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How having a child with special needs affects family functioning in families of different types

Victoria Nascati

Rowan University, vnascati@gmail.com

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**HOW HAVING A CHILD WITH SPECIAL NEEDS AFFECTS FAMILY
FUNCTIONING IN FAMILIES OF DIFFERENT TYPES**

by

Victoria L. Nascati

A Thesis

Submitted to the
Department of Psychology
College of Science and Mathematics
In partial fulfillment of the requirement
For the degree of
Master of Arts in School Psychology
at
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Thesis Chair: Dr. Roberta Dihoff, Ph. D.

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Dedication

I would like to dedicate this work to each and every person that has made up my support system for the past two years- my boyfriend, my family, and my friends.

Acknowledgments

I would like to express the utmost amount of appreciation to Dr. Roberta Dihoff for her guidance throughout this process. I am grateful for the knowledge she has passed on to me and for the help she has provided that made this work possible.

Abstract

Victoria L. Nascati

HOW HAVING A CHILD WITH SPECIAL NEEDS AFFECTS FAMILY FUNCTIONING IN FAMILIES OF DIFFERENT TYPES

2016-2017

Dr. Roberta Dihoff, Ph. D

Master of Arts in School Psychology

A number of children in the United States are diagnosed with Autism Spectrum Disorder each year. In the past several years, there has been an increase in this diagnosis. Along with this increase, there has been an increase in the variety of therapies, resources, and services available to children diagnosed with ASD. However, previous research has shown that there is a lack of resources for the parents and families of those children. The purpose of the current study is to gain insight into the daily lives of a family who has a child with Autism in order to assess the level of functionality and morale felt within the family from the perspective of a parent in both nuclear and non-typical families. A survey was used to collect data from 31 male and female parents who have at least one child diagnosed with Autism Spectrum Disorder between the ages of 3-21. Results of the study revealed that there is a correlation between the amount of stress felt within a family and the level at which they feel they function on a day-to-day basis. Understanding the stress felt by families of a child with special needs may lead to an increase in resources for the parents, siblings, and the families as a whole.

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Chapter 1

Introduction

Need

In 2013-2014, it was reported by the National Center for Education Statistics that nearly 6.5 million children and adolescents ages 3-21 were served under the Individuals with Disabilities Act (National Center for Education Statistics, 2015). This number tells us that 6.5 million families are caring for those children. More specifically, it was reported in March 2016 that 1 in 68 children in the United States are diagnosed with Autism (Centers for Disease Control and Prevention, 2016). Families are small communities that must run efficiently every day in order to get to the next. There have been several studies examining the family functioning when there is a child with special needs being cared for. Children with special needs typically need more extensive care, attention, and support. As cited in Myers, Mackintosh, and Goin-Kochel, parents of children with Autism experience higher levels of stress than parents of children who have other disabilities (Myers, Mackintosh, Goin-Kochel, 2009). This stress arises from a variety of factors, for example, Myers et al. noted that the severity of a child's impairment affects stress levels positively. M. Bayat conducted a study titled "Evidence of resilience in families of children with Autism." From the results, it was evident that several families that had a child on the Autism spectrum displayed factors of resilience; they felt stronger as a family as a result of their child's disorder (Bayat, 2007). These and several other studies investigate how families of a child with Autism function as a unit, many of them concluding that such families experience varying levels of stress, as well as strong levels

of happiness and fullness. However, there is little to no research on how Autism Spectrum Disorder affects different types of families, and whether or not typical/nuclear families thrive better than families that are not considered typical.

Purpose

The purpose of this study was to investigate how both nuclear or typical families and families of various backgrounds feel they thrive having a child with special needs. This study examined how families of various types kept their families functioning, happy, and whole. This study also examined whether or not family type has an effect on feelings of success and failure when keeping their families running.

Hypothesis

It was hypothesized that nuclear or typical families have a higher sense of positive family functioning and morale when compared to non-typical families.

Operational Definitions

A child with special needs: a child, aged 3-21, who has been diagnosed with a developmental, intellectual, or physical disability.

Nuclear/typical family: a family comprising of two parents and at least one child.

Non-typical family: a family comprising of one parent, foster parents, or extended family as parents.

Family Functioning: how a family moves through each day.

Assumptions

In this study, it was assumed that the participants answered survey questions honestly and to the best of their ability. It was also assumed that all respondents have a children or multiple children with special needs.

Limitations

There were limitations in this study surrounding the depth of answers participants were willing to give. Though a self-report survey, it was hoped that participants would give full-bodied answers about their feelings of functionality within their family. Further, limitations arose with the amount of parents willing to participate in the survey. Due to low participation numbers, data analysis was limited.

Summary

This study is necessary due to the growing number of families that have a child with special needs and the many things that the family needs to feel supported in their day to day lives. An investigation into the family functioning of these families may help lead to a better understanding of what families of a child with special needs may need to help their families feel more cohesive, happier, supported, and fulfilled as a unit. Results from this study may be useful in developing more organizations for families with children with special needs.

Chapter 2

Literature Review

The review of literature will first define Autism Spectrum Disorder (ASD) and the umbrella term “developmental disorders.” It will provide brief information on the prevalence of Autism Spectrum Disorder in the United States of America. This section will be followed by the second section that will discuss the various types of stressors experienced by parents of children with Autism Spectrum Disorder as well as other developmental disorders. The third section will provide information about the effect of marital quality in a family who has a child with a developmental disorder. Following this section, the functioning and resilience, both day-to-day and long-term, felt within families of a child or children with ASD will be discussed. The fifth topic to be discussed will be the financial strain of families with a child or children with Autism. Finally, all of the previous information will be summarized.

Autism Spectrum Disorder (ASD) and Developmental Disorders Defined

According to the National Institute of Mental Health, “Autism spectrum disorder (ASD) is the name for a group of developmental disorders. ASD includes a wide range, “a spectrum,” of symptoms, skills, and levels of disability (Autism Spectrum Disorder, 2016).” Another definition, according to Karst and Van Hecke, is “a spectrum of complex, neurological, and developmental disorders characterized by deficits in reciprocal social interaction and communication, along with the presence of restricted, repetitive, and stereotyped interests and behaviors (Karst and Van Hecke, 2012).” It was

reported in March 2016 that 1 in 68 children in the United are diagnosed with Autism Spectrum Disorder (Centers for Disease Control and Prevention, 2016). This supports the findings in recent years that there has been a steady increase in the diagnosis of Autism since the 1970's (Weintraub, 2011). This increase, according to Peter Bearman a sociologist at Columbia University, is due to environmental causes.

Though there has yet to be sound evidence of the cause, the rise of Autism is real and may be here to stay while a cause continues to be investigated (Weintraub, 2011). However, risk factors of the group of disorders are being identified (Baio, 2012). In 2012, a study by the CDC that collected data from 14 ADDM sites (The Autism and Developmental Disabilities Monitoring Networking) from the 2008 surveillance year, it was found that on average, rates of ASD were much higher in the ADDM sites that had access to education when compared to the sites that only had access to health related sources in order to identify the disorder (Baio, 2012). In a later study by the CDC in 2014, after collecting data from 11 ADDM sites, the per 1,000 diagnoses in eight year old children increased by 3.4 children on average (Baio, 2014).

Various Types of Stressors

As cited in Myers, Mackintosh, and Goin-Kochel, parents of children with Autism experience higher levels of stress than parents of children who have other disabilities (Myers, Mackintosh, Goin- Kochel, 2009). Children with special needs typically need more extensive care, attention, and support. This stress arises from a variety of factors, for example, Myers et. al noted that the severity of a child's impairment affects stress levels positively. In a study comparing mothers of children with ASD mothers of

children with Down Syndrome, it was found that mothers of children with ASD are more concerned about their children's dependence on others (Pisula, 2006).

In the same study, it was found that these mothers are most stressed about their children's future and the chronic nature of their disorder. The children's mothers are concerned about the level of dependency their children will have as they grow older. According to Karst and Van Hecke, approximately 85% of those diagnosed with ASD have such limiting cognitive and/or adaptive deficits that their ability to live independently is diminished. These limitations may lead to needing care or assistance from their parents, families, or friends well into adulthood (Karst and Van Heck, 2012). As cited in Karst and Van Hecke, a study by Seltzer et. al (2001) concluded that 50% of parents over 50 that had a child with a developmental disability still lived with their child. This possibility of a lifelong caregiver role likely aggravates all of the difficulties the family experiences as a result of the ASD diagnosis, may alter the parents perception of parenting, and may leave the family feeling hopeless about their own future (Karst and Van Hecke, 2012).

Another stressor indicated in the study is the level of understanding these mothers experienced about their children's disorders, leading to more difficulties in coping with the problems faced. The mothers in the study reported that they don't feel like a competent parents because of their lack of knowledge in how to raise and manage a child with ASD (Pisula, 2006). Due to the lack of public knowledge of the etiology of ASD, as well as no clear-cut cure in site, this makes the knowledge that is available difficult to

understand. The families must figure out the disability on their own, as well as treatments that work best for their children and resources that may help their family cope (Karst and Van Hecke, 2012). The difference in their child's behavior, social behavior, motor skills, communication, and play is another stressor experienced by parents of children with ASD even before receiving a diagnosis (Karst & Van Hecke, 2012). Parents notice these differences early on in development, as early as 6 months. According to Romanczyk, White, and Gillis, the primary core deficit in ASD is the aspect of social development (Romanczyk, White, and Gillis, 2005). As cited by Tsao from the DSM IV, the features of Autism include: (a) impairment in social interaction manifested by impairment in the use of nonverbal behaviors, failure to develop peer relationships; lack of spontaneous sharing, and/or lack of social/emotional reciprocity; (b) impairments in communication, manifested by delay in or lack of the development of spoken language, impairments in the ability to initiate or sustain a conversation, repetitive and idiosyncratic use of language, and/or lack of make believe play or social imitative play; and (c) restricted repetitive and stereotyped patterns of behavior, interests, and activities, manifested in preoccupation with restricted patterns of interests, inflexible adherence to routines, and/or persistent preoccupation with parts of objects (Tsao, 2008 p.40)

These features set aside children with ASD from typical children on the playground, in the classroom, and in every day interactions, which is the worry that their parents hold. Myers et. al collected statements from parents of children with ASD in a survey, and one parent expressed that due to the behavioral problems experienced by their

child, they have difficulty doing every day things such as car rides. Another parent wrote “We are ruled by his fixations and behaviors (Myers, Mackintosh, Goin- Kochel, 2009).” Several of the parents in the study conducted by Myers et. al had more to share about the difficulties they experience rather than the positive aspects of their life with a child with ASD (Myers, Mackintosh, Goin- Kochel, 2009).

Effect on Marital Quality

Being the parent of a child with Autism Spectrum Disorder, or any disorder, comes with difficulties that parents of typical children may never experience in their lives. These difficulties can cause strain on parental and family relationships. Hartley, Barker, Seltzer, Greenberg, Floyd, and Orsmond state that there have been reports of divorce rates of 80% between parents of children with ASD in the media (Hartley, Barker, Seltzer, Greenberg, Floyd, and Orsmond, 2010). While there is supportive literature noting that marriages suffer more when there is a child with ASD, there is little to no research done to empirical support the rate (Freedman, Kalb, Zablotzky, and Stuart, 2011). Though, according to Hartley, Papp, Blumenstock, Floyd, and Goetz, there is both theoretical and empercial research supporting that the interactions of parents that have a child with ASD are affected (Hartley, Papp, Blumenstock, Floyd, & Goetz, 2016) In marriages where there is a typical child/typical children, stress levels reach their highest prior to the teenage years and may cause strain on the parents’ relationship as the demands of their child or children increase, which leads to a certain neglect of their spouses’ needs. If the marriage survives this period, the couple is less likely to divorce and parental stress ideally decreases, as the child gets older. However, in parents with a

child with ASD, this stress does not decrease due to the nature of the disorder. The high stress is likely to maintain itself or increase causing a prolonged feeling of relationship neglect and increased strain (Hartley, Barker, Seltzer, Greenberg, Floyd, and Orsmond, 2010).

In 2011, results from the 2007 National Survey of Children's Health were taken in order to conclude whether or not children with ASD are more likely to become children of divorce. 77,911 parents were interviewed and of those parents, 913 had a child with ASD. After analyzing the results, Freedman, Kalb, Zablotsky, and Stuart found that children with Autism Spectrum Disorder are no more likely to become children of divorce in comparison to children who do not have the disorder (Freedman, Kalb, Zablotsky, and Stuart, 2011). Though there is little research on the direct correlation between children with ASD and divorce/separation rate, it has been found that raising a child with the disorder does negatively impact a marriage (Freedman, Kalb, Zablotsky, and Stuart, 2011). Decreased marital satisfaction, increased stress, and maternal depression were all found to have increased in parents raising children with ASD in comparison to raising a child with another disorder or a typical child (Freedman, Kalb, Zablotsky, and Stuart, 2011).

Parents of children both typical and non-typical experience a stage where they need to adapt to their new roles in their new child's life as well as their new roles to each other. This adaptation is likely to be a vulnerable time and this vulnerability may hinder their ability to effectively interact and communicate, and the willingness to engage in positive interaction may decrease due to the added stress (Hartley, Papp, Blumenstock,

Floyd, & Goetz, 2016) External stressors such as careers may also play a role in the less positive interactions (Hartley, Papp, Blumenstock, Floyd, & Goetz, 2016). The rearing of a child with a neurodevelopmental disorder adds another level of adaptation that may be difficult to navigate individually and may take a lot longer to be able to navigate together.

Functioning, Coping and Resilience

As cited in Bayat, “resilience has been described as the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful (Bayat, 2007.” Bayat surveyed 175 parents and primary caregivers who had a child with Autism Spectrum Disorder between the ages of 2 and 18 years. She investigated the resilience within families who have a child with the disorder. The study concluded that there is evidence in several families of children with ASD that display several factors of resilience and strength as a result of the disorder effecting their family (Bayat, 2007). In 2002, Taunt and Hastings asked families who have a child with a disability to report on two things. First, they were asked about the positive impact that the child with a disability had had on themselves, siblings, and extended family. Secondly, they were asked to report their opinions on what the future may hold for their child with a disability (Taunt and Hastings, 2002). In response to the first question, the parents reported that ASD has had positive effects on themselves and their families. Positive effects such as supporting each other, increased sensitivity, and changes in their perspectives on life (Bayat, 2007). In response to the second question, while there was some anxiety towards the futures of their children, there was a general sense of positivity for the futures of their children with a disability (Bayat, 2007).

In another study by Greef and Nolting focusing on parents of children with developmental disabilities, a positive correlation was found between acceptance of the situation, positive family communication, commitment to their families, a positive attitude towards life challenges, and adapting to their situations (Greef and Nolting, 2013). Pottie and Ingram sought out to research how the parents of a child with Autism adapt and cope to learning their child has the disorder. While there is little research about the coping of these parents, the research that has been conducted supports that there are positive effects that come from using various strategies (Pottie, Ingram, 2008). As cited in Pottie and Ingram, coping has a direct effect on the well-being of an individual. Additionally, though it has limited to no research, gender may be a variable in the effectiveness of coping strategies and their utilization. This may be attributed to the difference in stressors each parent may experience. (Pottie, Ingram, 2008). Little to no research was found on the effectiveness of support groups for parents of children with Autism Spectrum Disorder. Due to this finding, it may be able to be suggested that there are not many resources available to said parents which may be effecting the abilities of parents to cope, keep their family functioning, and achieve feelings of resilience within their lives.

Financial Strain

The diagnosis of Autism Spectrum Disorder has increased in the past several years. With this increase in diagnosis, there has also been a small increase in services and therapies available. While many, not all, therapies and services are covered under a number of insurance providers, not everything necessary to care for a child with Autism

is. As cited in Saunders, Tilford, Fussell, Schulz, Casey, and Kuo, the caregivers of children with ASD may experience a financial burden that caregivers of typical children may not experience (Saunders, Tilford, Fussell, Schulz, Casey & Kuo, 2015). With the diagnosis of Autism comes the uncertainty of the child's future and independence. Furthermore, the parents of a child with Autism may incur financial responsibilities well into their child's life. It has been reported that the lifetime cost of raising a child with ASD may be up to \$1.4 million, as cited in Saunders et.al (Saunders, Tilford, Fussell, Schulz, Casey & Kuo, 2015). Additionally, the mothers of children with ASD earned a substantial amount less, were less likely to be employed, and work fewer hours than mothers of children who experience other or no health limitations (Saunders, Tilford, Fussell, Schulz, Casey & Kuo, 2015). The potential of children diagnosed with ASD of having co-occurring disorders, such as ADD and intellectual disabilities, may contribute to the financial stress of the family due to the nature of caring for multiple conditions (Saunders, Tilford, Fussell, Schulz, Casey & Kuo, 2015).

After reviewing literature surrounding families of children with Autism, it is evident that there is much research on how these families thrive. There is also sufficient research on the marital quality of parents who have a child with ASD or another disability. With that said, there is little to no research that gives direct insight into the daily lives of these families as well as little to no research on effective strategies and resources available to parents that may help with maintaining functionality of their home and mental health. This study aimed to add to this research and dove into further

investigation on how families of several types function as a unit when living with a child with ASD.

Chapter 3

Methodology

Participants

The current study included parents of children with Autism Spectrum Disorder from a group of private schools in Southern New Jersey. A total of 31 parents chose to participate in this study. The sample in this study included 28 females and 3 males. The majority of participants, 22 (71%), were married, 9 (29%) of the thirty-one families were divorced, separated, never married, or single. 2 (6.5%) of the thirty-one families had adopted their child with Autism Spectrum Disorder. 28 (90.3%) of the respondents were female ranging from age 31 to 51. 3 (9.7%) males aged 44 and 55 participated in the survey, one was a divorcee. 16 (51.6%) of the participants were White, 8 (25.8%) were Hispanic/Latino, 6 (19.4%) were African American/Black, and 1 (3.2%) was Asian/Pacific Islander. More than half of the respondents were employed full-time, 18 (58.1%), and 7 (22.6%) were not working.

As represented in Figure 1, 14 (45.2%) of the participants fell into the \$70,000+ range in regards to income, 3 (9.7) made between \$21,00-\$30,000, and 3 (9.7) made between \$10,000-\$20,000. The remaining 10 participants reported making from \$31,000 to \$60,000. Only 2 (6.5%) of the respondents expressed financial hardships, both made between \$51,000 and \$70,000.

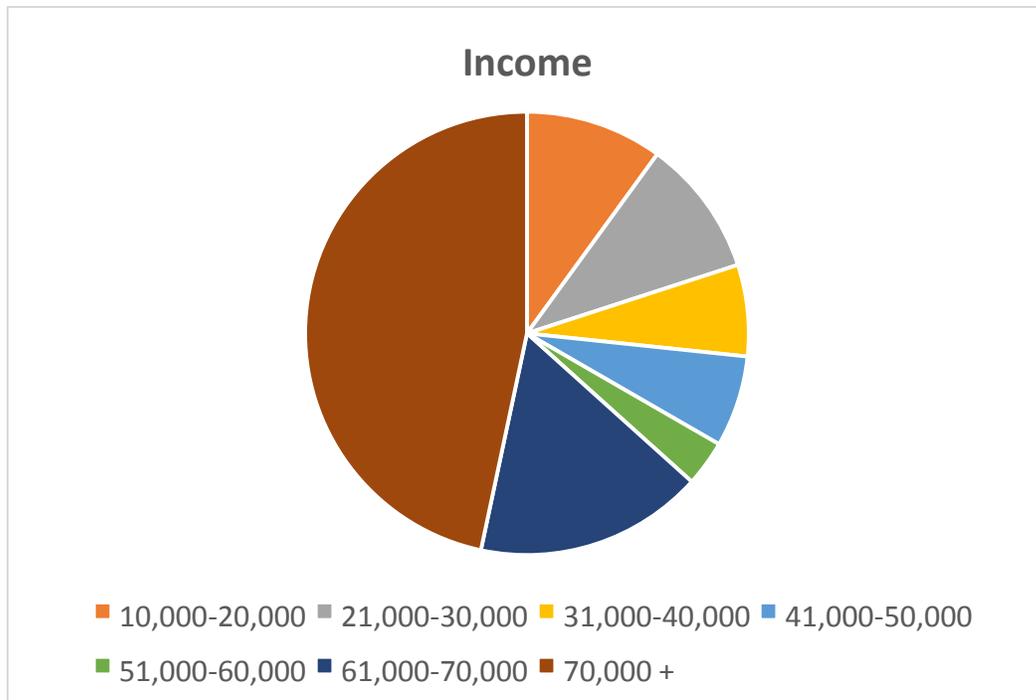


Figure 1. Income of families

11 (35.5%) of the families had two children, 8 (25.8%) had 3 children, and 7 (22.6%) had one child. Three of the families had two children diagnosed with Autism Spectrum Disorder. The ages of children diagnosed with Autism ranged from 5- 21 with 10 being the most frequent. 22 (71%) of the children diagnosed were males, 7 (22.6) females, and one parent preferred not to answer. One of the females and one of the males were adopted into their family through a non-familial adoption. 26 (83.9%) of the children were enrolled in a secondary education program, kindergarten- 12th grade, 4 (12.9%) were enrolled in an Early Intervention Program, and 1 child was enrolled in a program for 18-21 year olds as represented in Figure 2. 9 (29%) of the parents responded that their children had at least one co-occurring disorder. The disorders mentioned were:

Attention Deficit Disorder, Attention Deficit Hyperactivity Disorder, brain malformation, Epilepsy, migraines, Intellectual Disability, Sensory Processing Disorder, Insomnia, chronic constipation, weak eye muscles, fine and gross motor delays, Hip Dysplasia, sleep disturbances, Down Syndrome, and depression.

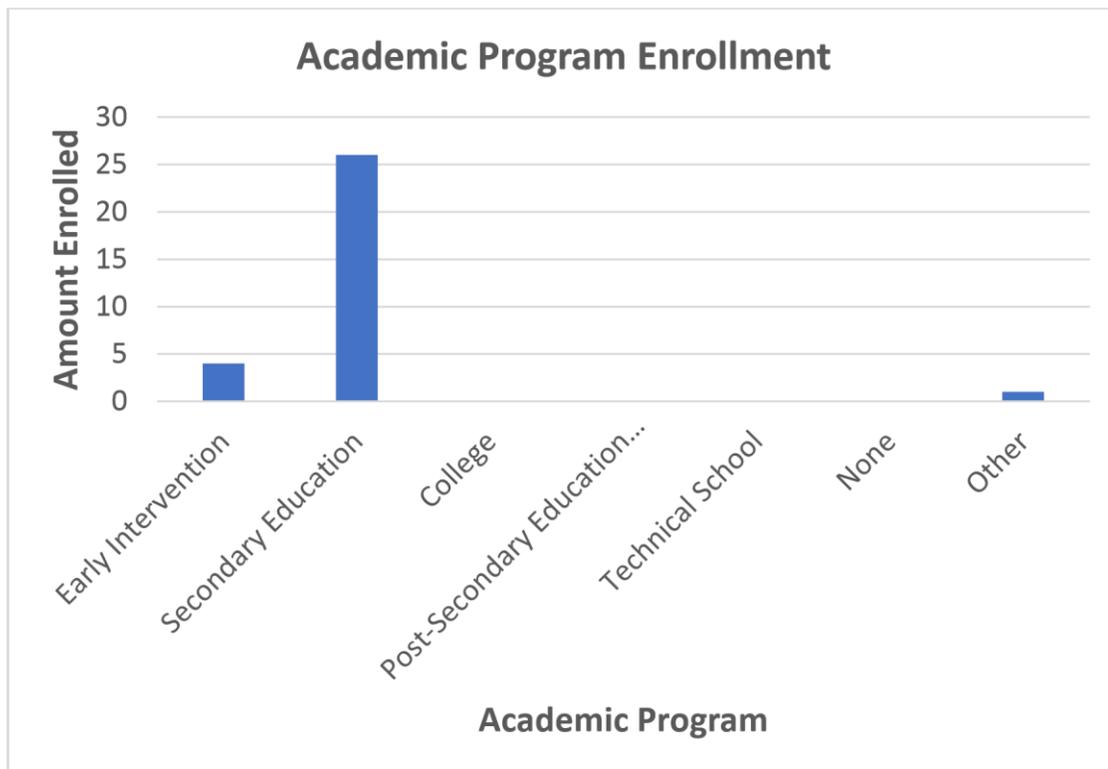


Figure 2. Academic Program

In order for a parent to participate in this study, they had to have at least one child with Autism Spectrum Disorder. This subject pool was comprised of parents whose children attended a private school in Southern New Jersey. Subjects had to have a child between the ages of 3-21 and be willing to answer questions surrounding their children and family. All participation in this study was done so voluntarily.

Materials

Collection of data took place during the spring semester of 2017. The only demographic information that was collected in the survey was the participant's gender (male, female, or prefer not to answer). The survey, created by the researcher, was used to evaluate the functionality of families that have a child with Autism Spectrum Disorder (See Appendix A). The survey was broken into three parts: questions about the parents and family, questions about the child, and short answer questions about family functioning and feelings. Another questionnaire created by Silva, L. M. T, and Schalock M, "Autism Parenting Stress Index," was used to evaluate the levels of stress felt by the parent answering the survey (Silva, L. M. T, and Schalock M, 2012) (See Appendix B).

Procedure

The participants in the study were parents of a child with Autism Spectrum Disorder and whose child or children attended a school for Autism in Southern New Jersey. All participants were at least 18 years of age. Thirty-one parents chose to volunteer to partake in this electronic survey and questionnaire. The survey and

questionnaire were accompanied by an online consent form. Interested parents were required to first read the consent form before completing the survey or questionnaire. It was not until after reading and agreeing to the consent that they were able to begin the survey and questionnaire. One section of the survey appeared at a time, whereas the entire questionnaire was viewable at once. All questions in both the survey and questionnaire were answered anonymously. Parents were allotted an unlimited amount of time to complete both the survey and questionnaire and upon completion were thanked for their time.

After all participation was completed, the data analysis process was put in place. The study was a descriptive and correlational study. All data from the surveys and questionnaires was inputted into IBM SPSS Statistics Version 21.0 for analysis.

Chapter 4

Results

It was hypothesized that typical families have a higher sense of positive family functioning and morale when compared to non-typical families. The hypothesis was not able to be supported or refuted after reviewing and analyzing the data. However, the researcher was able to correlate a relationship between the score of the Autism Parenting Stress Index and the score of the Family Functioning Likert scale regardless of other variables. This correlation was produced using an Independent-Samples Kruskal-Wallis test as referenced in Figure 3.

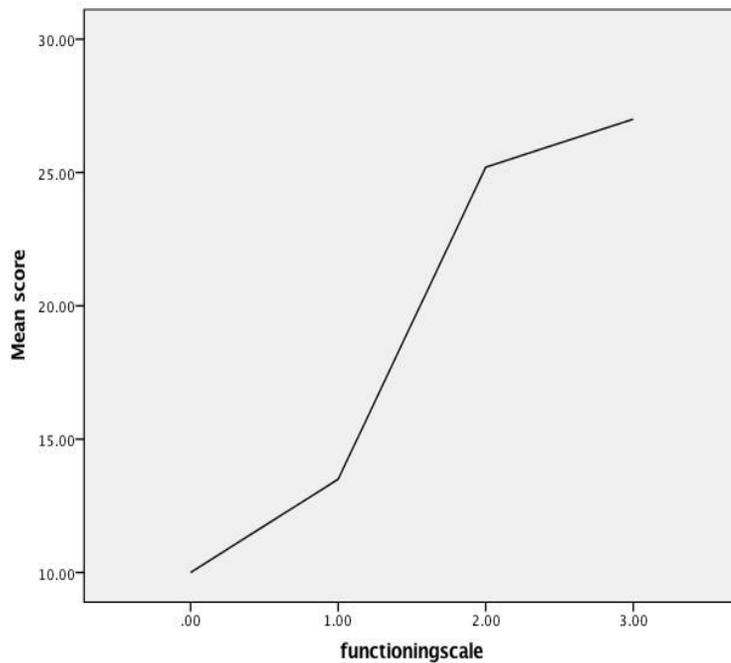


Figure 3. Correlation Between Scores

The mean score on the Autism Parenting Stress Index for married families was 16.8, while the mean score for non-typical families, including one of the adoptive families was 23.74 as shown in Figure 4 (Silva, L. M. T, and Schalock M, 2012). One of the two adoptive families chose not to participate in the stress index.

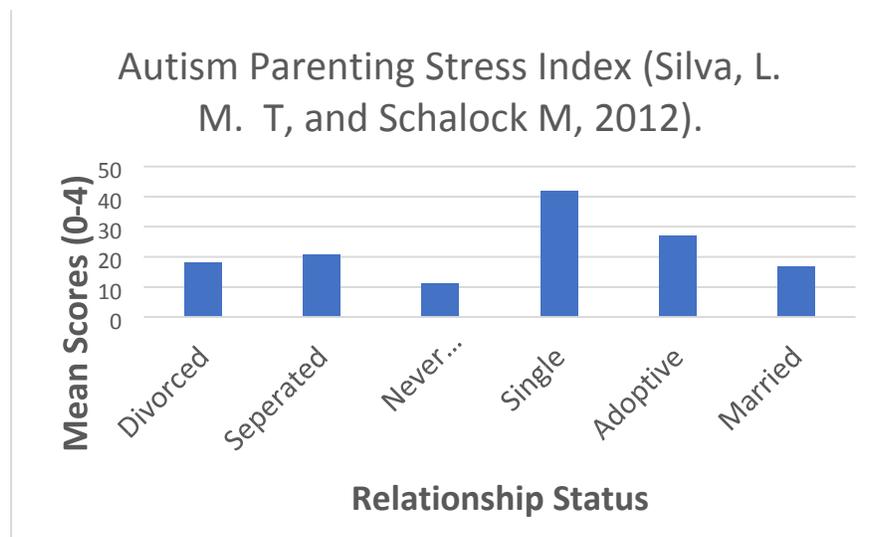


Figure 4. Mean Scores of Autism Parenting Stress Index (Silva, L. M. T, and Schalock M, 2012).

The average score on the family functioning Likert scale between non-typical families was 1.5 while the average score for typical families was 1.3 as represented in Figure 5.

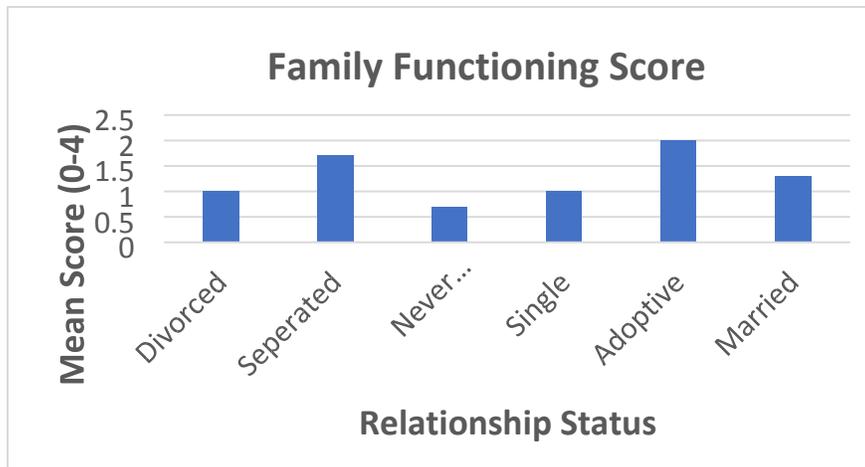


Figure 5. Mean Scores of Family Functioning Likert Scale

Participants were asked three open-ended questions based on their feelings of how well their family functions while having a child or children with a special need. Five common themes emerged from responses as represented in Figure 6: lives revolving around schedules, financial strain, concern for their child's or children's future, difficulty with understanding the disorder, and marital issues. 16 (51.6%) of participants expressed that their lives revolve around their child's or children's schedule, 14 (45.2%) did not mention the issue. 2 (6.5%) of the families reported financial strain, while the majority, 28 (90.3%), did not express the issue. 5 (16.1%) families shared their concern for their child's or children's future, while 25 (80.6%) did not express concern with issue. 2 (6.5%) of respondents expressed difficulty with either themselves understanding the disorder or family members not understanding, 28 (90.3%) did not share a lack of understanding. 6 (19.4%) of the families reported marital problems, 4 (67%) of them

were married and the other 2 (33%) were divorced and single. The remaining 24 (77.4%) did not share any marital issues.

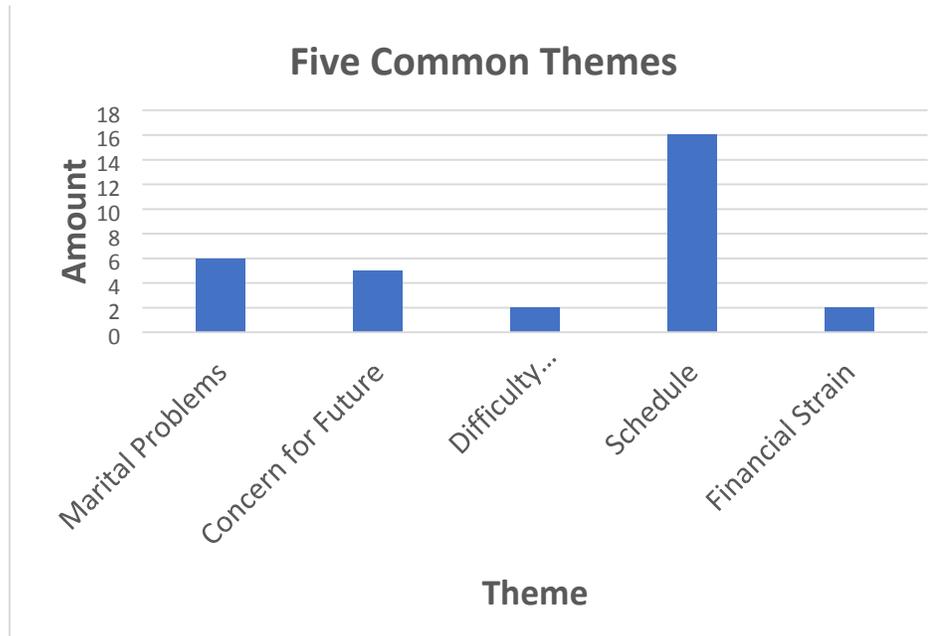


Figure 6. Common Themes

The first question was “How has having a child or children with ASD affected your family?” Several of the participants expressed that one thing that has been affected the most is the ability to leave the house, whether for short periods of time, i.e the grocery store, work, or long periods of time, i.e vacations. Many of the responses were filled with positive remarks such as “It has taught us all how to be more patient. It’s brought us

blessings and some rare opportunities that we may never have done.” Other responses expressed stress but remained filled with hope and understanding “It put a stressful strain on our family, especially dealing with our son’s behaviors, but we all still have the same love.” Some participants were affected by the adjustment that learning you have a child with a special need may bring “Every dream, expectation, hope and plan that we had for our family had to be rewritten.”

The second question asked participants “What are some changes that have occurred within your family due to having a child (children) with ASD?” Respondents expressed negative changes such as difficulties going back to work, the need for routine, days revolving around the behaviors and mood of the child with ASD, marital problems arising, and siblings feeling neglected. Other families expressed more positive changes such as the disorder bringing the family closer together, siblings stepping up to care for their sibling with ASD, increase in good communication, and learning parenting skills that they may not have learned raising a typical child.

The third and final response participants were asked to give was “In your own words, describe the functioning of your family on a daily basis.” Many parents described their daily routine and the necessity of the structure, the majority of which expressed that they are unable to get things done until the child has left for school. Some notable responses were: “We try our very best to keep a simple yet consistent routine which is mostly for our child with ASD but we have found that it is a great benefit to all in the family,” We have a daily routine and we all help each other out. If someone needs help one of the other family members pick up the slack,” His older brother is great with him.

He also plays a key role in the development of his brother. He plays with him and teaches him.”

Chapter 5

Discussion

Summary

The purpose of this study was to investigate how both nuclear or typical families and families of various backgrounds feel they thrive having a child with special needs. This study examined how families of various types kept their families functioning, happy, and whole. This study also examined whether family type influences feelings of success and failure when keeping their families running. It was hypothesized that nuclear or typical families have a higher sense of positive family functioning and morale when compared to non-typical families. Due to an insignificant amount of participants, this hypothesis was not able to be supported or refuted. While the proposed hypothesis was not able to be properly assessed, a correlation between Autism Parenting Stress Index scores and the Family Functioning Likert Scale scores was able to be analyzed to produce significant results. Although there was a limited number of participants, the data collected through survey questions surrounding the makeup of their families and daily functioning was able to provide insight on lives of families that have a child with Autism from the perspective of a parent.

Explanation of Findings

It was hypothesized in the current study that nuclear or typical families would function better and have a more positive morale than non-typical families. Unfortunately, the researcher was unable to support or refute this hypothesis due to low participation

numbers. However, through the non-parametric Independent-Samples Kruskal-Wallis test, a correlation between the Autism Parenting Stress Index score and the Family Functioning Likert Scale score was revealed regardless of other variables. These results suggest that the less stress felt by a parent the more positive they feel about the level of functionality their family is achieving.

The current study also revealed no significant increase in marital problems when caring for a child with ASD. These findings supported the findings of Freedman, Kalb, Zablotsky, and Stuart that children with ASD are no more likely to become a child of divorce when compared with a typical child. This may be due to the necessity of an increase in communication between parents in order to adapt to the parenting that may be required of a child with ASD. As revealed in several of the surveys, parents become a closer and stronger “team” when faced with raising a child with the disorder and possibly other children. The results of this study also suggest that while parents of children with ASD may experience an elevated level of stress and a variety of stressors that parents of typical children may not experience, the support of the private school their child attends may aid in alleviating concerns.

Implications

The findings from this study imply that there may be a strong correlation between the stress experienced by parents who have a child with Autism Spectrum Disorder and the likelihood of them having a positive outlook on the daily functioning of their family. This finding may suggest that an increase in resources for parents to turn to may alleviate their stress and therefore may lead to more positive outlooks for more families. The

current study may also imply that with a larger and more diverse sample of families, there may be a difference in stress levels between nuclear and non-typical families.

Additionally, there may be evidence to support that the enrollment in a private school focused on children with Autism Spectrum Disorder may offer more support than that of a public school setting.

Limitations

This study was limited by the amount of people who chose to participate in the surveys. Approximately 99 were sent out and only 31% were returned. Additionally, a limited number of males responded to the survey limiting the ability to fully assess gender differences in stress and feelings of functioning. Due to the amount of participation, significant results were unable to be produced in order to support or refute the hypothesis. Additionally, the survey may not have included questions that may have allowed the participants to give more insight into their daily lives and allowed for a fuller analysis.

Future Research

Future research of families with a child or children with special needs should focus on both the parents and the siblings. Additionally, research should include a variety of academic settings. A future study may want to require a larger sample size with more equal gender representation for more diverse results. Although there was a limited number of participants, the data collected was able to provide some insight on the daily lives of families that have a child with Autism from the perspective of a parent.

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Appendix A

Survey

Q1 What is the gender of the parent (parent answering survey)

- Male (1)
- Female (2) Prefer not to answer (4)

Q2 What is the age of the parent

Q3 Race or ethnic origin

- White (1)
- American Indian or Native American (2)
- African American or Black (3)
- Asian/Pacific Islander (4)
- Hispanic or Latino (5) Other (6) _____

Q4 Relationship status of parents

- Married (1)
- Widowed (2)
- Divorced (3)
- Separated (4)
- Never married (5) Single (6)

Q5 Employment status

- Full time (1)
- Part-time (2)
- Not working (3) In school unemployed (4)

Q6 Family income

- Less than 10,000 (1)
- 10,000-20,000 (2)
- 21,000-30,000 (3)
- 31,000-40,000 (4)
- 41,000-50,000 (5)
- 51,000-60,000 (6)
- 61,000-70,000 (7) 70,000+ (8)

Q7 Number of children

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5) 6+ (6)

Q8 Number of children with Autism Spectrum Disorder

- 1 (1)
- 2 (2)
- 3 (3)
- 4 (4)
- 5 (5) 6+ (6)

Q9 Age of children

Q23 Child's relationship to parent completing survey

- Biological (1)
- Adopted through family (2)
- Non-familial adoption (3)
- Legal guardian (i.e foster child, not legally adopted) (4)
- Other (5) _____

Q11 Age of child (children) with Autism Spectrum Disorder

Q12 Gender of child (children) with Autism Spectrum Disorder

- Male (1)
- Female (2)
- Prefer not to answer (3)

Q13 Child's diagnosis?

- Autism Spectrum Disorder (1)
- Asperger syndrome (2)
- Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) (3)
- Other (4) _____

Q14 Does your child have any co-occurring disorder(s)?

Yes (1) No (2) Display This Question:

If Does your child have any co-occurring disorder(s)? Yes Is Selected Q15
What co-occurring disorder(s)?

Q16 What type of academic program does your child attend?

- Early Intervention Program (birth-preschool) (1)
- Secondary Education (kindergarten- 12th grade) (2)
- College (3)
- Post-Secondary Education (not college) (4)
- Technical school (5)
- None (6)
- Other (7) _____

Q17 How has having a child (children) with ASD affected your family?

Q18 What are some changes that have occurred within your family due to having a child (children) with ASD?

Q19 How well do you feel your family functions as a unit?

	Extremely Poorly (1)	Not very well (2)	Sometimes well, sometimes not well (3)	Often well (4)	No problems in family functioning (5)
Family Functioning (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q20 In your own words, describe the functioning of your family on a daily basis

Appendix B

Stress Index

Q1 Please rate the following aspects of your child's health according to how much stress it causes you and/or your family by placing an X in the box that best describes your situation (Silva, L. M. T., & Schalock, M. 2012)

	Not stressful (4)	Sometimes creates stress (5)	Often creates stress (6)	Very stress on a daily basis (7)	So stressful sometimes we feel we can't cope (8)
Your child's social development (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your child's ability to communicate (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Tantrums/meltdowns (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Aggressive behavior (siblings, peers) (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Self-injurious behavior (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Difficulty making transitions from one activity to another (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Sleep problems (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Your child's diet (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bowl problems (diarrhea, constipation) (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Potty training (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Not feeling close to your child (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Concern for the future of your child being accepted by others (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Concern for the future of your child living independently (13)	<input type="radio"/>				
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Q2 Age of child with Autism Spectrum Disorder (*This question is not associated with the Autism Parenting Stress Index (APSI) (Silva, L. M. T., & Schalock, M. 2012))

Q3 Gender of child with Autism Spectrum Disorder (*This question is not associated with the Autism Parenting Stress Index (APSI) (Silva, L. M. T., & Schalock, M. 2012))

- Male (1)
- Female (2)
- Prefer not to answer (3)

Q4 Relationship status of parent completing index (*This question is not associated with the Autism Parenting Stress Index (APSI) (Silva, L. M. T., & Schalock, M. 2012))

- Married (1)
- Widowed (2)
- Divorced (3)
- Separated (4)
- Never married (5) Single (6)

Q7 Child's relationship to parent completing index (*This question is not associated with the Autism Parenting Stress Index (APSI) (Silva, L. M. T., & Schalock, M. 2012))

- Biological (1)
- Adopted through family (2)
- Non-familial adoption (3)
- Legal guardian (i.e foster child, not legally adopted) (4)