

5-2016

Identifying Supports For Parents Of Children With Autism Spectrum Disorder

Sarah Rushworth
Dominican University of California

<https://doi.org/10.33015/dominican.edu/2016.edu.03>

Survey: Let us know how this paper benefits you.

Recommended Citation

Rushworth, Sarah, "Identifying Supports For Parents Of Children With Autism Spectrum Disorder" (2016). *Graduate Master's Theses, Capstones, and Culminating Projects*. 230.
<https://doi.org/10.33015/dominican.edu/2016.edu.03>

This Master's Thesis is brought to you for free and open access by the Student Scholarship at Dominican Scholar. It has been accepted for inclusion in Graduate Master's Theses, Capstones, and Culminating Projects by an authorized administrator of Dominican Scholar. For more information, please contact michael.pujals@dominican.edu.

IDENTIFYING SUPPORTS FOR PARENTS OF CHILDREN WITH ASD

Identifying Supports For Parents Of Children With Autism Spectrum Disorder

Sarah Rushworth

Submitted in Partial Fulfillment of the Requirements for the Degree

Master of Science in Special Education

School of Education and Counseling Psychology

Dominican University of California

San Rafael, CA

May 2016

Signature Sheet

This thesis, written under the direction of the candidate's thesis advisor and approved by the department chair, has been presented to and accepted by the Department of Education in partial fulfillment of the requirements for the degree of Master of Science in Education. The content and research methodologies presented in this work represent the work of the candidate alone.

Sarah Rushworth
Candidate

May 16, 2016

Elizabeth Truesdell, Ph.D.
Department Chair

May 12, 2016

Suresh Appavoo, Ed.D.
Thesis Advisor

May 12, 2016

Colleen Arnold, MS.
Secondary Thesis Advisor

May 12, 2016

Copyright 2016 by Sarah Rushworth.
All rights reserved.

Acknowledgments

Thank you Suresh Appavoo, Kristin Tavernetti, Colleen Arnold, and Jaci Urbani for your supports throughout this educational journey. Your assistance and support made completing a master's thesis while working seem possible. Thank you for helping me achieve my educational goals so that I can further advance in my career.

I would like to acknowledge my colleagues and peers who have provided valuable constructive criticism throughout the process of my research. The opinions, advice, and peer editing have pushed me in my educational abilities and I thank each of you for your knowledge and assistance.

Thank you to my family and friends who have continually supported my desire to pursue higher education. My parents as well as the rest of my family have always encouraged me to follow my dreams and pushed me to never stop trying to achieve those dreams. They have always inspired me to find what I love to do and to pursue that as my career. Thank you for always believing in me and supporting me throughout my life decisions. It is because of your support and encouragement that I have found a field of work that I have developed such a passion and drive for.

Additionally, thank you to my uncle who has disabilities as well as all of the children I have ever worked with who have a disability. You continue to inspire me everyday. Thank you to everyone who has made this journey possible.

Table of Contents

Title Page	1
Signature Sheet.....	2
Acknowledgments	4
Table of Contents	5
Abstract.....	7
Chapter 1 Identifying Supports For Parents Of Children With ASD	8
Definition of Terms.....	9
Statement of Problem.....	12
Research Question	13
Purpose Statement.....	13
Theoretical Rationale	13
Assumptions.....	15
Background and Need.....	16
Summary	16
Chapter 2 Review of the Literature	19
Introduction.....	19
Historical Context	19
Statistical Information.....	21
Review of Academic Research	22
Tailoring Supports to Family Needs.....	22
Collaboration of Services.....	25
Parent Support.....	28
Access to Adequate Information.....	33
Summary	36
Chapter 3 Method	37
Research Approach	37
Interview Questions	38
Ethical Standards	38
Sample and Site.....	39
Access and Permissions	39
Data Gathering Procedures.....	39
Data Analysis Approach.....	40
Chapter 4 Findings, Discussion, and Analysis	42
Results.....	42

Discussion and Analysis of the Findings	46
Chapter 5 Conclusions and Recommendations.....	51
Conclusions from the Research	51
Limitations/Gaps in the Research	51
Implications for Future Reserach.....	52
Overall Significance of the Study	52
About the Author	53
References	55

Abstract

Children with Autism Spectrum Disorder (ASD) lack social and communication skills, leading to challenging behaviors. This impacts family functioning and can lead to parents being isolated and feeling stressed (Russa, Matthews, & Owen-DeSchryver, 2014). The parents of these children must learn how to handle the challenges that come along with the disorder. Parents of children with ASD need to have more supports in place to feel more supported (Nealy, O'Hare, Powers, & Swick, 2012). The literature revealed that the programs implemented today focus mainly on the child outcomes, lacking focus on parent needs (Samadi, McConkey, & Kelly, 2012). Parents find it challenging to identify the services and supports their child needs and have difficulties accessing them (Russa et al., 2014). There is also a need for collaboration between the various programs that these children obtain services from (Nealy et al., 2012). Additionally, parents report having problems finding information for their child (Russa et al., 2014, p. 95). Information on ASD is constantly changing, making it hard for parents to know what information is accurate and reliable. The study included interviews with parents who have a child with ASD. Each participant was asked eleven questions. The questions pertained to the quality of supports that the child and parent receive. Through evaluating parent responses, the researcher was able to obtain valuable information regarding how parents feel about the supports they receive.

Chapter 1 Introduction

ASD is a developmental disability that can cause social, communication, and behavioral challenges (Preece, 2012). ASD is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013).

There has been a major rise in the number of children reported to have ASD within the last two decades, since it was first recognized by the U.S. Department of Education as a disability in 1991. This is largely due to the increase in public awareness and education of ASD, as well the development of better diagnosis protocols, leading to an increased need to help those children and their parents (Ruble & Dalrymple, 2002). Today, one in every 68 children in the United States has autism (Centers for Disease Control and Prevention, 2016). Autism is four and a half times more likely to occur in boys than girls. When looking at the history of ASD, it is a relatively new disorder that still has a lot of unknowns (Ruble and Dalrymple, 2002). ASD has nonexistent boundaries when it comes to racial, ethnic, or social categories (Al-Shammari, Daniel, Faulkner, & Yawkey, 2010). Raising a child with autism is associated with increased family stress and depression (Karst & Van Hecke, 2012). Parents need more support on how to cope with having a child with autism in order to help improve these families overall quality of life (Hartley & Schultz, 2014).

As a Senior Behavioral Therapist, the researcher observes first-hand how having a child with autism affects parents and families. Every time the researcher is assigned to a new case and

comes into a family's home for the first time, she can see the look of worry and stress on the caregivers faces. They are eager to get the process started, or to continue where the last therapist left off. They open up their home to our teams and embrace us like part of their own family, hoping that we can improve their child's life. As a relationship forms, families open up and you can notice the effect that the child's diagnosis has on the family. Whether that becomes apparent through verbal encounters or through observation, it is well documented that most of the caregivers are emotionally drained and have a feeling of hopelessness (Nealy, et al., 2012).

My yearlong challenge was to come up with ways in which families with children with autism could become more confident and less stressed about raising a child with ASD. To do this, I interviewed parents with children with ASD to see what they felt they needed in order to be less stressed in their daily lives. Through these interviews and through my research, I was able to examine the possibilities for how parents who have children with ASD could live a better, less stressful life.

Definition of Terms

Autism spectrum disorder (ASD). ASD is characterized by persistent deficits in social communication and social interaction across multiple contexts, including deficits in social reciprocity, nonverbal communicative behaviors used for social interaction, and skills in developing, maintaining, and understanding relationships. In addition to the social communication deficits, the diagnosis of autism spectrum disorder requires the presence of restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013).

Applied behavioral analysis (ABA). ABA is a widely used method of behavioral therapy, which was created by O. Ivar Lovaas. It is a systematic, repetitive approach that focuses

on cognitive, language, and motor development and is typically sculpted to each child's individual needs (Sicile-Kira, 2004).

Occupational therapy (OT). Occupational therapists are uniquely positioned to address many of the difficulties children with ASD experience. OT services generally seek to enhance the performance of daily living activities such as feeding and dressing, as well as instrumental activities of daily living including community mobility, safety procedures, education, work, leisure, play, and social participation (Barnett & O'shaughnessy, 2015).

Physical therapy (PT). PT is a treatment option for children with neurological and motor impairments and delays (Jenkins & Sells, 1984).

Behavioral therapy (BT). BT is widely used for school-aged youth with ASD. BT methods explicitly promote the development of mental schemata that guide adaptive appraisals and behavior while suppressing previously learned maladaptive responses (Wood, Fujii, Renno, & Van Dyke, 2014).

Speech therapy (ST). Deficits in communication development are experienced by all children with ASD. ST is aimed at improving one's speech, language, and communication skills. In general, the teaching of speech, language, and communication skills to children with ASD is based on the behaviorism perspective that teachers can shape the learning directions and behaviors of these children by manipulating the external stimuli to elicit the desired learning outcomes (Hui Min & Lay Wah, 2011).

The positive behavioral interventions and supports (PBIS) approach. "PBIS is a family-centered, evidence-based practice, supporting families to become active in developing and implementing interventions that meet the needs of the child and family" (Russa et al., 2014, p. 98).

Parent to parent (PTP) model: Russa, et al., (2014), stated that:

PTP is a national organization that serves to connect parents of children with disabilities one-to-one with volunteer parents who can relate to their experiences and provide information and support. Mentors, who are parents of children with disabilities, are trained and then matched with parents seeking support. The availability of 24-hr support through PTP may be particularly important for parents with children with more severe disabilities. (p. 99)

The medical home and family navigator model. “The medical home and family navigator model helps to give families access to a vast amount of services and resources. Having more information and means of support could help decrease stress levels in families who have a child with autism” (Russa et al., 2014, 101).

Positive behavioral support (PBS). Preece (2014) said the following about PBS:

PBS was developed to support socially adaptive and appropriate behavior. PBS refers to a unified, holistic and non-aversive approach that includes both proactive strategies to change unwanted behavior in the long term and reactive strategies to manage such behavior when it occurs. The focus of PBS is to allow individuals who display challenging behavior to be able to participate in society, to be able to make choices and to have a greater sense of personal competence and self-efficacy. (p. 137)

COMPASS model. Russa, et al. (2014) described COMPASS:

COMPASS builds competencies in consulting and ASD knowledge by working with families and teachers through a systematic, empirically based consultation program. In this coaching model for teachers, specific steps define how teachers work as part of a

collaborative team with parents and other school professionals to define goals, establish educational priorities, and assess progress. (p. 99)

IDEA (2004). “IDEA mandates parent involvement in every phase of the special education process, and parents and school professionals share a desire to help the child succeed within educational environments; thus, a strong incentive exists for parents and schools to collaborate” (Russa et al., 2015, 98).

Diagnostic and statistical manual fifth edition (DSM-V). The DSM-V is a manual published by the American Psychological Association (APA) that is intended to be a resource that classifies criteria of mental disorders (Tsai & Ghazludden, 2014).

Statement of the Problem

Raising a child with autism comes with a lot of challenges, which significantly impacts parental stress (Karst & Van Hecke, 2012). The behaviors some children with autism display can be stressful to the parents of the child on a daily basis (Nealy et al., 2012). Parents of children with ASD experience significantly more stress than parents of children without disabilities, but also of parents whose children have other developmental disabilities (Samadi et al., 2012). “To date, only a handful of studies have examined the support needs of parents of children and adolescents with ASD or other types of developmental disabilities” (Hartley & Schultz, 2014, p. 1637). Currently, there are services for children with ASD that is covered under insurance for qualifying individuals with ASD, however even with these services for the child with autism, daily life still remains stressful for some parents (Nealy et al., 2012). A child can be as young as 18 months to obtain an initial diagnosis of ASD to begin receiving these services (Autism Speaks, 2016). Currently, there are few services for parents. The current services that exist today do help the individual with ASD, which in turn helps the parents, however more programs and

services for parents need to be available (Hartley & Schultz, 2014). “Understanding the important and unmet support needs of parents of children and adolescents with ASD is a critical first step towards better assisting parents, and subsequently, improving parent psychological well-being and family outcomes” (Hartley & Schultz, 2014, p. 1637).

Research Question

This study attempts to investigate the causes of stress for parents who have a child with ASD, who obtain services in the Northern California Region. This study focused on one primary research question: What are the causes of stress for a sample of three parents who have a child with ASD in the Northern California Region?

Purpose Statement

The purpose of this study is to examine how parents of children with ASD could be supported through collecting information on what is causing stress for these parents. The intention of this study is to obtain more knowledge of what is causing parents who have a child with ASD stress so that new programs can be created to make the parents feel better supported and more confident in their daily lives.

Theoretical Rationale

Currently, ASD represents a spectrum of complex, neurological, and developmental disorders (Karst & Van Hecke, 2012). The cause of ASD remains unknown; however there have been different theories on the cause throughout history. In the 1940s, people with ASD were considered mentally ill. In the 1950s and 1960s, based on a theory introduced by Bruno Bettelheim, many researchers in the medical community believed that autism was a psychological disturbance caused by mothers who were apathetic and uncaring towards their children-commonly referred to as “refrigerator mothers.” Mothers were held responsible for

causing their child's disorder (Bursztyn, 2007). During this time in history, parents, especially the mothers, were not supported, but instead blamed for their child's disability.

In the late 1960s, O. Ivar Lovaas devoted nearly half a century to groundbreaking research and practice aimed at improving the lives of children with autism and their families. When it was once thought that children with ASD were untreatable, Lovaas showed that children with ASD could improve through therapeutic intervention strategies. Lovaas pioneered applied behavior analysis (ABA) interventions to help decrease unwanted behaviors and establish communicative language in children with autism (Smith & Eikeseth, 2010).

ABA is the theory that supports the research question of this study. ABA was developed to help children with ASD and their families better function on a daily basis. The various models that are based on the ABA theory can cause noticeable and lasting improvements especially if the child begins services early and intensively. ABA-based interventions are considered to be the basis of the most effective intervention currently available for children with ASD. ABA interventions are easily implemented at home, allowing the child and parents to be able to stay at home if desired and have the professionals come to them (McPhilemy & Dillenburger, 2013).

ABA is based around the principles that focus on how learning takes places, such as positive reinforcement. ABA interventions help to reduce challenging behaviors and help the child acquire basic skills such as looking, listening, and imitating, as well as complex skills such as reading, conversing, and understanding another person's perspective. ABA techniques can produce improvements in communication, social relationships, play, self-care, school and employment (Autism Speaks, 2016). These improvements not only change the lives of the person with ASD but also drastically improve the lives of their parents and families as well.

Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning (Autism Speaks, 2016). ABA is the use of these techniques and principles to bring about meaningful and positive change in behavior. These techniques can be used in structured situations such as a classroom lesson as well as in "everyday" situations such as family dinnertime or the neighborhood playground. Parents and other family members of these children with ASD could potentially feel less stress and gain a better quality of life through the improvements that ABA can bring to the child (Autism Speaks, 2016).

The work of Lovaas helped to drastically change the way people in our society think about autism. Alongside his research, Lovaas devoted much of his energy to advocacy on behalf of autism and popularization of ABA. In the late 1960's, he helped found the parent organization now called the Autism Society of America. He emphasized the importance to include parents as active participants in the intervention. Lovaas' research and creation of ABA was key in our history as the start to helping children with ASD and their parents. Through his work of developing behavioral therapy, Lovaas showed that there was a way to help children with ASD, which in turn, helped the parents (Smith & Eikeseth, 2010). Lovaas' creation of ABA and inclusion of parents in therapy to help improve the lives of children and their families was key to the development of the present study. His work paved the way for helping children with ASD and their families. The current study aims at expanding this idea of ABA, focusing on gaining more knowledge on what else parents of children with ASD in the Northern California Region need to become less stressed in their daily lives.

Assumptions

The study assumes that the sample of parents selected for this study typically represent the population of parents of children with ASD. The study assumes that the parents participating in the study will honestly share their deepest feelings and fears with the researcher. Another assumption that the study makes is that the behavioral complexity that is associated with an ASD diagnosis brings stress to the parents who are participating in the study. It is assumed that after obtaining more information on the cause of stress from the sample of parents participating in this study, any proposed solution will have a positive impact for multiple parents.

Background and Need

Autism Spectrum Disorder (ASD) is a developmental disability that can cause social, communication, and behavioral challenges (Preece, 2014). Past studies show that having a child with autism can impact parental stress significantly, in particular with children who display challenging behaviors. Families with children with ASD need a lot of supports and overall feel as though they are not receiving the correct or enough supports (Preece, 2014).

Not a lot of research has been done on this topic of how to better help caregivers of children with autism. More research is needed to better meet the needs of families with children with autism spectrum disorder (Clifford & Minnes, 2013). Raising a child with autism is very challenging and requires a lot of support for both the families and children (Hartley & Schultz, 2014). Hopefully in the future, more families can be trained and educated on their child with ASD to help to decrease stress levels and increase their quality of life.

Summary

Parents of children with autism face unique parenting challenges. Having a child with autism is associated with increased stress levels in caregivers (Karst & Van Hecke, 2012). Through looking at past research, there appears to be a lot of families of children with autism

who feel as though they could use more support. Lack of access to appropriate information is one major factor that needs to be improved to help families with a child with autism (Samadi, et al., 2014). The period after diagnosis is especially difficult and stressful for parents, which is also due to lack of information (Samadi et al., 2014). Parents in past studies stated that “services need to coordinate better, as autism is a complex diagnosis often requiring interventions by multiple providers and agencies” (Russa, et al., 2014, p. 97).

The emotional impact, familial relationships impact, social impact, and financial impact of having a child with autism seems to be a common theme amongst many parents or guardians (Nealy, 2012). Increasing parent knowledge of ASD and the interventions available, increasing parent confidence, and encouraging parents to provide emotional support to one another could be ways in which parents could potentially decrease their levels of stress and increase their overall well being (Samadi et al., 2012). There is limited research around intervention aimed at promoting parental knowledge about autism and family well-being (Samadi et al., 2012). More research needs to be done around this area to better help these parents in need.

When you have a child with ASD, some days are good, and some are bad, but everyday comes with challenges and unknowns that leave these caregivers stressed and eager for providers to work with their child (Karst & Van Hecke, 2012). Yes, these services that are currently available for the child help improve their child’s life which in turn can help relieve some stress for the caregivers, but what about specialized programs for the parents, not just the child? I have worked at companies where there were parent goals which were apart of their child’s goals that we worked on, however what I mostly observed were parents who did not feel confident enough, even after my quick explanations of what they are to do and why, leaving me to have to follow

the families to get them to act on a goal so as to generalize it and attempt to make the caregiver feel more confident in his or her abilities to interact with the child.

These families needed more than just these two goals every six months to help them better understand their child. Perhaps they needed a monthly training to help better explain to them what ABA is, or even what autism is. Perhaps they would benefit from seeing a psychologist, rather than talking to the behavior therapists about issues, when a behavior therapist is not a licensed psychologist. Whatever service it may be that could be of help, what I have learned so far is that each family I work with or have worked with feels stressed and lacks confidence, making them feel as though they are enduring an never ending battle. Through this study, I hope to find out what exactly it is that is causing these parents stress, and to take that information to try to develop a way to relieve the stress they feel.

Chapter 2 Review of Literature

Introduction

This section is an examination of the research literature on support for parents who have a child or children with ASD. Information was gathered from academic library searches using online resources, peer reviewed articles, the DSM-V, as well as textbooks used in autism specific graduate level courses. Research information is organized in the following categories: Historical Content, Statistical Information, and Review of Academic Research. Historical Context documents the discovery of ASD and the development of the various interventions available to help children with ASD and their parents. Statistical Information on the prevalence of ASD is illustrated through a table and the review of academic literature includes information from a number of studies that create a context for this research study. The review also describes different models that have been created to help children with ASD and their parents, as well as parent reports on support needs.

Historical Context

The Latin word Autismus was first used by the Swiss psychiatrist Eugen Bieuler in 1910. Bieuler was defining symptoms of schizophrenia. Autismus is from the Greek word autos meaning an isolated self (Ataman, Bicer, & Vatanoglu-Lutz, 2014). This refers to the early idea that people with ASD want to be socially isolated, removed from social interaction. In the early 1940's a Austrian psychiatrist and physician named Leo Kanner, observed a small group of children with a condition he called Infantile Autism. This began the scientific study of autism (Thompson, 2013). For nearly three decades after this report, research progress in understanding and treating autism was minimal. However, since the late 1960's, the growth of what we know

about ASD has been exponential, with many new findings published over the past two decades (Thompson, 2013).

The way society views ASD has greatly changed over time. The concept and definition has also changed over the years (Ataman, et al., 2014). ASD was first described as the earliest form of schizophrenic psychosis. Advances in the understanding of the clinical neurofunctional and genetic aspects of ASD has significantly changed the concepts and practices for diagnosis, exploration, and therapies. Surprisingly, ASD was not recognized by the U.S. Department of Education (USDOE) as a handicapping condition until 1991 (Ruble & Dalrymple, 2002). Today, Autism is known as a complex developmental disability (Ataman, 2014). The perception of ASD, the diagnostic, the theoretical references studied, assessment, care, and educational practices have all drastically changed within the past few years as more and more studies and information is obtained on this important disorder that continues to grow (Ataman et al., 2014).

Today, ASD is considered to be a biologically based pervasive neurodevelopmental disorder affecting from the first days of life, social communication, and adjustment to the environment (Ataman, et al., 2014). Currently, there is no cure for ASD, it is a lifelong disorder. The exact cause of ASD is also uncertain. Contrary to past beliefs, today ASD is thought to be one of the most heritable of all psychiatric conditions. Autism has a strong genetic basis, although the genetics of autism are complex and it is unclear whether ASD is explained more by rare mutations with major effects, or by rare multigene interactions of common genetic variants. Environmental factors have also been claimed to be a cause of ASD, although this evidence is anecdotal (Ataman et al., 2014). Much research has been done in the past and continues in attempt to identify the causes of ASD. Although the cause of ASD is still in question, an enormous amount of progress has been made within the past seven decades (Thompson, 2013).

Statistical Information

Currently, 1 in every 68 children in the United States has a diagnosis of Autism Spectrum Disorders (ASD). The table below is from the Centers for Disease Control and Prevention (2015) and shows the prevalence of ASD in the United States per 1,000 children. The table shows the increase in ASD diagnosis from the year 2000 to 2010. The prevalence of children with ASD in 2000 was 6.7, 1 in 150 children having a diagnosis of ASD, and in 2010 the prevalence increased to 14.7, 1 in 68 children having a diagnosis of ASD. (Centers for Disease Control and Prevention, 2016). The reason for this increase is unclear however it may be due to several factors such as better diagnostic services than in the past (Ruble & Dalrymple, 2002), changes in diagnostic criteria, increased awareness of ASD, or even a true increase in the population (Kogan et al., 2008).

Identified Prevalence of Autism Spectrum Disorder ADDM Network 2000-2010 Combining Data from All Sites				
Surveillance Year	Birth Year	Number of ADDM Sites Reporting	Prevalence per 1,000 Children (Range)	This is about 1 in X children...
2000	1992	6	6.7 (4.5 – 9.9)	1 in 150
2002	1994	14	6.6 (3.3 – 10.6)	1 in 150
2004	1996	8	8.0 (4.6 – 9.8)	1 in 125
2006	1998	11	9.0 (4.2 – 12.1)	1 in 110
2008	2000	14	11.3 (4.8 – 21.2)	1 in 88
2010	2002	11	14.7 (5.7 – 21.9)	1 in 68

Review of Academic Research

Tailoring supports to family needs.

Although there is research that indicates that parenting a child with ASD is very stressful, there is still little research on what would help to alleviate this stress (Clifford & Minnes, 2013). It is important to look further, and examine what these parents need to be better supported. Most programs designed for children with ASD focus mainly on the child outcomes rather than parental needs. A lot of the time, the content of the programs are determined by what professionals believe parents need to know rather than identifying their wishes (Samadi et al., 2012).

In other cases, some programs do not even help children and their parents if they do not meet qualifications. In a study done by Searing, Graham, and Grainger (2015), parents who have a child with ASD were surveyed. A parent was quoted saying, “We’ve had no end of trouble getting support. Actually, we don’t get any! We’ve been turned down for every type of assistance saying ‘he’s not bad enough to be helped” (p. 3698). This can be very frustrating for these parents. In this situation, the parent is seeking help and needs it but is not receiving any due to professionals assuming that the child and parent do not need help because the child is high functioning. Something needs to change so that parent’s voices are better heard and that they receive the supports for their particular needs.

Positive Behavioral Interventions and Supports (PBIS) is one model that has been created to help better support parents of children with ASD. Russa et al. (2014) stated that:

This approach provides a useful framework for implementing parent support to meet family needs over the life span. As a family-centered, evidence-based practice, PBIS supports families to become actively engaged in developing and implementing

interventions that meet the needs of the child and family. This model, derived from ABA, emphasizes creating a meaningful lifestyle for the child and the family by focusing on developing the child's communication, and supporting the family during challenging routines, with the goal of reducing problem behavior. To reduce problem behaviors, parents are assisted to design family contexts in which problem behaviors are no longer relevant, effective, or efficient in achieving desired outcomes. (p. 98)

The lack of communication skills that children with ASD exhibit cause the behaviors that many children with ASD display. These aggressive behaviors as well as repetitive behaviors can be very frustrating and upsetting to parents. Parents of children with ASD report more symptoms of anxiety and depression compared to parents of children with other disabilities and parents of typically developing children (Clifford & Minnes, 2013). It is apparent that these parents need supports in this area and are not receiving these supports. Professionals need to focus more on what specific factors each parent of a child with ASD needs support in, as each child is so different, requiring different types of supports for both the child and the parent. Tailoring the support services to meet the needs of parents is especially important when it is a parent of a child with ASD due to this increase in health problems amongst these parents than any other parental group. The behavior interventions that are available today are designed to help support parents assume that these problems are due to the challenge of parenting a child with ASD. However, it is in question whether the behavior programs provide long-term support to parents of children with ASD, as this may require a more holistic approach, rather than a short term solution (Falk, Norris, & Quinn, 2014).

Falk et al., (2014), conducted a study regarding stress in the parents of children with ASD. In this study, they sent out a questionnaire to parents who have a child with ASD. The

results indicate that parents of children with ASD have difficulties understanding their child's behaviors. When parents do not see positive changes in their child's behavior, they start to feel ineffective as a parent. This study indicates that providing parents with behavioral plans may be ineffective after this point. If the parent already perceives themselves as having failed, new behavioral management plans, even if effectively practiced, may not change this perception (Falk, Norris, & Quinn, 2014). These results show that a one-size fits all approach to parent support and intervention does not work and is not effective. Russa (2014), found that:

Many families with a child with ASD have a difficult time identifying the services and supports they need, determining where they can find these services, and readily accessing them. Once services are identified, navigating the service systems requires knowledge, time, and persistence, since families rarely have a care coordinator to assist them through the process. (p. 97)

Searing et al., (2015), found through surveying parents that accessing helpful support and maintaining access is difficult. Many parents in this study expressed that "something would be better than nothing" (p. 3698). Finding the right person with the correct knowledge is also difficult. One parent in the study commented, "It took numerous nervous breakdowns and years to get access to the respite and holiday care" (p. 3698). Parents face challenges with maintaining supports as staff typically do not stay long, limited funding, and administration challenges.

In a study by Kogan and colleagues' (2008), a review of the National Survey of Children with Special Health Care Needs (NS-CSHCN) was conducted. In Kogan's review of the NS-CSHCN, parents of children with ASD reported having more unmet needs compared to other children with special health care needs (Kogan et al., 2008). These parents were also less likely to be satisfied with their child's care. These results also showed that the parents of children with

ASD are at an increased risk for problems with access to family centered care and support services (Kogan et al., 2008).

Collaboration of services.

Establishing and maintaining a collaborative partnership between family and school of children with ASD is very important. Russa et al., (2014) stated that:

IDEA 2004 mandates parent involvement in every phase of the special education process, and parents and school professionals share a desire to help the child succeed within educational environments; thus, a strong incentive exists for parents and schools to collaborate. However, not all families will be involved with their school in the same way, and therefore a single approach or list of activities for working with families is not feasible. (p. 98)

Russa et al., (2004) said that:

The Collaborative Model for Promoting Competence and Success for Students with ASD or COMPASS Model builds competencies in consulting and ASD knowledge by working with families and teachers through a systematic, empirically based consultation program. In this coaching model for teachers, specific steps define how teachers work as part of a collaborative team with parents and other school professionals to define goals, establish educational priorities, and assess progress. (p. 99)

In a study by Ruble & Dalrymple (2002) about the COMPASS collaborative model for students with ASD, it is stated that “collaboration reinforces the intent of IDEA by providing opportunities for parents and school personell to work together” (p. 77). Ruble & Dalrymple (2002), found that issues of generalization and maintenance of skills that children with ASD

obtain through therapy are minimized in treatment plans that develop from a collaborative approach (Ruble & Dalrymple, 2002).

A study conducted by Nealy, O'Hare, Powers, and Swick (2012), gathered information from mothers who have a child with ASD. The mothers in this study reported that their stress was most frequently caused by the barriers in services that their families face (Nealy et al., 2012). Children with ASD can be referred to numerous and varied services, including school support, occupational therapy (OT), physical therapy (PT), speech therapy (ST), respite care, and home and community supports (Nealy et al., 2012). Accessing these services can be difficult, as well as obtaining the funding, finding available service providers, and scheduling of these services can all create more stress in the parents lives (Nealy, 2012).

Family-school partnerships involve building partnerships between families and educators to work together in the process of developing goals and plans. The Positive Behavior Support (PBS) approach has been found to be highly effective for young children with disabilities and challenging behavior. PBS is an approach to prevent and proactively reduce inappropriate behavior of children with behavioral challenges by teaching more appropriate behavior and providing the contextual supports necessary for successful outcomes. PBS along with other interventions for children with ASD emphasize parent involvement in not only school, but the entire process, from assessment to intervention (Blair et al., 2011).

The effectiveness of intervention is maximized when it is generalized across environments. Little research exists on supporting children with ASD through this family-school collaboration. Most research on interventions for children with ASD focus on either school-based or home-based interventions, and a lot do not even involve the parents in the studies. Schools who teach children with ASD do encourage parents to be involved, and even mandate

that a guardian be involved in the individualized education plan (IEP) process, however rarely are parents asked or taught how to do the interventions or strategies at home (Blair et al., 2011).

In the study conducted by Blair et al., (2011) parents of children with ASD participated in PBS intervention, focusing on family-school collaboration. The parents and teachers worked together to help the children in the study decrease unwanted behaviors and increase positive behaviors. Observations of the interactions were recorded and data was collected in the school and home setting. A behavior support plan was development and implemented for each child. After the interventions, the children's appropriate behavior increased, unwanted behavior decreased, and the mothers and teacher positive interactions increased as well (Blair et al., 2011). This study showed that effective collaboration between the members of the child's life in school and at the home, helps to lessen stress, and increase positivity in the parents lives, as well as help the child improve to his or her full potential.

Harper, Dyches, Harper, Roper, & South (2013), conducted a study regarding parent supports and martial quality. Harper gave a questionnaire to parents who have a child with ASD. The findings for this study showed that the more respite care couple had, the better their martial quality was (Harper et al., 2013). The findings in this study are important to professionals who work with parents who are raising a child with ASD. These professionals should know about the available respite care options in the area to better serve the parents that they work with. Counselors, therapists, psychologists, physicians, school administrators, special education teachers, social workers, and family advocates must be unified in their approach to informing parents and helping them access both formal and informal respite care services. These professionals should not assume that these parents are accessing respite care through a separate

provider and should make sure that the parents are educated and aware of the respite care options in their area.

Harper et al., (2013) found that parents need this coordinated approach to better help them obtain and navigate ongoing respite care. A parent in this study noted that, “agencies often set up meetings, training sessions, and workshops for parents, without offering supportive services like child care, and wonder why parents don’t show. Those who cope best will be there; the others will need to be lured” (p. 2614). Schools and other agencies that do provide parent trainings or support groups often fail to provide respite care during these meetings, not allowing all parents who wish to attend to do so. Additionally, respite care needs to be provided by people who can be trusted and trained so that families feel comfortable leaving their child with them (Harper et al., 2013). This study found that many families have the grandparents or other extended family watch their child for them when needed. These family members are not trained and do not necessarily know how to go about watching a child with ASD. Professionals could provide training for extended family and community members who are willing to give respite care so they can be confident in how to handle challenging behaviors and to facilitate social skills and effective communication (Harper et al., 2013).

Parent support.

Research shows that parents of children with ASD experience more stress than other parents. Both formal and informal supports are important for these parents to obtain. Formal supports includes supports provided by an agency and can include family doctors, early intervention programs, and respite care providers. Families use formal supports for information and professional guidance. Informal supports refers to support provided by someone in the persons social network such as friends, family, neighbors, or acquaintances. Parents use informal

supports such as support groups to obtain more emotional support than information like formal supports do (Searing et al., 2015). Parents can access support groups both in person, by invitation from other parents or from agency staff, and as part of the services offered while their child is on a wait-list for government-funded intervention as well as over the phone or for free on the internet (Clifford & Minnes, 2013).

In a study by Clifford & Minnes (2013), parents who have a child with ASD participated in a parent support group to see if parental well-being would increase following participation in a support group. The parents in this study were asked to rate their experience with the support group. Clifford & Minnes (2013) found that the parents enjoyed participating and found the support group to be very valuable and helpful, recommending it to other parents. These parents also had positive reviews about the group helping them deal with problems they were having regarding their child. Parents reported that receiving support and understanding through the group was very useful. “Parent Support groups (PGS) are one way to help parents of children with ASD cope with their stress, meet other parents, and develop a sense of belonging. Support groups for parents are a relatively cost effective and easily-implemented intervention for supporting the needs of these families” (Clifford & Minnes, 2013, p. 1). The parents in this study said that they enjoyed being able to connect with the other parents, gain information about resources, and were able to help other parents as well as being helped.

Karst, et al., (2012) speak of the impact that Autism Spectrum Disorder has on parents and families. It is stated in the article that caregiver and family distress related to ASD typically begins long before a formal diagnosis is provided. Parents of children with ASD report experiencing a loss of social support and a decrease in opportunities for family fun when their child receives an autism diagnosis (Nealy et al., 2012). There is a lack of awareness and

education about ASD, making it hard to find family members or caregivers to care for the child with ASD to give the parents a break. Due to this, parents lose relationships with family and friends. Parents report feeling alone, feeling as though nobody understands their child's unique behaviors (Nealy et al., 2012).

Past studies show that mothers of children with autism, mutually supporting each other, is valuable and helps to reduce parental stress. Searing et al., (2015), conducted an online survey to obtain more information on social support groups for parents of children with ASD and found that support groups can be very valuable for these parents in need. One parent in this study said, "Meeting other parents with children with ASD is probably the best support for me as they will be the only ones who truly understand what you have to go through on a daily basis" (Searing et al., 2012, p. 35). Parents of children with disabilities who have attended parent support groups report an increased sense of control in the world, an increased sense of belonging or being part of a community, and positive changes in their relationship with and perception of their child (Clifford & Minnes, 2013). Additionally, parents who receive informal supports from friends and peers could also have reduced parental levels of stress and improve their overall well-being (Samadi, 2012).

Russa (2014) describes Parent-to-Parent PTP:

PTP is a national organization that serves to connect parents of children with disabilities one-on-one with volunteer parents who can relate to their experiences and provide information and support. Mentors, who are parents of children with disabilities, are trained and then matched with parents seeking support. The availability of 24-hr support through PTP is particularly important for parents with children with more severe disabilities. Surveys of PTP recipients suggest that having someone to listen and

understand, having the opportunity to obtain information about services and resources, and being able to discuss the child's disability and strategies for managing behavior are the greatest benefits of the program. (p.99)

Social support groups such as the one described above can be a helpful resource for parents of children with ASD.

Many parents notice early on that their child is not progressing at the normal rate and begin to worry what it is that is causing this to happen. The actual diagnosis typically does not happen until the child is around three years of age (Karst & Van Hecke, 2012). It was found that these parents who are waiting for a diagnostic assessment for ASD experience distress and anxiety while they wait (Connolly & Gersch, 2013). Having access to a support group during this time would be very beneficial for these parents.

Through doing a literature review of current research, Karst & Van Hecke (2012), found that raising and supporting a child with ASD appears to have negative effects on parents and families regardless of the severity or the time since diagnosis. It is stated in the article that raising a child with ASD appears to contribute to a general decrease in parental well-being and increase in mental health concerns. The impact of having a child with ASD extends beyond caregivers to the entire family system. The increase in parenting stress, financial strain, conflict, and child behavior problems contributes to a higher rate of divorce for parents of children with ASD than in families with typically developing children. The article stresses the importance of developing coping strategies and use of social support by other families raising a child with ASD. This can greatly help the overall well being of these families. (Karst & Van Hecke, 2012).

Karst & Van Hecke (2012) reviewed literature on parent and family impact of ASD and proposed a model for intervention evaluation. Karst & Van Hecke found that parents of children

with ASD have to deal with unique challenges. Due to this, support and understanding from other parents who do not have a child with ASD can be hard to obtain. Karst & Van Hecke (2012) surveyed parents who have a child with ASD, asking if they go or have gone to a support group meeting. The results showed that two-thirds of the parents surveyed had or do go to a support group for parents of children with ASD. These parents that did go were mostly well-educated, middle-income families, and had a child who was older, and who exhibited problems related to sleep, language, and/or self-injury (Karst & Van Hecke, 2012).

Social support groups can help parents talk with other parents who truly understand what they are going through. Parents in these groups can also share information with each other such as information about new programs or therapies, training workshops, school services, or social events for parents of children with ASD. They can also share stories or experiences they have with their child living with ASD (Mandell & Salzer, 2007). Parents can vent out their anger and frustrations during these meetings without the worry of being judged. Online and in person support groups are available and out there for parents of children with ASD, although in person support groups are supposed to be more beneficial, providing community and face to face contact (Mandell & Salzer, 2007).

Although parent support groups seem to be very beneficial to many of these parents in need, it is also important for these parents to remember that everyone with ASD is different. One way of going about something for their child may work for one parent but may not work for another parent. This is important to remember when parents are communicating and engaging in discussions (Elder & D'Alessandro, 2009).

Access to adequate information.

From the moment that ASD is first raised as a possibility for child to have, the parents want information on ASD and the diagnostic process (Connolly & Gersch, 2013). “Lack of access to appropriate information for parents with a child with ASD, both early on and as the child ages, is a significant barrier to adjustment for families with a child with ASD” (Russa et al., 2014, p. 96). After the child is diagnosed, parents report feeling frustrated because it can be difficult to obtain information and access services for their child (Russa et al., 2014). These parents often feel overwhelmed and have a difficult time differentiating the legitimate interventions with the faddish, unproven approaches (Elder & D’Alessandro, 2009).

Russa et al. (2014) discusses parent needs:

Even when parents are able to find quality information to address the child and family needs, they often must start the search over again soon after, due to the types of information that vary over the lifespan of the child with ASD, from information about diagnosis, to materials about their child’s rights, to sources of funding and support.

Internet offers a great deal of information that was not previously available to parents, yet parents often have difficulty discriminating high-quality, accurate information among the overwhelming amount of information that they find online. (p. 96)

Parents of a child with a disability feel that information is power. It is how they can help and better support their child to be more successful through obtaining the skills that are necessary to do so. A study by Pozo, Sarria, & Brioso (2014) gave parents who have a child with ASD a questionnaire to measure the quality of life and psychological well-being in parents of children with ASD. Pozo et al., (2014) found that professionals need to provide parents with clear and consistent information on the characteristics of ASD and with information on the steps

to take over the child's lifetime. Informing parents of the resources available to them will help the parents better understand ASD, allowing the parents to feel more in control of the situation that they are in. This will help parents feel as though raising their child is more manageable and will help to emphasize the positive aspects of the situation (Pozo et al., 2014). Obtaining this information is particularly important for parents who have a child with ASD as there are several treatment plans that claim that a child's behavior can greatly be modified if therapy and treatment is followed correctly by the professionals as well as the parents and family (Deris, 2012).

Connolly & Gersch (2013), reviewed past studies that surveyed parents regarding support while parents of children were on a waiting list for an assessment for ASD. In 1999 a study by Pain regarding the information needs of parents of children with disabilities found that information helped parents to cope emotionally with their child's differences (Connolly & Gersch, 2013). A survey conducted in 2006 by Murphy and Tierney revealed that the professionals in the community who were the parent's first point of contact were unable to provide the parents with specific information in relation to ASD. Another survey in a study by Fogarty and Cronin (2008) found that parents felt as though the waiting period could be improved by receiving written information and having the professionals at the pre-assessment clinics act as a point of contact for the parents during this time (Connolly & Gersch, 2013).

There is a clear need for parents of children with ASD to become better informed and education about ASD (Samadi et al., 2012). Supports and services that are available to help give parents the information and knowledge they need are not available and easily accessible to all parents of children with ASD. Group-based training of parents who have a child with a disability is a good, cost-effective way of providing education and support to parents when professional

expertise is scarce. However, this type of training has received limited attention for parents of children with ASD (Samadi, 2012). The little training that is available to parents of children with ASD is a one-on-one training approach (Samadi et al., 2012).

Russa et al (2014), stated that:

The Medical Home Model is one model that has been developed and supported by a range of national organizations as a means to improve services for all children with disabilities. The Medical Home model aims at treating the “whole person” by linking the patient to a full range of coordinated, intervention, and prevention-focused services.

Families of children with ASD struggle with care that is not well coordinated and information that does not adequately match the needs of the parent. (p. 99)

The Family Navigator Model is another model that offers information, support, and assistance to families of individuals with ASD to identify resources, access services, and develop plans of action based on informed decisions (Russa et al., 2014). Russa et al., (2014), said that:

A Family Navigator may be a professional or a parent with training to help families to overcome barriers to receiving services while modeling effective advocacy within systems. Through the process of working with a Navigator, families are mentored to become advocates for their own services and supports in the future. (p. 100)

Parents of children with ASD report having significant information needs before, during, and after their child’s diagnosis. This included needs related to practical advice as well as strategies to help manage their child’s challenging behaviors (Connolly & Gersch, 2013). Some programs and services for children with ASD do offer information and education opportunities for the parents however this access to knowledge about ASD is still not yet available for everyone. This needs to be available on a widespread scale to parents of children with ASD to

better support and help these parents (Connolly & Gersch, 2013). Hopefully these models and various supports become more accessible and are implemented more within programs for children with ASD to better inform and help these parents in need.

Summary

The approaches discussed above, PBIS, COMPASS Model, PTP, the Home Medical Model, and the Family Navigator Model are a start in helping parents with their children with autism. “Addressing the issues faced by families with ASD has been a challenge because the issues are broad, and they evolve over the course of the child’s development” (Russa et al., 2014, p. 96). Many past studies also contain small sample sizes, making it difficult to know the validity of the findings. Families with children with ASD need a lot of supports and overall feel as though they are not receiving the correct or enough supports. More research needs to be done on this topic. There is still so much to learn about the effects of having a child with ASD on the parents. More research needs to be done to help us better understand the impacts ASD has on families and what can be done to help relieve some of the stress that comes along with the diagnosis. If possible, larger sample sizes should be looked at as well to obtain a more accurate sample of the impact that ASD has on families. Raising a child with ASD is very challenging and requires a lot of support for both the parents and children. Hopefully in the future, more parents will be trained and educated on autism to help relieve stress and increase confidence.

Chapter 3 Method

Research Approach

The intention of this study was to find out what variables cause stress for parents of children with ASD. The study uses a qualitative research design. Qualitative research design is used for understanding the meaning individuals attribute to a human problem. The process of research involves emerging questions and procedures, data typically collected in the participant's setting, data analysis building from particulars to general themes, and the researcher making interpretations of the meaning of the data. A qualitative research design includes open-ended questions, emerging methods, interview/observation, document, and audio-visual data. This type of research focuses on individual meaning, and the importance of interpreting the complexity of a situation. It focuses on one concept and validates the accuracy of findings (Creswell, 2009).

The questions in this study were created on the basis of professional discussions with practitioners and professors, as well as taken from the literature related to studies that inquired into the variables that cause stress for parents of children with ASD. The parents who were involved in this study were selected based on having a child with ASD, and proximity to the researcher. One parent who participated is a current client of the researcher, the other two participants are not. The participants were asked eleven questions related to their child's ASD diagnosis and how it impacted their daily lives. Based on the primary research questions, and the reviewed scholarship, a qualitative research design using a personal interview was selected as the best approach to use because of the sensitive nature of the topic under study, and because it involved parents, their children, and stress. Personal interviews also fit organically into the role of the researcher as a practitioner, because researcher contact with parents is a routine and regularly occurring process in providing care for the children as also to engage in a

understanding and nonjudgmental way. The researcher also chose this research design to use because the concept is “immature” due to a conspicuous lack of previous research, and a need exists to further explore the topic and develop a solution (Creswell, 2009). Below are the set of questions the researcher used in this study.

Interview Questions

1. When was your child (or children) diagnosed as having Autism Spectrum Disorder?
2. How long did it take to receive a diagnosis? Did you feel supported during this process? If so, how?
3. How did you feel after receiving your child’s diagnosis? Did you feel supported during this time? If so, how?
4. What are your child’s strengths?
5. What are the most challenging aspects of having a child with autism?
6. What are your thoughts on the level of support for caregivers? What works? What could be better?
7. What do you feel you need in terms of school, respite, home support? How much support do you feel you need?
8. What do you as a family unit need (parents, siblings, grandparents, etc)?
9. Do you receive all services under one company or multiple providers and agencies? Describe coordination/efforts between agencies
10. Do you feel you have access to appropriate information about autism readily available to you?
11. Do you have somebody in your child’s team that you feel you could approach to help you and your family receive more support?

Ethical Standards

This paper adheres to the ethical standards for protection of human subjects of the American Psychological Association. The researcher also kept the identities of the participants anonymous by using a pseudonyms to replace real names. Additionally, a research proposal was

submitted and reviewed by the Dominican University of California Institutional Review Board for the Protection of Human Subjects (IRBPHS), approved and assigned number 10424.

Sample and Site

The participants in this study were three parents who have at least one child with autism who live in the Northern California region. The children of the participants are between the ages of three to seven years old. The researcher interviewed two fathers and one mother. The parents were selected based on proximity to the researcher. The site where the interviews were conducted was at the homes of the participants. The parents who participated in this study are all from a high income bracket.

Access and Permissions

I previously worked as a Behavior Therapist with the child of a parent who participated in this study. Another parent participant in this study has a child who is provided services at the company that the researcher works for, but the researcher does not directly work with this child. The other participant is a parent of a child that the researcher currently works with. The researcher obtained permission through email from her administrator to interview this parent. The participants were initially emailed to request participation. The consent forms were given to and reviewed, with the participants in person, on the day of the interview. Informed consent from the participants were obtained in writing on the day of the interview. Sample copies of the letters and documents that were used are in the appendix.

Data Gathering Procedures

Data were gathered through personal interview with each participant. The interview consisted of eleven open-ended questions related to having a child with autism in order to obtain more knowledge about the stress that parents and caregivers of children with autism experience.

The interviews were recorded and later transcribed by the researcher. Hard data has been stored in a locked file cabinet and the digital data is password protected. The transcripts were reviewed by the researcher and the information was grouped based on similar responses to help better organize the data for analysis.

Data Analysis Approach

Data was evaluated after all three of the interviews were conducted. The interview questions inquired about support levels, challenges, and needs, in order to address this study's primary research question to examine the causes of stress for the participants.

First, the researcher listened to the audio recording of the interviews and digitally transcribed all of the responses verbatim. Next, the researcher reviewed each transcript and identified the common themes as well as differences between each participant. The researcher focused on the main ideas within each transcript, picking out the main causes of stress for each of the parents. The researcher obtained the main ideas from the responses to each question. The researcher looked for key words within each question that denoted a main idea. The main causes of stress as identified by the response themes/patterns from each parent were then identified, listed, and then compared to generate a tentative list of the similarities and differences among and between each participant. The findings from this generative list were organized by interview question to provide specificity. The researcher included direct quotes from the responses to support the specific findings from the analysis.

The theoretical rationale supporting the research question for this study Applied Behavioral Analysis (ABA) is based on an intervention approach that was developed to help children with ASD, and their families. Many different models and programs have been developed from the theoretical framework of ABA. ABA is helpful for the parents as well as the

child who can become more independent through acquiring these skills as well as better able to communicate, reducing frustration, stress, and challenging behaviors ((McPhilemy & Dillenburger, 2013).

Chapter 4 Findings, Discussion, and Analysis

Results

The researcher interviewed three participant parents who have a child or children with ASD. Two participants were fathers, and one was a mother. Eleven questions were asked during the interview with each parent participant. The questions asked were developed from previous interview research literature on this topic, and from professional discussions with practitioners and professors. Below are relevant questions along with the responses from each of the participants,

“How long did it take to receive a diagnosis? Did you feel supported during this process? If so, how?”

Parent A stated that, “For Samantha it took about 3-6 months before we were told that she had signs. I did not feel supported. I felt they didn’t care and it was a problem for us” (Parent A, 2016, p. 1).

Parent B stated, “It was hard because Max’s future seemed so uncertain and we felt so overwhelmed by his diagnosis. What were we supposed to do and how and who. So many questions and fears and not knowing where to turn to” (Parent B, 2016, p. 1). Parent B also reported that the ASD diagnosis took 4 years to obtain as diagnosis of other disabilities (speech delay, then PDD-NOS) were given prior to finally receiving the ASD diagnosis. Parent B said that they enrolled their son into a early start intervention school and felt a lot of support there. Parent B also said that once their child was in the school district they had a horrible experience with them and their case manager that they were given.

Parent C stated, “From the moment we suspected he was disabled, we called our doctor. Between that call and diagnosis it took close to a month. We did not feel supported during this time” (Parent C, 2016, p.1).

“How did you feel after receiving your child’s diagnosis? Did you feel supported during this time? If so, how?”

Parent A reported that he felt lost and felt like he failed a parent. He blamed himself for a long time but he said that he is thankful for his family and friends that were there to support him during this time. He stated that he did not have any other supports during this difficult time.

Parent B stated that her son was first diagnosed with a speech delay, then PDD-NOS, and then finally with ASD. After the first diagnosis of speech delay, parent B knew it was something more than just that. Parent B said that they had to pay for services for this because it was not covered under insurance unless he had a diagnosis. Finally, once her son received a ASD diagnosis, parent B (2016) said that:

I went through denial, fear, sadness, anger, and finally acceptance in that order. I didn’t feel supported in what I needed to do for him. I had no idea of the types of therapies he needed and how to go about building his therapy team. (p. 2)

Parent C said that him and his wife felt devastated and that they did not receive any support during this time.

“What are your thoughts on the level of support for caregivers? What works? What could be better?”

Parent A said that his family has been very happy with and grateful for the high quality therapists that they have had so far. Parent A said consistency is key so having less substitutions and changes of therapists is important to him. He mentioned that they have been rather lucky in

having therapists stay a good amount of time. Parent A said that the front office could be better. He said that the administration needs to know what the parents go through and manage their administrative duties such as billing.

Parent B reported that the school districts need to be better at offering services and showing parents what need to be done. Parent B said, “They will not give anything unless asked and after much evidence and persistence on the parent’s part to convince the school district that the service is necessary for their child to access their education” (Parent B, 2016, p. 3).

Parent C said that the level of care from therapy that they have received is mediocre. He said that consistency of therapists is lacking, making it hard to get to know the people working with his child on a personal level. Parent C said this lack of continuity makes it hard for the therapists to really know his son or his family well. He also said that there are not well written and detailed reports that get passed along to the next person, which causes much frustration and sets back the progress that had been made.

“What do you feel you need in terms of school, respite, home support? How much support do you feel you need?”

Parent A said that he is pleased with the therapy and feel as though they do not need any more supports at this time. He also said that him and his wife rely on family for support, to help take care of the children as well as emotional support.

Parent B stated that she would love respite or live in support but said that live in support costs too much and that it is hard to find a sitter who is qualified and understands ASD to provide good enough care. Parent B also said that she wished that paraprofessionals at school were better trained and that the schools would keep the paraprofessional support consistent over the years rather than giving less support as the years go on.

Parent C said that he feels as though his child has all of the supports available in regards to therapy but wishes that the quality of these supports was better. Parent C said, “I would trade less therapy hours for better quality and more consistency” (Parent C, 2016, p. 3).

“What do you as a family unit need (parents siblings, grandparents, etc)?

Parent A did say that he wishes that there were a better way to do the therapy as the various therapies take up a lot of hours each week, which is hard for his young child to do along with going to preschool.

Parent B reported that as a family unit they need to all remember to have patience with each other. She also said that they need people they can trust and who are knowledgeable to watch their children when they need a break or need to do something without their children.

Parent C said that he does not feel as though support groups would help since every child with ASD is different and therefore goes through different things. Parent C said that he would like to be able to obtain good, accurate information around ASD. He stated that there are too many resources and a lot of bias in what you read. He would like these resources to be narrowed down so that they can obtain educated and informed information. He would like this type of information around the therapy goals that his son has.

“Do you receive all services under one company or multiple providers and agencies?

Describe coordination/efforts between agencies”

Parent A said that they receive all therapy services under one company but that there is still little to no coordination between the different therapists.

Parent B said that they receive services through multiple providers and that all of the services have been great. Parent B said the billing coordination is lacking and dealing with insurance is time consuming and stressful.

Parent C said that there is no coordination between the different services that they receive. Parent C said that they obtain services through multiple providers. He said that each provider has its own biases and do not collaborate together.

“Do you feel you have access to appropriate information about ASD readily available to you?”

Parent A said that if he has a question he can ask someone on their team but that he does not have a means of obtaining information elsewhere.

Parent B reported that she believes there is a lot of good, useful information out there but that finding it is not always easy. She said that having a list of helpful sites, resources, and support groups would be helpful. She stated that she feels that she would not have felt so alone if she had access to these types of resources during the initial diagnosis period.

Parent C said that there is so much information available that it is almost impossible to access information that is relevant to their specific child.

“Do you have somebody in your child’s team that you feel you could approach to help you and your family receive more support?”

Parent A said that they do not have anybody that they could approach but that they are now fine with that. Parent A relies on family for support. Again, if he has a question parent A does feel comfortable asking the team but does not have support beyond that.

Parent B said she feels lucky to have a few people that work closely with her child that she feels comfortable enough to approach for support. Parent B said overtime they have created a little “village” of support and can send out emails and get responses back.

Parent C said that they do not have anyone that they could approach for more support.

Discussion and Analysis of the Findings

Through evaluating the responses of the participants in this study, it is clear that this sample of parents in the current study all need more supports. All three of the participants had several of the same unmet needs and desires for future support. This includes, better coordination of the various services, an improved billing system for the different services, and access to current and valid information on ASD. The three parents who were interviewed all expressed what supports were important to them and if they were provided to them or not. Fortunately, all of the parents in this study felt as though they have obtained the best supports in regards to current therapies that are available in the area for their child. All three of the parents said that their child has ABA therapy and speech therapy. Parents B and C reported that their child has an aide at school. Parent A stated that his child does not have an aide because his child is not yet in elementary school and does not need an aide at this time. Parent B said her child has a part time aide and parent C said that his child has a full time aide with him at school. All three of the participant's children are not in a special education classroom at school. Although the parents in this current study were fortunate enough to not have difficulties obtaining services, the parents did express their dissatisfaction with some or many of the services that they do have.

Parent B and parent C said that their child is receiving ABA, has a paraprofessional aide, and has speech services. These services are provided by multiple agencies. Parent A said that his child receives ABA and speech services from one company but that the coordination between the various therapists is still lacking. Parent B and C said that the coordination between these services was lacking and sometimes did not exist. This is similar to the results found by Blair et al., (2011) who found that when the parents and the teachers worked together and collaborated more frequently, the challenging behaviors from the child with ASD decreased, while positive behaviors increased. This study showed the need for better collaboration amongst teachers and

parents in order to see better outcomes for the child. Better collaboration helps to lessen stress and improve the quality of life for the child (Blair et al., 2011). In addition to issues with collaborating, all of the parents expressed their stress of dealing with the various billing problems and said that it took up a lot of their time because there is a poor billing system in place when going through the multiple agencies and services.

The three parents also all said they felt unsupported during the initial diagnosis period by the professionals that they came in contact with. However, all three of the parents who participated in this study felt supported from the beginning of the process by their extended family and friends. Despite this support, the parents all discussed how they felt very isolated and lost during the initial diagnosis period. The parents said that they had so many questions and fears and did not know where or who to turn to during this confusing time in the process. The parents said that receiving the diagnosis was a relief since they all knew something was going on, but that they also experienced a great deal of denial, sadness, and anger period. This is similar to what Russa et al., (2014) and Connolly & Gersch (2013) found in their studies regarding parents feeling frustration when they tried to access information and support before and directly after their child's diagnosis. Connolly & Gersch (2013) found that more information during this difficult time helped parents cope emotionally with their child's differences.

In regards to supports, Parent A felt as though he did not need anymore than the therapy that his child is currently receiving while parents B and C said that they would like more support within their school districts by the school's guiding the parents through the process in a more efficient way. Parent C said he would like better quality therapy services, as there is a high turnover rate so it is hard to form quality relationships with the professionals working with his child. This makes it difficult to form strong, long term relationships with these professionals.

This is similar to the research by Searing et al., (2015) who found parents have difficulties maintaining supports as staff do not stay long, making it hard for both the parents and child to form a lasting relationship with the therapists.

Parent B said she would like paraprofessionals at the school who are better trained. Parent B also mentioned having access to affordable, but quality respite care would also be beneficial. Parents A and B said that they felt they had people on their teams that they could approach to ask questions and get better supports, while parent C said that they do not have anyone that they felt comfortable to go to for help. This is similar to the results found by Hartley and Schultz (2014) who said that parents had unmet needs with the relationships they had with the professionals. Hartley and Schultz (2014) found that parents did not feel that they have a close relationship with the therapists to feel comfortable enough to ask for help. The consistency of therapists is also an issue for parents of children with ASD, as therapists change frequently.

Today, there is so much available online that three parents in this study said they did not know where to start and what to believe. The parent participants want to obtain a list of helpful sites, resources, and support groups available in the area in hopes to receive current, accurate information about ASD and the issues that arise. This is similar to the results found by Samadi et al. (2012) who found that there is a need for increase in parental knowledge of ASD so that parents can feel less guilt and better understand the complex disorder of ASD. The results from the study showed that the parents who participated in the study did feel empowered, less stressed, and experienced an increase in family functioning following the intervention.

Additionally, in the study by Preece (2014), one parent stated that it was disempowering to not fully understand her child's diagnosis and to not know what is best for her child (p. 148). Hartley and Schultz (2014) found that parents had many of the same stressors and fears as the

parents in this current study. Hartley and Schultz (2014) found the parents felt that they needed to be better educated about their child's disorder to be better decision makers about their child. The parents who were interviewed in the study wanted more information on ASD just as the parents in this study did to be able to understand their child better and to be able to be more confident in knowing what is best for their child.

The variety of support needs from the parents in this study will require a variety of different supports that should be offered or altered to better help these parents in the future. The similar challenges that were found both in the current study and in past literature help to show the similar needs amongst parents who have a child with ASD. Comparing the results from the current study to past research and literature further shows the need for change within the current supports and services available.

Chapter 5 Conclusions and Recommendations

Conclusions from the Study

The results showed that the participants who were interviewed do feel stressed as a result of their child's disability due to ASD. All of the participants said that they currently felt that they had all of the programs they need for their child that are currently available, but that they received little support from the schools and companies that provide services for their children.

The findings suggest that the variety of support needs identified by the parents in this study will require a variety of different supports that should be offered or altered to better help such parents in the future. The similarity in the challenges that were found both in this study and highlighted in the literature help to add further credence to the shared similarity of needs amongst parents who have a child with ASD. A comparison of the results from this study to previous findings from the research literature indicates that there are still gaps in the needs of parents that have not been addressed, and also that there is a need for change within the current supports and services that are available.

Limitations/Gaps in the Research

The sample of participants in this study was very small, and included only three participants. One participant currently works with the researcher, another participant previously worked with the researcher, and the last participant receives services from the same company that the researcher works at. These connections that the researcher has to the participants could have altered the participants responses. The participants are all from one portion of the Northern California Region and are all upper-middle class to upper-class families, and therefore cannot be construed to be a representative sample. The background of the participants denote that they are soci-economically well off, thus allowing better access to services and supports due to their level

of health insurance and safe well run schools. The three parents in this study are all still married to their spouses, and while it was not within the purview of this study, it is possible that marital status may have an effect upon the variables causing stress. While this study may add credence to the existent body of scholarship illuminating the causes of stress and the needs of parents who have children with ASD, it cannot, and should not be generalized to the needs of every parent who has a child with ASD.

Implications for Future Research

The study suggests that a more effective program or service that helps parents access the appropriate information on ASD and how to handle certain behaviors that come up throughout the child's life should be designed and made available to parents. The literature as well as the participants in this study emphasized this great need, since there is a vast amount of information that has become available, making it very confusing as to what really works and what to believe is accurate information. There needs to be a greater recognition, and awareness among providers when information is disseminated, because every child with ASD is uniquely different, and a standardized approach may not work for each child and their family. Additionally, the findings in this study indicate that a specially designed program to help parents cope during the process, before and after diagnosis, is warranted, and would benefit at least this sample of participants, if not other parents of children with ASD. Based on prior research as well as the findings from this study, it is apparent that many parents could greatly benefit from a program that better supports them through the process of diagnosis and the aftermath by answering questions, counseling, and accurately informing them.

Overall Significance of the Study

This small study further contributes and corroborates the existent literature about the causes of stress for parents of children with ASD, and what they need to feel better supported. This study provides a limited view of how parents of children with ASD do need access to more, and better supports for themselves as well as their children.

About the Author

Sarah Rushworth is a Graduate Student at Dominican University of California obtaining a Master's Degree in Special Education. While earning a Bachelor's of Art Degree in Psychology at the University of Arizona, she became interested in ASD when she had the opportunity to work part time as a Behavioral Therapist at a company in Tucson, Arizona. After greatly enjoying this rewarding job, she continued her work in the same field when she graduated and moved to San Francisco. Once she gained more experience and knowledge at the company in San Francisco that she worked for as a Behavioral Therapist, she decided to go back to school to earn her MS in Special Education. The goal of earning this degree was to be able to grow within the field, helping the parents along with the children. As a behavioral therapist, you mainly work with the child one-to-one, but also try to assist the parents when able to. The researcher noticed a constant theme while working with many different families in both states and within the various companies she has worked at. This theme was that the parents appeared to be very stressed and in need of more help, but never seemed to receive more help when they asked for it. While going to graduate school, the researcher changed companies and is now a Senior Behavioral Therapist at a different company in San Francisco. After obtaining her MS in Special Education, she plans to become a Program Director. The researcher is also enrolled in classes to obtain certification as a Board Certified Behavior Analyst (BCBA) in hopes to continue to further her career in this important field. As a Program Director, the researcher will still be working with children with

ASD, but more closely with the parents. This goal after graduation was the motivator behind this thesis project topic. The researcher hopes to continue to grow and expand her knowledge on ASD to better support parents with children with ASD.

References

- Al-Shammari, Z., Daniel, C., Faulkner, P., & Yawkey, T. D. (2010). Improving inappropriate social behavior of autistic students using the LISTEN intervention strategy. *Journal of Instructional Psychology, 37*(4), 286-249. Retrieved from <http://search.ebscohost.com>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5*. Arlington, VA: American Psychiatric Publishing.
- Ataman, A. D., & Bicer, S., Vatanoglu-Lutz (2014). Medicine in stamps: History of autism spectrum disorder (ASD) through philately. *Journal of Neurological Sciences, 31*(2), 426-434. Retrieved from <http://search.ebscohost.com>
- Autism Speaks. (2016). Facts about autism. Retrieved from www.autismspeaks.org
- Autism Speaks. (2016). Applied Behavior Analysis (ABA). Retrieved from: <https://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-aba>
- Blair, K. C., Lee, I., Cho, S., & Dunlap, G. (2011). Positive behavior support through family–School collaboration for young children with autism. *Topics in Early Childhood Special Education, 31*, 22–36. Retrieved from <http://search.ebscohost.com>
- Burszytn, A. (2007). *The Praeger handbook of special education*. Westport, CT: Praeger
- Clifford, T., & Minnes, P. (2013). Logging on: Evaluating an online support group for parents of children with autism spectrum disorders. *Journal of Autism & Developmental Disorders, 43*(7), 1662-1675. doi:10.1007/s10803-012-1714-6
- Connolly, M., & Gersch, I. (2013). A support group for parents of children on a waiting list for an assessment for autism spectrum disorder. *Educational Psychology in Practice, 29*(3), 293-308. doi:10.1080/02667363.2013.841128

- Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed method approaches*. Thousand Oaks, CA: Sage Publications.
- Deris, A. R. (2012). Investigation of social supports for parents of children with autism. *International Journal of Early Childhood Special Education*, 4(1), 17-31. Retrieved from <http://search.ebscohost.com>
- Elder, J. H., & D'Alessandro, T. (2009). Supporting families of children with autism spectrum disorders: Questions parents ask and what nurses need to know. *Pediatric Nursing*, 35(4), 240-253. Retrieved from <http://search.ebscohost.com>
- Falk, N., Norris, K., & Quinn, M. (2014). The factors predicting stress, anxiety and depression in the parents of children with autism. *Journal of Autism & Developmental Disorders*, 44(12), 3185-3203. doi:10.1007/s10803-014-2189-4
- Harper, A., Dyches, T., Harper, J., Roper, S., & South, M. (2013). Respite care, marital quality, and stress in parents of children with autism spectrum disorders. *Journal of Autism & Developmental Disorders*, 43(11), 2604-2616. doi:10.1007/s10803-013-1812-0
- Hart Barnett, J. E., & O'shaughnessy, K. (2015). Enhancing Collaboration between Occupational Therapists and Early Childhood Educators Working with Children on the Autism Spectrum. *Early Childhood Education Journal*, 43(6), 467-472. Retrieved from <http://search.ebscohost.com>
- Hartley, S. L., & Schultz, H. M. (2014). Support Needs of Fathers and Mothers of Children and Adolescents with Autism Spectrum Disorder. *Journal of Autism And Developmental Disorders*, 45(6), 1636-1648. Retrieved from <http://search.ebscohost.com>
- Jenkins, J. R., & Sells, C. J. (1984). Physical and Occupational Therapy: Effects Related

to Treatment, Frequency, and Motor Delay. *Journal Of Learning Disabilities*, 17(2).

Retrieved from <http://search.ebscohost.com>

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders:

A review and proposed model for intervention evaluation. *Clinical Child and Family*

Psychology Review, 15(3), 247-277. Retrieved from <http://search.ebscohost.com>

Kogan, M. D. G., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P.

C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005– 2006. *Pediatrics*, 122,

1149–1158. Retrieved from <http://search.ebscohost.com>

Low Hui, M., & Lee Lay, W. (2011). Teaching of Speech, Language and Communication

Skills for Young Children with Severe Autism Spectrum Disorders: What Do Educators

Need to Know?. *New Horizons In Education*, 59(3), 16-27. Retrieved from

<http://search.ebscohost.com>

Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of

children with autism? *Autism*, 11(2), 111–122. doi:10.1177/1362361307077506.

McPhilemy, C., & Dillenburger, K. (2013). Parents' experiences of applied behaviour

analysis (ABA)-based interventions for children diagnosed with autistic spectrum disorder.

British Journal Of Special Education, 40(4), 154-161. doi:10.1111/1467-8578.12038

Nealy, C. E., O'Hare, L., Powers, J. D., & Swick, D. C. (2012). The impact of autism spectrum

disorders on the family: A qualitative study of mothers' perspectives. *Journal of Family*

Social Work, 15(3), 187-201. Retrieved from <http://search.ebscohost.com>

- Pozo, P., Sarriá, E., & Brioso, A. (2014). Family quality of life and psychological well-being in parents of children with autism spectrum disorders: A double ABCX model. *Journal of Intellectual Disability Research*, 58(5), 442-458. doi:10.1111/jir.12042
- Preece, D. (2014). Providing training in positive behavioral support and physical interventions for parents of children with autism and related behavioral difficulties. *Support for Learning*, 29(2), 136-153. Retrieved from <http://search.ebscohost.com>
- Ruble, L. A., & Dalrymple, N. J. (2002). COMPASS: A Parent-Teacher Collaborative Model for Students with Autism. *Focus On Autism And Other Developmental Disabilities*, 17(2), 76-83. Retrieved from <http://search.ebscohost.com>
- Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. (2015). Expanding supports to improve the lives of families of children with autism spectrum disorder. *Journal of Positive Behavior Interventions*, 17(2), 95-104. Retrieved from <http://search.ebscohost.com>
- Samadi S.A., McConkey, R., & Kelly, G. (2012). Enhancing parental well-being and coping through a family-centered short course for Iranian parents of children with an autism spectrum disorder. *Autism*, 17(1), 27-43. Retrieved from <http://search.ebscohost.com>
- Searing, B. J., Graham, F., & Grainger, R. (2015). Support Needs of Families Living with Children with Autism Spectrum Disorder. *Journal Of Autism And Developmental Disorders*, 45(11), 3693-3702. Retrieved from <http://search.ebscohost.com>
- Sicile-Kira, C. (2004). *Autism spectrum disorders: The complete guide to understanding autism, Asperger's syndrome, pervasive developmental disorder, and other ASDs*. New York, New York: The Berkely Publishing Group. Retrieved from <http://search.ebscohost.com>

- Smith, T., & Eikeseth, S. (2010). O. ivar Iovaas: Pioneer of applied behavior analysis and intervention for children with autism. *Journal of Autism & Developmental Disorders*, 41(3), 375-378. doi:10.1007/s10803-010-1162-0
- Thompson, T. (2013). Autism research and services for young children: History, progress and challenges. *Journal of Applied Research in Intellectual Disabilities*, 26(2), 81-107. doi:10.1111/jar.12021
- Tsai, L., & Ghaziuddin, M. (2014). DSM-5 ASD moves forward into the past. *Journal of Autism & Developmental Disorders*, 44(2), 321-330. doi:10.1007/s10803-013-1870-3
- U.S. Department of Health and Human Services. (2016). Autism Spectrum Disorder: Data and Statistics. *Centers for Disease Control and Prevention*. Retrieved from <http://www.cdc.gov/ncbddd/autism/data.html>
- Wood, J. J., Fujii, C., Renno, P., & Van Dyke, M. (2014). Impact of Cognitive Behavioral Therapy on Observed Autism Symptom Severity during School Recess: A Preliminary Randomized, Controlled Trial. *Journal Of Autism And Developmental Disorders*, 44(9), 2264-2276. Retrieved from <http://search.ebscohost>

Appendix A

**CONSENT FORM TO BE A RESEARCH SUBJECT****Postsecondary Outcomes****Sarah Rushworth**

1. I understand that I am being asked to participate as a subject in a research study designed to identify how to better support parents of children with Autism Spectrum Disorder. This research project is being conducted by Sarah Rushworth, graduate student with Dominican University of California.
2. I understand that participation in this research will involve a 30 to 45 minute interview.
3. I understand that my participation in this study is completely voluntary and I am free to withdraw my participation at any time.
4. I have been made aware that the interview will be audio recorded. All personal references and identifying information will be eliminated when these recordings are transcribed, and all subjects will be identified by numerical code only; the master list for these codes will be kept by Sarah Rushworth, in a locked file, separate from the transcripts. Coded transcripts will be seen by the researcher, her graduate advisors, and graduate student peers only for the purpose of analysis. One year after the completion of the research, all recorded materials will be destroyed.
5. I am aware that study participants will be furnished with a written summary of the relevant findings and conclusions of this project. I understand that any publications concerning this research will protect my anonymity.
6. I understand that I will be discussing topics of a personal nature and that I may refuse to answer any question that causes me distress or seems an invasion of my privacy. I may elect to stop the interview at any time.
7. I understand that my participation involves no physical risk, but may involve some psychological discomfort, given the nature of the topic of having a child with Autism Spectrum Disorder.
8. I understand that if I have any further questions about the study, I may contact Sarah Rushworth via phone (415-250-8204) or email (rushworthsc@gmail.com). I may also contact Colleen Arnold, supervising professor, at (415) 482-1860 or email (cmurph99@gmail.com). If I have further questions or comments about participation in this study, I may contact the Dominican University of California Institutional Review Board for the Protection of Human Subjects (IRBPHS), which is concerned with the protection of volunteers in research projects. I may reach the IRBPHS Office by calling (415) 482-3547 and leaving a voicemail message, by FAX at (415) 257-0165 or by writing to the IRBPHS, Office of the Associate Vice President for Academic Affairs, Dominican University of California, 50 Acacia Avenue, San Rafael, CA 94901.
9. All procedures related to this research project have been satisfactorily explained to me prior to my voluntary election to participate.

I HAVE READ AND UNDERSTAND ALL OF THE ABOVE EXPLANATION REGARDING THIS STUDY.

I VOLUNTARILY GIVE MY CONSENT TO PARTICIPATE. A COPY OF THIS FORM HAS BEEN GIVEN TO ME FOR MY FUTURE.

Name _____

Signature _____

Date _____

***School of Education and Counseling Psychology 50 Acacia Avenue, San Rafael, California
94901-2298 p. 415-482-2462 – f. 415-458-3790 – www.Dominican.edu***



RESEARCH PARTICIPANT'S BILL OF RIGHTS

Every person who is asked to be in a research study has the following rights:

1. To be told what the study is trying to find out;
2. To be told what will happen in the study and whether any of the procedures, drugs or devices are different from what would be used in standard practice;
3. To be told about important risks, side effects or discomforts of the things that will happen to her/him;
4. To be told if s/he can expect any benefit from participating and, if so, what the benefits might be;
5. To be told what other choices s/he has and how they may be better or worse than being in the study;
6. To be allowed to ask any questions concerning the study both before agreeing to be involved and during the course of the study;
7. To be told what sort of medical treatment is available if any complications arise;
8. To refuse to participate at all before or after the study is stated without any adverse effects. If such a decision is made, it will not affect his/her rights to receive the care or privileges expected if s/he were not in the study;
9. To receive a copy of the signed and dated consent form;
10. To be free of pressure when considering whether s/he wishes to be in the study.

If you have questions about the research you may contact me at rushworthsc@gmail.com.

If you have further questions you may contact the Dominican University of California Institutional Review Board for the Protection of Human Subjects (IRBPHS), which is concerned with protection of volunteers in research projects. You may reach the IRBPHS Office by calling (415) 257-1389 and leaving a voicemail message, or FAX at (415) 257-0165, or by writing to IRBPHS, Office of Associate Vice President for Academic Affairs, Dominican University of California, 50 Acacia Avenue, San Rafael, CA 94901

***School of Education and Counseling Psychology 50 Acacia Avenue, San Rafael, California
94901-2298 p. 415-482-2462 – f. 415-458-3790 – [www. Dominican.edu](http://www.Dominican.edu)***

Appendix C



This place changes people.

February 6, 2016 Dear (Parent),

My name is Sarah Rushworth and I am a graduate student at Dominican University of California. I am conducting a research study to identify how to better support parents of children with Autism Spectrum Disorder. This research project is an important part of my graduate thesis requirements. Colleen Arnold, MS will be supervising my research.

I am seeking your voluntary participation in a 30-45 minute in person interview, which will include a reflection and/or background regarding you, your family, and your child. The interview will be audio recorded. All personal references and identifying information will be eliminated when these recordings are transcribed. The interview transcript will remain anonymous.

If my request to interview you meets with your approval, please send three dates/times that are convenient for the interview.

Sincerely,

Sarah Rushworth

50 Acacia Avenue

Dominican University of California

San Rafael, CA 94901

Email address: rushworthsc@gmail.com

*School of Education and Counseling Psychology 50 Acacia Avenue, San Rafael, California
94901-2298 p. 415-482-2462 – f. 415-458-3790 – [www. Dominican.edu](http://www.Dominican.edu)*