalence, it is also affecting a greater rate of males than females. Specifically, males are affected at a rate 4.5 times higher than females (Rice & Centers for Disease Control and Prevention, 2009).

Given its prevalence in society, there are millions of families that must adapt to life with a child with ASD. The diagnosis of ASD completely shifts the family dynamic (Goehner, 2007). Family experiences vary in severity, complexity, affect, and level of adversity. Many parents experience feelings of blame (Barnes, Hall, Roberts, & Graff, 2011). In addition to the effect on parents, the sibling(s) of a child diagnosed with ASD are similarly impacted (Hartmann, 2012). Siblings routinely experience worry, anger, embarrassment and have an inability to understand the diagnosis (Hartmann, 2012). With this problem in mind, this study describes the conceptual framework of ASD, makes a case for the significance of ASD's impact on the family and describes a number of ways in which families can manage individual perspectives, emotions and experiences to successfully cope and overcome the diagnosis.

Purpose of the Study

The purpose of this research study is to carefully examine the social and emotional issues experienced by families that naturally flow from children diagnosed with ASD. As previously discussed, many families are impacted by a child's ASD diagnosis. The symptoms of ASD are wide ranging; thus, no two families are "perfect twins" when observing the emotional, developmental, and growth opportunities that an ASD diagnosis presents. Given the multitude of familial experiences, which this study will examine, a goal of the research is to empower families, including siblings, whose family member is diagnosed with ASD in a way that allows them persevere. For example, for some parents, the attempt to cope or deal with such a condition within the household can be very challenging; however studies tend to prove that effective coping mechanisms positively ensure better outcomes (American Academy of Pediatrics, 2013). Therefore, this study also seeks to serve as a platform for discussion— allowing families to come together, collectively, to assist and support one another in effectively navigating the daily struggles of ASD so that all affected families not only cope, but flourish.

Significance of Study

The significance of this study is to join the scholarly and empirical discussion surrounding ASD and its impact on the entire family unit, and to also facilitate a holistic and community based support system for all families affected by a child's diagnosis of ASD; shedding a light on the ways in which families can persevere together as a unit in overcoming the diagnosis. Specifically, just as the ASD spectrum varies, so does each family's experience. For example, after hearing their child's diagnosis, one study found

that, “52% [of parents] felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame.” (Banach, Iudice, Conway, & Couse, 2010 p. 70).

This paper will build from the findings of Banach et al. (2010) and additional studies to offer further guidance and support for how families, including siblings, can turn those initial feelings of an immediate family member’s ASD diagnosis into positivity which will ultimately enable the entire family to flourish as a unit.

Research Questions

The two research questions addressed in this qualitative study are presented below:

1. What are the perspectives of families when an immediate family member is diagnosed with ASD?
2. How can families build upon their individual perspectives, feelings and experiences in a way that enables and assists families to persevere?

Key Terms

For purposes of this study, ASD will be defined as impairments in socialization, communication, and restricted and repetitive behaviors (American Psychiatric Association, 2007).

Chapter 2

Review of the Literature

This chapter provides a context for the study and a review of relevant literature. The chapter begins with an overview of ASD that addresses core characteristics, and an evolution of its prevalence and diagnosis. Key studies that have examined the impact of an ASD diagnosis on families are then synthesized and include research conducted with parents and siblings.

Overview of ASD

In 1943, ASD was officially diagnosed as a clinical disorder (Hartmann, 2012). At this time, ASD was extremely rare with approximately two through four out of every 10,000 children being diagnosed (Hartmann, 2012). Prior to the ASD diagnosis, affected children were either classified as emotionally disturbed or mentally retarded (MacFarlane & Kanaya, 2009). ASD is an extremely complex diagnosis, presents a number of symptoms and is categorized as a pervasive developmental disorder (Hartmann, 2012). An individual diagnosed with ASD may communicate verbally or nonverbally, they may follow restricted and repetitive routines as well as exhibit restricted motor mannerisms (American Psychological Association, 2000, p. 72). In addition, children diagnosed with ASD are generally interested in friendships but lack the social skills to develop these relationships and are often times unable to relate to peers (American Psychological Association, 2000, p. 72). Those diagnosed with ASD as a child often display abnormal sensory related behaviors such as excessive rocking, spinning and twirling in order to self-stimulate (American Psychological Association, 2000, p. 75).

In May 2013, new diagnostic criteria for ASD was published. Physicians, psychologists and psychiatrists will therefore use the following criteria when evaluating and diagnosing individuals with ASD. Specifically, “persistent deficits in social communication and social interaction across multiple contexts will be manifested by: (1) deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions; (2) deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication; and/or (3) deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers” (Diagnostic and Statistical Manual of Mental Disorders, 2013).

In addition, a diagnosis of ASD may also result in individuals with “restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following: (1) stereotyped or repetitive motor movements, use of objects, or speech (*e.g.*, simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases); (2) insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (*e.g.*, extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat

food every day); (3) highly restricted, fixated interests that are abnormal in intensity or focus (*e.g.*, strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest); and/or (4) hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (*e.g.*, apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement) (Diagnostic and Statistical Manual of Mental Disorders, 2013).

Further, the symptoms caused by ASD result in clinically significant impairments to social, occupational and other important areas of daily functioning (Diagnostic and Statistical Manual of Mental Disorders, 2013). Such symptoms must be present in the early developmental period, however they may not completely manifest until social demands exceed an individual's limited capacities, or may be masked by strategies learned by the individual in later stage of life (Diagnostic and Statistical Manual of Mental Disorders, 2013).

Further, sound sensitivity is another aspect present in those diagnosed with ASD (American Psychological Association, 2000, p. 78). Children diagnosed with ASD may be observed covering their ears or wearing a headset to minimize unwelcome sounds (Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). Behavioral symptoms also recognized in children diagnosed with ASD including hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors and excessive temper tantrums (American Psychological Association, 2000, p. 72).

The Prevalence of ASD in American Society

ASD is becoming more prevalent in American society. Though studies report different numbers regarding its prevalence, the fact remains that ASD is apparent and ever present in today's children. For instance, it has been found that in children 18 years of age and under, the prevalence of ASD ranges from five cases per 10,000 to 60 cases per 10,000 (Altieri & Kluge, 2009). A study done by the Autism Developmental Disabilities Monitoring ("ADDM") Network indicates an overall prevalence of ASD to be 9 in every 1,000 children (Rice & CDC, 2009). Findings from a 2010 study indicate that ASD affects one in every 110 children at a growing rate of 10% - 17% per year (Meadan et al., 2010). Due to the growing prevalence of ASD, the impact of ASD and its effect on families is that much more meaningful. Most recently, the Center for Disease Control and Prevention ("CDC") (CDC, 2014) reported that 1 in 68 children and 1 in 42 boys in the United States are diagnosed with ASD. This statistic marks a 29% increase from the CDC's prior 2012 report (CDC, 2012).

Gender, too, plays a role in the prevalence of ASD diagnoses. Findings indicate the prevalence of ASD in males range from state to state, with 7.3% in Florida to 19.3% in Missouri whereas the ASD prevalence among females ranged from 1.0% in Florida to 4.9% in Arizona (Rice & CDC, 2009). More recent studies by the CDC show an increased prevalence in the state of the present study, New Jersey, of 1 in 46 individuals and 1 in 28 boys (CDC, 2014).

These results bring overall prevalence ratio across all American states to 4.5:1— with males being diagnosed 4.5 more than females (Rice & CDC, 2009). ADDM also

indicates the prevalence rate of ASD to be 4.5 times higher in males than in females. ADDM found that the ASD prevalence was 14.5 per 1,000 males and 3.2 per 1,000 females in children eight years of age (Rice & CDC, 2009). According to ADDM, ASD increased across all sex, racial/ethnic, and cognitive functioning subgroups from 2002-2006 (Rice & CDC, 2009).

Impact of ASD on Families

The experiences of families impacted by ASD may change the family dynamic as everyday activities must be modified and the child with ASD will likely require extra attention from his or her parents (Hartmann, 2012). Research shows that learning that a child is autistic can result in a wide range of emotions for a family unit as each family handles the vision of their child differently (Hartmann, 2012). Moreover, just as the ASD spectrum varies, so does each family's experience (Hartmann, 2012). Parents often experience stressful situations beyond the initial diagnosis that relate to their child's behavior, adapting to a new lifestyle and the complexity of finding access to the appropriate services which will be useful to the family (Banach et al., 2010). Stressors from an ASD diagnosis can cause a strain on parent's marital relationship (Banach et al., 2010), increase financial burdens in the family (Banach et al., 2010) and result in parents socially isolating themselves from others in their community (Hunt-Jackson, 2007).

Parents and siblings often experience stress as a result of modifying goals and activities for a child diagnosed with ASD, having to implement different arrangements for the child's education, and having to deal with emotions of grief due to limited opportunities offered to their family member (Naseef, 1989). Research findings further

indicate that mothers report having more stress than fathers related to their child's diagnosis, as mothers are generally reported as being the primary care giver of children and are generally more active in the child's education (Dabrowska & Pisula, 2010).

This chapter provides a review of the literature beginning with ASD's affect on parents, followed by the research on siblings, and concluding with consideration of the stigmatism of ASD.

The Effect of ASD on Parents

This chapter reports upon the effect of ASD on the family unit. Surprisingly, not all effects are negative. Despite the negativity and struggle that surround raising a child with ASD, research tends to show that parents frequently report positive consequence of an ASD diagnosis (Corcoran et al., 2015; Lutz et al., 2012; Hunt-Jackson, 2007).

Corcoran et al. (2015) conducted a meta-analysis of the lived experiences of parents of children with ASD. The researchers identified 14 prior qualitative studies. Corcoran et al. (2015) found that parents reported the diagnosis of a child brought strength to the family unit, reporting "of the 14 studies, 10 discussed the concept of appreciating the little things as learning how to recognize their child's strengths and accomplishments" (Corcoran et al., 2015, p. 362). For example, one parent explained, "I've learned to see the positive things that people wouldn't normally see . . . making lemonade out of lemons" (Lutz et al., 2012, p. 210). Another father elaborated on a moment when his son, diagnosed with ASD, returned a wave and blew a kiss, stating, "I was just blown away . . . I was so elated" (Hunt-Jackson, 2007, p. 55). Parents described receiving the diagnosis as a life-changing experience (Hunt-Jackson, 2007).

The range of feelings did however, include shock, guilt, anger, and relief (Hunt-Jackson, 2007). In another study, Hutton and Caron (2005) conducted 21 phone interviews with families about the recognition and diagnosis of ASD in their child, intervention services accessed and the impact of having ASD on their family. Regarding reactions experienced by families immediately following the delivery of the diagnosis, the study found that “52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame” (Hutton and Caron, 2005, p.180).

The feelings of affected families are generally consistent across studies. In interviews with affected families, Midence and O’Neill (1999) found that those families experienced a sense of relief after receiving the diagnosis. However, the families also reported not receiving the support they needed afterward (Midence and O’Neill, 1999). The need for improved follow-up support after a diagnosis was again reported by Boullier et al. (2008). In that study, ten families were interviewed about their experience of receiving an ASD diagnosis, along with five physicians who were interviewed about their experience delivering a diagnosis. Families and their respective physician reported anger, sadness, disbelief, and disagreement but also relief, increased closeness, and understanding (Boullier et al., 2008). Families identified the need for improved follow-up services post-diagnosis to address their reoccurring feeling of inadequate support (Boullier et al., 2008).

The common feelings of sadness, anger, depression, and disagreement revealed in these studies demonstrates the numerous feelings innate in the grief process, as grief is

certainly a part of a family's experience following an ASD diagnosis (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003).

The Effect of ASD on Siblings

In addition to parents, children are also very much impacted by their sibling's ASD diagnosis. Siblings, however, may not fully understand the initial diagnosis as they might not be present for explanations from specialists and are still developing themselves (Hartmann, 2012). Tanaka, Uchiyama, and Endo (2011) conducted a study of how children were informed of their sibling's ASD diagnosis. The study was comprised of a survey of 77 parents, and asked parents to complete a survey regarding the way in which they informed their child about his/her sibling's ASD diagnosis. Of the 77 parents, 66.7% informed their children about their sibling's diagnosis, and usually did so when they were around 9 years of age. Close to 80% (77.9%) of the siblings had guessed the diagnosis or noticed something different about their sibling with ASD and 77.3% of them reacted moderately to their parent's explanation. Siblings showed a more accepting attitude than expected as well as an understanding and a desire to learn more about the diagnosis (Tanaka et al., 2011). The findings suggest that siblings do adequately react when informed by their parents about their sibling's ASD diagnosis, and that it is important for siblings to be informed of their brother/sister's ASD diagnosis so they are able to connect with peers who are experiencing the same situations. Yet, a sibling's relationship with their peers as it relates to their immediate family member's ASD diagnosis generally presents certain stressors (Tanaka et al., 2011).

One stressor for siblings is the embarrassment around peers. In having a sibling with ASD, research shows that siblings may say or do things that others find “weird” and/or exhibit aggressive behaviors (Hartmann, 2012). A sibling may feel awkward or nervous bringing friends around their affected brother/sister with the fear that their friend will judge them (Autism Society, 2011). Hartmann, (2012) conducted interviews with affected siblings to ascertain their experience. The study indicated sibling’s ages 7-20 who have a brother/sister diagnosed with ASD experience feelings of embarrassment and stress, particularly concerning their parent’s grief and stress as “a child is able to sense when a parent is stressed which in turn stresses out the child” (Hartmann, 2012, p. 12).

A second stressor for siblings is jealousy regarding the amount of time parents spend with their brother/sister diagnosed with ASD. Hartmann (2012) found that due to the significant needs of children with ASD, siblings may feel as though he/she is being ignored by their parents. The study also mentioned that dealing with ASD may be hard for some parents, specifically as it relates in balancing time with their other children if their child with ASD is in high need of care and attention (Hartmann, 2012). For example, a child with high needs may require assistance with eating, toileting, personal care and behavior modification which can occupy the parents’ time (Autism Society, 2011).

A third stressor for siblings is the frustration over not being able to engage or receive a response from their brother/sister with ASD (Orsmond and Seltzer, 2007). It can be hard for siblings, especially at a young age, to figure out how to engage with their brother/sister with ASD (Autism Society, 2011). A study conducted by Orsmond and

Seltzer (2007), regarding the way in which siblings internalize and deal with a family member's ASD diagnosis reported that of siblings ages 8-15, 84% reported aggression produced by their brother/sister with ASD when trying to interact with them.

Finally, the concern over their role in future care giving of the child diagnosed with ASD can be stressful for siblings. Orsmond and Seltzer (2007) indicated that siblings reported significant concern regarding the future of their brother/sister's ASD. For instance, siblings may feel obligated to take over for the parents when they are no longer able to care for the child diagnosed with ASD. On the other hand, siblings may be persistent about taking over for the parent with the fear that they will not be able to provide appropriate care and financial stability by the time such care is needed (Hartmann, 2012). Consequently, siblings might often worry about what will happen to their brother/sister with ASD in the future (Autism Society, 2011).

The Effects of Support

Given the transformative effect of an ASD diagnosis to the entire family unit, a review of the literature was also conducted on the ways in which support can positively impact a family. To design more effective interventions for families, an understanding of the existing forms and functions of support families seek is necessary. Tway, Connolly, and Novak (2006) analyzed the responses of 55 parents of children with ASD who completed the Family Crisis Orientation Personal Evaluation Scales (F-COPES). The F-COPES includes questions related to types of support. The results indicate that 68% of parents sought general support from friends and 93% sought information and advice from families with a similar diagnosis. Furthermore, 80% also sought information from professionals.

These findings indicate that though general support from friends is important, specific support from families who have had the same experiences or support from professionals with knowledge about ASD is especially important (Troy et al., 2006). A study conducted by Guralnick et al (2008) buttressed the need for support, demonstrating the effects of five different types of support for both parent and siblings. Guralnick and colleagues (2008) analyzed the responses of 55 mothers, at the initial time of the study and then again two years later, regarding the capacity to cope with their everyday stressors ASD presents. The study looked at “parenting support,” which was defined as help and advice specific to their child and caretaking needs and “general support,” which included general emotional support and time availability. Four distinctions of general support were made based on the source of the support: partner (spouse), friend, extended family and community. The findings indicate that by the second evaluation two years later, four types of support had some impact on reducing stress and establishing a better sense of well-being for parents. The correlation was significant when accounting for all four types of support combined. Community support alone, however, was not correlated with reducing stress. Notably, the parenting support variable was the only one that demonstrated a high rate of effectiveness. That finding indicates that though having a general support network can benefit parents, receiving parenting support specific to their child and his/her needs is of critical importance in helping families (Guralnick et al., 2008).

Group support can also offer families skills needed to overcome the stress of an ASD diagnosis. In a study by Woodgate, Ateah, and Secco (2008), in person interviews

were conducted with 14 families affected by ASD. Families were questioned about their initial feelings after the diagnosis and the types of support utilized in coping. A common experience described by 14 parents of children with ASD was extreme social isolation and lack of understanding from the public. Half of the families felt that group support was helpful to them in overcoming their feelings of isolation as it made them realize that they were not alone in their feelings. This finding suggests that one of the greatest needs for families coping with a diagnosis is finding acceptance and support from others. Law, King, Stewart, and King (2001) reported similar findings that parents of a child with a disability experience substantial positive gains from involvement in support groups. The parents interviewed reported an increased sense of belonging with peers in their support group. They also discussed feeling an increased sense of power in their ability to come together and advocate on behalf of their children, at the community level and within service systems and agencies. The study found that parents in support groups felt increased knowledge and skill in dealing with behavioral issues and other day-to-day concerns (Law et al., 2001).

Conclusion

The above cited studies were all completed to gather and collect both parent and sibling perspectives on the diagnosis of ASD as well as effective means to providing families with support. The qualitative studies corroborate the finding that families who receive a diagnosis of ASD for their child are faced with a plethora of feelings and information that must be sorted through, and that in the immediate aftermath of receiving a diagnosis, the encouragement and assistance gained through adequate and effective

support mechanisms can be invaluable in helping the entire family unit to get through a challenging time. In both the control group studies and qualitative interviews reviewed, parents were empowered, provided with a better sense of overall well-being, and more effectively able to overcome an ASD diagnosis when effective support was utilized. This paper will further examine the perspective of families through a qualitative investigation of the experiences of parents and siblings in families experiencing an ASD diagnosis.

Chapter 3

Methodology

The purpose of this research study was to examine the social and emotional ways in which ASD affects the family dynamic. Specifically, this study aimed to:

1. Examine the social and emotional experiences of parents that naturally flow from a child being diagnosed with ASD.

2. Explore and identify the ways in which families can successfully overcome the negative impact of an ASD diagnosis and ultimately persevere as a family unit.

This chapter is divided into several sections that include a description of the qualitative research methods used to complete this study of the impact of an ASD diagnosis on the family unit.

Research Design

This qualitative study featured structured interviews and surveys of families whose child has been diagnosed with ASD. Four families/ respective parents whose child answered interview and survey questions, both open-ended and direct questions, aimed to understand and explore in a critical and targeted approach the individual perspectives, emotions, perceived and experienced challenges, and coping mechanisms utilized following the child's ASD diagnosis. The participants were interviewed by the researcher and thereafter complete the structured survey questions. The qualitative research interview and survey questions were developed to garner an in-depth and personal understanding of the individual participants experience in coping and preserving through their child's ASD diagnosis (Leedy & Ormond, 2017).

This research study aimed to gather information by asking research participants verbal and written questions and by analyzing both verbal and written descriptions and narratives. Qualitative research includes data collection, data analysis and ultimately drawing conclusions through coding (Leedy & Ormond, 2017). In addition, this qualitative research study was both exploratory and descriptive, and sought to discover how the individual parent participants structure and give meaning to their everyday lives as it relates to their child's ASD diagnosis and the impact such diagnosis has had on their familial unit. The narrative interviews which were conducted as part of this study allowed participants to express their feelings and experiences regarding the impact of an ASD diagnosis.

Sample Selection

The researcher approached four families whose child was diagnosed with ASD, through the process of convenience sampling. Convenience sampling is defined as the selection of samples that are both readily accessible and convenient to the researcher (Monette et al., 2008). Through convenience sampling, four sets of participants were chosen and agreed to participate. The researcher identified these participant families as they were adequately suited to provide a parental perspective on ASD and the various impacts the diagnosis had on their family. Essentially, these participants all held the parental perspective required to sophisticatedly opine on not only ASD, but also on the familial consequences and adaptations their respective families were required to work and persevere through upon receiving such a diagnosis.

Family 1 is comprised of two married parents, whom are parents to a male, high-

school aged child with ASD and one daughter in middle school. Family 2 is comprised of two married parents, whom are parents to four children—one set of triplets (two boys with ASD and one girl, unaffected) and one son, college-aged, who is unaffected. Family 3 is comprised of two married parents, who have two college-aged males, one with ASD, and the other unaffected. The last family is comprised of two married parents and one college-aged male with ASD.

Instrument

The instruments used for this study were parental structured interviews through both standardized questions and open-ended, exploratory questions and survey questionnaire checklists. The researcher took detailed notes of each interview and required the participants to transcribe the survey portion of the study in order to obtain and collect, in the participants' exact words, this critical aspect of each interview.

Interview script. The families were interviewed with the following interview questions in order to gain a greater understanding of each family's individual experiences with ASD:

1. What are your feelings surrounding your child's ASD diagnosis?
2. What did you know about ASD prior to your child's diagnosis?
3. What knowledge did you obtain after your child's diagnosis with ASD? How did you obtain such knowledge?
4. How has your child's ASD diagnosis changed your family dynamic?
5. How has your child's ASD diagnosis affected your inter-familial relationships?
6. What support systems did your family put in place to help cope with diagnosis?

7. Has your family accepted the diagnosis? If yes, how? If no, why not and do you think your family will ever accept it?

8. What educational supports has your family put in place to persevere through the diagnosis?

Parent survey. In addition to the above interview, the families were also asked to complete a paper survey, with pre-determined questioned, as outlined below:

1. How old is your child? What grade are they in?
2. What kind of school do they attend?
3. Were there any characteristics that stood out to you when your child was younger?
4. What behavioral characteristics stand out to you now?
5. What are some of their interests?
6. Did they have difficulty communicating at a young age? How?
7. How are their communication skills now? Have they changed?
8. What signs/behaviors did you notice and how old was he/she when you noticed signs of ASD?
9. How old were they when they were diagnosed?
10. Do you feel ASD was explained to you well?
11. What changes have been made in school since he/she was diagnosed? Are there special services for him/her?
12. Are you satisfied with your school's program and services?
13. What do you find most challenging about raising a child with ASD?

14. How did it change your life?
15. What have you learned about raising a child with Autism/Aspergers?
16. What advice can you give to other parents raising a child with Autism/Aspergers?
17. Is there anything else important to you and your family that you would like to share?

Parent chart/checklist. The participating parents also completed a checklist, which is provided below. Participants were instructed to complete the checklist by placing an “X” in the appropriate box of a six-point Likert scale. The participants’ answers, based on the six-point scale (as shown below), were then aggregated to reach an average answer and determine a general consensus among the families. See Figure 1.

Statement	Fully Agree 6 points	Mostly Agree 5 points	Somewhat Agree 4 points	Somewhat Disagree 3 points	Mostly Disagree 2 points	Fully Disagree 1 point
Autism is an emotional disorder.						
Early intervention can lead to significant gains in children’s social and communication skills.						
All children with autism display poor eye contact.						
Autism is more frequently diagnosed in males than in females.						

Figure 1. Checklist completed by each participant.

Statement	Fully Agree 6 points	Mostly Agree 5 points	Somewhat Agree 4 points	Somewhat Disagree 3 points	Mostly Disagree 2 points	Fully Disagree 1 point
Children with autism typically perform better when tasks are presented visually than when tasks are presented verbally.						
Problems with social relatedness that are present in autism are different from social problems seen in other psychiatric conditions.						
Children with autism do not show attachments, even to parents/caregivers.						
Research indicates that sensory integration therapy is an effective treatment for autism and its symptoms.						
Children with autism are deliberately uncooperative.						
Autism tends to run in families.						
Children with autism do not show affection.						

Figure 1. (continued)

Statement	Fully Agree 6 points	Mostly Agree 5 points	Somewhat Agree 4 points	Somewhat Disagree 3 points	Mostly Disagree 2 points	Fully Disagree 1 point
Most parents/caregivers of children with autism report their first concerns were related to the child's social behavior.						
Children with autism can grow up to live independently.						
There is one approach/program that works for all children with autism.						
It is important that all children diagnosed with autism receive some form of special education services at school.						
Autism occurs more commonly among higher socioeconomic and educational levels.						
Autism can be diagnosed as early as 18 months.						

Figure 1. (continued)

Statement	Fully Agree 6 points	Mostly Agree 5 points	Somewhat Agree 4 points	Somewhat Disagree 3 points	Mostly Disagree 2 points	Fully Disagree 1 point
With the proper treatment, most children diagnosed with autism eventually outgrow the disorder.						
The need for routines and sameness is one of the earliest behavioral features of autism.						

Figure 1. (continued)

Procedures

The interviews and surveys took place over two days per each participating family, approximately an hour to an hour and a half each day. The participants' responses and information obtained were subsequently analyzed and synthesized over a one month period. Furthermore, since this study was conducted and is associated with a Master's Degree course, the written work product took approximately four to five months to complete in its entirety. The study was conducted at the Cherry Hill and Moorestown Public Libraries, in addition to the participants' homes. Some interview responses were conducted via telephone conversation and remained confidential and protected. Survey responses were recorded on paper.

Additionally, in order to protect the participants in this research study, confidentiality was addressed. The researcher obtained the confidentiality of each

participant by password protecting each audio tape and survey questionnaire (after scanning the written surveys into the researcher's computer file and subsequently shredding all paper copies). The participants' names were not used in this study and pseudonyms were created. Further, the requisite consent forms signed by each participant were maintained in Rowan University's protected Institutional Review Board ("IRB") portal and all paper copies were shredded upon their upload to the IRB portal.

Validity

The researcher is a special education teacher of seventeen years, whose interest in this phenomenon, because of his work with children with ASD over the last three summers, was significantly sparked, compelling him to seek further advancement by completing his Master's degree in this field of study. "It is critical to pay attention to positionality, reflexivity, the production of knowledge and the power relations that are inherent in research processes in order to undertake ethical research..." (Sultan 2007, p. 380). Given the researcher's dedication to the topic, the research ensured that all data processes were effectively recorded and validated. Thus, the research processes used to maintain study validity included an audit trail. The audit trail used to validate this research study detailed the date and time of each interview and survey and was organized and maintained throughout the entire study. See Figure 2.

The role of the researcher and its potential impact on the analysis of the study was also considered. The researcher is an acquaintance of all four of the families chosen to participate in this study. However, the researcher's acquaintance did not impact the

results of this study as he remained impartial at all times and asked the same questions to all families to ensure consistency across the data points.

<u>Family Interviewed</u>	<u>Date of Interview</u>	<u>Time Start</u>	<u>Time End</u>
Family 1	12/18/17	6:00p	7:30p
	12/28/17	7:00p	8:30p
Family 2	12/12/17	5:00p	6:00p
	12/16/17	2:00p	3:00p
Family 3	1/28/18	12:30p	2:00p
Family 4	1/14/18	11:00a	1:00p

Figure 2. Audit trail of interviews.

Data Analysis

The researcher used content analysis to code data gathered as a result of this study (Hartmann, 2012). Content analysis is a method that is used to transform data from a qualitative to quantitative form (Hartmann, 2012). Coding, specifically thematic coding analysis was utilized after completing all participant interviews by categorizing the research into a limited number of categories (Monette et al., 2008). Thematic coding analysis is one of the most common forms of analysis in qualitative research. It emphasizes pinpointing, examining and recording patterns or themes within data (Guest,

2012). Themes are patterns across data sets that are important to the description of a phenomenon and are associated to a specific research question (Guest, 2012).

Therefore, the coding conducted pursuant to this study allowed the researcher to identify the major themes, similarities and differences presented in the participants' interview, survey questionnaires and uniform checklist responses as it relates to their child's ASD diagnosis and accordingly, its familial impact. Themes and codes will be presented in Chapter 4.

Chapter 4

Results

Parent data were collected via multiple sources including: (1) parent interviews, (2) open-ended surveys, and (3) a researcher developed parent ASD checklist. The researcher took detailed notes of each interview and required the participants to transcribe the survey portion of the study in order to obtain and collect, in the participants' exact words, this critical aspect of the interview—particularly the ways in which individual families were and are affected by their child's ASD diagnosis.

Following the interviews, data received from the participants were coded using content analysis. Content analysis is a method that is used to transform data from qualitative to quantitative form (Hartmann, 2012). Coding was done in this study by sorting the research into a limited number of categories (Monette et al., 2008). This approach allowed the researcher to identify the similarities and differences between families who are impacted by ASD. Content analysis also enabled the researcher to identify the major themes, as provided for below, presented by these families in relation to each category. The categories were (a) feelings around autism, (b) knowledge around autism, (c) life changes, (d) affect on relationships, (e) support systems, including educational supports and (f) acceptance, meaning and advice.

Demographics

As explained in detail in Chapter 3, Family 1 is comprised of two married parents, whom are parents to a male, high-school aged child with ASD and one daughter in middle school. Family 2 is comprised of two married parents, whom are parents to four

children—one set of triplets (two boys with ASD and one girl, unaffected) and one son, college-aged, who is unaffected. Family 3 is comprised of two married parents, who have two college-aged males, one with ASD, and the other unaffected. Family 4 is comprised of two married parents and one college-aged male with ASD.

The demographic characteristics of the participating families are as follows: all four sets of parents are Caucasian, middle to upper economic status; one mother is a nurse, one mother has a Doctorate degree in Education, another parent has a Master's degree in Education (Early Childhood), and another parent is a real estate broker. All participants reside in New Jersey. The age ranges of the participating parents are 38 years old through 52 years old. As noted above, the families will be referred to as Family 1, 2, 3 or 4, for anonymity.

Research Question 1: Parent Social and Emotional Experiences

Interview responses. Through the interviews, parents were asked about the following related to their social and emotional experiences: (a) feeling surrounding ASD, (b) knowledge of ASD before and after diagnosis, (c) how the diagnosis changed their family dynamic, and (d) affect on inter-familial relationships. Emerging themes related to the social and emotional experiences of parents as a result of a child being diagnosed with ASD include mixed emotions along with the identification of an autism diagnosis resulting in several life changes, which can and do vary by family, and a lack of support.

Feelings surrounding ASD. In the interview portion of the study, the four participant families were first asked about their feelings about ASD, and their answers resulted in the emerging theme of mixed emotions.

Family 1 reported feeling sad, stating “so many families have it and struggle to survive.” While some families have a difficult time accepting the diagnosis and deny literature reports that describe ASD symptoms, Family 1 noted their immediate acceptance of the diagnosis. However, Family 1 suggested feeling a lack of support from some of the school districts they dealt with and felt strongly that every diagnosed child should be afforded access to the necessary resources to be able to live up to their potential/capabilities.

Family 2 reported that ASD is a huge, incredible, insufferable disease that is a life altering diagnosis and that has the potential to destroy family relationship, particularly marriages. Family 2 has twins, both of whom were diagnosed with a high degree of ASD and which consumes “every minute of every day.” Family 2 further explained that the diagnosis is debilitating to their family. Family 2 also stated that “we experience grief on a daily basis that never dims nor lessens. It is an emotional heartbreaking challenge and an increasing financial strain on our family.”

Family 3 reported feelings of “heartbreak” upon receiving the diagnosis. They noted feelings of frustration some days and moments of joy on other days. Family 3 also said these feelings of frustration are “on-going, nothing is figured out, and no one is able to specifically tell you what to do, there is no handbook on dealing with ASD.”

Family 4 reported experiencing a spectrum of emotions. Like Family 3, Family 4 noted some days are “horrifying and disastrous while other days will have moments of joy and happiness.” Moreover, Family 3 explained that they were amazed at how many different issues can arise from having a child with ASD and said “it has been one hell of a

rollercoaster ride from time of our child’s diagnosis at 27 months until now at [the child’s] 20 years of age.”

Knowledge of ASD before and after diagnosis. The families were next asked: “What was your knowledge of ASD before the diagnosis and what paths did you take to learn more?” The results were varying—some families knew much about ASD from prior life experiences while other families knew virtually nothing and dedicated their time and resources to learn more. Emerging themes are parenting related and include parenting concerns and the importance of parental networking.

Family 1 reported having very limited knowledge initially and stated they only knew of the title Autism Spectrum Disorder prior to their child’s diagnosis. Before the diagnosis, Family 1 thought for a long time that their child’s peculiar behavior stemmed from their parenting ability. After the diagnosis, Family 1 was relieved to learn that their parenting had not played a role in their child’s behavior, and began to work together to better understand the disease. In addition, Family 1 currently feels that because of their research and due diligence on ASD, they were able to help control their child’s behaviors by not always “giving in” and ultimately were able to help their child adjust. Overall, Family 1 reported that their knowledge has enabled them to understand that ASD results in a wide spectrum of symptoms, some of which result in children whom are non-verbal, verbal, with limited capabilities, or very intelligent capabilities. Family 1 also explained that their knowledge of ASD comes down to “a mixed bag of life challenges and everything in between.”

Both Family 2 and 4 reported having no knowledge of ASD prior to the diagnosis. However, after their respective child's diagnosis, Family 2 and 4 used parental networking services to assist them in finding out what to expect and request from educational institutions, physicians, and other available services to help them better serve their child. Both families reported that at the time of diagnosis, they learned relatively quickly that available public research on ASD was not as up to date as they would have liked and therefore they "had to guess at what to do in some instances."

Family 4 also explained that they learned, not from literature or from their physician, but from experience that ASD is a "rollercoaster ride that doesn't have to be all bad and you still have some sort of quality of life to look forward to." Moreover, both Family 2 and 4 stated that they learned, again from experience that "you have to have a doctor, a lawyer, a special education teacher and of course dedicated parents to help navigate through the maze of advocacy and responsibility that this diagnosis requires."

Family 3 reported at the time of their child's diagnosis, the mother was employed as a middle school special education teacher. Therefore, Family 3 had some knowledge of ASD through the mother's work with autistic students, although such work was in a limited capacity. After the diagnosis, Family 3 took to the internet, in a vigorous fashion, to read up on the latest information and innovations companies and scientists had to offer for families affected by the disease. Shortly after the diagnosis, Family 3 also sought what they believe to be the most important source of information for coping families – a parent network. Family 3 therefore participated in a local support group, comprised of families whose child or children were diagnosed with ASD. The support group enabled

them to speak with similarly situated families and learn coping mechanisms, advocacy methods, qualified physicians, and the like. In explaining the parent network for which they derived much of their knowledge of ASD, Family 3 stated, “the parents of a child affected with ASD are the people who are distinctly qualified to provide information and comfort when your world is spinning out of control, the people that understand what your life is like and the people who are there in time of need.”

How did the ASD diagnosis change your family dynamic? Findings indicate that an ASD diagnosis often results in changes in the family dynamic (Autism Society, 2011). Therefore, the four families were asked, how did ASD change your family? Emerging themes include life changes (affecting finances and job status) and sibling impact.

Family 1 reported that their family dynamic remained strong despite overwhelming feelings of disbelief, sadness and stress. Family 1 recalled that a notable change to their family was the constant need to always accommodate their son’s issues and the need to keep the same daily routine for their child with ASD, which greatly impacted their daily lives as one parent had to stop working in order to be home during the day care for their child.

After being asked the question, Family 2 was initially too emotional to respond, which is perhaps the most telling response of the ways in which ASD can affect a family. After some time, Family 2 stated:

Daily life for us was being exhausted, sleepless nights, and always aware of the next days’ challenge. Our whole world and what we the life we had hoped our child to have has changed and our lives as a family will never, ever be the same or normal. Every day is an accommodation and our other children often were overshadowed and felt forgotten,

and at times resentful. Those moments when we were unable to give our other children the attention and care they desperately needed will never be given back to us and for that we will always have regret.

Family 3 reported that their family changed due to the “added pressure to become knowledgeable on all issues concerning ASD as well as needing all types of resources.” Family 3 sought therapy for themselves individually as well as together, as well as occupational and speech therapy for their child. Further, Family 3 noted that they were unable to “do activities as a family unit that normal families can do such as going to the movies, out to dinner, shopping, and especially shopping at toy stores.” Moreover, the unaffected sibling/child in Family 3 experienced jealousy when professionals came to their home to play and provide occupational and speech therapy with the autistic child, not knowing that it was therapy. Family 3 explained that their other child was jealous and frequently felt neglected because his sibling with ASD received more attention and resources than he did, feelings which were hard to cope with for the parents. In response, Family 3 stated they ultimately hired someone from the community to come over just to play and chat with the unaffected child so he wouldn’t feel “left out.” In sum, as a result of the diagnosis, Family 3 experienced difficulties with their unaffected child and conveyed feelings of sadness that they were unable to live life as a “normal family.”

Family 4, who only has the one male child, affected by ASD, reported that it was very stressful financially as “all of our life decisions and finances were based on ASD.” The family further explained that the ASD diagnosis dictated “which one of us would work based on the salary and benefits of our jobs, where we worked, and how long our work day could be.” At work, both parents reported feeling just as “stressed as if we were

home because of the anxiety of thinking about what was happening at the house.”

Additionally, Family 4 recalled an abundance of “tension on all fronts and our situation created barriers amongst our friends as well. It changed who we could be friends with and/or who would accept us. Eventually, this life altering diagnosis changed how and where we vacationed, what family events/holiday functions we could attend and where we could go on a daily basis.”

How did the ASD diagnosis affect inter-familial relationships? Research indicates that a child’s ASD diagnosis can have an adverse, and sometimes serious, effect on inter-familial relationships (Orsmond & Seltzer, 2007). Thus, the participating families were asked how their child’s ASD diagnosis affected their relationship with their other children. The question was only applicable to three of the four families as one of the families (Family 4) does not have other children. Emerging themes include, again, sibling impact, and experiences of mixed emotions.

Family 1 stated that they were very lucky in the fact that their unaffected daughter was too young at the time of their affected son’s diagnosis such that she was not negatively affected, as least initially, by all the extra and necessary attention their son garnered. Their unaffected daughter was also too young to understand and learn from the defiance, “the sounds of frustration and lack of communication” that their affected son experienced. However, Family 1 did note that as both of their children got older, their daughter was able to notice some of the issues, emotions, communicative hardships that ASD creates, which did affect their children’s sibling relationship as their son was unable to communicate in the same manner as their daughter.

Again, and perhaps most indicative of the ways in which an ASD diagnosis can affect inter-familial relationships, Family 2 was too emotional to respond and declined to answer.

Family 3 reported having major issues with their other unaffected child. Following the diagnosis, their unaffected child experienced significant jealousy as it pertained to the amount of attention, time, care and accommodation required to care for their affected son. This jealousy and difficulty in adapting to having a sibling with ASD caused a strain on the children's relationship as the unaffected son consistently felt that he was not receiving the same attention as his affected brother. Family 3 explained that their unaffected son "would get upset whenever he felt isolated from the family, which happened frequently in the early years and he would take his frustration out on his brother." As explained above, Family 3 sought to help their unaffected son cope by hiring a fake therapist to play with the unaffected child while their affected son was in therapy "just to make him feel as though he too was special."

Open-ended survey responses. Responses to the parent open-ended survey questions were coded according to the themes emerging from parent interviews of mixed emotions, life changes, parenting, strength of family unit, and sibling impact.

Mixed emotions. Parent written narrative corroborated the theme of mixed emotions emerging from the interviews. In response to a question about how having a child with ASD has affected their life, Family 3 reported the positive affect of learning to appreciate small accomplishments, yet also the negative emotions related to changing family dynamic:

Everything about my life has been impacted by autism. It has made me a stronger person, it has taught me to appreciate every small accomplishment in life, and has pulled our family closer together, and it has taught me to not care about the perceptions of others . . . I also feel autism has greatly affected my extended family as a whole. I have a sister who also has a child with autism. I imagined my sister and I would raise our three children as cousins that grow up together in the traditional sense. Instead, the dynamic became about autism, how to handle and overcome related obstacles for our boys throughout their childhood...

Similarly, Family 1 stated that ASD made their family stronger in terms of improving their patience and allowing them to grow as individuals. Specifically the mother of Family 1 explained that ASD “gave her insight” about herself and “growing up since” her son “has largely been a mirror” of her. Also, the diagnosis has taught Family 1 that “not all changes that come from having ASD are bad, and we have tried to adjust to the many life changes by introducing change slowly.” Family 1 ended by stating that “the negative aspect is that we are very similar emotionally and tend to bounce off each other and escalate issues that come up between us.”

Life changes (including jobs changing). Parent written narrative corroborated the theme of career choices, or the decision of which parent should work and which should stay home as the caretaker, emerging from the interviews. In response to a question about how has ASD affected their daily lives, Family 1 explained that after the diagnosis and learning of the specific care that was needed for their child, which required a parent available during the day to satisfy the needs of and support their child, “we knew that as the mother, I would stop working and be the caregiver and my husband would work full time.”

Likewise, Family 4 stated that it was very stressful financially for their family following the diagnosis “as all of our life decisions and finances were based on ASD.” Family 4 further explained that the ASD diagnosis directed “which one of us would work based on the salary and benefits of our jobs, where we worked, and how long the work day would be.”

Parenting (concerns; network). Parent written narrative established that seeking support, of various forms, is just one part to providing a child with ASD the resources they need to succeed. The other crucial piece is acceptance and unconditional love of the child. In responding to a question about what advice they would give to other parents raising a child with ASD, Family 4 explained:

It’s also important to network with other parents as this will be their best source of information. They need to learn to advocate for their child, wither through hiring of an attorney or immersing themselves in the how the system works for the EI, through the school years, into transition planning and young adulthood. But always remember, the key is NOT to get lost in this process. This is a child who needs most of all your touch, your smiles and encouragement. He or she needs to be engaged and have life experiences which will lead to new opportunities, so rather than trying to change them, it’s important to make a connection wherever they are and build slowly on their strengths and interests. As much as they need to learn from you, be willing to learn from them and appreciate who they are. This will provide a foundation you cannot get from any therapy or school program.

Family 1 explained a similar sentiment, reporting:

Understanding that this is a miracle will help people. It’s a miracle that you get to learn from and love a child that is yes, different, but still has so much to offer. We as parents need to let go of the “what ifs”; and “I should have”; and “what else can we do”; and be more in the present with our

child who has so much to teach us about the world, just like we have so much to teach them.

Strength of family unit. Parent written narrative also corroborated the theme that ASD can have the effect of either strengthening or weakening the family unit, as made clear in the participating families' responses when asked about the changes in their family dynamic. Family 1 specifically had a positive reaction to the strength of their family unit, reporting that the family "became stronger than ever despite the overwhelming feelings of disbelief, sadness and stress. We were able to withstand the trials and tribulations of ASD and its ability to separate families."

To the contrary, Family 2 provided a much different answer, explaining that:

Every day is an accommodation and our other children often are overshadowed and feel forgotten and at times resentful. All of these feelings have separated and fractured our family and it may never recover from what will be a life-long process.

Sibling impact. Parent written narrative corroborated the theme of from the interviews that siblings of affected children often feel ignored by their parents and therefore relate negatively to their sibling. In response to a question about how their other child have been impacted, Family 3 explained that their unaffected child experienced jealousy when professionals came to the home to either play or provide occupational and speech therapy to their affected child:

Our other child was jealous and frequently felt neglected because his sibling with ASD received more attention and resources than he did, feeling which were just as, if not harder, for us as parents to cope with. We wanted our children to feel equally loved, and we were failing at that.

Family 1 reported that:

Early on our daughter was too young to understand and learn from our other child's defiance, the sounds of frustration and lack of communication. But as she got older, she began to inevitably notice these issues, emotional outbursts, and communicative hardships that ASD caused for her brother, which took an emotional toll on her as she realized that she would receive less and less attention and quality time from us—her parents.

Research Question 2: Ways Families Overcome the Diagnosis

Interview responses. In the interviews, participants were also asked about the following two areas related to their social and emotional experiences, (a) support systems, including educational supports and (b) acceptance, meaning and advice. Themes related to the ways in which families cope and overcome a child being diagnosed were identified as various forms of therapy and strong family bonds. Similar to the social and emotional impact of ASD on a family unit, coping strategies varied by family—some families sought no support and felt dissatisfied with the available educational resources provided to their child, while others took many steps to receive outside support and communicated feelings of complete satisfaction with their educational supports.

Support systems. Support systems play an extremely important role in parents' ability to cope and manage the stressors that exist in caring for a child with ASD (Meadan et al., 2010). As such, the families were asked about outside sources of support they sought for their child after learning of the ASD diagnosis. Emerging themes were familial support, parent networks, and therapy.

Family 1 reported reaching out to an art therapist, which had tremendous results for their affected child. Arts specifically seemed to calm and smooth many of their

child's episodes, as it "gave him an outlet to be more expressive and provided him with a feeling of worth."

Family 2 did not seek outside support following their children's diagnosis. In fact, Family 2 did the opposite, and isolated themselves from support systems, family and friends, due to "the enormous challenges and episodes twins with ASD can create."

The mothers in Family 3 and 4 are sisters, both having children with ASD. Therefore, Families 3 and 4 reported that their strong family relationship played a large part in their support system. In addition, both families utilized parent networks on the internet for answers, support, and references for outside support systems. Ultimately, both families retained the same therapist to assist and support their affected child. Further, Family 3 took their affected child out of public school, choosing to enroll the child in a Christian-based school program which offered and ensured smaller class sizes, with dedicated support to their child. Family 3 worked closely with the Christian school to create a special program to help nurture and foster a better life for their child with activities that allowed their child to have positive interactions with other students. Family 3 reported that the program enlisted many student volunteers.

Educational support. The families were next asked, what educational support did they have to help guide them through these challenging times? The results yielded mixed results regarding the educational supports received by their school districts, with some families finding strong support in their school districts and others resulting to litigation to enforce their child's rights under the law.

Family 1 and 4 reported having a great deal of success in finding the necessary resources within their school district to support their families. Family 1 stated, “the best change and support we got is when we left our previous district and go into Moorestown School District. Moorestown’s child study team took our son’s individual educational plan (IEP) that had him placed in self-contained and moved him to inclusion with supports. His support teacher gave him a device (fidget toy) for his hands to use to help him stay focused and process information. This change promoted phenomenal growth and he is still flourishing now a senior in high school.”

Family 4 stated, “having a one-on-one, classroom aides with special education degrees, small group instruction, speech, physical and occupational therapy were all essential in our son’s growth.” In addition, “our school district’s picture exchange communication system was instrumental early on in giving our son confidence and helped him with his ongoing frustrations ... those big, colorful pictures saved him and us. It was just the start we so desperately needed.”

The mother in Family 3 similarly explained, “since being a special education teacher, I had some prior knowledge of the type of issues that can and do arise from autism and I continued to self-educate myself after my child’s diagnosis.” Moreover, Family 3 continued to reach out to other families and professionals to receive educational support. Lastly, Family 3 started their own private organization, a relationship developmental intervention program, which is a treatment program for ASD based on the belief that the development of dynamic intelligence is the key to improving the quality of life and educational outcomes for autistic students.

Family 2 reported having an entirely different perception than the other families regarding educational support from their school district. Upon being asked the question, Family 2 family replied, “what educational support? We spent years fighting with our home district to come up with appropriate tools and resources to aid in our children’s growth. We strongly believe the public school system failed in their duties to help advocate and allocate the necessary resources for the needs of our family. It’s been a rough year. Very rough. We had to sue our district in a groundbreaking legal court to enforce home based learning program. After the legal battle, we now have the honor and stress of hiring, planning, and overseeing the entire program on their dime.”

Acceptance and advice. The families were asked if they have accepted the diagnosis and whether they had any advice to offer other parents whom are coping with a child’s ASD diagnosis. Emerging themes are both full acceptance of the diagnosis, and struggles to adapt and accept the diagnosis.

Family 1 explained, “after the diagnosis we were actually relieved. We have gone through so much and his episodes at times became violent and hard to contain and we didn’t know what to do. Again, it was a relief to us because we now realized he didn’t choose to be defiant and it wasn’t bad parenting. We now understand what is working in his brain and what is not and are appreciative of this particular diagnosis rather than it being a dangerous one like if he didn’t take his medication he could hurt himself or someone else.”

Family 2 added that although they have learned to accept it, “life has not been kind” as their twins have a higher degree of ASD symptoms than the other families,

which “results in all issues and symptomatic episodes being doubled.” Family 2 also offered the following advice for parents: “be a warrior, trust your gut and do not listen to schools. It is not easy, but there is no choice but to walk day by day, hand and hand, to fight the fights your child may never be able to do on their own.”

Like the other families, Family 3 and 4 have also accepted the diagnosis. Family 3 stated, “absolutely, we all have accepted this life challenge. We are so proud of our son. He has had many obstacles in his path growing up and has built up such determination and drive which has allowed him to have a seat in the inclusion classroom. Lastly, he has come so far that he has been chosen to participate on the track team.”

Family 4 similarly expressed, “we have most definitely accepted our situation our priority is to ensure he can be the best person he can be and receive the highest quality of life possible.” Family 4 also offered the following advice to other similarly situated families, “in order for families to be more successful, they need to have a different perspective and expectations for their child and be able to find themselves in all this mess.”

Open-ended survey responses. Responses to the parent open-ended survey questions were coded according to the themes emerging from parent interviews of familial support, therapy, acceptance of the diagnosis, struggles to accept the diagnosis, strong school district support and litigation to enforce their child’s educational rights under the law.

Familial support. Parent written narrative corroborated the theme of familial support emerging from the interviews. Family 2 relied heavily on their parents for support, writing:

Having twins with a high degree of ASD and many issues and episodes, made us feel like we would be a burden to anyone else if we asked for help. We just wanted to keep everything inward and suffer in silence. But we ultimately turned to our parents to for support and guidance and due to their unconditional love for us as their child and their grandchildren, they supported us every step of the way and we are forever grateful that they did. Our parents are the reason we made it through the beginning years.

Similarly, the mothers in Family 3 and 4, who are sisters, relied on one another. Family 3 explained:

I also feel autism has greatly affected my extended family as a whole. I have a sister who also has a child with autism. I imagined my sister and I would raise our three children as cousins that grow up together in the traditional sense. Instead, the dynamic became about autism, how to handle and overcome related obstacles for our boys throughout their childhood.

Therapy. Parent written narrative corroborated the theme of therapy emerging from the interviews. Family 1 wrote:

We used various resources to help stabilize and support our family. We relied heavily on self-education by researching and reading the latest book articles as well as journals, use of videos on the internet, and with the request of our therapist, we found art therapy to be a promising activity which helped our child focus and allowed him to doing something that enriched his life.

Acceptance of the diagnosis. Parent written narrative corroborated the theme of acceptance of the diagnosis emerging from the interviews. Family 1 explained that although it took years to fully come to terms with the diagnosis, their family was ultimately able to accept their “new normal.” Specifically, Family 1 wrote:

We fully accepted it, embraced it, and took it upon ourselves to gain as much knowledge about ASD, but realized the information was about five years old. Also, early on our psychologist was really resistant to diagnose it as ASD even though school officials and our immediate family agreed that the symptoms pointed to ASD. At that time the psychologist wanted to treat for bipolar disorder. We gained more knowledge as we gained experience and changed providers. And since our affected child is our oldest, we are not sure what it would have been like to have a “normal-neurotypical” child, but at this point all that matters is that we continue on supporting our child.

On the other hand, Family 2 has not been able to accept the diagnosis, explaining:

Unfortunately, I do not think we have accepted the diagnosis. We have two other teenage children who are not affected and who will have to deal with this and eventually fill our role as caretaker one day. They know and we know it but it is too much to bear. Our lives have been very hard and rough. Very rough.

Strong school district support and litigation against the school district. Parent written narrative corroborated the theme of varying satisfaction with the educational support provided to a child diagnosed with ASD. For example, the half of the participating families reported satisfaction with the education made available to their child and other half reported extreme dissatisfaction. As it relates to satisfaction, Family 1 explained:

I am very satisfied with all of the services provided by my district. I am not sure how much progress our son would have made in the previous district if we had stayed there.

Along those same lines, Family 4 wrote:

We are currently satisfied. This is primarily because our district suggested a settlement agreement which allows us to have our child placed in a very small private program which is tailored to meet the needs, specifically, of non-verbal ASD children. Our child is challenged; he feels competent and confident which allows him to participate in school at a higher level. Our school district did not feel they could offer an appropriate placement for our child so they have always been flexible in considering private options.

Conversely, Families 2 and 3 both reported dissatisfaction with their school districts ability to adequately serve their child. Family 2 reported:

We had to sue our school district to get basic educational support. We had a groundbreaking legal court enforced agreement for a home program and we now have the honor and stress of hiring, planning, and overseeing our children's education. It's been really hard and we are extremely disappointed and angry with the lack of care, resources, and understanding of the district.

Likewise, Family 3 responded to the question, writing:

Nope. The school has two options: autistic support for students with co-occurring intellectual disability- a life skills program with no academic emphasis, OR, autistic support that is separate from but parallels the typical curriculum required of all students. As every student with autism is unique and has specialized needs, this tracking is not ideal.

See a reporting of categories and emerging themes in Figure 3.

Research Question	Categories	Themes
Impact of ASD on Parent Social and Emotional Experiences	Feeling surrounding ASD	Mixed emotions
		Life changing
		Lack of support
	Knowledge of ASD	Parenting (concerns)
Parenting (networking)		
Impact on family dynamic	Strong family unit	Life changing (job)
		Sibling Impact
		Affect on Inter-familial relationships
Affect on Inter-familial relationships	Sibling Impact	
	Mixed emotions	
Ways Families Overcome the Diagnosis	Support systems	Family Relationships
		Parenting Networks
		Non-acceptance
	Acceptance of diagnosis	Relief
		Setting Realistic Expectations
		Research
	Educational supports	Use of 1-1 Aide
		Compliance with IEP
		Litigation

Figure 3. Categories and emerging themes.

Parent checklist results. In addition to the open-ended interview questions, the participating families completed a parent checklist, which asked survey questions on a scale of fully agree, mostly agree, somewhat agree, somewhat disagree, mostly disagree and fully disagree. The researcher subsequently distilled the numerous survey questions into seven topical questions that are most salient and pertinent to the research questions

which guide this study. The researcher also awarded a point scale to those seven questions (6 = fully agree to 0= fully disagree), in order to reach quantitative conclusions regarding ASD's affect on families. The results of the parent survey checklist are in Table 1 below.

Overall, parents somewhat agreed (M=4) that ASD has an emotional impact on their child. Parents mostly agreed (M=5.5) that ASD translates into their child's social behavior as being different from other psychological conditions. Parents also mostly agreed (M=5) that their first indication of the ASD diagnosis was their child's social behavior, yet parents agreed, albeit on the lower end of "agree" (M=3) that ASD runs in the family. Conversely, parents mostly disagreed (M=1.5) that their child does not show attachment to themselves as parents or to caregivers, that their child is deliberately uncooperative, and that their child does not show affection.

Table 1
Parent Checklist Results

	ASD has an emotional effect on the child	Socially different from other psychological conditions	Child does not show attachment to parents/caregivers	Child is deliberately uncooperative	Parents' first concern/indication of ASD was social behavior	ASD runs in family	Child does not show affection
F1	6	4	2	2	5	5	3
F2	6	6	2	2	6	1	1
F3	3	6	1	1	6	5	1
F4	1	6	1	1	3	1	1
Mean	4	5.5	1.5	1.5	5	3	1.5

Note. F1= Family 1; F2= Family 2; F3= Family 3; F4= Family 4; Likert scale 6= fully agree; 5= mostly agree; 4 = somewhat agree; 3 = agree; 2 = somewhat disagree; 1= mostly agree; 0= fully disagree

Conclusion

The purpose of this research was to examine the impact of ASD on families. The interview and survey responses were analyzed with a goal to empower future and current families who are raising a child with autism as well as to provide vital information that can be applied to their specific situation. Chapter 5 provides a detailed discussion of the findings of this study.

Chapter 5

Discussion

The purpose of this research study was to examine the social and emotional ways in which ASD affects the family dynamic. Specifically, this study aimed to:

1. Examine the social and emotional experiences of parents and siblings that naturally flow from a child being diagnosed with ASD.
2. Explore and identify the ways in which families can successfully overcome the negative impact of an ASD diagnosis and ultimately persevere as a family unit.

Findings

Themes related to the social and emotional experiences of parents as a result of a child being diagnosed with ASD were identified as mixed emotions and experiences as an autism diagnosis often produces several life changes, which can and did vary by family. Themes related to the ways in which families cope and overcome a child being diagnosed were identified as various forms of therapy and strong family bonds. Similar to the social and emotional impact of ASD on a family unit, coping strategies varied by family—some families sought no support and felt dissatisfied with the available educational resources provided to their child, while others took many steps to receive outside support and communicated feelings of complete satisfaction with their educational supports. This study corroborates the findings of Ryan and Cole (2009) and Schwartz (2001) who found that parents use of services for their child varies, including the type of services and interventions used as well as the availability of services and overall satisfaction with services received. Parents described an array of different

interventions and services. Support groups were used by some parents who found them helpful.

While some parents really appreciated the services they received, many others described frustration at various points of the diagnosis. Parents' concerns about their inability to manage their children and their children's behavioral signs were brushed off and dismissed by pediatricians and specialists, so that diagnosis was delayed (e.g. Martinez 2009; Schwartz, 2001). Once a diagnosis was made, one of the major sources of frustration was the difficulty in obtaining services. This aligns with the findings of Hutton and Caron (2005) who quoted a parent sharing a similar experience to those in the present study, "My child was put on a waiting list for being assigned to a case manager. I was told that in the meantime, I should do the case management and coordination of services, which was appalling since I was already so stressed" (Hutton & Caron, 2005, p. 185).

Parents

Banach et al. (2010) found that upon hearing their child's diagnosis, "52% (of parents) felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame" (Banach et al., 2010). Findings of the present study align with those findings as one parent felt relieved that her son had autism and not a dangerous type of diagnosis such as one that if their medication cycle were to be interrupted there could be severe and dangerous repercussions to them or others. The other families reported feelings of shock, grief and sadness.

Another prior study (Schaaf et al., 2011) indicates that parents have to rearrange

their daily routines to accommodate their child with autism as the child is unpredictable and often unable to regulate their behavior. Parents reported that routines were much easier to follow in familiar spaces such as their own home, however, more difficult in unfamiliar places such as another relative's home or out in the community (Schaaf et al., 2011). Schaaf et al. (2011) also found parents' morning routines to be most difficult as most meltdowns occur during this time due to sensory issues, causing the child to be late for school and the parent to be late for work. Findings of the present study are similar to findings of Banach et al. (2010) and Schaaf et al. (2011) in that participants reported changing their daily routines significantly to support and accommodate their child with autism. One family reported that they were unable to do activities as a family unit that normal families can do such as going to the movies, out to dinner, shopping, and especially shopping at toy stores. Moreover, one family emphasized that daily life for them was being exhausted, sleepless nights, and always aware of the next days' challenge. Family 2 stated, "Our whole world and what life we had hoped our child to have has changed and our lives as a family will never, ever be the same or normal. Every day is an accommodation and our other children often were overshadowed and felt forgotten and at times resentful."

Implications and Recommendations

Autism is defined as a "persuasive developmental disorder" and those affected commonly express deficits in social communication, presence of restricted interests and repetitive behaviors that result in life-long impairments and disability, as well as creating significant burdens on the families, schools, and society as a whole (American

Psychiatric Association, 2000). However, with the help of parent networks, self-education, therapists, and a warrior's mentality, families can overcome the negative impact and challenges that arise from autism and still preserve as a family unit.

Limitations

This study has some limitations as the researcher only used families that he had a prior relationship with. The four families chosen are all Caucasian, with an middle-upper class socioeconomic status and are from a class of people that may have access to more professional resources and better educational systems than families of low-poor socioeconomic status. Similarly, a second limitation with this study is the absence of racial diversity as it relates to the participating families and their affected children. Results could have been much different by having a variety of races and cultures weighing in on their experiences with ASD and its impact on the family unit. Diverse cultures could produce diverse responses, different emotions, as well as acceptance of the diagnosis by way of cultural indifference. Finally, findings may be strengthened by an increase in the number of families, which is limited in this study to four.

Conclusion

ASD does not just affect the diagnose child—it affects the family as a whole and the parents as a couple. Parents have described the difficulty in balancing the needs of the family and the marital relationship along with the needs of the child with ASD. There is no exemption from ASD. It affects people of all social and economic status. As a matter of reference, this study could have benefited from a larger sample of participants and family members along with minority and lower socioeconomic representation across

the board to foster a better understanding of the impact and successful strategies in raising a child with ASD. However, the implication of this research nonetheless provides a deeper knowledge base and insight when working with families experiencing an autism diagnosis. Consequently, the research allows social workers, teachers, therapists and non-affected families to gain personal experiences from families who have a child or sibling with ASD. The research also reinforces the importance of providing appropriate resources to guide and support families who have a sibling or child with autism. All in all, it is essential for professionals to inform and empower future and current families who are faced with an ASD diagnosis.

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