

A VIEW OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER
THROUGH MASLOW'S HIERARCHY OF NEEDS:
A PHENOMENOLOGICAL STUDY

by

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Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

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ABSTRACT

Parents of children with Autism spectrum disorder (ASD) encounter many stressors beyond the typical parenting pressures that parents of children without disabilities face. Along with the additional challenges, parents of children with ASD face complex needs that differ from parents of children with other types of disabilities. The purpose of this qualitative study was to consider the needs of parents ($N = 10$) with children with ASD served in a public school system in North Georgia through the framework of Maslow's (1943) *Theory of Human Motivation*. A transcendental phenomenological design was used to provide a voice to parents of children with ASD. Data was collected through timelines, personal interviews, and focus groups. The data was then analyzed in accordance with Moustakas' (1994) transcendental approach using bracketing, horizontalization, and developing clusters of meaning in order to determine to the essence of the experience of the participants. Five major themes emerged from data analysis: (a) understanding challenging experiences; (b) searching for knowledge; (c) searching for acceptance; (d) searching for self-worth; and (e) desiring to help others.

Keywords: Autism spectrum disorder (ASD), parental needs, Maslow's hierarchy, parent-teacher relationship

Dedication

First and foremost, reaching this educational goal would not be possible without the God given opportunity and blessings I have received. God has blessed me with a fulfilling occupation to help others and serve Him. May all glory be given to Him, and any continuing research from this study be in His service.

To my parents, John and Carolyn DeBord: You have always been the greatest educators in my life. You instilled in me the true value of education. You taught me the importance of hard work, patience, perseverance, love, and forgiveness. Thank you for your continual support and guidance. Thank you for encouraging me and believing in me in each endeavor I have ever imagined. Mom, you have shown me how to be a genuine educator and love the students who need it the most. Your selfless acts to others and servant heart have provided a great model for me and your granddaughters. Dad, thank you for teaching me the balance of academic education and practical “common reasoning” education. You both have been my steady source of unconditional love and support.

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Table of Contents

ABSTRACT.....	3
Dedication.....	4
Acknowledgments	6
Table of Contents.....	7
List of Tables	12
List of Figures.....	13
List of Abbreviations	14
CHAPTER ONE: INTRODUCTION.....	15
Overview.....	15
Background.....	15
Situation to Self	18
Problem Statement.....	19
Purpose Statement.....	20
Significance of the Study.....	20
Research Questions.....	21
Research Plan.....	22
Delimitations.....	23
Definitions	23
Summary.....	24
CHAPTER TWO: LITERATURE REVIEW	25
Overview.....	25

Background of Autism.....	25
Types of ASD	28
Diagnosis	30
Prevalence.....	32
Characteristics of Children with Autism	32
Relating to Others.....	33
Communication.....	34
Restricted Repetitive Behavior.....	35
Co-existing Behaviors and Emotional Issues.....	36
Stress.....	40
Parental Stress.....	41
Personal Stress.....	47
Stressors During the IEP Process.....	52
Theoretical Framework.....	55
Physiological Needs.....	57
Safety Needs.....	58
Love Need.....	59
Esteem Needs.....	60
Self-Actualization Needs.....	62
Summary.....	62
CHAPER THREE: METHODS	64
Overview.....	64
Design.....	64

Research Questions.....	66
Setting.....	66
Participants.....	68
The Researcher's Role.....	70
Data Collection.....	71
Questionnaire.....	72
Timeline of Significant Events.....	72
Interviews.....	74
Focus Groups.....	77
Data Analysis.....	79
Bracketing.....	79
Horizonalization.....	79
Clusters of Meaning.....	80
Textural Description.....	80
Structural Description.....	80
Composite Description.....	81
Trustworthiness.....	81
Ethical Considerations.....	83
Summary.....	83
CHAPTER FOUR: FINDINGS.....	84
Overview.....	84
Participants.....	84
Carolyn.....	85

Carrie.....	86
Cameron.....	88
Jodi.....	89
Heather.....	89
Jamie.....	90
Owen.....	92
Becky.....	93
Billy.....	94
Angel.....	95
Themes.....	96
Understanding Challenging Experiences.....	97
Searching for Knowledge.....	102
Searching for Acceptance.....	104
Searching for Self-Worth.....	107
Desiring to Help Others.....	108
Results.....	109
Research Question 1.....	110
Research Question 2.....	112
Summary.....	113
CHAPTER FIVE: DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS	115
Overview.....	115
Summary of Findings.....	115
Discussion.....	116

Empirical Contributions.....	116
Theoretical Contributions.....	117
Implications	120
Implications for Educators.....	120
Implications for Teacher Education Programs.....	123
Implications for Parents.....	123
Limitations	126
Recommendations for Future Research.....	127
Summary.....	127
REFERENCES	129
APPENDIX A.....	150
APPENDIX B.....	151
APPENDIX C.....	154
APPENDIX D.....	157
APPENDIX E.....	158
APPENDIX F.....	159
APPENDIX G.....	160
APPENDIX H.....	161
APPENDIX I.....	162
APPENDIX J.....	163

List of Tables

Table 1: Participant Demographics	69
Table 2: Standardized Open-Ended Interview Questions.....	76

List of Figures

Figure 1: Maslow's Hierarchy of Needs.....	57
Figure 2: Maslow's Hierarchy of Needs with Themes Interwoven.....	98

List of Abbreviations

Asperger's syndrome (AS)

Attention-deficit hyperactivity disorder (ADHD)

Autism spectrum disorder (ASD)

Center for Disease Control (CDC)

Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition – Text Revision
(DSM-IV-TR)

Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

Free appropriate public education (FAPE)

Individuals with Disabilities Education Act (IDEA)

Individualized Education Program (IEP)

Least restrictive environment (LRE)

National Institute of Mental Health (NIMH)

Pervasive developmental disorders (PDD)

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)

Public Law (PL)

Science Technology Engineering Mathematics (STEM)

CHAPTER ONE: INTRODUCTION

Overview

Currently, topics in special education have been broadly studied and researched; however, limited studies exist on understanding the challenges parents of children with autism spectrum disorder (ASD) face during the process of developing an Individualized Education Program (IEP) in schools. Maslow's (1943) *Theory of Human Motivation*, in which he described individuals' hierarchy of needs, served as the theoretical framework for this study to close the gap in literature on understanding the needs of parents of children with ASD.

Background

According to the National Institute of Mental Health (2012), "Autism is a group of developmental brain disorders, collectively called autism spectrum disorder (ASD)" (p. 2). Additionally, autism is referred to in the Individuals with Disabilities Education Act (Individuals with Disabilities Education Improvement Act [IDEA], 2004) as a developmental disability that impacts communication, social interaction, and educational performance. According to the Centers for Disease Control (Centers for Disease Control and Prevention [CDC], 2014), autism is the fastest growing developmental disability affecting one in 68 children. Previously referred to as pervasive developmental disorders (PDD), ASD is considered a spectrum disorder due to the wide range of impairments. Autism may have mild effects on some children; however, it may be disabling to other children causing extreme impairments in social, communication, and cognition skills (National Institute of Mental Health, 2012). Behavior characteristics of ASD include repetitive actions, resistance to environmental changes, and difficulty with sensory stimuli (Stuart, Flis, & Rinaldi, 2006). Additionally, Hartley et al. (2010) found that children with autism have (a) abnormal sensory responses, (b) sleep distributions, (c) gastrointestinal

disorders, (d) self-injurious behavior, and (e) display aggression. These challenging behaviors demand extra time and attention from parents.

Autism spectrum disorder can encompass terms such as: Classic autism, Pervasive Developmental Disorder (PDD), Asperger's syndrome, Rett's syndrome, or Childhood Disintegrative Disorder. Classic autism typically involves significant language, social and intellectual impairments. Asperger's syndrome is a term applied to high functioning individuals who display mild symptoms of ASD, such as social challenges, but have average or high average intellectual abilities. Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS) or atypical autism is a less common term used to refer to children with mild challenges in social or communication areas.

While several studies have found that parents of children with disabilities have high levels of parenting stress, current research suggests that parents of children with ASD have higher levels of stress than parents of children with other types of disabilities (Estes et al., 2009; Hartley et al., 2010; Silva & Schalock, 2012; Zaidman-Zait et al., 2010). Parenting stress was identified by Hayes and Watson (2013) as “distress or discomfort that results from demands associated with the role of parenting” (p. 629). Many factors contribute to the heightened level of stress on the families. Children with ASD have a wide range of challenges in the areas of communication, social development, and atypical behavior (Suppo & Floyd, 2012).

Parenting a child with ASD can also lead to internal stress within the family. Stress from the demands of having a child with ASD can impact the marital relationship (Hartley et al., 2010) and quality of life for parents (Cappe, Wolff, Bobet, & Adrein, 2011). Quality of life is influenced by the financial, social, physical, and psychological strains on the family (Cappe, Wolff, Bobet, & Adrien, 2011). Additionally, parents face extra challenges when planning the

educational needs of their child. On top of other responsibilities, Turnbull et al. (2010) stated that parents of children with ASD have a greater amount of educational responsibilities compared to parents of children without disabilities. Additionally, Turnbull et al. (2010) found that parents of children with disabilities have added roles as decision makers in the IEP process. According to the reauthorization of IDEA (2004), parents play an increasingly important role in the IEP process. Specific reauthorizations of IDEA (2004) were made to mandate an increase in parental duties such as communication and active participation in their children's IEP process (Turnbull & Turnbull, 2006). The parents of a child with a disability are necessary participants in the development of the IEP. It is important that the parents provide information about their views of the student's progress or lack of progress, as well as express any concerns about the overall educational development of the child. Parents provide important information about how the child behaves and performs outside the school setting. According to IDEA (2004), parents should participate in the development of the IEP. This includes providing input on their child's present level of performance, goals, accommodations, participation on assessments, and transition services when appropriate. Advocating for a child's educational needs requires extra responsibilities for parents. In addition to caring for their child, parents must educate themselves on the disability, child's needs, and special education laws, in order to work collaboratively with educators. These additional challenges on a family warrant further investigation on family needs.

According to the concepts in Maslow's (1943) *Theory of Human Motivation*, basic needs are tiered according to levels of necessity. Maslow (1943) described the levels of need as (a) physiological needs required for survival such as food, shelter, and sleep, (b) safety needs such as safe from harm, and shelter, (c) social needs such as love, relationships, and acceptance, (d) esteem needs which are respect by others and self, and (e) self-actualization needs or reaching

one's full potential. According to Maslow (1943), the primary basic needs are the most significant and become an individual's driving force. Maslow's (1943) theory has been applied to several areas of education including how students learn (Finnan & Kombe, 2011), and how teachers are motivated (Mattar, 2012); however, a research gap exists on how Maslow's theory can be applied to parents of student with disabilities.

Situation to Self

As the researcher, I am also a professional special education teacher. In my role as a special education teacher, it is my responsibility to work effectively with families and implement appropriate interventions. In order to work and communicate with parents effectively, I feel it is essential to understand parents' experiences and perspectives. Therefore, my motivation for conducting this phenomenological study is to better understand the experiences of the parents of children with ASD in order to create a better understanding for special educators which can, in turn, contribute to the development of more effective working relationships in the IEP process.

Additionally, I have methodological philosophical assumptions relating to this study. According to Creswell (2013), methodological assumptions are characterized by the researcher observing a topic within its natural context, using 'inductive logic,' and constructing an "emerging design" (p. 20). I believe that participants need to be studied in their natural environment to understand the personal experiences of the participants. Also, I believe the information will emerge through a process of understanding the individual.

Additionally, I have a constructivist worldview. Creswell (2013) stated that through a constructivism perspective, researchers "seek understanding of the world" and "their views are formed through interactions with others" (p. 24). Through personal interactions and interviews, I gained a better understanding of the participants' perspectives. My personal belief about

education is that the primary source of education occurs in the home, and school is supplemental to what takes place in the home. Therefore, I believe that establishing parent-teacher collaborative relationships and effective communication with parents is essential to provide a well-rounded education to students I serve.

Moreover, I believe that each person with a disability is an individual and has a specific, unique experience, which is the reason a qualitative study was selected. My motivation for this study was to contribute to the field of special education by providing insight to special educators about the perspectives of the families. As an educator, I see that many parents of children with disabilities went through a difficult or negative experience at some point in the IEP process. The initial process of referral, evaluation, and eligibility can be lengthy and overwhelming for parents. Additionally, meetings consisting of several school staff members can be very intimidating for parents. Many times, parents have to self-educate themselves on special education laws and terminology to advocate for their child. Unfortunately, these factors can limit parental participation in the child's education.

Problem Statement

In the educational realm, Turnbull and Turnbull (2006) reported that parents of children with developmental disabilities are typically less involved in educational collaboration than parents of children without disabilities. Likewise, Fish (2008) also noted that factors exist which alienate parents during the IEP process. Weintraub (2012) suggested that collaborative relationships between parents and special educators should be studied. Furthermore, Stuart et al. (2006) stated that learning about the experiences of parents is an essential part of building collaborative relationships. While Maslow's (1943) *Theory of Human Motivation* has been broadly studied and applied to education (Finnan & Kombe, 2011; Freitas & Leonard; 2011;

Ghazi, Ali, Shahzad, Khan, & Hukamdad, 2010; Mattar, 2012; Tikkanen, 2011), limited studies exist on understanding the needs of parents of children with ASD. Likewise, Brown et al., (2011) stated, “Researchers are only beginning to examine characteristics associated with perceived unmet needs among families of children with ASD” (p. 1291). For this study, the focus was on closing the gap in the literature on understanding the needs of parents of children with ASD.

Purpose Statement

The purpose of this transcendental phenomenological study was to understand the needs of parents of children with ASD who are currently served in a special education program in North Georgia. The phenomenon of parental needs, defined as the (a) physiological, (b) safety, (c) love, (d) esteem, and (e) self-actualization needs of parents of children with ASD who are involved in an IEP process, was examined through the framework of Maslow’s (1943) *Theory of Human Motivation* to help educators identify and better meet the unique needs of parents.

Significance of the Study

This study provides empirical, theoretical, and practical contributions to the field of special education by providing insight on the perspectives of parents of children with ASD as they navigate the IEP process in schools. It is increasingly important for special educators to be equipped with knowledge about supporting families with ASD because public education is the only service that all children in the United States have free access to regardless of demographics due to the rule of free appropriate public education mandated through IDEA (Murphy & Rubel, 2012). Therefore, this study provides practical contributions to the education field by increasing understanding and improving collaborative relationships between parents and school personnel.

Through this qualitative study, empirical contributions are made to the research in the field by providing a documented description of the needs of parents with children with ASD as they navigate the IEP process. Currently, the needs of children with ASD have been extensively studied (Jordan & Jones, 2012). Likewise, the impact of having a child with a disability has been researched (Estes et al., 2009; Hartley et al., 2010). By conducting this research, empirical contributions help to close the gap in literature which exists on understanding the specific needs of parents of children with ASD.

Additionally, theoretical contributions are made to the field by describing the needs of parents of children with ASD through Maslow's (1943) *Theory of Human Motivation*. Although Maslow's (1943) theory has been studied extensively and applied to many fields to better understand human needs, this is the first known research using Maslow's (1943) theory to expand on the needs of parents of children with ASD. Maslow's (1943) well-established theory provided a framework to explore and better understand the unique set of challenges parents of children with ASD encounter.

Research Questions

Research questions were developed following Moustakas' (1994) recommendation for developing phenomenological research questions, which is to develop broad questions about the central phenomenon. The two broad questions allowed me to develop rich, textural and structural descriptions of the shared experiences of the participants, which led to a description of the essence of the phenomenon (Moustakas, 1994). The research questions are as follows:

Research Question 1: How do parents of children with ASD experience support through the IEP process?

For parents of children with ASD, the IEP process can lead to even greater turmoil and stress (Zeitlin & Curcic, 2014). While advocating for their children, parents may be misunderstood and often not receive an appropriate amount of support (Elder, 2013; Weiss, Cappadocia, MacMullin, Vicili, & Lunskey, 2012). Therefore, I used information to create a rich structural description of the experience of having a child with ASD in a special education program. According to Moustakas (1994), a structural description describes how the phenomenon is experienced by the participants. This question was designed to focus on how the situation impacts the participants' experiences. How the phenomenon is experienced was examined by inquiring on the transition that occurred and the emotions of the parents as each individual went through the life altering experience of having a child diagnosed with ASD.

Research Question 2: What are the needs of parents of children with ASD as they navigate the IEP process?

Currently, a limited amount of studies exist on understanding the needs of parents of children with ASD (Brown et al., 2011). Brown et al. (2011) suggested that research should be conducted on the unmet needs of parents of children identified with ASD. Information provided by the parents was used to create a comprehensive textural description of the experience of having a child with ASD served in a special education program. Moustakas (1994) stated that a textural description is what a participant experiences in terms of the central phenomenon.

Research Plan

This study employed a qualitative approach to understand the needs of parents of children with ASD as they navigate the IEP process. A qualitative approach was chosen to investigate the human element and provide a voice to the parents of children with ASD (Creswell, 2012). A phenomenological design was utilized as the purpose is to describe the lived experiences of

parents who have children with ASD as each experience relates to the IEP process specifically here somehow. A phenomenological design allowed me to understand the central meaning of navigating the IEP process for parents of children with ASD (Moustakas, 1994). By using a transcendental phenomenological approach, I took measures to consciously set all personal philosophical assumptions aside and truly describe the parents' experiences rather than seek to interpret, analyze, or judge experiences. Moustakas (1994) defined transcendental as "perceived freshly, as if for the first time" (p. 34). By conducting a transcendental phenomenological design, I intended to identify the experiences of participants and develop an authentic description to provide special educators with an understanding of parents' needs in order to develop collaborative working relationships which benefit the families involved.

Delimitations

As the researcher, I only selected participants who are parents of children who have been identified as having any type of ASD, and who were at that time, served in an Individualized Education Program in a Creek County School District (pseudonym). The purpose for establishing this boundary was to collect meaningful data that could be used to provide guidance and understanding to general and special educators. The setting for this study, North Georgia, was selected due to the higher prevalence of ASD, and convenience, which allowed me to have personal interviews and observations with the participants.

Definitions

1. *Autism spectrum disorder (ASD)* - A collective term for neurological disorders which cause impairments in language, socialization, and repeated behaviors (National Institute of Mental Health, 2012).

2. *Parenting stress*- “distress or discomfort that results from demands associated with the role of parenting” (Hayes & Watson, 2013, p. 629).
3. *Individualized Education Program (IEP)* - Legal document documenting the specifics of a child’s special education services.
4. *Needs*- The drive that motivates human behavior (Maslow, 1943).

Summary

Due to the increasing prevalence of ASD and the necessity to work collaboratively with parents, it is imperative to understand the unique needs of the parents. Stuart et al., (2006) identified learning about parents’ past experiences as an important factor in building working relationships. Through this study, the unique needs of parents of children with ASD were presented to provide educators with insight. A transcendental phenomenology design was used to provide a voice to the participants and understand the essence of their shared experiences.

CHAPTER TWO: LITERATURE REVIEW

Overview

The purpose of this transcendental phenomenological study was to understand the needs of parents of children with autism spectrum disorder (ASD) who were served in a special education program in North Georgia. Maslow's (1943) *Theory of Human Motivation* was used as the framework to understand the unique needs of parents as they navigate the IEP process. ASD has been widely studied in the medical, educational, and psychological fields; however, many uncertainties about the disorder still remain. With continual research being conducted on ASD, the understanding of causes and best practices are constantly changing and many aspects of the nature of ASD are often misunderstood (Karst & Van Hecke, 2012). While previous research has helped shed light on the etiology and manifestations of ASD, limited research exists on the long-term impact ASD has on families, particularly parents (Karst & Van Hecke, 2012). With the increase in prevalence and challenges associated with raising a child with ASD, as well as the importance of parental involvement in the educational process, it is imperative to investigate the perspectives of parents. Therefore, current literature was reviewed to provide an understanding of ASD and challenges relating to parenting children with ASD and was followed by information on Maslow's (1943) *Theory of Human Motivation* in which he described a hierarchy of human needs.

Background of Autism

Autism spectrum disorder (ASD) is a neurologically based developmental disability with fundamental impairments in the areas of socialization, communication, and repetitive actions. ASD is referred to as a spectrum disorder because individuals with ASD may have an expansive range of abilities and limitations. Children with ASD may have very mild impairments with high

functioning abilities, or they may have profound impairments with very limited independent functioning abilities.

Dr. Leo Kanner, a clinical psychiatrist at Johns Hopkins University, first applied the term autism to refer to a specific condition in which an individual is severely withdrawn from relating or interacting with others in his 1943 paper, *Autistic Disturbances of Affective Contact*. The term “autism,” derived from the Greek word for self, was used as a general term in psychology to describe an individual with a self-absorbed personality; however, Kanner was the first to apply the term to a specific syndrome (Fischbach, 2007). In his study, Kanner (1943) clinically observed 11 children and families with similar characteristics who shared a “basic desire for aloneness and sameness” (p. 249). Although these children varied in degree of ability and impairment, Kanner (1943) identified primary areas of impairment in these children as (a) inability to relate to others, (b) impaired communication skills, and (c) dysfunctional behaviors. Kanner (1943) additionally noted secondary impairments in sensory integration, repetition in actions and a strong desire for consistency with emotional disturbances to change in routine. These historic notations remain evident in children with ASD and are currently used as categories for diagnosis. Kanner’s investigation also revealed emotional disturbances in children with autism such as anxiety, fear of change, frustration, and anger (Nicpon, Doobay, & Assouline, 2010). Through his study, Kanner (1943) helped change the way children with ASD were viewed and treated. Kanner (1943) identified children with ASD as being intellectual individuals “endowed with good cognitive potentialities” (p. 247). Kanner (1943) predicted, “These characteristics form a unique ‘syndrome,’ not heretofore reported, which seems to be rare enough, yet is probably more frequent than is indicated by the paucity of observed cases” (p. 242).

Ironically, Hans Asperger, a child psychiatrist studying in Austria at the University of Vienna during the same time period as Kanner, identified similar characteristics in children and also used the term autism in his 1944 paper, *Autistic Psychopathy in Childhood* (Kanner, 1944). Asperger (1944) studied intellectually high functioning children with similar impairments in relations, communication, and emotion regulation, which came to be known as Asperger's syndrome (AS) or high functioning autism. Like Kanner, Asperger (1944) also identified the primary trait of autism as an inability to relate to others, or "shutting-off of relations between self and the outside world" (p. 39). Asperger (1944) described children with autism as "egocentric in the extreme" and "having a genuine defect in their understanding of the other person" (p. 81). While the children Asperger studied were high functioning, intelligent individuals, he identified an impairment in perceived language skills and overall lack of expression or flat affect (Asperger, 1944; Nicpon et al., 2010). Asperger's findings helped expand the understanding of autism and identify autism as a spectrum of ranging abilities (Fischbach, 2007).

Rooted in Humanistic psychology, Kanner (1943) and Asperger (1944) are credited with debunking the previous Freudian influenced views on children with these characteristics, which identified the children as having child psychosis or schizophrenia (Fischbach, 2007). Although it took several decades, Kanner (1943) and Asperger's (1944) work provided a more appropriate understanding of children with autism and influenced diagnostic measures to identify autism in children (Fischbach, 2007; Qian, 2011). In his seminal paper, Kanner (1943) stated, "Since 1938, there have come to our attention a number of children whose condition differs so markedly and uniquely from anything reported so far, that each case merits-and, I hope, will eventually receive- a detailed consideration of its fascinating peculiarities" (p. 217). Fortunately, knowledge on ASD has expanded significantly due to Kanner (1943) and Asperger (1944) providing a

foundation for understanding and studying autism. Since the 1940s, ASD remains one of the most researched topics in child disorders and special education (Qian, 2011).

Although additional research in the area of autism increased after the initial recognition by Kanner (1943), there remained a lack of public knowledge and understanding about the cause of the disability. Theories emerged as scientists tried to explain the phenomena. Bruno Bettelheim (1967), an author and psychologist studying during the same time as Kanner and Asperger, was credited with promoting the “refrigerator mom” idea. Bettelheim (1967) theorized that autism was a result of an unloving mother (Malott, 2004). This theory impacted society’s view of parents of children with ASD and placed blame on parents for their child’s disability. For decades, parents of children with ASD were considered cold, frigid, and distant (Malott, 2004). These societal views on parents added additional stress on the already challenging task of parenting a child with a disability. The “refrigerator mom” theory was finally disproven by Dr. Bernard Rimland (1964) when he found autism to be a neurological based disorder. However, the negative societal views and blame placed on parents unfortunately still afflict society today and have a strong impact on parents of children with ASD.

Types of ASD

Autism spectrum disorder (ASD) is an expansive term used to refer to a set of developmental disabilities with similar core symptoms. Children with ASD can have a wide range of abilities and impairments and each child is affected in a different manner. Autism spectrum disorder includes Classic autism, Pervasive Developmental Disorder (PDD), Asperger's syndrome (AS), Rett's syndrome, and Childhood Disintegrative Disorder. Classic autism is a developmental disorder, which consists of significant impairments in the areas of language,

social, and intellectual abilities. Additional impairments can occur in behavior, sensory integration, restricted interests, cognitive functioning, and motor skills.

Asperger's syndrome is a term applied to high functioning individuals who display mild symptoms of ASD, such as social challenges, but have average or high average intellectual abilities. Children with Asperger's syndrome have average to above average development in language and cognition with characteristics of autism in social interaction and communication. Weaknesses are also present in executive functioning skills such as planning, organizing, and multi-tasking. Children with Asperger's syndrome typically have low thresholds for frustration and increased levels of anxiety (Nicpon et al., 2010). Adolescent years are particularly complicated for individuals with Asperger's syndrome as they go through physical developments and hormone changes. During the adolescent years, individuals with AS may realize they are different, thus compounding their social stress and anxiety (Nicpon et al., 2010).

Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS), or Atypical autism is a less common term used to refer to individuals with slight challenges in social and communication areas. Repetitive behaviors and interests may be noticeable. In PDD-NOS, some features of autism are present; however, symptoms do not meet full criteria for a diagnosis of Classic autism.

Rhett's syndrome is a neurological disorder characterized by regression of cognitive and motor abilities. Rhett's syndrome is a rare disorder in which a child reaches major developmental milestones, but shows a regression or loss of skill between the ages of one and four years of age.

Childhood disintegrative disorder (CDD) is also a developmental disability in which a child experiences a significant loss of previously acquired skills in language, social function,

intellectual, and motor abilities. CDD has been referred to as late onset autism as it does not have the same early detectible symptoms as autism.

Diagnosis

Guidelines for diagnosing ASD were recently updated in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-V)* (American Psychiatric Association, 2013) which was released in May 2013. Previously, disorders were identified in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition - Text Revision (DSM-IV-TR)* (American Psychiatric Association, 2000), which is published by the American Psychological Association. According to the DSM-IV-TR (American Psychiatric Association, 2000), autism spectrum disorders consist of: (a) Autistic disorder (Classic autism), (b) Asperger's syndrome (AS), (c) Pervasive developmental disorder not otherwise specified (PDD-NOS), (d) Rhett's syndrome, and (e) childhood disintegrative disorder (CDD). Children identified as having ASD between the years of 2000 and 2013 may have a diagnosis containing one of these titles. However, diagnosis occurring under the guidelines of the updated DSM-V, will all be titled ASD only. A study conducted by the Center for Disease Control (CDC) in 2014, indicated that the rate of diagnosis of ASD was at an all-time high. This study found that 1 in 68 children in the United States were diagnosed with a type of ASD, (CDC, 2014). The rate for the State of Georgia is slightly higher with 1 in 64 children identified as having ASD (CDC, 2014). While the cause of ASD is undetermined (NIMH, 2012), a correlation has been found with environmental (Dufour-Rainfray et al., 2010; Lyall, Schmidt, & Hertz-Picciotto, 2014) and genetic (Blumenthal et al., 2014; Constantino et al., 2013) factors contributing to ASD. Prenatal exposure to environmental toxins such as medications, pollutants, heavy metals, and pesticides were found to be a contributing factor in ASD (Dufour-Rainfray et al., 2010; Lyall, Schmidt, &

Hertz-Picciotto, 2014). Additionally, Blumenthal et al. (2014) found that certain inherited genes are significant risk factors for ASD, specifically genes “responsible for neuronal development and immune response” (p.871). Likewise, Constantino et al. (2013) identified an increase in co-occurrence of ASD within families due to genetic factors. While the etiology of ASD is still being studied, it is understood that several contributing factors are related to the development of ASD.

Research indicates the importance of early identification and diagnosis of ASD to better provide treatment and intervention options (Janzen, 2014; Karst & Van Hecke, 2012). Early diagnosis is important due to the high success rate of early intervention programs (Barnard - Brak, Davis, Schmidt, & Richman, 2014; Starr, Martini, & Kuo, 2014). While signs of ASD are apparent in children as early as 18 months, many children are diagnosed at age three to six (Karst & Van Hecke, 2012), and research suggests that the diagnosis age is even later for children in rural areas (Lord et al., 2006; Murphy & Rumble, 2012). In accordance with IDEA (2004), developmental screenings are conducted by pediatricians at routine check-ups for infants and toddlers, and early intervention programs are available to children with developmental delays. Pediatricians may also refer the child to a psychologist or developmental pediatrician to conduct a comprehensive evaluation for ASD. Autism is diagnosed behaviorally through a series of observations rather than through a medical examination. A diagnosis is determined based on observations, interviews with parents and often educators, a review of developmental history and professional judgment. Because it is diagnosed behaviorally, some areas of the process may be subjective. The subjective nature of the diagnostic process may lead parents to question or not accept the diagnosis (Plumb, 2011; Renty & Roeyers, 2006; Samadi, McConkey & Kelly, 2013).

Prevalence

Nationwide research conducted by the Centers for Disease Control identified a dramatic increase of 119.4 % in prevalence of ASD among children in the United States over the course of ten years from 2000 to 2010 (CDC, 2014). Further research from the Centers for Disease Control and Prevention (CDC) found ASD to be more prevalent in males than females (Baio, 2014). Baio, (2012) found that 1 in 54 males were diagnosed with ASD, whereas ASD was diagnosed in 1 in 252 females; therefore, it was approximated that ASD is four times more prevalent in males than females. Additionally, ASD was identified as the fastest growing developmental disability in the United States with an annual growth rate of 10% to 17% with an average of sixty-seven children diagnosed each day (Baio, 2012). ASD occurs in children of all races, ethnic backgrounds, socio-economic status levels, or levels of education (Durkin, Maenner, Meaney, Levy, & DiGuseppi, 2010; Hartley & Sikora, 2009). Additionally, Baxter et al., (2014) found that the prevalence of ASD has increased on a global level with an estimation of 52 million reported occurrences internationally.

Characteristics of Children with Autism

Autism is a neurological based disorder which impacts the way the brain processes information (Uljarević, Prior, & Leekam, 2014). As a result, children with ASD have impairments, which limit their abilities to understand their surroundings and interact appropriately to changes within their environment. A triad of interrelated symptoms manifests differently in each individual affected by ASD. As first documented by Kanner (1943), individuals with ASD have primary symptoms in the following areas: (a) ability to relate to others, (b) ability to communicate, and (c) ability to regulate behavioral responses. Further investigations expand on these characteristics and refer to the three areas as primary or core

symptoms. While children with ASD share these common core symptoms, each symptom may present differently in each individual child with varying intensity. Additionally, Hartley and Sikora (2009) found that symptoms of ASD are similar in male and female children with ASD with communication deficits being greater in females and repetitive behaviors being more intense in males. As primary caretakers, parents are confronted with managing the challenging behaviors resulting from core symptoms as they arise. The severity and intensity of symptoms is directly related to the amount of parental stress reported; as core symptom behaviors increase, parental stress also elevates (Lyons, Leon, Phelps, & Dunleavy, 2010; Wang et al., 2012).

Relating to Others

The limited ability to relate to others was described by Kanner (1943) as “an extreme autistic aloneness that, whenever possible, disregards, ignores, shuts out anything that comes to the child from the outside” (p. 242.). This limited interaction within his or her environment restricts the child’s development and learning opportunities (Janzen, 2014). Kanner (1943) noted the “fundamental disorder is the child’s inability to relate themselves in an ordinary way to people and situations” (p.242). Asperger (1944) also observed extreme impairments in social interaction as a primary symptom of ASD autism. These social impairments include a lack of empathy, inability to understand others’ feelings, and an atypical affect (Asperger, 1944; Nicpon et al., 2010). Children with ASD typically do not develop age-appropriate social relationship skills such as making eye contact with others or engaging in imaginative play within their environment. Children with ASD keep to themselves and generally have a flat emotionless disposition. Children often display a lack of attachment or limited affection to other individuals, including parents (Beurkens, Hobson, & Hobson, 2013). Additionally, children with ASD typically do not display genuine affection to other people, but rather relate to objects with special

interest (Asperger, 1944). Children with high functioning autism or Asperger's syndrome also have an impairment in ability to process social information appropriately such as understanding social norms, emotional expressions, and interacting with others appropriately (Assouline, Nicpon, & Doobay, 2009; Nicpon et al., 2010).

Communication

Impairment in communication skills is a core symptom of ASD. Children with ASD also have a wide range of impairments in functional language and communication skills (Kjellmer, Hedvall, Fernell, Gillberg, & Norrelgen, 2012). Children can range from non-verbal to highly-verbal with an immeasurable vocabulary. Communication, anything that conveys a message, can be greatly impaired resulting in a lack of verbal speech or response to spoken language. In severe cases, children may be mute or have a lack of functional language ability (Allen & Lewis, 2015). Children with limited verbal abilities may often repeat or echo words and phrases that were previously heard; this is known as *echolalia* (Asperger, 1944).

Even though children with ASD may have verbal ability, some may not be able to use verbalization as a means of functional communication with others. Thus, expressive language is impaired because the children with ASD struggle to convey a message or express desires effectively. Children with higher verbal abilities may not be able to regulate speech tone, inflection, and intensity of word choice. Receptive language skills are commonly impaired in children with ASD, so they misinterpret messages received in communication with others and cannot interpret facial expressions (Eack, Mazefsky, & Minshew, 2014). Children with ASD struggle to distinguish and understand components of language such as tone of voice and implied messages.

Children with high functioning autism have impairments in understanding social or pragmatic language (Norbury, 2014). This includes understanding tone and inflection in a speaker's voice and nonverbal language such as body language and gestures (Eack et al., 2014; Nicpon et al., 2010). Children with ASD are generally concrete thinkers and have a difficult time processing figurative language or making inferences in speech and text (Norbury, 2014). Even for highly intelligent individuals with ASD, the many conventions of language can be difficult to understand and apply in an academic setting. Language deficits strongly impact a child's ability to comprehend reading, and express himself or herself when writing and speaking. An impairment in communication skills leads to increased frustration and problematic behaviors in a child with ASD (Eack et al., 2014).

Restricted Repetitive Behaviors

Repetitive actions and limited interests influence behavior in children with ASD. In 1943, Kanner observed, "Behavior is governed by an anxiously obsessive desire for the maintenance of sameness" (Kanner, 1943, p. 245). When an undesired change or stimuli is introduced, children with ASD typically respond with uncontrollable behaviors. According to the DSM-V (American Psychiatric Association, 2013), restrictive repetitive behaviors (RRB) include: (a) repetitive speech or movements, (b) insistence on the same patterns or routines, (c) restricted interests on objects or activities, and (d) abnormal sensory interests. These non-functional behaviors, including stereotyped movements, repetitive actions, and spontaneous outbursts, have been observed in children with ASD as young as age two (Kim & Lord, 2010; Stronach & Weatherby, 2014). Often referred to as stimming, these self-stimulating behaviors increase when a child is frustrated, anxious, nervous, or excited and provide reinforcement to the child (Reed, Hirst, & Jenkins, 2014; Wilke et al., 2012). Repetitive behaviors have been found to

be a comfort to children with ASD as the behaviors alleviate some distress and provide sensory stimulation (Lidstone et al., 2014). Children with ASD may also have sensory seeking behaviors or a desire for stimulation (Asuderau et al., 2014), which may result in an increase in repetitive behaviors. Along with repetitive behaviors, children may exhibit extreme interest in objects and inflexibility to change in routine or schedule. Intense restrictive repetitive behaviors can become dangerous and may interfere with a child's ability to perform functional tasks, such as self-feeding. These repetitive behaviors are restrictive in nature and can limit the child's social and academic opportunities. Repetitive restrictive behaviors can also be challenging for parents and may limit family activities.

Co-existing Behaviors and Emotional Issues

Along with core symptoms, many children with ASD display co-morbid or co-existing behaviors and emotional issues. Hartley et al. (2010) found that children with autism have the following externalizing behaviors: (a) abnormal sensory responses, (b) sleep disturbances, (c) gastrointestinal disorders, (d) self-injurious behavior, and (e) display aggression. Co-existing problematic behaviors are often extreme, uncontrollable, and spontaneous reactions, which pose a challenge for the child and caretakers. These behaviors negatively impact the child with ASD and other individuals exposed to the behaviors. For the child with ASD, behavior difficulties may hinder children from interacting with peers and limit learning opportunities (Uljarević et al., 2014).

Behaviors also increase physical risk and emotional distress for caretakers. Severe problematic behaviors are related to significant increases in parental stress (Huang et al., 2014). Consequently, co-existing behaviors may cause more distress to parents than core symptoms (Hartley & Sikora, 2009; Fulton, Eapen, Črnčec, Walter, & Rogers, 2014; Hartley, Sikora, &

McCoy, 2008). As emotional and behavioral problems increase, levels of parental stress also rise (Estes et al., 2013; Walsh & O’Leary, 2013).

Sensory. The most common co-existing behavior in individuals with ASD is sensory processing impairments. Approximately 80% of children with ASD exhibit sensory processing issues (Case-Smith, Weaver, & Fristad, 2014). Impairments to sensory processing includes atypical responses to stimuli such as an increased or decreased sensitivity to audio, visual, tactile, and oral stimulation in the environment (Asuderau et al., 2014; Germani, et al., 2014; Kirby, Dickie, Baranek, 2014). Increased sensitivity may cause a child with ASD to overreact when a stimulus is present or have an aversion to specific stimuli (Asuderau et al., 2014; Uljarević et al., 2014). Sensory overload is a common issue leading to inappropriate and misunderstood behavioral responses since children with ASD often respond with extreme distress to perceived adverse or undesirable stimuli (Germani, et al., 2014; Cermak, Curtin, & Bandini, 2014). This overreaction may be disturbing or even harmful to others. For example, a child may scream with pain or push others out of the way to escape a loud noise. Aversion is also commonly seen in food selectivity and sensitivities to texture, odor, or color when eating (Cermak et al., 2014). In his original observation, Kanner (1943) identified certain stimuli such as food and loud noises as a disruption to the child: “There is an all-powerful need for the child being left undisturbed. Everything that is brought to the child from the outside, everything that changes his [or her] external or even internal environment, represents a dreaded intrusion” (p. 242).

Sensory issues strongly impact the daily lives of children with ASD and family members (Bagby, Dickie, & Baranek, 2012; Kirby, Dickie, & Baranek, 2014). Behaviors associated with sensory issues limit family activities and influence daily routines (Bagby et al., 2012; Cermak et al., 2014). Issues with sensory processing also dictate daily routines such as eating, sleeping, and

behavior patterns (Case-Smith et al., 2014). Thus, daily routines in the home such as bathing and cooking can become incredibly stressful for caretakers of children with ASD. Expectedly, parents commonly withdraw from public and community activities due to the unpredictably and challenging behavior occurrences (Trigonaki, 2002; Weiss et al., 2012).

Sleep disturbances. Research indicates that increases in core symptoms results in an increase in sleep disturbances for children with ASD (Moss, Gordon, & O'Connell, 2014). Patterns of disturbed sleep can also lead to anxiety and increased emotional and behavioral problems (Case-Smith et al., 2014). Over time, sleep disturbances develop into chronic and troublesome sleep disorders. With chronic insomnia being ten times greater in children with ASD than in children without developmental disabilities (Johnson, Giannotti, & Cortesi, 2009; Sivertsen, Posserud, Gillberg, Lundervold, & Hysing, 2012), the quality of life and overall wellbeing of both child and family members are also greatly affected (Sivertsen et al., 2012). Since sleep disturbances in children results in poor sleep quality for parents, many parents report being fatigued and unable to meet the daily demands of parenthood due to sleep deprivation (Giallo et al., 2011; Seymour, Wood, Giallo, & Jellett, 2013).

Gastrointestinal disorders. Gastrointestinal (GI) problems occur frequently in children with ASD and may be linked to anxiety, social issues, behavior problems, and increased sleep disturbances (Peters et al., 2014). While the connection with ASD and GI problems is unknown, frequent and severe symptoms are common for children with ASD, which may lead to frustration and increased behavior problems, especially for nonverbal children (Adams, Johansen, Powell, Quig, & Rubin, 2011). Gastrointestinal troubles can range from minor stomach pain, discomfort, and nausea to more complicated forms such as reflux, constipation, and diarrhea (Coury et al., 2012; Peters et al., 2014). While not only bothersome to child and care takers, severe GI issues

can lead to chronic issues such as nutrition depletion and impaired immune systems (Coury et al., 2012; Peters et al., 2014) which can be further complicated with food selectivity and sensory issues (Peters et al., 2014). Chronic GI issues are also associated with an increase in anxiety and behavior problems (Mazurek et al., 2013). Parents have reported that adhering to strict diets such as gluten-free and casein-free options help relieve issues associated with GI issues (Navarro et al., 2014; Penneis & Klein, 2012); however, these diets require much planning and are expensive to maintain (Elder, 2013). GI issues and treatments add to the overwhelming caretaking and financial demands on parents of children with ASD.

Self-injurious behavior. Parents are faced with the additional challenge of ensuring children are safe from self-inflicted injury, since approximately 50% of children with ASD engage in some form of self-injurious behaviors (Minshawi et al., 2014). These behaviors are of particular concern because they cause physical harm to the child. These behaviors typically include actions such as biting, hitting, scratching, strangling, and hair pulling which can be extreme and lead to serious injury or permanent mutilation (Minshawi et al., 2014). On top of the physical and emotional demands these behaviors place on caretakers, parents are also faced with providing costly treatment for injuries and infections as well as purchasing expensive specialized gear such as padded helmets to prevent the child from further injury.

Aggression. Aggressive behaviors are also common occurrences for children with ASD and are strongly related to the child's inability to communicate effectively with others (Fulton et al., 2014). Frustrations associated with miscommunication and being misunderstood intensifies the child's behaviors. Likewise, an inability to understand social norms leads to increased anger and frustration (Nicpon et al., 2010). These maladaptive behaviors include intense physical and/or vocal outbursts (Hartley et al., 2008). Physically aggressive behaviors include, but are not

limited to: hitting, kicking, biting, and pinching others. Aggressive and injurious behaviors cause harm and produce fear in others which may restrict the child from being included in social and educational opportunities (Fulton et al., 2014). Combined with the task of managing aggressive behaviors, parents have added concerns about their child's social development and face challenges relating to advocating for proper educational settings and services since aggressive behaviors may limit their child's ability to interact appropriately with others (Fulton et al., 2014).

Internal behaviors. Co-occurring internalizing behaviors include emotional disturbances such as, depression, anxiety, somatic complaints, withdrawal, defiance, and inattentiveness (Hartley et al., 2008). Nicpon et al. (2010) reported that 70% of adolescents with ASD continue to display emotional and behavioral difficulties (e.g., aggression, self-injurious behavior, inappropriate sexual behavior) which are intensified in the teen years by physical development, hormone changes, and an increasing awareness of social limitations. Children with high-functioning ASD are reported to be at a higher risk for mood disorders, social anxiety, depression, and suicidal behaviors (Nicpon et al., 2010). Managing challenging behaviors places additional physical, emotional, and financial strain on parents. These behaviors also add to daily demands placed on parents and increase parental stress levels (Peters-Scheffer, Didden, Krzilius, 2012).

Stress

A general model of stress was explained by Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen (1986) as a result of an individual's inability to meet the demands or cope with challenges in his or her environment. Folkman et al. (1986) stated that stress is subjective and different for each individual. There are also several factors to consider such as the amount of stressors present, the overall health of the individual, and how an individual manages stress.

Therefore, an event that may be considered extremely stressful to one individual may not inflict the same level of stress to another individual. Additionally, *parenting stress* occurs when an individual is unable to cope with the demands associated with stressors related to parenting (Hayes & Watson, 2013). Specifically, parenting stress is the internal strain that results from the demands of being a primary caretaker in a parenting role. It is important to consider parental stressors as high levels of stress impact the overall health and well-being of the parents which in turn impacts parenting performance and child outcomes (Samadi et al., 2013; Totsika et al., 2013; Weiss, Wingsiong, & Lunsky, 2013).

Parental Stress

Parents of children with disabilities face additional challenges related to the severity of the disability, added caretaking responsibilities, and challenging behaviors associated with the disability (Weiss & Lunsky, 2011). For parents of children with ASD, the unique set of challenges is complicated due to the complex nature of the disability (Karst & Van Hecke, 2012). Research suggests that parents of children with ASD report higher levels of parenting stress than parents of children with other types of disabilities such as intellectual impairment and Down's syndrome (Dabrowska & Pisula, 2010; Estes et al., 2013; Rao & Beidel, 2009; Seymour, Wood, Giallo, & Jellett, 2013; Silva & Schalock, 2012; Simon-Tov & Kaniel, 2011).

It is not surprising that the triad of core symptoms found in children with ASD can be overwhelming for parents to manage. An increase in core symptoms also causes an increase in parents' level stress (Wang et al., 2012). Moreover, co-existing behaviors may be more problematic for parents than core symptoms (Fulton et al., 2014), and when behaviors intensify, parental stress also escalates (Estes et al., 2013; Huang et al., 2014; Walsh & O'Learly, 2013). Rao and Beidel (2009) found that children with higher intellectual functioning still exhibit

problem behaviors. Therefore, higher functioning children still present problematic behaviors, which impact parents' stress levels.

The combination of core symptoms along with maladaptive behaviors and the need for constant care create an intensified stressful situation for care takers (Johnson et al., 2009; Shtayermman, 2013; Silva & Schalock, 2012). Additionally, this heightened level of stress is found in parents of children with ASD regardless of ethnic or cultural backgrounds (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010). Moreover, due to ASD being a lifelong disability, elevated parental stress associated with parenting a child with ASD continues across the lifespan and develops into a situation of chronic stress (Barker et al., 2011, Siman-Tov & Kaniel, 2011). The chronic parenting stressors can escalate into a crisis situation for families with negative coping skills (Weiss & Lunsky, 2011; Weiss, Wingsiong & Lunsky, 2013; White et al., 2011). Crisis situations interfere with the parents' ability to cope, adjust and function effectively (Weiss & Lunsky, 2011), resulting in elevated stress levels which negatively impact the overall health and wellbeing of parents (Giallo, Wood, Jellett, & Porter, 2013). Along with elevated levels of stress, parenting a child with ASD is also associated with higher levels of psychological distress (Weiss et al., 2012).

Certain events may be extremely traumatic for parents. The diagnosis process can be particularly stressful for parents since it is a life-changing event (Keenan, Dillenburger, Doherty, Byrne, & Gallagher, 2010). First of all, "time and effort required to obtain a firm diagnosis of ASD are often considerable" (Renty & Roeyers, 2006, p. 372) as many parents report being concerned about their child during infancy and struggling to find answers. A lack of quality information, locating understanding practitioners, and uncertainty about diagnosis adds to parents' challenging situation (Plumb, 2011; Renty & Roeyers, 2006; Samadi et al., 2013).

Additionally, research indicates that parents go through an initial period of grieving when their child is diagnosed with ASD (Muscott, 2012; Samadi et al., 2013; Tway, Connolly, & Novak, 2007; Yen & Mao, 2011). Research has illustrated that parents need to mourn the loss of the idea of a typically developing child, and parents continue to mourn at developmental milestones throughout the child's life (e.g. birthdays, graduation) (Muscott, 2012). It is not uncommon for parents to feel, shock, denial, or even acute symptoms of depression stemming from the traumatic diagnosis of their child's condition (Fleischmann, 2004; Plumb, 2011). Some parents have been found to suffer from post-traumatic stress disorder (PTSD) after the life changing event of a diagnosis of their child depending on severity of symptoms and parents' level of psychological acceptance (Casey et al., 2012). In sum, the diagnosis experience is a significant event which impacts the parents' functioning and outlook (Karst & Van Hecke, 2012).

After the diagnosis experience, parents are faced with the challenge of forward planning which increases worry about their child's future and how the child will be taken care of when the parents are no longer able to provide care (Eaves & Ho, 2008; Shtayermman, 2013; van Heijst & Geurts, 2014). Forward planning for the child's future is an emotionally stressful time for parents due to the uncertainty of the child's future and level of independence (Keenan et al., 2010). According to Cappe et al., (2011), stress from the compound demands of having a child with ASD can impact the quality of life for parents. Quality of life is influenced by the physical, financial, emotional, and social strains on the family (Cappe et al., 2011).

Physical challenges. For parents of children with ASD, the physical demands of meeting the needs of their children can be exceptionally cumbersome. Due to social, communicative, and behavioral needs, families of children with ASD have an increase in daily demands. These needs

often require specialized services and therapies for the child. Meeting the needs of their child includes extensive scheduling for behavioral, medical, and educational treatment as well as educational placement (Yen & Mao, 2011). Brown et al. (2011) found that children with ASD require specialized medical, educational, and social therapy, which are often up to the family to coordinate. Locating, scheduling, and maintaining treatment is an added stressor for parents (Peters-Scheffer et al., 2012). Families in rural areas have limited access to specialized treatment, which further complicates the physical challenges placed on parents (Fulton et al., 2014; Minshawi et al., 2014). Specialized services and therapies imposes a financial, emotional, and scheduling burden on families (Stuart et al., 2006).

Parents of children with ASD in search of a cure may become vulnerable to deceptive treatments and false hope (Green, 2007; Thompson, 2010). These treatments are both time consuming and expensive for the parents, and most treatments are not covered by insurance (Green, 2007). Many parents of children with ASD have sought out treatments or cures, some of which are not scientifically researched or doctor recommended (Green 2007; Stuart et al., 2006). Applied behavior analysis, sensory integration, vitamin supplements, art and music therapy are just a few of the additional treatments parents have invested in; however, parents reported that educational interventions were the most successful treatment (Stuart et al., 2006). Specialized diets have also been reported as successful interventions to support behavior improvements (Pennesi & Klein, 2012). Successful interventions often require parental involvement, training, and implementation in the home to carry out treatment, which increases demands on parents (Karst & Van Hecke, 2012).

Due to the unique behaviors and co-existing medical needs of children with ASD, parents also face challenges when securing appropriate medical care for their child. Many times, parents

will struggle to locate medical professionals who specialize in treating children with ASD and have appropriate training in understanding the unique behaviors and symptoms of autism. Due to commonly occurring co-existing disorders, children with ASD may also be diagnosed with conditions needing medical treatment such as attention-deficit hyperactivity disorder (ADHD), generalized anxiety disorder, or seizure disorder (Antshel & Heir, 2014). These medical conditions require expensive and time consuming treatments and medications (Barnard-Brak et al., 2014).

Financial challenges. Children with ASD often require specialized services and early intervention treatments, which are very costly for the families (Wang et al., 2012). Parents have increased expenses with behavioral therapies, medical expenses, providing transportation, and accommodations related to the services (Wang et al., 2012). Many families do not have insurance that covers therapy sessions, and it is up the family to arrange for supplemental services. Also, service providers may not be available to parents in certain areas.

Due to the increase in prevalence in ASD in recent years, treatment options have also been on the rise; however, often these treatment options are not scientifically validated and provide parents with a false sense of hope as well as an increase in expense (Green, 2007). Additionally, children with ASD often have other exceptionalities such as having a specific learning disability, and/or being a gifted learner which increase the challenges of parenting (Silva & Schalock, 2012). Securing appropriate childcare and keeping a job are especially difficult for parents of children with ASD since trained care providers are limited (Harris, 2008). Challenges with securing appropriate childcare often prevents or limits employment opportunities for the primary care giver (Dillenburger et al., 2010) thus, increasing the financial strains on families.

Social and emotional challenges. Raising a child with ASD places a considerable emotional burden on caretakers (Divan, Vajaratkar, Desia, Striken-Lievera & Patel, 2012). Emotional and behavioral problems pose an increasing emotional challenge on parents (Shtayermman, 2013), and put caretakers at greater risk for impaired mental and emotional health (Zablotsky, Bradshaw, Anderson, & Law, 2013). Time and financial burdens of parental responsibilities limit parents' ability to take proper care of themselves and seek help for mental and emotional services (Karst & Van Hecke, 2012).

Additionally, Sikora et al., (2013) indicated that family stress that is externalized in the home increases problem behavior in children with ASD, which leads to a cycle of increased parental stress and poor child behavior. Kanner (1943) found it important to note in his primary study on children with ASD that parents were strongly impacted by their child's condition; hence referring to parents as having emotional strain and breakdowns. Internal struggles are further complicated when parents, who use emotion based coping strategies such as blame or avoidance, have higher rates of personal stress (Zablotsky et al., 2013).

Many parents of children with ASD isolate themselves from social interaction outside the family (Trigonaki, 2002; Weiss et al., 2013). Parents face social challenges such as maintaining relationships and dealing with seclusion (Divan et al., 2012). This social withdrawal results in negative long-term effects on parents' wellbeing (Karst & Van Hecke, 2012). Parents of children with ASD have expressed feeling frustrated with social stigma present in society, even among medical and educational professionals (Samadi et al., 2013). Many parents reported being judged and having to deal with society's perceptions about their child (Plumb, 2011; Samadi et al., 2012). Some parents even report encountering discrimination in public (Divan et al., 2012).

Some parents also chose to limit community and church involvement due to the anticipation of negative experiences (Divan et al., 2012).

Challenging behaviors also reduce activities and recreational time such as taking vacations or going out with friends (Rao & Beidel, 2009; Weiss et al., 2013), which is particularly troublesome since social support, consisting of relationships or interactions among family, friends, and community members, can reduce the impact of daily stressors (Plumb, 2011; Simon-Tov & Kaniel, 2011). Additionally, a strong support system in the nuclear family is linked to reduced levels of stress in parents (Renty & Roeyers, 2006). Extended family, friends, neighbors, religious groups, and support groups can also provide beneficial social support to parents (Renty & Roeyers, 2006). It is increasingly important for parents of children with ASD to seek social support as research indicates social support reduces stressors (Karst & Van Hecke, 2012) and symptoms of depression (Ekas, Lickenbrock, & Whitman, 2010).

Personal Stress

Parenting a child with ASD can also lead to personal stress and internal frustration within each individual. Beurkens et al. (2013) stated “stress in parenting a child with a developmental disability can lead to negative feelings toward the child, alter parent expectations, and lead to a reduced sense of parenting competence” (p. 12). Factors related to personal stress include level of education, financial resources, and personal health (Weiss & Lunsky, 2011). Parental stressors can also impact the health and wellness of parents. Compounded stressful parenting experiences over the course of several years develop into chronic condition of stress which leads to poor mental and physical health for the parents (Benson, 2010; Barker, Mailick, & Smith, 2014). Parenting a child with ASD has been associated with impaired mental health

resulting from psychological distress and higher than normal parental stress levels (Weiss et al., 2012).

Rates of psychological distress such as depression and anxiety remain high for parents of children with ASD (Barker et al., 2010; Estes et al., 2013; Shtayermman, 2013; Tway et al., 2007; Weitlauf, Vehorn, Taylor, & Warren, 2014). Hoffman, Sweeny, Hodge, Lopez-Wagner, and Looney (2009) found a significant relationship between parenting a child with ASD and parents' physical and mental health. The psychological distress is further complicated by internal struggles and self-blame as many parents also blame themselves for their child's disability (Giallo et al., 2013; Hoffman et al., 2009). Shtayermman (2013) also found that many parents reported being diagnosed with psychological disorders such as depressive disorder or generalized anxiety disorder.

Previous research suggests that elevated levels of stress is present in mothers and fathers of children with ASD (Brobst, Clopton, & Hendrick, 2009; Harper, Dyches, Harper, Roper, & South, 2013). However, current research suggests that parenting stressors have a greater impact on the overall well-being of mothers than fathers (Gau et al., 2012; Harper et al., 2013; Hartley & Shultz, 2014). Conversely, Bendixen et al. (2011) debated that studies are limited on fathers of children with ASD, and although fathers may display stress differently, fathers are also greatly affected by parenting stress. High levels of fatigue were reported by mothers of children with ASD due to poor sleep quality, a lack of physical activity (Giallo et al., 2013; Seymour et al., 2013). Physical and mental exhaustion impacts parents' parenting efficacy and sense of satisfaction (Giallo et al., 2013). Fatigue is also significantly linked to depression, anxiety, and chronic stress in the individual (Giallo et al., 2013; Seymour et al., 2013).

Relational stress. While the increased daily demands on parents of children with ASD remain undisputed, parents also face internal strains on the family system. Research supports the idea that a family is a system and each individual is connected to each other, thus each individual in the family is greatly impacted by the interactions with family members (Burr et al., 1994). Additionally, siblings face challenges as many have higher rates of depression, poor social skills, and problematic relationships with other family members (Macks & Reeve, 2007; Weiss et al., 2013).

Families generally withdraw from society as parents report that a lack of public understanding and tolerance of ASD symptoms limits family member's abilities to engage in outside activities such as going to church, dining in restaurants or going shopping (Hartley, Barker, Seltzer, Greeberg, & Floyd, 2011; Rao & Beidel, 2009). Family's cohesion is also impacted by the limited abilities to participate in activities as a family (Gau et al., 2012). For example, Suppo and Floyd (2012) found that behavioral and social challenges may limit family recreational activities and limit siblings' involvement in desired activities. This social isolation impacts the entire family system and negatively impacts each family member (Samadi et al., 2013; Siman-Tov & Kaniel, 2011).

The home environment usually revolves around the needs of the child with a disability (White, McMorris, Weiss, & Lunsky, 2012) and extra support for the child with ASD can overshadow the needs of a sibling; therefore, siblings may have feelings of neglect and resentment, as well as behavioral and emotional issues (Karst & Van Hecke, 2012; Suppo & Floyd, 2012). Unsurprisingly, strained relationships were commonly reported among all family members in a household due to stressors related to having a child with ASD (Zablotsky et al., 2013). Parenting a child with ASD can also lead to internal stress within the family (Harper et

al., 2013), such as low family cohesion, affection, low marital satisfaction; and poor communication (Harper et al., 2013; Gau et al., 2011; Shtayermman, 2013; Walsh & O'Leary, 2013; Weitlauf, Vehorn, Taylor, & Warren, 2014). Parents of children with ASD have reported more relational difficulties and family dysfunction than families with typically developing children (Gau et al., 2012).

Marital relationship. It has been well established that satisfied social and love needs are important to an individual's emotional and physical health (Maslow, 1943). A strong, supportive marital relationship can support challenges the parents may encounter as a spouse is a primary source of social and emotional support (Hartley et al., 2011; Shtayermman, 2013). Hartley et al. (2011) determined that problem behavior in children with ASD also leads to heightened parental stress and marital conflict. In turn, child behavior and well-being is also affected by marital conflict.

Quality of marriage is an important factor in parents' wellbeing as research has revealed that parents who are satisfied with their marriage and level of spousal support experience less parental stress (Hartley et al., 2011; Renty & Roeyers, 2006). Also, the quality of a marital relationship is directly related to spouses' perceived quality of parenting (Shtayermman, 2013). Furthermore, the "wellbeing of one partner influences the emotional and relational well-being of the other partner" (Hartley et al., 2011, p. 689). Hoffman et al. (2009) also found that parents may blame their spouse for their child's disability; these negative perceptions of one's spouse also negatively impact the marital relationship and entire family system. The increased emotional burdens and financial demands of raising a child with ASD add extra strain on parents' relationship, which could become overwhelming and lead to low marital satisfaction (Shtayermman, 2013; Weitlauf et al., 2014) and an increased rate of divorce (Baeza-Valasco,

Michelon, Rattaz, Pernon, & Baghdadli, 2013). Hartley et al. (2010) found that the rate of divorce is significantly higher for parents of a child with autism due to the stress, loss of intimacy, and parental conflicts that may arise. However, Freedman, Kalb, Zablosky, and Stuart (2012) reasoned that although parenting a child with ASD does indeed cause marital strain, there are too many factors to consider in a relationship to conclude if having a child with ASD leads to divorce.

Marital challenges continue and may increase as the child with ASD ages and developmental milestones are typically not reached (Hartley et al., 2011). Behavior and emotional challenges increase as children reach adolescent years and parents' roles as caregivers and levels of parenting stress continue as children progress into adulthood (Hartley et al., 2008; Nicpon et al., 2010). Children with ASD typically do not develop skills to become mainly independent; therefore, parent's role as the primary caregiver remains. The extended caregiving roles reduces the parents' time together to maintain a strong relationship and can take away from time with other children and family members. With the compound levels of stress on parents, it is not surprising that families of children with disabilities have lower levels of family cohesion and marital satisfaction than families of children without disabilities (Baeza-Valasco et al., 2013; Brobst et al., 2009; Ekas, Whitman, & Shivers, 2009; Gau et al., 2012; Zablosky et al., 2013). While limited research exists on single parents of children with ASD, it is understood that single parents also have elevated levels of stress that may be more extensive without the social support and ability to share parenting responsibilities with a spouse.

Parent-child relationships. The demands of raising a child with ASD, including challenges with core symptoms and problem behaviors, can lead to atypical parent-child relationships; challenging behaviors and lack of emotional connection to the child with ASD can

negatively impact the relationship of a parent and child with ASD (Beurkens et al., 2013). Parent-child relationships strongly influence child development, personality, and social skills (Janzen, 2014). In turn, lack of social and emotional reciprocity impact the parent-child relationship (Cappe et al., 2011), the child's social development (Janzen, 2014), and the child's language development (Karst & Van Hecke, 2012). Severity of symptoms also significantly impacts the level of closeness and adds strain to parent-child relationships (Hoffmann et al., 2009). Since children with ASD have an impairment in ability to relate to others, often children do not display a strong sense of attachment or offer affection to parents, which leads to negative feelings and greater internal struggle for the parents (Beurkens et al., 2013). These lower quality interactions (Zablotsky et al., 2013) between a parent and child have a direct impact on parental stress (Zaidman-Zait et al., 2010).

Stressors During the IEP Process

Along with increased daily demands and stressors, the educational responsibilities of parents of children with disabilities are heightened (Turnbull et al., 2010; Weiss et al., 2012). These expectations are further increased with legislative mandates for increased parental involvement in education (Turnbull et al., 2010) since an Individualized Educational Program (IEP) must be developed if the disability impacts the child's academic performance.

IDEA. The Individuals with Disabilities Education Improvement Act (IDEA, 2004), also called Public Law (PL) 108-446, is the federal law that requires public schools to provide a free appropriate public education (FAPE) in the least restrictive environment (LRE) to all children with disabilities. Thus, children with disabilities are served free of charge in a special education program and have access to direct services such as speech and language therapy, and related services such as therapy for fine and gross motor skills, and social skills training if appropriate

for the child (Aron & Loprest, 2012; Murphy & Ruble, 2012). Also, each child is to receive instruction in a general education class with peers to the greatest possible extent that meets the needs of the child (Aron & Loprest, 2012). IDEA is particularly important for children with disabilities because public education is the only service all children have free access to, and for children in rural areas, public education may be the only service children receive (Murphy & Ruble, 2012). Reauthorizations to IDEA (2004) have increased parental involvement requirements and expectations for parents to be knowledgeable in special education law and able to be a contributing member of their child's IEP committee (Turnbull et al., 2010). IDEA also mandates collaboration with parents and teachers throughout the IEP process (Valle, 2011).

The IEP process. IDEA mandates that an Individualized Education Program (IEP) be developed for students who qualify for special education services. The IEP must be developed by a committee, which meets at least one time annually to review the student's progress (Lo, 2012). The IEP process consists of the following steps: referral, evaluation, eligibility determination, development of IEP document, implementation, and annual review of progress. While parent involvement in the IEP process is strongly emphasized through the entire process (Lo, 2012), the IEP meeting is the main point of collaboration between teachers and parents; the quality of collaboration is significant to the effectiveness of the program (Reiman, Beck, Coppola, & Engiles, 2010).

However, parents of children with disabilities have described the IEP process as an emotional experience that can bring greater stress on the parents (Zeitlin & Curcic, 2014). Parents' first experience with an IEP meeting was described as "confusing" and a feeling of being "lost" which led to dissatisfaction of the process (Stoner et al., 2005, p. 49). Parents reported that IEP meetings were negative and focused only on the child's weaknesses (Trussel,

Hammond, & Ingalls, 2008). Additionally, negative meetings impact parents' levels of stress and ability to comprehend information (Lo, 2012). Parents also indicate not knowing how to prepare for a meeting and not being able to follow along in a meeting due to the use of educational jargon (Turnbull et al., 2010). Parents described not being treated as an equal in the meeting (Keenan et al., 2010); they were provided prepared forms, and not included in discussions (Fish, 2006; Reiman et al., 2010). Parents' concerns were further complicated by interpersonal meetings with committee members focused on computers rather than engaging in meaningful discussion (Zeitlin & Curcic, 2014), and documents that were difficult to understand (Karila & Alsutari, 2012).

Understanding complicated laws that relate to their child posed an additional challenge for parents (Smith & Elder, 2012; Weiss et al., 2013), and many parents reported self-learning about laws and rights through research (Thompson, 2014). Also, parents with cultural and language differences found IEP meetings to be more stressful due to the communication barrier, even if a translator is present (Geenen, Powers, & Lopez-Vasquez, 2005; Lo, 2012). It is not surprising that parents found the process of advocating for educational services for their child to be overwhelming (Smith & Elder, 2012; Weiss et al., 2013).

Parental involvement. The importance of parent involvement in education has been widely researched and recognized in academic fields (Henrich, 2013). Parental involvement is so significant to academic success that parent-teacher collaboration is legally mandated by IDEA (2004). However, low rates of parental involvement are found with minorities, children from low socio-economic status, and children with disabilities (Bower & Griffen, 2011). Understanding and working cooperatively with parents of children with ASD is increasingly important since parental involvement is linked to academic success and social development (de Bruine et al.,

2014; El Nokali, Bachman, & Votruba-Drzal, 2010; Henrich, 2013). While parental involvement may come in many forms and levels of participation, Henrich (2013) defined effective parental involvement in education to include parent-school collaboration.

Many factors impact parental involvement such as family circumstances, parents' beliefs and perceptions, and parents' level of education (Hornby & Lafaele, 2011). Understanding parents' experiences is important because the past experiences, being positive or negative, influence parents' willingness to work with professionals and impact the way parents interact with educators (Weiss & Lunsky, 2011; White et al., 2012). Parents are more involved when there is collaboration with teachers and interactions are positive (Renty & Roeyers, 2006). Therefore, it is crucial for educators to understand and develop working relationships with families since providing an appropriate education for children with ASD requires a team working collaboratively (Weiss et al., 2013).

Theoretical Framework

Even though effective collaboration is essential for student success, Turnbull and Turnbull (2006) revealed that parents of children with developmental disabilities are typically less involved in educational settings than parents of children without disabilities. Likewise, Fish (2008) also identified existing factors, which alienate the parents during the IEP process. For this reason, collaborative relationships between parents and special educators should be studied (Weintraub, 2012), and learning about parents' experiences is an essential part of building collaborative relationships (Stuart et al., 2006). Also, the needs of children with ASD overshadow the parents' needs (Trigonaki, 2002). The unmet needs of parents may impact their ability to effectively advocate for their child. Therefore, it is important for educators and professionals to understand the needs and the challenges of parents of children with ASD, so

effective support can be provided (Reiman et al., 2010; Weiss & Lunskey, 2011). Also, Brown et al. (2011) indicated that research needs to be conducted on the unmet needs of parents with children identified as having ASD.

For this study, Maslow's (1943) *Theory of Human Motivation* served as a framework to explore and seek understanding of parents' needs and how to support parents' progress to self-actualization and improve collaboration in the process. Additionally, Thapa, Cohen, Guffey, and Higgins-D'Alessandro (2013) identified effective relationships among teachers, parents, and students as an essential basis for academic engagement and success, and Maslow's theory has been identified as an effective theory for promoting collaborative relationships in academic settings (Larson, 2014; Thapa et al., 2013).

Maslow's (1943) theory is well recognized and is one of the most studied theories in the areas of education and psychology (Adiele & Abraham, 2013; Wininger & Norman, 2010). Maslow first introduced his idea of human needs in a paper in 1943 titled *A Theory of Human Motivation*. Maslow (1943) described the basic needs as the driving force or motivators of one's behavior and explained that each need is related to the level of satisfaction of other needs which can vary among individuals. Additionally, Maslow (1943) stated, "human needs arrange themselves in hierarchies of prepotency" (p. 370). Through the use of clinical observations and empirical data, Maslow (1943) identified these tiers as (a) physiological needs, (b) safety needs, (c) social needs, (d) esteem needs, and (e) self-actualization needs (Poston, 2009; Wininger & Norman, 2010). According to Maslow (1943), "Appearances of one need usually rests on the prior satisfaction of another, more pre-potent need" (p. 370). Often referred to as a hierarchy of needs, Maslow (1943) explained that human needs were arranged in levels of necessity and that individual's behavior is driven by the need to satisfy and maintain satisfaction of needs in an

order. Furthermore, the order of needs is not rigid and a need does not need to be completely fulfilled for the next need to become a motivator (Wininger & Norman, 2010). Maslow (1943, 1958, 1987) continued to refine his theory in multiple publications over the course of four decades to further develop his ideas; however, the central ideas remain the same.

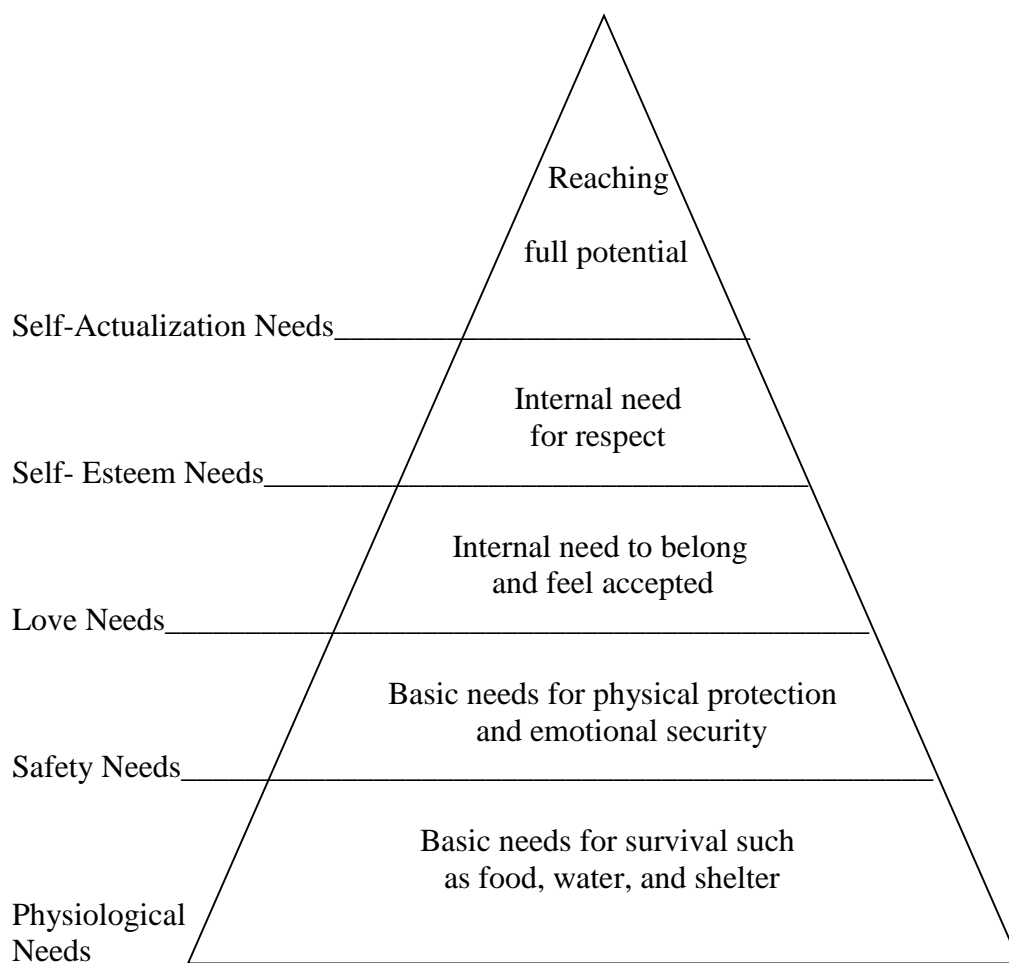


Figure 1. Maslow's Hierarchy of Needs

Physiological Needs

Maslow (1943) identified physiological needs as a basic drive for survival such as food and water, and he stated “physiological needs are the most pre-potent of all needs” (p. 373).

Physiological needs are the most fundamental needs as they are essential to maintain life such as

eating and sleeping. Essentially, these basic needs dominate an individual, and drive behavior; once the need is satisfied, another higher need arises (Maslow, 1943).

Many parents of children with ASD are expected to have challenges fulfilling basic physiological needs. Financial challenges associated with raising a child with ASD may make it difficult to provide basic necessities (Weiss et al., 2013). Parents of children often lack resources and access to services necessary to improve their situation (Divan et al., 2012). Sleep is also a basic need required for functioning, and high levels of fatigue were reported by parents of children with ASD which impacts the parents' physical health and abilities (Giallo et al., 2013). It is increasingly important to investigate the physiological needs of parents since financial and physical strains on the family can lead to poor quality of life (Cappe et al., 2011).

Safety Needs

When an individual has acquired physiological needs, safety needs arise. Safety needs may be identified as shelter, protection, wellness, and consistency. Safety needs include physical safety as well as mental and emotional security. A loss of security results in fear and anxiety (Poston, 2009). An individual's safety needs include security in environments and relationships, stable family life, and economic stability (Poston, 2009). Adults are driven by safety needs in an emergency situation; "Their reaction is often to unknown, psychological dangers in a world that is perceived to be hostile, overwhelming, and threatening. Such a person behaves as if a great catastrophe were almost always impeding, i.e., he is usually responding as if to an emergency" (Maslow, 1943, p. 379). It is not surprising that many parents of children with ASD describe their lives with terms such as: "always being in a state of emergency," "chaos," and a "chronically bad situation" (Samadi et al., 2013, p. 1439).

It is expected that parents of children with ASD have trouble meeting safety needs on many levels. As previously mentioned, parents are faced with countless physical and emotional stressors which may threaten an individual's sense of security. Parents of children with extreme co-existing behaviors may also struggle for personal protection and to protect their child from self-inflicted injury (Fulton et al., 2014). Parents are also presented with the struggle to maintain a stable environment in the home and prepare for the unknown future of their child.

Maslow (1943) further identified knowledge as an important factor in an individual's safety and security needs. For parents of children with ASD, the unknown or lack of information can be extremely troublesome since parents report a lack of information as a common need (Samadi et al., 2013). Additionally, limited access to information prevents parents from receiving available resources and support (Harris, 2008); however, parents with knowledge are empowered to make decisions and advocate for their child's needs (Samadi et al., 2013). Without quality information about ASD, some parents never fully accept the diagnosis and choose to use emotional coping styles such as avoidance and denial which are troublesome because psychological acceptance is an important factor in parents' ability to cope (Weiss et al., 2012). Additionally, knowledge is linked to positive perceptions and reduced feelings of guilt in mothers (Samadi et al., 2013). With this information, it is important to further investigate the safety needs of parents since fear and a loss of security leads to further psychological distress such as depression or anxiety (Hayes & Watson, 2013).

Love Needs

Maslow (1943) identified love needs as a person's need to give and receive love or affection. Love needs include a person's need for socialization and acceptance by others. Poston (2009) explained love needs as an emotional need to belong and a social ability to build

relationships with others. Maslow (1943) indicated that unmet love needs may result in mental and emotional disorders.

It is anticipated that families of children with ASD struggle with unmet love needs since parents of children with ASD report a high need for social support (Altiere & von Kluge, 2009; Giallo et al., 2013), and family time, attention and psychological support is limited for family members (Weiss et al., 2012). A lack of affection and emotional reciprocity from children with ASD negatively impacts parents (Estes et al., 2013; Karst & Van Hecke, 2012). Parents without quality social support are more sensitive to stressors and more prone to psychological distress such as depression and anxiety (Cappe et al., 2011). Additionally, in educational areas, previous studies suggest that parents do not feel accepted or viewed as an important member of their child's IEP committee (Keenan et al., 2010). It is important to consider the emotional needs of parents since social support can help improve psychological acceptance, empowerment (Weiss et al., 2012), and promote resilience for parents (Baker et al., 2014). Furthermore, positive social support leads to adaptation, lower levels of stress, increased well-being, and improved quality of life (Cappe et al., 2011).

Esteem Needs

Maslow (1943) explained that esteem needs consist of an internal desire for achievement, a sense of importance, independence, and respect from others. Maslow (1943) expounded, "Satisfaction of the self-esteem need leads to self-confidence, worth, strength, capability and adequacy of being useful and necessary in the world" (p.382). Since needs are internal and difficult to identify, Poston (2009) extended the understanding of esteem needs to include reputation, recognition, validation, self-respect, and confidence in ability. Individuals meet esteem needs by reaching personal goals and overcoming challenges. Esteem needs are the

intrinsic drive that pushes a person to improve him/herself and his/her situation. Therefore, met esteem needs create a positive sense of self-worth and confidence in abilities within an individual.

Based on recent research, it is expected that parents of children with ASD have many unfulfilled esteem needs since many parents have reported having low self-esteem (Weiss et al., 2012), and chronic stress from the demands of having a child with ASD negatively alters an individual's level of confidence (Weiss et al., 2013). When advocating for their child, parents have reported not feeling valued as a meaningful part of the IEP committee (Turnbull et al., 2010). Parenting self-efficacy, a feeling of competence and satisfaction in parenting skills, was also found to be low for parents of children with ASD (Giallo et al., 2013). Emotion-oriented coping strategies such as distraction and avoidance were found to be common among mothers of children with ASD (Samadi et al., 2013), and emotional based coping strategies have negative effects on a parent's self-esteem (Lyons et al., 2010). Whereas, parents who exhibit effective coping skills become more resilient and report a positive self-image (Bayat, 2007; Estes et al., 2013; Harris & Grasberg, 2003) and confidence in their abilities as parents (Lyons et al., 2010; Samadi et al., 2013). In turn, greater family resilience is associated with lower levels of stress (Plumb, 2011). Moreover, some families indicated that the challenges associated with parenting a child with ASD made them emotionally stronger with higher levels of self-esteem (Bayat, 2007), and overcoming adversity helped strengthen relationships within the family (Freedman et al., 2012; Weiss et al., 2012). Therefore, it is essential to understand the esteem needs of parents and how esteem needs are met to help promote parents to self-actualization.

Self-Actualization Needs

Maslow (1943) explained the need of self-actualization as a desire “to become everything one is capable of becoming” (p.382). Self-actualization is the internal need of achievement, and it is how an individual defines oneself and abilities (Poston, 2009). The self-actualization need is the utmost need identified in the hierarchy and arises when other needs are mostly satisfied. Much like the esteem needs, the need for self-fulfillment is an intrinsic desire that cannot be seen, but it drives the individual to reach his or her full potential. Self-actualization needs are fulfilled when an individual uses talents and abilities to become all a person is capable of becoming; however, Maslow (1943) noted that only a small percentage of people actually fulfill the self-actualization need.

Due to the extended challenges faced by parenting a child with ASD, and the difficulty of an individual to reach full potential, it is expected that most parents of children with ASD have an unfulfilled self-actualization need. Although, as noted in previous findings, some parents do gain confidence, resilience, and self-efficacy (Lyons et al., 2010; Samadi et al., 2013). These parents feel empowered to make the best of their situation and may become fulfilled. For example, some parents adjust and become experts and community advocates (Turnbull & Turnbull, 2006). Others may strive for improving public knowledge and making changes in their community.

Summary

Maslow’s (1943) hierarchy of needs has been applied to countless fields to better understand and meet human needs (Finnan & Kombe, 2011; Mattar, 2012). Due to the knowledge that fulfillment of individuals’ needs is essential to learning, the education system is designed to meet students’ basic needs through programs such as free or reduced lunch, counselors, nurses, safety drills, transportation, and anti-bullying programs, to name a few

(Prince & Howard, 2002). Additionally, understanding the needs of teachers (Adiele, & Abraham, 2013) and specific needs of students with disabilities (Prince & Hadwin, 2013) have been a focus in education. Although the need to work collaboratively with parents has been well established (Scully, Barbour, and Roberts-King, 2015), limited studies exist on understanding the needs of parents in the educational process, specifically the needs of parents of children with ASD. Parents of children with ASD have reported experiencing unmet needs (Brown et al., 2011) and limited support (Altiere & von Kluge, 2009; Giallo et al., 2013). Therefore, the purpose of this study was to close the gap in literature on understanding the unique needs of parents of children with ASD as they navigate the IEP process.

As previously mentioned, since parents of children with ASD experience a unique set of needs, a limited amount of research has been focused on understanding the unique needs of parents of children with ASD as the primary care giver and as it relates to their experiences navigating the IEP process in schools. The research provided on the additional challenges that parents of children with ASD face makes it increasingly evident that parents have unmet needs on many different levels. Maslow's (1943) *Theory of Human Motivation* provides a comprehensive framework to help gain a better understanding of parents' various needs relating to their role in the educational process of their child with ASD.

CHAPTER THREE: METHODS

Overview

The purpose of this study was to gain a comprehensive understanding of the needs of parents with children identified as having ASD who are served in a special education program. A qualitative design was used following recommendations from Moustakas (1994) for data collection, data analysis, and ethical considerations. Data was collected through timelines, one-on-one interviews, and focus groups. Data was triangulated and analyzed using a system of bracketing, horizontalization, and developing clusters of meaning (Moustakas, 1994). Then, a description of the essence of the lived experience was developed.

Design

A qualitative approach was used to provide a voice to the parents of children with ASD. Creswell (2013) stated that qualitative research is used to address “the meaning individuals or groups ascribe to a social or human problem” (p. 44). The social or human problem to be explored is the needs parents of a child with ASD experience as they navigate the IEP process. Maslow’s (1943) *Theory of Human Motivation* was used as a guide to understand various human needs. Currently, several bodies of research have been conducted on understanding the social and educational needs of children with ASD; however, limited research exists on understanding the overall needs of parents of children with ASD (Brown et al., 2011). Because the challenges of parenting a child with ASD can be so dissimilar, a qualitative design was chosen to identify the individuals’ unique challenges. Through the use of qualitative research, data is observed in a natural setting and analyzed through a process that allows themes to emerge. This process allowed me to gather an understanding of the participants’ perspectives.

Phenomenological studies are designed to focus on describing the meaning of a lived experience, or phenomenon (Creswell, Hanson, Plano, & Morales, 2007). The essence of the lived experience is described through what the unique experience is, and how individuals experience the phenomenon (Moustakas, 1994). Philosophical assumptions of the researcher are set aside and the data is perceived as new information (Moustakas, 1994). For this study, a phenomenological design was used to investigate the personal experiences of the participants using Maslow's (1943) seminal *Theory of Human Motivation* to frame this exploration of the needs of parents. Maslow's (1943) theory was chosen as the framework for this study as it provides structure for exploring the needs of parents as related to the hierarchy of needs described in his theory.

A transcendental phenomenological study helps provide insight into the participants' lived experiences to reveal a common understanding or meaning. Moustakas (1994) explained that a phenomenological study describes *what* the participants experience using textural descriptions, and *how* they experience a phenomenon through structural descriptions. The textural and structural descriptions, when combined, provide an understanding of the essence of the experience (Creswell et al., 2007). By using the transcendental phenomenological method, I provided a rich description of the needs of parents of children with ASD as they navigate the IEP process and how parents experience support through the IEP process. Furthermore, Moustakas (1994) identified a transcendental approach as a method to reduce bias and to better understand individual experiences by using bracketing and epoche. By using bracketing, I was able to identify my personal beliefs and consciously remove personal views from the study through the use of reflective note taking and journaling (Moustakas, 1994). Further bias was reduced through epoche, or by striving to perceive the information as if for the first time (Moustakas, 1994). I

used a transcendental phenomenological approach to set my own assumptions aside and describe the essence of the shared experience of the participants (Moustakas, 1994).

Research Questions

Research questions for this phenomenological study were developed according to Moustakas' (1994) recommendation to develop broad questions that provide focus to the central phenomenon. The two broad questions allowed me to develop a rich textural and structural description of the shared experiences of the participants (Moustakas, 1994). Therefore, the research questions were developed to be general in nature and are as follows:

Research Question 1: How do parents of children with ASD experience support through the IEP process?

Research Question 2: What are the needs of parents of children with ASD as they navigate the IEP process?

Setting

Georgia was chosen as the setting for this study due the high prevalence of ASD with one in 64 children identified as having ASD as opposed to one in 68 in the nation in 2014 (CDC). Additionally, Creek County School District (pseudonym), located in Northwest Georgia, was chosen because Creek County School District had received parental satisfaction scores below the state average for the past three years as reported by the Georgia Department of Education (2014). The parental satisfaction scores were obtained from the Georgia Annual Performance Report of the Georgia State performance plan. In accordance with IDEA (2004), Indicator 8 of the Georgia State performance plan measured the percent of parents with a child served in special education programs who report that schools "facilitated parent involvement as a means of improving services and results for children" (20 U.S.C. 1416(a)(3)(A)). During the

2012 fiscal year, 41% of parents surveyed countywide reported an improvement in special education services. While this was an improvement from 34% in 2011, Creek County did not meet the target goal, which was set at 44% for overall parental satisfaction. The survey, conducted by the Georgia Department of Education (2014), consisted of questions relating to how teachers communicated with parents, if parents' concerns were addressed, and if parents were treated like a valued committee member in the IEP process. Because this study is focused on parents who have children with ASD served in Creek County School District, participants may receive special education services from multiple schools in the school system. Creek County School District consists of 41 schools: 23 elementary schools, one intermediate school, seven middle schools; six high schools; one special needs center, one Charter school, one evening school, and one Psycho-Educational Center. Of the 41 schools, four are Science Technology Engineering Mathematics (STEM) academies, two are Fine Arts academies, two contain special needs preschools, and six contain specialized programs for students with autism.

The setting for data collection was a central location in a community located in North Georgia. Meeting locations for each participant varied due to the comfort level and needs of the participants. For some interviews, I was able to observe the families in their natural environment within their home settings. The focus groups were conducted at a public library in the county. The library was chosen because it was in a central location for participants, and it had a conference room, which provided a comfortable and private area for discussions.

By studying parents whose children attend Creek County schools, I intended to understand and describe the unique needs of parents of children with ASD as they navigate the IEP process in schools. Additionally, my proximity to the sites allowed me to have personal contact with the participants through personal interviews and focus groups.

Participants

Participants for the study were selected using a combination of purposeful and snowball sampling procedures. Purposeful sampling allows the researcher to select participants based on select criteria; Creswell (2013) identified purposeful sampling as a procedure of choosing participants who can provide information or contribute to a phenomenological approach. Therefore, I used purposeful sampling to ensure that participants meet the following criteria for the study: parents of a student identified as having any type of ASD who have a child with an IEP and are currently served in any school in Creek County School District. Additionally, by using purposeful sampling, I ensured maximum variation in types of ASD in children and cultural diversity in families sampled.

Table 1

Participant Demographics (N = 10)

Pseudonym	Ethnicity	Age Range	Gender	Age of Child	Level of Education	Level of Stress
Carolyn	Caucasian	50-59	F	20	Bachelors	7
Carrie	Caucasian	40-49	F	10	Grad School	5
Cameron	Caucasian	30-39	F	15	Grad School	4
Jodi	Multi Racial	30-39	F	6	High School	8
Jamie	Caucasian	50-59	F	18	Bachelors	6
Owen	Caucasian	40-49	M	11	Grad School	8
Billy	Caucasian	40-49	M	6	Bachelors	7
Angel	Hispanic	40-49	F	9	Bachelors	6
Heather	Jewish	40-49	F	13	Bachelors	7
Becky	Multi Racial	30-39	F	11	High School	8

Note. Level of Parenting Stress was based on a self-report on a scale of 1-10 with 10 being the highest.

With approval from the school district, a parent mentor assisted in locating potential contacts for the study. The parent mentor is employed by Creek County to assist parents who are going through the IEP process. The parent mentor is a certified teacher and a parent of a teenage son with ASD. Additionally, the parent mentor has developed rapport with many parents of children with ASD in the community. She agreed to distribute an invitation to participate in the study via email to parents she was in contact with (see Appendix A). The email contained information about the purpose of the study along with a Google Docs link to a survey consisting of the informed consent (see Appendix B) and questionnaire (see Appendix C). Additionally, parents were asked to forward the invitation to other parents they know who would be willing to

participate in the study. This created a snowball sampling procedure, which was utilized to expand the sample size. The final sample consisted of ten different parents of children with ASD who have experienced the IEP process in Creek County School District.

Parents from at least ten different families were used in the study to ensure thematic saturation, as advised by Creswell (2013) for a phenomenological study. Ideally, both parents were included as participants when possible, but families were not excluded if only one parent could participate. Additionally, written informed consent (see Appendix B) was obtained from each participant. I reviewed the method of research with each participant while obtaining consent to ensure each individual thoroughly understood the types of research, reason for data collection, and how the data will be used. Participants were provided with information on the purpose of the research, and participants were allowed to withdraw from the study at any time.

The Researcher's Role

As the researcher, I served as the human instrument in the study (Lincoln & Guba, 1985). According to Patton (1990), the qualifications of a researcher may also add to credibility of research. I received a Master's of Education in special education, and a specialist degree in special education, and I am a parent of a child with an exceptionality in the area of speech and language. Being the parent of a child with an IEP, I know first-hand how difficult it can be to advocate for my child and search for support, even with formal training in the area of special education.

Additionally, I have been a teacher of students with various disabilities for the past eight years. I feel that my career working with children with disabilities is my ministry, and my goal is to improve services and quality of life for children and families of children with disabilities. As a special education teacher, my mission is to provide students with disabilities with the

appropriate level of support and guidance needed to ensure each student becomes an independent and contributing member of society. Although I have served in several areas of special education, I have had limited experiences with students with ASD. I believe my limited experience with students with ASD will be beneficial to this study because I have limited predetermined ideas or notions about ASD.

As the researcher, I used a disability interpretive lens in which a disability is a difference, not a defect (Creswell, 2013). As a special education teacher, I have noticed that the IEP process, especially the meetings, can be very intimidating to parents. Several parents have expressed concerns to me about negative experiences in the past, which impacted their views and participation in the IEP process. Using this knowledge, I was understanding to parents' past experiences with the IEP process. However, I took special caution to bracket my personal beliefs out through reflective note taking to ensure my own experiences with the IEP process and previous professional relationships with parents did not carry over into the study.

Data Collection

Prior to data collection, I requested and obtained IRB approval from Liberty University (see Appendix D) and permission to conduct research from Creek County School District (see Appendix E). Upon receiving informed consent from participants through the responses on the Google Doc survey, parents completed a short questionnaire (see Appendix C) as referenced previously to obtain demographic information related to the study. Additional data was obtained using timelines, one-on-one interviews, and focus groups. The combination of data collection techniques allowed me to gather multiple forms of information in varied response style from the participants while increase authenticity and credibility through triangulation of data (Lincoln & Guba, 1985).

Questionnaire

The first data obtained was from a questionnaire. The questionnaire served as a tool to obtain informed consent in electronic format and ensure the participants met the selected requirements to be in the study (see Appendix C). The questionnaire was composed in Google Docs, and a link was sent to possible participants in an invitation email (see Appendix A). Therefore, the informed consent was on the first page of the questionnaire and the first item explained the purpose of the study and obtained consent from the participants. As possible participants received the invitation, they read and completed the demographic questionnaire electronically. The following questions ensured the respondents were parents of children with ASD who were served in a special education program within Creek County School District at the time of the study. Additional ethical considerations were made due to the human nature of the study and the emotions or stressors that could have risen from reliving experiences. Therefore, I included two questions relating to the current level of stress for the responders. The purpose of these questions was to identify individuals who may be undergoing extreme stress and dismiss the individual from the study in an effort to prevent further distress the study may cause. Two possible participants were dismissed due to personal stress ratings obtained in the initial questionnaire. The remainder of the questionnaire provided demographic questions related to the study. The purpose of the demographic information was to develop a sense of and description of the participants in order to increase transferability of findings to other persons and populations with similar characteristics.

Timeline of Significant Events

After receiving the questionnaire and prior to interviews, I asked participants to compose a timeline of significant events and explain why those events were significant in their lives (see

Appendix F). The responses on the timeline supported the two research questions and allowed me to provide rich descriptions of the significant experiences in the parents' lives. The information on the timeline provided me with a better understanding of the participants' situations and ensured the responses were in the participants' own words. I conducted a follow up correspondence with each participant with questions that arose from each response. Additionally, information received from the timelines guided interview questions and revealed important information that was further explored in the interviews. Timelines were used to obtain additional written information from the participants. Information obtained from the timelines served as descriptive information rather than diagnostic. Timelines were accepted in hand written and electronic formats depending on the participants' level of comfort with electronic usage and availability of computer or Internet use.

Fleischmann (2004) found that Internet correspondence by parents of children with ASD is an effective tool to convey "the personal perspective of the parents and the changes that have taken place in their outlook" (p. 36). Timelines allowed for participants to respond at their convenience since it is well established that parents of children with ASD have busy schedules. Additionally, it was considered that participants might be more comfortable communicating through writing than in person. Since the timeline was the first piece of data collection and helped guide interview questions, I received and reviewed responses prior to conducting interviews and focus groups. Therefore, I asked participants to complete the timeline within the first 2 weeks of collecting data. If parents did not complete the timeline within two weeks, I sent an email reminder and contacted the participant via phone call to see if the participant needed more time or had questions.

Interviews

Interview questions were developed based on Patton's (1990) qualitative interview guide that emphasizes the use of general topics for discussion, which can be rephrased by the interviewer rather than following a confining list of questions. According to Patton (1990), this approach to interviewing is systematic and comprehensible, yet the tone of the interview is comfortable and relaxed. Using Patton's (1990) interview guide, I outlined topics to be discussed. This allowed me to change wording and question order as needed to keep the interviews informal in nature and open to discussion. Questions were open-ended to allow for varied participant response. Interview and questionnaire questions were reviewed by and piloted with experts in the field. Ms. James (pseudonym), a parent mentor employed in Creek County served as the expert reviewer and pilot participant. Ms. James is a certified teacher and parent of a teenage son with ASD. Ms. James is trained and knowledgeable in the areas of ASD and provided personal insight on how the questions should be presented to parents of children with ASD. Then questions were piloted with a select group of participants to allow for suggestions and feedback. Necessary revisions were made to the interview questions.

One-on-one interviews were conducted with participants to gather direct information. Interview questions were designed to address the participants' needs following the framework of Maslow's (1943) *Theory of Human Motivation*. Individual interviews consisted of open-ended questions to allow for participant elaboration. As the researcher, I facilitated the interview by probing for a thorough conversation to maximize understanding and allow the participant to raise new topics to be discussed that I could have missed in the interview guide (Patton, 1990). Additionally, I ensured all topics on the interview guide were covered so information could be systematically analyzed. As the researcher, I added additional questions or prompts during the

interview to clarify my understanding of participant responses, but I took extra precautions to not ask leading questions or influence the responses. Also, the interviews were audio taped so each could be transcribed verbatim.

Table 2

Standardized Open-Ended Interview Questions

Interview Question	Primary Needs Addressed
1. Please tell me about your family (number and age of children, etc.).	Love Needs
2. What types of activities does your family enjoy doing together?	Love Needs
3. Can you tell me about your spouse and what roles/responsibilities you each have in the home, with children outside of the home?	Love Needs
4. Can you tell me more about (child's name)? Please tell me about (child's name) as a baby, a toddler, a preschooler, etc. Can you give me specific examples or stories?	Love Needs
5. Please tell me about when and how you first learned that (name of child) may have a developmental delay. How did you feel? How did this impact you?	Safety Needs
6. How did the diagnosis impact you as a parent? Your outlook or goals as a parent?	Esteem Needs
7. It is understood that the diagnosis process is challenging for parents. Can you please share challenges you faced when undergoing a diagnosis?	Safety Needs
8. Please describe any social support you received. How did you locate social support or support groups?	Love Needs
9. Please describe the type of information that was made available to you about ASD. How did you gain more information on ASD? What was the experience like?	Safety Needs
10. What has been the most difficult aspect of parenting a child with ASD? Most rewarding?	Esteem Needs
11. Have your social activities been impacted by having a child with ASD? If so, how?	Love Needs
12. Do you feel that your overall health has been impacted by parenting a child with ASD? Please explain.	Physiological Needs
13. Can you please describe the physical challenges of parenting a child with ASD such as providing full time care and the fiscal responsibilities?	Physiological Needs
14. How have relationships inside and outside of the family been impacted? Interactions with your child/children?	Love Needs
15. Can you please explain the personal struggles and benefits relating to having a child with ASD?	Physiological Needs

16. How was (child's name) entry into school? Did prior (child's name) have an IEP prior to entering school or was one created after entering school? Please tell me about the process.	Safety Needs
17. Please tell me about your best experience with the school or teachers.	Esteem Needs
18. Please tell me about your worst experience. How could the school or teachers have handled the situation differently?	Safety Needs
19. What do you wish educators understood about what it's like to raise a child with ASD?	Safety Needs
20. What, if any, are ways you have felt valued or included in the IEP process?	Esteem Needs
21. Have you experienced a lack of respect or valuing of your opinion in the IEP process? If so, how?	Esteem Needs
22. Knowing what you know now, how would you counsel someone just beginning this process or journey?	Self-actualization Needs

Throughout the review of current literature, several key constructs were identified as being significant and interview questions were designed to provide more information on the important constructs. The first four questions stem from research that entire family dynamics are impacted by parenting a child with ASD (Gau et al., 2012). Therefore, questions 1-4 were designed to gain a better understanding of the participant and the family roles. Additionally, these questions were chosen as an introduction to set a comfortable tone for the interview. Research identifies parents of children with ASD to be experiencing high levels of parenting stress (Dabrowska & Pisula, 2010; Estes et al., 2013; Rao & Beidel, 2009; Seymour et al., 2013; Silva & Schalock, 2012; Siman-Tov & Kaniel, 2011). This increased level of stress is credited to increased caretaking responsibilities and challenging behaviors associated with the disability (Weiss & Lunsky, 2011). Additionally, certain events such as the diagnosis process (Keenan et al., 2010) and searching for information are especially challenging (Plumb, 2011; Samadi et al., 2012). Therefore, interview questions 5 through 10 focus on parenting related stressors associated with parenting a child with ASD.

Personal stress was also identified as a key construct with factors relating to level of education, financial resources, and personal health (Weiss & Lunskey, 2011). Furthermore, stress was found to greatly impact mental and physical health for the parents and lead to psychological distress (Benson, 2010; Barker et al., 2014; Estes et al., 2013; Shtayermman, 2013; Tway et al., 2007; Weitlauf et al., 2014). Additionally, parenting a child with ASD impacts the quality of relationships with family members including marital relationships and parent-child relationships (Divan et al., 2012; Hartley et al., 2011; Walsh & O'Leary, 2013). Therefore, questions 11 through 15 were designed to further investigate the personal stress and needs of parents of children with ASD.

Advocating for educational services and support is a key construct in the review of literature. Parents of children with ASD have increased educational responsibilities in the IEP process (Turnbull et al., 2010; Weiss et al., 2012). However, research indicates that parents of children with ASD have described the IEP process as an emotional and stressful experience (Zeitlin & Curcic, 2014) where they were not valued (Fish, 2006; Keenan et al., 2010; Reiman et al., 2010). Therefore, Questions 16-22 were designed to gain further insight on the parents' perspective of the IEP process.

Focus Groups

Data was collected from focus groups with the participants. The focus groups allowed participants to discuss their experiences of having a child with ASD and navigating the IEP process in a group setting. Two meeting locations were utilized for this study; a public library in the north end of the county and a public library in the southern part of the county. Since it is well established that parents of children with ASD have busy schedules and limited free time, I included an inquiry in the questionnaire see if participants prefer meeting face-to-face or

responding online in discussion groups. While an online discussion group may limit interaction, it was also expected that online discussions may allow conversations to take place that would otherwise not happen in face-to-face meetings as participants will be more comfortable and identity will be concealed. Plans were made to divide the participants into two focus groups depending on the parent's schedules and availability related to the meeting locations for participant convenience. All participants preferred to meet face to face, so the groups were determined based on locations that were convenient for participants. Each group consisted of five participants.

Patton (2002) stated that focus group interviews can be beneficial to a study by providing internal balance among participants. Morgan (1998) defined focus groups as a "research technique that collects data through group interaction on a topic determined by the researcher" (p. 130). Additionally, Morgan (1998) emphasized three essential components to focus groups:

First, it clearly states that focus groups are a research method devoted to data collection. Second, it locates the interaction in group discussion as the source of the data. Third, it acknowledges the researcher's active role in creating the group discussion for data collection purposes. (p. 130)

Additionally, synergy within the focus groups can increase participant involvement and can lead to unprompted discussions that may not be addressed otherwise (Morgan, 1998). Open-ended topics were presented and participants were allowed to answer collaboratively (see Appendix G). During the focus groups, data was audio recorded. Also, observations took place to note parent perceptions and interactions during the focus groups. I kept ongoing field notes of the observations (see Appendix H for an example).

Data Analysis

Data received from questionnaires, timelines, interviews, and focus groups was transcribed verbatim by myself and double-checked for accuracy. A process of analysis and phenomenological reduction by Moustakas (1994) was conducted using bracketing, horizontalization, and creating clusters of meaning to determine to the essence of the experience of the participants.

Bracketing

I first used the process of bracketing to purposefully identify and then separate from the study any personal related experiences or beliefs I held. Moustakas (1994) identified bracketing as a valid means to remove subjectivity and ensure the research is not altered by the researcher's role. Additionally, I used epoche, a process identified by Moustakas (1994) as a means to eliminate any prejudgments in the study. Moustakas (1994) explained epoche as a process "in which everything is perceived freshly, as if for the first time" (p. 34). Through the use of reflective note taking, I monitored my personal assumptions and consciously set aside my experiences and beliefs (Moustakas, 1994). Additionally, I ensured that I was providing an accurate and truthful description of each of the participant's experiences. The use of bracketing and epoche also increased validity to the study through confirmability, or ensuring the study is free from researcher bias (Schwandt, Lincoln, & Guba, 2007).

Horizontalization

I used horizontalization to list meaningful experiences and quotes that were significant to the study (Moustakas, 1994). By analyzing the transcribed data and identifying the meaningful statements, I further reduced the data by removing the comments that were redundant or not meaningful to the study. Following Moustakas' (1994) rule of horizontalization, emerging

statements were considered equally significant and importance was not yet placed on specific ideas. This prevented themes from being inadvertently or prematurely chosen by the researcher. The reoccurring themes then naturally emerged through the data analysis process as the significant statements identified in the horizontalization process were then arranged according to meaning.

Clusters of Meaning

From the statements identified in the horizontalization process, meanings were identified for each statement and grouped accordingly. After identifying the significant statements for meaning, I then analyzed the data to find clusters of meanings by grouping common ideas which were identified as significant (Moustakas, 1994). From the information received, I developed a textural description of *what* the participants experienced and a structural description of *how* the participants experienced the phenomenon in order to develop a composite description of the essence of parenting a child with ASD while navigating the IEP process (Creswell, 2013).

Textural Description

A textural description of *what* the parents experienced was then developed from the themes generated from the procedures described above. According to Moustakas (1994), a textural description emerges from the “themes and delimited horizons of each research participant’s experience” (p.133). A composite textural description was developed by analyzing the information received from each participant and constructing a rich description explaining what the participants experienced.

Structural Description

A structural description was then developed to explain *how* each participant experienced the phenomenon. Structural descriptions convey the “underlying dynamics of the experience, the

themes and qualities that account for how feelings and thoughts connected” (Moustakas, 1994, p. 135). Imaginative variation (i.e., considering all perspectives), reflection, and analysis was used to determine how the participants experienced the phenomenon (Moustakas, 1994).

Composite Description

From the textural and structural descriptions, I created a composite description of the meaning or essence of the shared experience of the participants. A composite description of the textural and structural descriptions composed of a combination of responses from all participants was created to vividly describe the meaning and essence of the experience of parenting a child with ASD while navigating the IEP process. By creating a composite description, I strived to paint a descriptive picture of the true essence of the lived experience of navigating the IEP process for a child with ASD.

Trustworthiness

Trustworthiness was established in the study through steps taken to increase credibility, transferability, dependability, and conformability (Lincoln & Guba, 1985). Credibility entails maintaining truth and accuracy in the study. According to Lincoln and Guba (1985), triangulation is a primary method to ensure credibility to a qualitative study by using multiple forms of data to compare for a comprehensive understanding. I used triangulation by obtaining three forms of data for accuracy. I included tangible data from questionnaires, timelines, interviews, and focus groups. Also, I used member checks to allow participants to review notes for accuracy. Member checks were conducted by having participants review transcribed records, as well as the textural and structural descriptions to ensure that I accurately described the experience. Also, member checks were conducted throughout the data collection phase by double checking with participants and asking for clarification when necessary. Additionally, peer

debriefing was also used to ensure credibility by having a peer analyze the study and providing feedback through peer debriefing sessions (Lincoln & Guba, 1985).

For this study, the reviews by the dissertation committee also served as expert reviews. As mentioned previously, Patton (1990) indicated that the background, qualifications, and experience of the researcher also add to credibility of a study. Therefore, my training and education in the special education profession increased trustworthiness in the study.

Transferability, which is the ability of the study to be relative or applied to other areas, was ensured by using thick, rich descriptive data (Lincoln & Guba, 1985). I used detailed description throughout the study to describe the setting and participants so the study can be understood and transferred by others to similar settings and populations. Transferability was also enhanced through maximum variation in sampling, which is purposefully selecting a diverse group of respondents with varied backgrounds and children with various typed of ASD, so results can be easily transferred to a wide range of groups.

Dependability, or consistency in findings, was enhanced by providing an audit trail consisting of detailed field notes and using an external auditor to check the data (Lincoln & Guba, 1985). The external auditor is a parent of a child with ASD who is also a certified teacher. I discussed the importance of keeping statements and findings confidential with the external auditor. Additionally, a confidentiality statement was signed by the external auditor prior to review (see Appendix I). Additionally, I recorded interviews and transcribed responses verbatim to increase reliability (Creswell, 2007).

Confirmability, or objectivity, was established by ensuring the data is reported in an impartial and non-bias method (Schwandt, Lincoln, & Guba, 2007). Bracketing and epoche processes were used to decrease the influence of researcher bias and judgment through reflective

note taking. Triangulation of data and member checks also enhanced confirmability by ensuring transcripts were authentic and reflective of the participants' narratives of their experiences with the study phenomenon (Creswell, 2007). Steps were taken at every stage of research to maintain and enhance trustworthiness.

Ethical Considerations

Ethical considerations were addressed to ensure the safety and confidentiality of people and documents. Pseudonyms were used for all names and locations to protect participant identity. Locking up all paper documents ensured security of data transcripts. Electronic documents were backed-up electronically and protected with a password. Sensitivity of information was considered and participants were allowed to withdraw from the study at any time. As the researcher, I sought to maintain an objective stance, while also using person-centered strategies to display empathy to all participants sharing their personal experiences. Additionally, I followed Liberty University's high standards of academic and ethical integrity by putting the participants' best interests first and providing authentic accounts of the participants' experiences. Debriefing was also provided to address emotional concerns the parents may have as a result of communicating emotional topics in the study (see Appendix J).

Summary

A transcendental phenomenological approach was utilized in this study to provide an account of the shared experience of participants. Through this qualitative design, I was able to study the unique needs of parents of children with ASD. I followed Moustakas' (1994) recommendation for phenomenological studies for data collection and data analysis to triangulate data and allow information to emerge through data reduction. From the gathered information, I developed a rich, textural and structural description of the shared experiences of the participants

to provide an understanding of the essence of parenting a child with ASD while navigating the IEP process.

CHAPTER FOUR: FINDINGS

Overview

The purpose of this phenomenological study was to provide a voice to parents of children with ASD, specifically the needs that parents encounter as they advocate for their child's needs and navigate the IEP process. A phenomenological design was chosen to explore the needs parents experienced through the framework of Maslow's (1943) *Theory of Human Motivation*, which described a hierarchy of needs. Moustakas (1994) recommended the use of phenomenological research to understand the *essence* of human experiences.

An introduction of each participant is provided in this chapter, along with a presentation of the themes central to their shared experiences. The participant's experiences were analyzed based on data from timelines, interviews, and focus groups to answer the following two research questions:

Research Question 1: How do parents of children with ASD experience support through the IEP process?

Research Question 2: What are the needs of parents of children with ASD as they navigate the IEP process?

Participants

A total of 10 individuals participated in this study. Each participant and family member referenced in the study was given a pseudonym to ensure confidentiality. Each participant provided an interesting and varied perspective to the group of individuals. Each participant was a parent of a child with ASD who is currently enrolled in a school in Creek County School District

(pseudonym) and has an IEP. Participants represented a diverse group of individuals from various backgrounds, races, socio-economic status, educational experiences, and areas of employment. However, participants all shared the common experience of advocating for their child with ASD through the IEP process.

Carolyn

Carolyn is the mother of Sam, a 20-year-old male diagnosed with Classic autism. Sam, an only child, has limited verbal ability and has been served in a self-contained program to gain daily living skills. Carolyn has been the primary caregiver for Sam and has been an active advocate for his needs since she noticed a “difference in typical milestones” when Sam was 6 months old. Prior to motherhood, Carolyn was studying in an educational program to become a special education teacher. She indicated that her formal training in child development allowed her to notice atypical delays and advancements in her son at an early age. Carolyn put her education and career on hold to provide needed care and therapy for her son.

Although he was not a behavior problem, I had to stay at home to take care of him. A church preschool told us not come back because there was not a special needs program, and they could not work with us . . . and he was not a behavior problem at all! They were just afraid because they did not understand autism. I started a daycare in my home just to help him socialize with others.

Carolyn stated that many physical and financial challenges were endured during the years following Sam’s diagnosis. With Carolyn unable to work and needing to provide full time care of Sam, finances were limited. Their financial situation was further complicated with expensive treatments and therapies which the family usually had to charge to their credit card. However, Carolyn stated, “God always provided for us. When we thought there was no other way to make

it, He showed us He was in charge.” Despite challenges they have faced, she and her husband have a healthy relationship, which has been strengthened by the parenting responsibilities of their son. Their parenting responsibilities are very balanced and decisions are based on what is best for the entire family. Carolyn concluded by stating that she knows her purpose, and it is to help others in similar situations.

Carrie

Carrie, a 45-year-old stay at home mother, is the mother of Danny, a 10-year-old boy with Classic autism. Danny is the younger of two children and did not noticeably miss developmental milestones until he was three years old. Carrie described Danny as a pleasant, calm infant who was not motivated to communicate. His outgoing older sister typically spoke for him. She explained:

Both of our children were very different. Our daughter was advanced, so we realized that his vocabulary was not as developed as hers at that age. He was speaking and knew several words, but it was the inability to put words together clearly that was the first sign for us.

Danny was diagnosed with ASD at the age of two and received an IEP at age three through the early intervention program in Georgia. He was able to attend a Special Needs Preschool and receive related services such as speech therapy at the age of three. Carrie, who holds a bachelor’s degree in business, was not able to pursue a career due to the increased demands of parenting. “Fortunately, we were in a position that my husband could take on additional work, and we could make ends meet. I don’t know what we would have done otherwise.” Carrie also indicated their financial stability allowed them to focus on balancing the family roles.

The expenses really add up. We continue to have countless therapies, treatments, camps and transportation to and from. I am able to take on the hands on responsibilities like cooking, cleaning, taxi service, and school work. My husband does more of the recreation and guy stuff with Danny, which helps since Danny is becoming bigger. He will take him swimming or to the theater. He also helps with hygiene care like baths. The balance really helps with Danny's behavior because he knows what to expect, and it helps us to have a stable relationship. Also, now that Danny is in school, I am able to volunteer, so I am busy but not tied down if the school needs me.

In the educational realm, Carrie stated that she has been very pleased with both the quality of services and the respect she has received. However, since Danny was in a self-contained program, he had the same teacher for the six years he was in elementary school. The teacher got to know Danny's needs and developed a working relationship with the family. The only time Carrie was uncomfortable during the IEP process was when she felt like decisions were being made based on what was best for the school instead of what was best for her child. The committee was able to work through the issue and determine a solution because Carrie was able to voice her concern. As far as advice for educators, she stated that she wants teachers to know that she does not have the answers.

Many times, I would receive phone calls from the school about Danny's behaviors or wanting to know how they should handle a situation. I would just have to laugh and say I don't know! He is my son and I should know him better than anyone, but I just don't have the answers. He is different every day, and if I expect him to react one way to something, he usually does the opposite. I just don't have the answers.

Cameron

Cameron is the mother of Casey, a 15-year-old male with high functioning ASD. Cameron has a master's degree in education and just received a contract to begin her first year teaching. Cameron has been a certified teacher since Casey was an infant, but was not able to have a career in the field due to the need to be available. Now that Casey is entering high school and has a better understanding of his social skills and how to handle frustration, Cameron is able to start her career.

When he was an infant, he was fine with me. I mean he was temperamental and wanted his way, but what two year old doesn't? I didn't see the behaviors until he started preschool. I got called to come get him early every day for a month. He would scream and hide from the teachers. I was picking him up so much that I had to pull him out of preschool. I mean, I was paying for him to be in school, but he would only stay an hour or so each day. He would calm down as soon as he was in the car and knew we were going home. Eventually, I had to pull him out completely because he was getting worse. I thought it would be better, but the principal learned him by name on the first day of kindergarten and the calls started coming again.

Although Cameron was aware of the concerns with Casey's behavior and response to stimuli, she did not think he had ASD. Her brother has autism, so she was knowledgeable about ASD; however, the symptoms were not similar in each person. Casey was diagnosed with high functioning autism, or Asperger's syndrome through the school system when he was in first grade. Cameron thought she was prepared for the initial IEP meeting; however, she stated that she shut down after hearing the results of his evaluation.

It was an extremely long meeting that seemed to be focused on formalities rather than the needs of my son, or myself. I just wanted to get out of the room and go get my son, but the talk continued. I don't even know what was said after the word autism.

Jodi

Jodi (age 35) is the mother of three children; Sami (6), the middle child, has ASD. Jodi was employed as a restaurant manager prior to Sami turning two and made what Jodi described as “an incredible salary.” However, she stated that she had to quit her job due to the demands of taking care of Sami and being pregnant at the same time. Her husband was able to increase his hours at work but could not bring enough income home to support the needs of the family. Jodi did freelance work from home to supplement their income, but the couple eventually had to sell one car and move when their lease was up. Even downsizing and reducing expenses was not enough to cover the rising medical and treatment cost the family was accruing.

I thought it was an all-time low when my husband would go without dinner to make sure the kids and I had enough food while I was pregnant. We were able to get assistance with food and medical expenses, but I was still in the position of not being able to take my daughter for the treatments that I knew she needed. Now Sami is in school receiving therapy and my neighbor watches my youngest, so I can work my way back up to a decent salary. We were just able to buy a used car, so I can attend meetings and visit the school on my day off. Things are improving for us as a family, but I will never forget the pain of not being able to provide for my children.

Heather

Heather is the mother of Macy, a 13-year-old female with ASD. Macy is higher functioning and is able to be in general education classes with support. However, she was

delayed as a child and required intensive therapies. Currently, in the general education setting, she requires accommodations to assist her with communication, focus, and work completion. Heather described Macy, the oldest of four children, as “highly intelligent and creative with a lack of social awareness and time management.”

I still get phone calls from teachers who are concerned about (Macy’s) grade. Just last week, one of her teachers called because she has a 66 in Social Studies. I think they expect me to be upset, but I have learned to laugh at it. Now I just get really excited and say I am so proud! When the teacher tried to help me understand that the 66 was not passing, I was able to say, “No, you don’t understand; she did not speak until she was six. So for a teacher to call me saying that she is making a 66 in a regular class that she is not interested in really is a big deal, and I am proud!”

Heather is a photographer and has been able to create her own schedule based on her family’s need. She is able to work more jobs now that all of her children are in school to supplement the therapies Macy receives. Macy has been successful with art therapies and hippotherapy, a form of therapy incorporating horseback riding, that have supported her language development. As a 13 year old, Macy struggles to speak in certain situations, especially when she is frustrated and cannot find the correct words. When this happens, Macy can successfully communicate through drawing or the use of technology. Heather joked, “We can be in the same room, and she is texting me, so really we are just like every other family with teenagers.”

Jamie

Jamie, a 54-year-old office manager, invited me into her home for a warm and welcoming interview. She has an 18-year-old son with high functioning autism, and her step-son

was recently diagnosed with ASD. Jamie described Alex, her oldest of two biological children, as a very calm and compassionate individual. “Evan as an infant, he was easily content and would play alone with his toys for hours; I would have to interrupt him to make sure he was eating” Jamie explained. Jamie credits the knowledge she received from her psychology degree with providing her with the ability to recognize delays in Alex’s development.

He was a unique child with his very own personality. He was lovable and concerned with others. He just did not know how to interact. He was two when my daughter was born and that is when it became more noticeable. He was inquisitive about the baby, but it was like he was struggling internally to know how to act. He would copy what I was doing. He would hold and cuddle a teddy bear like it was a baby. It did not seem unnatural to me as his mom, but his behavior definitely disturbed his dad. Um, he [Alex’s dad] was constantly upset and correcting him because he was not a typical acting boy.

Jamie described extreme struggles with getting an appropriate diagnosis for Alex. Resources were very limited and pediatric milestone screenings were not regularly conducted when Alex was an infant. Jamie stated that she went to several pediatricians, and one doctor even laughed at her about her concerns. She felt like she had limited spousal support during that time also. Jamie described feeling defeated because she was “fighting to help Alex, and his father was ignoring the situation wanting it to go away.” Eventually, Jamie and her husband divorced when Alex was four years old due to irreconcilable differences.

I do not blame my divorce on Alex having autism. We were both adults and made our choice. I guess there were many factors involved, and we became different types of parents. I know I was intense during the process because I felt that I was doing the work of both parents and did not have support. I had quite the opposite and was belittled for

doing what I knew was best for my son. It was a stressful situation that I fueled as well, but I do not have regrets. We are both better parents apart.

Alex received a diagnosis of Asperger's syndrome at the age of nine from a clinical psychologist. Jamie described the diagnosis process as a "rollercoaster." Alex had a previous evaluation at school, but only qualified for speech services. However, as he got older, impairments began to impact him academically due to both language and social impairments. He continued to struggle in some areas, but was extremely advanced in others. Jamie stated that the diagnosis was a relief but the struggle for advocacy and appropriate placement in school continued.

Jamie remarried this past year and resides with her husband, Owen, her two biological children, and Owen's son, Luke. Luke was recently diagnosed with ASD. Jamie was able to recognize some similarities in the struggles he was having and was able to use her past experiences to push for an evaluation for Luke.

Owen

Owen (46) is Jamie's husband, and he quickly volunteered to participate in an interview about his experiences with his son, Luke (11). Owen is a retired officer in the military and served in Afghanistan for three deployments. While Owen was in the service, Luke stayed with his grandparents, as Luke's mother left the family before his first birthday. Owen does not credit Luke's disability with his former wife's departure, rather her choice was due to "an addiction she was unable to overcome."

Everything finally seemed to be in place for us. I was home. We have a nice house, new family members, consistency, and financial stability. But then he started getting in

trouble at school, real trouble. I was getting calls from the vice principal two to three times a week. He was yelling, hitting people, stealing things. I couldn't believe it. I started internalizing- it was because I was away or probably because he was from a broken home, or the violent video games. Then, I'm embarrassed to say, I started blaming my parents for coddling him while I was away. After the evaluation, I was like holy smokes, this is real!

Owen has since been able to work with the school to develop an IEP for Luke. He is receiving services at school and has outside therapies. He is also on a specialized diet, and the family has noticed an improvement with behavior and academics. Owen stated that the support at school has been great, but the understanding of others has helped more than anything. "He is no longer viewed as a bad kid. He has challenges and others are more willing to work with him now."

Becky

Becky (age 46) contacted me to become a participant based on another participant's referral. Becky was very eager to share her story; however, she had a limited schedule due to taking care of her twin boys with ASD. We were able to meet for an interview while her twin sons were in music therapy. Both boys, who are currently age 11, were diagnosed with ASD at age three. Her oldest son, Dominique, is very low functioning. In addition to ASD, he has both physical and cognitive impairments. He is in a motorized wheelchair that someone else has to operate for him. He is non-verbal but can communicate through head and eye gestures; however, Becky described his usual communication as "wailing when distressed." In school, he is in a self-contained classroom for students with severe impairments. He is able to get speech,

occupational, and physical therapies in school; however, Becky expressed that he needs more intensive therapies in a clinical setting to show progress.

Becky's youngest son, De'Andre, is more functional. Although he has a gait, he is physically capable of walking. Becky noted that he is a "toe walker because he does not like to wear AFO (ankle foot orthosis) devices on his feet." Andre is also in a self-contained classroom for students with mild-moderate impairments so he can learn life skills. Although he is verbal, Becky explained that many of his verbalizations are not true forms of communication, but repetitions of things he has heard before such as songs or lines to a movie.

Although Becky is able to be a stay at home mother, she described her job as "packed" and "hectic." Even though the boys are in school, Becky's days are spent preparing for them.

I am always on the go. Even when they are not with me, like right now, I am doing something for them. I am either planning appointments, buying the foods they want, or shuttling them somewhere. Even though they are older now, they are still as demanding as newborns. I can rest for a little while when they are at school, but it is like my world revolves around them. I am no longer (Becky), I am the mom of two severely disabled children. My life is demanding. Seriously, I cannot unwind enough to go get my hair fixed, cause I am afraid that my boys will need me, but I will be stuck in that chair with foil in my hair.

Billy

Billy, age 47, is an outspoken advocate for "autism awareness" and currently works on a committee to write proposals for new laws to be passed. His son, Jason, a six-year-old, was diagnosed with ASD at the age of two. Billy has made it his personal goal to improve the lives of families of children with ASD. He stated that the most difficult aspect of parenting a child with

ASD has been the financial struggle to provide therapies. Billy stressed, “Although I may have struggled to maintain the income needed for treatment, I have been able to provide for my son; the real tragedy is that many parents in our community cannot reach into their pockets to pay for these additional services.”

Billy indicated that he and his wife chose to send their son to a private institute for some time because they felt like the school system did not provide the services and behavioral treatments needed. At the age of nine, Jason just completed his first year of public school. Billy and his wife have been overall pleased with the support received and have felt valued in the IEP process.

I do feel like we have been treated as equals and our requests have been respected. But, we also have worked hard to bring our part to the table. We have done our homework and are knowledgeable on the process and services he should receive. I get the feeling that many parents do not discuss ABA with the teachers. From my perspective, I can see how parents can be overwhelmed by the meetings if they are not fully aware of what is going on.

Angel

Angel, a 47-year-old Spanish interpreter, is the mother of nine-year-old Roberto. Roberto was identified as having signs of ASD at 18 months old when this pediatrician conducted developmental screenings. Angel described noticing Roberto’s language delay and blamed herself. She stated, “I thought I had hurt him by speaking in both Spanish and English at home, and he just didn’t understand me.” However, Angel realized the language delay was complicated when his sister, who is 16 months younger, started speaking for him. Roberto is currently served

in all co-taught classes and receives speech therapy at school. Angel explained that he has made many advances, and credits the early identification and intervention with his improvements.

Angel, who is a certified teacher, now serves as a language interpreter for several schools. She attends conferences and IEP meetings to translate information for families who primarily speak Spanish. She feels like she makes more of an impact on the community by being able to bridge the communication gap with teachers and families.

I really love my job because I can relate to the mothers and what they are dealing with. Somedays, it just breaks my heart though. Many times I have to have the conference through the phone because the parents are afraid to come to the school. I typically hear how truly appreciative the mothers are, but they feel isolated . . . alone. My husband is a teacher and comments about the same struggles with communication and involvement. We as society have come so far, but we still have a long road ahead of us.

Themes

At the conclusion of the data collection process, all data, including timelines, interviews, and focus groups were transcribed verbatim and analyzed. During the analysis process, significant statements were identified and coded. Five major themes emerged from the codes. The significant themes include (a) understanding challenging experiences; (b) searching for knowledge; (c) searching for self-worth; (d) searching for self-worth; (e) desiring to help others. After the themes were determined, they were arranged for discussion based on Maslow's (1943) hierarchy of needs with the most basic physiological needs occurring first, followed by safety needs, love needs, esteem needs, and self-actualization needs.

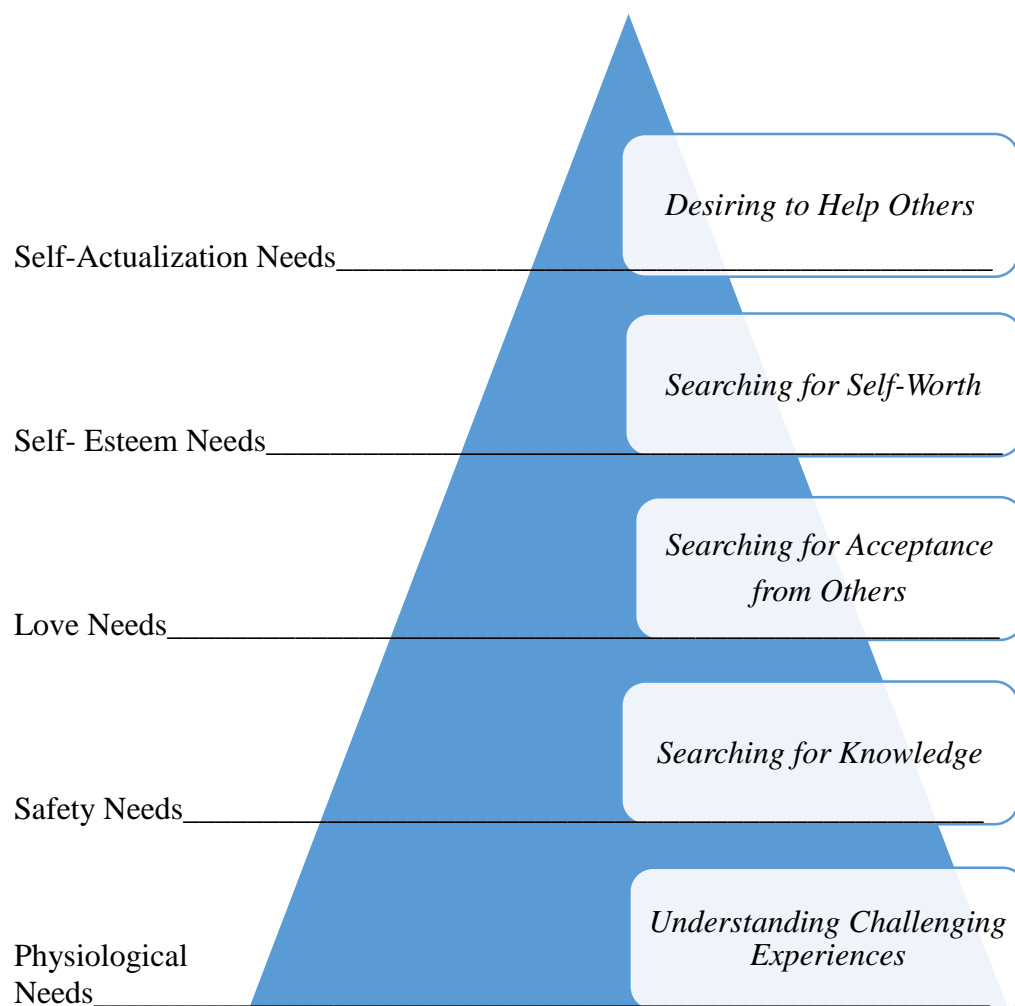


Figure 2. Maslow's Hierarchy of Needs with Interwoven Themes

Understanding Challenging Experiences

The first theme identified in this study is *Understanding Challenging Experiences*. This theme emerged through multiple statements throughout the process. The theme also applies to several subthemes discussed by participants.

Diagnosis experience. Each participant identified the diagnosis experience as a significant moment in their lives on their timelines. Angel described the diagnosis experience as a “critical moment that makes you examine your priorities.” Jamie commented that the diagnosis of her son was “a turning point in her life.” Participants in the focus groups unanimously agreed “there is no way to prepare for hearing your child has a lifelong condition.” Even though some participants had expected their child had ASD, the confirmation through diagnosis was difficult to receive. Carrie described receiving the diagnosis as an “epiphany experience.” She stated, “Finally, it made sense and we had a name for it, but then the realization came and numbness sat in.”

Grieving. The diagnosis experience has been referred to as stage of mourning in recent research (Muscott, 2002; Samadi et al., 2012; Tway et al., 2007; Yen & Mao, 2011), which was confirmed by the participants. Participants explained their initial loss of their expectation of parenting as well as their deep concern for their child and his or her unknown future.

It sounds selfish, but I had this glorified idea of my child being a star student or a star athlete, you know then it hit me, and I got really sad for her and the experience she would miss out on.

Jodi explained of her thoughts during the diagnosis process. Likewise, Owen described his personal emotions of the initial diagnosis:

I went through a common grieving pattern. At first I was just angry. I was just angry with the situation. Why did this happen to my son that already faced more challenges than some adults? Then I was mad at myself. Was it my fault? Maybe if I was there more or had a better relationship with him. I even tried ignoring the situation. Then I had to come to terms with it and press on to do what he needed me to do.

Carolyn explained the reoccurring grieving process as follows:

It is a grieving that does not go away; it reoccurs at every critical life stage. Just last week, I was working on my son's senior page for the yearbook. Other parents are doing tributes to their child who is going to college. I'm sure people will wonder why I even made a page for him because he will not realize what it is about. I had to come to terms with the fact that I was doing it for the other children ... so they will remember him, learn from him, and know it is okay if they see others who are like him in the future. My point is that I was mourning that he was not experiencing the typical senior year, and I as a parent do not get to share those moments with him.

Others described events such as birthday parties or social events as triggers for grieving as they serve as constant reminders. The IEP process is also a constant reminder to parents, and participants referred to IEP meetings as "dreaded or negative" experiences because they were reminders of their child's disability. Jodi explained, "Even daily struggles like doctor's appointments and financial strain added to the grief I was experiencing."

Survival. Several participants mentioned important statements about the basic needs for survival. According to Maslow (1943), the needs for survival are the basic needs necessary to sustain life, and human behavior is driven by this need in an emergency situation. Cameron stated, "Suddenly, I found myself in a position of reprioritizing what was important in order to survive." Additionally, Billy stated the following:

For the first few years after my son's diagnosis, we were in survival mode only focusing on what we needed. Most times that was just food and sleep. But most nights, we went without much sleep. We were stressed and barely functioning in our personal lives. I can

understand how people get caught up in the cycle. When we were able, we had to get support.

Others agreed that the need to survive took control of their daily lives. Physical, mental, and emotional stressors became an increasing part of life that the participants had to cope with. Understandably, participants communicated the need to seek medical help some point and even take medications overcome health challenges. Participants agreed that the demands needed to survive overshadowed personal lives and impacted relationships including spousal relationships and parent child relationships. Carrie commented:

The need for money to cover treatments and appointments grew. Instead of planning the summer vacation, I was planning doctor's appointments and searching for a dentist that would see Danny. The basic tasks that seemed simple became cumbersome and challenging to complete. Our routine at home was whatever it took to keep the peace. Even with a supportive husband and stable income, we still had our moments of breakdown. I look back and still wonder how we survived.

Others described daily life as "monotonous" and "tense" as the basic needs of sleeping and eating became a struggle. Additionally, Jodi indicated that not being able to provide for her family was a "pain like no other." It was agreed in the focus group that day-to-day life became a struggle to survive on many different levels. Some participants indicated providing the basics such as shelter and water was difficult, while others referred to the survival of their marriage or lifestyle. In the educational realm, participants indicated they were not mentally or emotionally prepared to advocate for their child's education, especially meeting responsibilities demanded by the IEP process. Likewise, parents communicated that they internally struggled with not being able to provide what was needed for a quality education.

Lifestyle change. A commonality among participants was a change in lifestyle or life plans. Many participants indicated a change in employment or professional aspirations. Cameron went to college to become a teacher, but put her plans on hold until her son started high school, so she would be available to help him. Additionally, several participants found themselves in a position of resigning from employment to take care of their child with ASD. Other lifestyle changes were driven by additional financial needs or the need for support. Carolyn explained that her family had to use money set aside for Sam's college fund to pay for early treatments. Carolyn continued:

We both had great jobs and started putting college money aside for children before we tried to get pregnant. By the time (Sam) was five, his college savings were gone, and we began to use our credit card. We had no other option. We had to give him the help we felt he needed. We tried special diets and vitamin therapy; we even flew to Washington State [from Georgia] to see a doctor for probiotic treatments- this was cutting edge 20 years ago. Before long, we owed \$40,000 in credit card bills. We put our house on the market and walked away with exactly \$40,000 at closing. Just enough to pay our bills and break even. See God really does provide what you need.

Becky described her life change as a "complete 180." She went from a college graduate "ready to take on the world" to a primary caregiver of two boys with severe disabilities. Becky stated the following about her lifestyle change:

I never thought I would be the person I am today. I struggle the most with my loss of independence. I cannot make a quick run to the store or go out with girlfriends. I really can't even have girlfriends over anymore unless they have kids with disabilities too. But I do not want to complain. Despite the stress, I am a better person than I ever thought I

would be. My idea of success has changed, but when I look at my boys, I can't help but praise God that I am a part of their lives, and He chose me to care for them.

Additionally, many participants were faced with challenges such as physical or mental illnesses they had to cope with due to the stress associated with parenting a child with ASD. A wide variety of illnesses were discussed including anxiety, depression, sleep disorders, and even PTSD. Owen, a Purple Heart recipient, described being aware of PTSD symptoms and knowing he needed to seek help.

Overwhelmingly, participants indicated that having a child with ASD impacted and inevitably changed their lives. The lifestyle changing experience caused each participant at some point to refocus on the basic or physiological needs to maintain survival (Maslow, 1943).

Searching for Knowledge

The second significant theme identified in data analysis is the participants' *Searching for Knowledge*. During the focus group session, all participants agreed that feeling helpless at some point in their journey was due to a lack of knowledge about their child's condition. Maslow (1943) included knowledge as a safety need for individuals.

Lack of quality information on ASD. Carolyn described her experience of searching for answers. Her son was diagnosed with Pervasive Developmental Disorder (PDD), which was explained as a type of autism. She indicated struggling to find resources since little was known about the condition 20 years ago. She went to the local library to search for articles, and she had countless doctors' appointments without receiving viable information. Carolyn explained:

We knew something was not right. When the diagnostician said the word autism, she literally pushed herself back away from the table like she was afraid I was going to hit her. I was not upset though. It was a relief to have a name for this, but I was not prepared

for how little information was out there about autism. Now, a Google search will give you thousands of links, but back then I was searching for anything I could get my hands on about autism. I even put an ad in the local newspaper to find others who were searching for information too.

Likewise, others agreed that they did not receive information about what ASD was from pediatricians or psychologists when their child was diagnosed. Many did not know what autism was and reported having to learn about it on their own. “The Internet is full of information on autism, but most is not accurate or reliable,” explained Angel. Parents wanted to provide for their children, but they felt lost. Also, Heather added that not knowing what she needed to provide for her daughter was a challenge. Heather exclaimed that she did not realize autism was a lifelong condition when speaking to the doctor. “I probably acted like it was no big deal at first. It did not dawn on me until I was reading a book on it that she would have autism for the rest of her life,” Heather added.

Participants also explained how their search for knowledge of ASD is further complicated by the ever changing information and recommendations for ASD. Jamie explained,

Every time I get a newsletter, there is new information on causes and treatments for autism. It makes me feel like I can never do my best as a parent because no matter what, a new and better treatment will be out next month.

Additionally, Carrie stated another frustration with information it that everyone she meets seems to be misinformed and have suggestions. “Random people will come up to me in a store and say something like I should not give him milk or that his behavior is caused by lead poisoning.”

Lead down the wrong path. Unfortunately, parents also indicated they had felt exploited by people proposing cures for ASD and did not know who to trust. All participants discussed feeling “victimized” or “targeted” by companies selling remedies. “It is sad that certain people feel it is okay to prey on the emotions of individuals in vulnerable situations, especially when children are involved,” Billy explained. Others shared experiences of being contacted by people with “radical” claims to have a cure. Jamie described one experience in the following:

I received a phone call from a lady claiming that her son had ASD, and after his blood was cleaned of toxins, her son was cured. They were actually selling a treatment where blood is purified in a process similar to dialysis for thousands of dollars. It sounds inhumane to do that to a person by choice. You know desperate people are taking out second mortgages to try and help their child.

According to Maslow (1943), individuals have a need to feel safe from harm and danger. Participants felt that “predators with false claims” were threatening their safety needs. Participants also communicated concerns about others who could possibly “have to learn the hard way about these scams.” Fear or reluctance that parents feel due to past experiences may carry over into the IEP process and limit parents’ involvement.

Searching for Acceptance

The third significant theme identified through data analysis is *Searching for Acceptance*. The need for acceptance came up in a variety of statements. Acceptance was identified as a major characteristic needed for someone to be fulfilled in both the love and esteem needs tiers. Participants explained why acceptance is vital to them in many different aspects.

Acceptance from others. All participants explained that being understood and accepted by others in their community was important. “God made us to be social beings and seek comfort

in others,” Heather acknowledged. Many participants experienced a tendency to withdraw from others and try to deal with their situation within the inner family. However, they all agreed on the importance of being able to engage in social or public activities such as going to a restaurant or movie theatre as a family. However, there is still a struggle to be understood in society. Carrie explained how she plans ahead before taking Danny in public:

I made sticky labels for him that have his name and that he has autism and my contact information. Many think it is for his safety, but it is actually twofold. (Danny) looks normal but has strange actions. He may shout unexpectedly or he is fascinated with hair, so he may walk up to someone and start rubbing their hair. The sticker helps raise awareness to others, so they know he has a condition. People respond differently and are generally more understanding when they realize he has a disability.

Discussion among participants in the focus group also revealed that each participant found the need to seek social support and understood the value of local support groups. They even indicated having a social network consisting of other parents of children with disabilities. “When I am with my friends we can share and support each other without being judged. Sometimes I just need to vent and need to be understood.” Becky explained the importance of sharing her story with others: “I am often busy and don’t get to socialize. It is important to me that people know my experiences and understand why I am the way I am.”

In her personal interview, Carolyn was very passionate about the need for acceptance and inclusion in society. She created lessons at home about how to act appropriately and spent a lot of time helping her son apply the learned skills in public settings. She made a point to either get Sam out of the house or have playgroups to her home, so Sam would develop social skills. Carolyn had the following success story about being included and understood:

On one of our outings, I took [Sam] to a football game at our local high school. I walked him to the bathroom, and made sure to go over the bathroom rules with him before he went in alone, you know- don't touch anyone, don't laugh, just do your business, wash, and come back out. I was waiting outside the door for him when I saw a teenager who was covered in gold spirit paint walk into the bathroom. I went into a panic knowing [Sam] could not resist touching a painted person. I glanced inside the door and saw [Sam] in slow motion, walk over to him and rub him all over his gold painted chest. I wanted to run in and save him but I couldn't. I expected the worst to happen, but it did not even phase the golden teenager. As he walked out, I stopped the guy with paint, and all I could say was 'I'm sorry, I'm sorry, I'm so sorry he touched you!' The teenager just looked at me and said, 'I understand.' That was the moment I knew the true value of inclusion . . . others were aware and accepting.

In a discussion on the IEP process, parents expressed their need to be treated as an equal. They want to be valued and treated like the expert on their own child. Parents felt they were not valued when decisions were made without their input, or when discussions were not based on what was best for the child. Parents also felt excluded by formal procedures and impersonal meetings. One participant described an IEP meeting as "an intimidation experience because I was in a room full of people, so I was outnumbered, and I was hardly acknowledged. Others spoke and often spoke over me about my own son. I was not respected at all."

Maslow (1943) identified acceptance as an important component for love and esteem needs. The participants discussed the importance of being understood by others and having social support. Likewise, participants also identified esteem needs through self-acceptance and

choosing to value themselves. In the IEP process, parents were more inclined to participate and had higher self-esteem in their parenting roles when they felt accepted and valued by others.

Searching for Self-Worth

The third significant theme to emerge was *Searching for Self-Worth*. Inevitably the hardest obstacle for some participants to overcome was to learn to accept and value themselves. Many revealed in both interviews and the focus group that they had to come to terms with their challenge and make a choice to move forward. It was such a significant shared event, that six of the 10 participants identified a turning point of self-acceptance on their timeline. For example, statements were identified such as: “Though I struggle, I am a good parent,” “We will make it because we deserve it,” “I realized I could not do it on my own . . . I needed help. That was the first step toward becoming a better me,” “I was in a dark spot, I did not see it until I looked back. I am glad I learned to love myself too,” and “I had been dealt this hand. When I looked at it through my son’s eyes and not my own self-pity, I realized that is was not a bad hand, just a different game that I needed to learn how to play.”

Making a choice. For some, the choice to move forward was fundamental to their ability to be a parent and advocate for their child. Angel explained, “I was in a downward spiral of stress and tension. I could not sleep, and I could not mentally function as a parent. I had to make the choice to improve myself first.” Like other participants, Angel explained how she had to take steps toward self-improvement to find herself. She enrolled in a higher education program and focused on education and career. Juanita continued, “It was my outlet and gave us the routine we needed when Roberto was in school.” Likewise, other participants discussed their outlets during the focus group. Each participant had an individualized hobby that served as self-therapy. For Cameron, running became an essential part of her daily routine to help her relieve stress and

cope with the challenging situation. She stated, “When I run, I am able to relieve so much that weighs me down daily. I had to choose healthy options other than cake and Coke. It was a choice I had to make for myself.” For Jodi and Heather, art is a form of self-expression that allows each to decompress. Owen summed up the discussion with the following:

Regardless of the coping mechanism one chooses to use, you have to do it. You have to find what works for you and do it for yourself. Once you realize you are good enough and love who you are, you have to take care of yourself, so you can take care of others who love you and deserve for you to be your best. Once I realized that, I felt better and my health started to improve. I am no longer having to take blood pressure medicine, but I had to work hard to get to this point.

Maslow (1943) identified esteem needs as a desire to feel valued and respected by oneself. The fulfillment of esteem needs leads to confidence and provides a drive for an individual to improve himself/herself (Maslow, 1943). Likewise, participants were able to identify significant points in their lives when each reached the point of being able to choose a path of self-improvement.

Desiring to Help Others

The final theme that emerged was *Desiring to Help Others*. While not as mutual among participants as other themes due to possible unmet needs at previous levels, 3 out of 10 participants identified a desire to help others through community involvement or advocacy. Two participants even described having a purpose to help others. For Carolyn, having a son with ASD has been her “calling in life.” Referring to her background in education, she stressed that God prepared her for her job as a parent of a child with a disability. Throughout her experiences, she continually reached out to others through creating her own support groups and serving as a

parent mentor for others in similar situations. Likewise, Billy was also passionate about his role to serve the community and help other families who “may not be able to overcome situations that I understand and empathize with.” All three participants who displayed having reached their full potential shared characteristics of determination and problem-solving abilities. Each participant demonstrated the desire to overcome challenges in his or her situation. For example, Carolyn explained:

After the first IEP meeting, I felt overwhelmed. I received a lot of information that I did not understand and had no value to me. I felt like we actually went backwards in the beginning. I was not going to be defeated. I just took in on like a real challenge. I decided that I was going to be the one in charge of the situation because it was my job to take care of my son. So I spent every moment I could at the local library looking up as much information I could. When I finally felt confident, I realized that I could share the information I found with others.

Maslow (1943) identified self-actualization as a need to reach one’s full potential. Maslow (1943) additionally noted that only a small percentage of people will be able to obtain Self-Actualization. Therefore, since only three out of 10 of participants were identified as fulfilling this need, it is still noted as a significant theme due to the alignment with Maslow’s (1943) original findings.

Results

Two research questions were developed in study to identify the needs of participants. The research questions are:

Research Question 1: How do parents of children with ASD experience support through the IEP process?

Research Question 2: What are the needs of parents of children with ASD as they navigate the IEP process?

Research Question 1

Research question 1 was answered through direct data collected from participants in interviews, focus groups, and timelines. Participants were from various backgrounds and all at different stages in the IEP process. Overwhelmingly, participants identified the initial meeting of the IEP process as a “stressful” and “unclear situation.”

Initial IEP meeting. Every participant concurred that the initial development of an IEP plan was unclear, and they did not know what to expect. For Carrie, the IEP development occurred in the same meeting as the diagnosis. She stated, “I had just heard the word autism, and I don’t remember what was said after that. I had to look up what an IEP was later when I got home.” Heather stated, “I walked into the meeting blind not realizing what it was about.” Even though participants wanted to plan for the meeting, and some even researched the topic prior to the meeting, they did not know what to plan for or how to plan. Participants indicated that they did not feel valued in the initial meeting because they did not know how to contribute. Additionally, participants felt overwhelmed with the amount of information received. One participant recalled walking out of the meeting with a stack of paper but not knowing where to start. Two participants discussed concerns about their first IEP meeting being intimidating due to room full of people providing information. Participants were asked questions but did not feel like they were treated like the expert on their own child.

Although participants were dissatisfied with the intense initial meeting, most agreed that the following meetings and support received from teachers was appropriate. However, two participants verbalized not being satisfied with the support and opted to go to a private school.

Their rationale for choosing a private institution was that they did not feel like the school offered services needed for their child's unique needs. However, both parents decided to reenroll their child in public schools and have been satisfied with their choice.

Support during IEP process. Parents described support received after the initial meeting as direct and personal support from teachers and school personnel. They felt like their child had an advocate in the school and someone just looking out for their child's best interest. Ongoing communication between parents and teachers was the most agreed upon form of support participants discussed. Becky stated, "Even a simple communication folder or checklist was helpful since my son is non-verbal." Parents expressed a reduced amount of stress and apprehension when they had someone to contact about concerns. However, some stated that too much communication was overwhelming at times. One participant stated that she did not want to get a phone call every time her son was not acting appropriate; rather, she preferred to have the school deal with it in a consistent manner.

In addition, parents indicated that they felt teachers who tried to accommodate their busy schedules when scheduling meetings met their needs. Three of the participants indicated feeling grateful that they were made aware of childcare available for younger children so parents could attend the meetings. Other forms of support received included referring to a parent mentor or respite care service. One participant stated that she began to cry when she was presented with information on services that could help her at home. She knew that the teacher understood she needed support with more than her child's educational needs.

Participation in IEP process. Additionally, parents felt that they were more satisfied with the IEP process and level of support when they chose to be active participants. Participants stated that they felt like it was their responsibility to stay informed and stay in contact with

teachers also. Owen explained that a collaborative relationship takes “two-way communication and work on both parts.” One participant concluded, “As a parent, I cannot sit back and expect someone to take responsibility for my child; we have to work together. All I expect are results.”

Research Question 2

Research question 2, which addressed the needs of parents of children with ASD as they navigate the IEP process, was answered by information received in the focus groups and personal interviews.

Need for acceptance from others. The consensus of the participants was that first, the parents have an overall need to be understood by service providers. All of the participants had prior negative experiences and struggles while advocating for their child before the IEP process began. Some parents struggled for several years through multiple doctors’ appointments and therapies, while others indicated they struggled just to get to the diagnosing stage. Participants further described their need to be understood to include understanding that their child is unique and different than other children. Heather described the remarkable gains her daughter had experienced and felt the need to remind teachers every year that her child was a miracle. She did not need to hear how she her daughter was behind other children her age.

Additionally, parents have a need to be respected and treated as an equal in the IEP process. Participants expressed concerns about situations of not being valued when they were spoken down to. Cameron explained that educational jargon was used in her previous meeting, which was frustrating for her. Participants in the study stressed that they need to be treated as the experts on their child and on what their child needs. They expressed that they should feel welcomed to meetings, agreeing that meetings that just go through formalities and do not focus on the child are not productive. Jodi described a meeting as “inappropriate” because she was not

respected and neither was her time because decisions were “predetermined without her input.” Others agreed that meetings should be inviting and personable, rather than uptight and uncomfortable.

Understanding of child’s needs. Further, parents have a need for service providers to understand the child’s unique needs and have realistic expectations of the child’s performance. All parents agreed that at some point, a service provider did not really understand their child. They all experienced meetings where they felt the provider did not know the child and set unrealistic goals either being too high or too low to benefit the child. Parents mentioned that some negative expectations occurred due to curriculum that was not appropriate, but felt that overall the information on expectations was not conveyed appropriately or in the child’s best interest.

Participants also agreed that they needed to be informed and needed assistance understanding the IEP process itself. Even after self-research, parents had to reach out to teachers for help understanding the process. Parents stated that they feel like the student themselves sometimes and need guidance on how to carry out interventions at home for their child. They need to be supported and have feedback on their child’s performance toward goals.

Summary

For this study, 10 participants from diverse backgrounds, who have children with various types of ASD, provided information about their shared experience of parenting a child with ASD. Descriptions were provided of each participant as well as a composite description of their experiences. Five major themes emerged from the data analysis. The significant themes include (a) understanding challenging experiences; (b) searching for knowledge; (c) searching for acceptance; (d) searching for self-worth; and (e) desiring to help others.

The research questions were answered based on the themes that emerged from the data analysis. Research Question 1 stated: How do parents of children with ASD experience support through the IEP process? Significantly, participants communicated a lack of quality information and support leading up to the initial meeting. Parents did not know what to expect and found the initial meeting both intimidating and overwhelming. However, participants noted an increase in support as service providers helped meet their needs throughout the IEP process. Furthermore, parents indicated that their needs were more thoroughly accommodated when they were active participants and made efforts to be involved in the ongoing IEP process.

Research Question 2 stated: What are the needs of parents of children with ASD as they navigate the IEP process? Participants expressed an overall need for acceptance from service providers. Acceptance in the form of respect and understanding helped the participants feel like equals and contributing members in the IEP process. Additionally, parents needed for service providers to be open and understanding of their child's unique needs.

CHAPTER FIVE: DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS

Overview

The purpose of this qualitative study was to consider the needs of parents with children with ASD as they navigate the IEP process through the framework of Maslow's (1943) *Theory of Human Motivation*. This chapter explains conclusions drawn from the study as well as possible empirical, theoretical, and practical contributions to the fields of research and education. Additionally, limitations and recommendations for further research are included in this section.

Summary of Findings

Following guidelines by Moustakas (1994) for a phenomenological study, data was collected from timelines of significant events, personal interviews, and focus groups. Data from the ten participants (2 males; 8 females) was analyzed for significant statements and themes. Five significant themes emerged in the process. The themes are identified as: (a) understanding challenging experiences; (b) searching for knowledge; (c) searching for acceptance; (d) searching for self-worth; and (e) desiring to help others. The themes are addressed in the following answers to the research questions.

Research Question1 stated: How do parents of children with ASD experience support through the IEP process? Overall, parents agreed that they received limited support and had a lack of understanding of the process prior to the development of their child's IEP. Parents struggled to locate reliable information and had apprehensions of not knowing who to trust. However, all participants agreed that support increased after the IEP was developed. Parents were grateful to have a personal connection and a contact person at the school who was watching

over their child. Likewise, they indicated that the increased support eased personal stress for each of them. However, participants overwhelmingly agreed that quality of support was congruent with their own choices to be active and informed members of the IEP team.

Research Question 2 stated: What are the needs of parents of children with ASD as they navigate the IEP process? Participants need to be understood and valued in the IEP process by being treated as an equal decision maker. Participants indicated the need for service providers to understand that they have encountered prior struggles just to get to the support level an IEP offers, and these experiences may have made the parent skeptical or reluctant of the types of services offered.

Discussion

Empirical Contributions

This research provides empirical contributions to the field of research by both supporting previous research and identifying additional information to close the gap in research about the needs of parents of children with ASD.

Stress. Interestingly, participants in this study agreed that the greatest amount of stress they endured was due to stress they put on themselves. A discussion during the focus group session revealed that participants were in their greatest time of need when they used negative coping strategies such as self-loathing, placing blame, and using maladaptive behaviors (i.e., binge drinking, abusing drugs, instigating arguments, etc.). Very little research was identified in the review about the importance of coping strategies with this particular population of individuals. These additional findings on internalized stress and coping strategies are a contribution to the field of research.

Acceptance. Particularly, the purpose of this study was to investigate the needs of parents, as there is a gap in literature on the impact autism has on parents (Karst & Van Hecke, 2012). The responses of participants indicate that parents have a group of similar needs. The unanimous need indicated by participants is the need to be understood and accepted. Participants communicated that they need people to be aware of and understand their unique struggles. One participant explained that if others knew of the struggles parents went through, then others would have more respect for the situation. Therefore, all participants wanted to raise awareness of ASD.

Likewise, parents of children with ASD need others to understand that their child has unique needs and expectations. Additionally, participants felt it was important for teachers to understand their prior experiences and possible struggles the parents have experienced in the educational realm. Participants also communicated the strong need to be treated as an equal both in public and in educational settings. Parents stressed that their child's disability is just a difference and the family should not be judged based on the disability. Additionally, parents need to be informed and have quality information on their child's condition and progress. These findings help support previous research in which parents need to be accepted and valued by professionals (Keenan et al., 2010). Additionally, findings extend previous research that social support can empower (Weiss et al., 2012), promote resilience (Barker et al., 2014) and improve self-esteem (Cappe et al., 2011) for parents of children with ASD.

Theoretical Contributions

Theoretical implications identified in this study extend Maslow's (1943) *Theory of Human Motivation* by addressing how the theory applies to parents of children with ASD. According to Maslow (1943), human needs are arranged in a hierarchy of importance with the most basic need for life occurring first. Maslow (1943) identified the human needs as follows:

(a) physiological needs, (b) safety needs, (c) social needs, (d) esteem needs, and (e) self-actualization needs

Physiological needs. A large majority of previous research identified multiple stressors, which may impact a person's ability to fulfill physiological needs. Wang et al. (2012) found that the financial demands for treatment, medical expenses, and transportation become costly for parents of children with ASD. Participants in this study shared that the expenses combined with a reduction in income for many families due to the primary caregiver not being able to maintain employment was a major obstacle for them. Likewise, previous research concluded that parents of children with ASD are more likely to experience physical and mental health distress (Barker et al., 2011; Estes et al., 2013; Shtayermman, 2013; Twoy et al., 2007; Weitlauf, Vehorn, Taylor, & Warren, 2014). Six out of 10 participants in this study experienced distress including: anxiety, depression, PTSD, and sleeping disorders. While research is more abundant on the stressors that relate to physiological needs, participants acknowledged struggling to meet these needs; however, that it was not the most challenging need for each to fulfill.

Safety needs. Maslow (1943) explained the safety need for individuals to be safe from harm and have access to knowledge. Previous research indicated that parents struggle to locate quality information and have uncertainty about their child's diagnosis (Plumb, 2011; Renty & Roeyers, 2006; Samadi et al., 2012). For most parents, the search for knowledge about ASD and reliable information was a significant struggle after their child was diagnosed. To further complicate the situation, many participants in this study communicated feeling threatened by people exploiting their emotions or selling false hope. Becoming vulnerable to deceptive treatments and false hope was also identified in previous research (Green, 2007; Thompson, 2010).

Love needs. Maslow (1943) identified love needs as the necessity to give and receive love. This includes the need to be accepted by others. A major theme identified in the study is the need for acceptance. Participants communicated that they needed to be understood and accepted by others. Participants also stressed the importance of social support and some had success through social groups. This finding supports the previous research that parents of children with ASD have a high need for social support (Altiere & von Kluge, 2009; Giallo et al., 2013). However, the study's findings can help extend this understanding; four out of 10 participants indicated that they had to change their social groups to be around other parents of children with disabilities to find real acceptance.

Esteem needs. Maslow (1943) identified esteem needs as self-respect and self-confidence. Previous research suggests parents of children with ASD may have a lack of self-esteem and self-confidence (Cappe et al., 2011; Weiss et al., 2013). However, seven out of 10 study participants were very clear on their explanations of self-respect being the most difficult, but most rewarding need to fulfill. It was described as an internal choice the individual had to make to accept themselves. Participants explained remembering the moment they chose to accept themselves as a turning point in their lives, while others described regaining strength and identity when their esteem was up. This finding on the esteem needs is a significant theoretical contribution as it applies to this particular group of individuals.

Self-actualization needs. Self-actualization is referred to by Maslow (1943) as reaching one's full potential. Previous research concluded that some parents of children with ASD reported gaining confidence, resilience, and self-efficacy (Lyons et al., 2010; Samadi et al., 2013); however, no direct research on self-actualization could be located in the review of literature. During this study, three out of 10 of the participants made significant statements

relating to self-actualization, such as “I know my purpose. It is to help others.” These participants were driven by a desire to help others in similar situations. They also have taken action to improve the quality of life for others and awareness and ASD at a community level. While Maslow (1943) suggested that self-actualization may be attainable for only a small amount of people, these findings suggest that self-actualization is obtainable and innate in some individuals. This is a notable theoretical contribution on understanding the potential to reach self-actualization.

Implications

In addition to theoretical and empirical contributions, practical implications can also be drawn from the findings in this study. Findings from this study can be applied to the field of education to help special educators better understand and meet the needs of parents of children with ASD. Likewise, these findings can also provide insight for parents in similar situations. The following practical implications were identified through participants’ responses and can help foster working relationships between families and educators.

Implications for Educators

Implications for educators were determined based on feedback from participant interviews and focus group discussions. Recommendations for educators include: (a) inquire about prior experiences; (b) be aware of prior successes; and (c) communicate the positives.

Inquire about prior experiences. Participants identified the importance of educators wanting to understand their perspective. Also, participants mentioned the importance of educators understanding prior experiences and struggles they have been through for their children. One parent stated:

It is important for educators to realize that I have been advocating for my son for several years before sitting down at a table for an IEP meeting. I don't mean to come across as difficult or reluctant to try a new service, it is just my job to make sure we do what is in his best interests. And I know the strategies we have already tried and the things that do not work for him.

Special educators should make contact with the parents to provide an introduction at the beginning of the school year or term with the student. Parents expressed appreciation for the teachers who made verbal contact through a phone call or conference at the beginning of the year to develop a working relationship. Based on parents' responses, the following suggested conversation starters can help special educators build rapport with parents during the introduction discussion: (a) To better carry out your goals for your child, is there anything specific that you would like for me to know about your child that is not in the IEP? (b) Are there specific strategies used in the past that either work well for your child that we should implement or that cause frustration for your child that we should avoid? (c) Based on your previous experiences, do you have any recommendations or suggestions on how I can best support you and your child?

Be aware of prior successes. Responses from participants indicate that parents also want educators to be aware of the accomplishments the child has already made. For example, one parent shared about how her daughter did not speak until she was six. The family feared she would be nonverbal. However, the child has since made great improvement. When teachers tell her that her child is behind other students, it creates disconnect because the educators do not understand the incredible improvements made. Likewise, other parents communicated that educators' focus has been on the child's weaknesses and how their child compares to other

students without disabilities. Consistent with previous research, parents communicated that IEP meetings are stressful due to a negative focus on the child's inabilities (Trussel, Hammond, & Ingalls, 2008).

Suggestions developed from the results of this study include the following procedures for special educators: (a) review current and previous IEPs as well as Psychological Evaluations for documented gains or improvements; (b) communicate your knowledge of the improvements to parents; (c) communicate your desire to support the family and child on continued progress.

Communicate the positives. Participants in the study indicated feeling overwhelmed with negative information. Most meetings and appointments focus on weaknesses or what the child cannot do. Parents agreed that it is important to have positive communication about what the student can do or areas the child is experiencing success. Parents also noted that both the parent-teacher relationship and the child's development were more successful when working with a teacher who would celebrate the successes. For example, Carolyn noted that the best IEP experience she had was with a teacher who was positive with all communication. Carolyn stated, "Even when we were discussing an issue or concern, she had a solution approach; it was like she really understood what it was like to be in my shoes." The positive communication should be ongoing throughout the IEP process. Additionally, continued positive communication with parents can make the annual review meeting less stressful for all committee members.

Special educators can build a positive foundation by first identifying the child's strengths and interests, by reviewing the current IEP and psychological report, conducting interest inventories, and requesting feedback from the parents. Educational strategies and behavioral interventions should then be developed that build upon the students' strengths and interests. All communication to parents should highlight the students' growth and convey a positive message.

Implications for Teacher Education Programs

While teacher education programs provide guidance in content and pedagogical knowledge, professional communication and conferences with parents, training programs generally do not offer guidance on parents' perspectives or the needs of parents of children with disabilities. Therefore, this study offers insight on possible implications to include in educator training programs. Specifically, understanding parents unique needs and how to best meet their needs. Training programs can include the implications for educators and develop into a training model to guide future teachers.

Implications for Parents

The IEP is an ongoing process for parents, children, and special educators. While the primary focus of this study was to provide insight on the needs of parents of children with ASD to guide special educators, implications also arose from interview and focus group discussions which could be beneficial to parents. Particularly, a question was asked to participants about advice they offer to other parents who may be beginning the IEP process with a child.

Foremost, parents indicated that their most critical time was during the diagnosis experience. Specifically, parents were overwhelmed with trying to locate quality information and know who to rely on. During discussion, parents concurred that "Google" [search engine] is not a reliable place to locate information. Parents discussed the vast amount of information on the Internet, which they, through trial and error, discounted as invalid. Fortunately, trustworthy information is available at professional and educational websites, doctor's offices, and educational settings. If a diagnosis is conducted in a clinical setting (e.g., pediatrician, psychologist, psychiatrist), the diagnosing professional can guide the parents to additional resources. Also, if the student qualifies for an IEP, the school system will be able to guide

parents with additional information including how to access outside community services and/or respite care in the community.

Overwhelmingly, participants agreed that participating in a support group is beneficial. Being able to discuss topics with people in similar situations provided participants with social support needed to move forward. Many social support groups have community-based meetings as well as online resources or blogs for discussion. Support groups can be located through school networks, local newspapers, social media, and by signing up for additional information from established organizations focusing on autism.

Additionally, participants stressed the importance of getting to know their child's caseholder. The caseholder is the person responsible for watching over the child at school and guiding the IEP meetings. Parents indicated the importance of knowing how to contact the caseholder and their ability to communicate with him/her. Ideally, the caseholder should initiate contact with the parents prior to start of the new school year. Likewise, parents can request early contact by calling the school to establish a conference or walkthrough during the week before school starts. If parents are unable to contact a caseholder, they can get immediate attention by calling and requesting to speak to a Special Education Facilitator or an administrator over special education.

Also, participants agreed that it is important to ask for clarification or more information on confusing topics in education. Parents stated that they had all been afraid to speak up and ask for an explanation on a topic in an IEP meeting. Parents stressed the importance of seeking clarity from educators on educational topics. Additionally, special educators are able to provide parents with resources or a list of public services available to families at the parents' request.

Progress towards self-actualization. Through this research, participants explained a similar progression of movement toward self-actualization as needs were satisfied. Thus, progression that was described by participants can help other parents of children with ASD understand the unique stages of each need and how to possibly satisfy a need. Primarily, all participants described finding themselves focused on the most basic, physiological needs during the diagnosis of ASD and/or initial IEP experience for their child. The diagnosis caused participants to focus on the immediate needs of the family such as overcoming grief, providing for the child's care, financial changes, and personal changes in health to heightened levels of stress. In accordance with Maslow's (1943) explanation of physiological needs, the basic needs drive an individual's behavior, and become the primary focus of the individual. Participants were able to meet physiological needs by finding productive ways to relieve stress and grief, as well as making lifestyle changes, employment changes, and seeking medical help when necessary.

When parents were able to meet their physiological needs, the need for safety became the focus. Safety needs were described by participants as the need to keep their child safe from harm and by having knowledge of how to help their child. As parents gained an understanding of ASD and the needs of their child, each were able to satisfy the safety need and begin working on love needs. Love needs were identified by Maslow (1943) as the need for acceptance and socialization with others. Participants were able to satisfy their love needs by engaging in activities within the community, interacting with others, and participating in support groups for social support.

Following the satisfaction of love needs, esteem needs arose in which participants satisfied through finding confidence and self-worth. For most, esteem needs were met by the individual taking steps to improve their personal situation. When esteem needs were satisfied,

parents were able to move toward self-actualization by becoming problem-solvers, advocates, and leaders within their communities. For parents of children with ASD or parents of children undergoing a diagnosis, these findings can offer suggestions on how to identify stages of need and how to satisfy personal needs to progress toward self-actualization, or reaching one's full potential.

Limitations

This study has several limitations. First, while a diverse group of participants were selected for the study, participants resided in the same geographic location and some participants knew each other. Therefore, findings may have cultural influences and may not be transferable to individuals in other settings. Also, participants were volunteers who were aware of the nature of educational research and had time to devote to the data collection tasks. Two participants requested to be in the study, but were not selected due to the extremely high amount of stress they indicated they were experiencing at the time. Likewise, 4 people were interested in participating, but could not commit to the time needed to participate in the data collection methods. Therefore, the study does not include feedback from individuals who are undergoing the greatest amount of stress and busiest schedules as indicated in the literature review. Additionally, after reviewing results, it was evident that most participants are currently in a position of having basic needs or higher met. While all participants could relate to struggles with basic needs, the respondents were more expressive about their current struggles. In addition, socioeconomic struggles were difficult for individuals to discuss in a focus group setting.

Recommendations for Future Research

This research can be expanded in future research to include participants from a wider population. A larger response group consisting of participants from different areas may produce a different response. Also, including responses from individuals who are at differing tiers on Maslow's (1943) hierarchy of needs is recommended to confirm and expand theoretical contributions. Additionally, considering the findings with the participants in this study, a similar study using a theory on resilience as the theoretical framework may provide additional information on the experiences and choices of participants. This study can be extended as a phenomenological study with caseholders to consider the perceived needs of parents or to study the needs of parents of children with a different disability. Additionally, a case study can be conducted with both parents and teachers as participants. Further, a longitudinal study looking at the needs of parents across all stages of child development could make a significant contribution to the field.

Summary

This transcendental phenomenological study was developed to explore the needs of parents of children with ASD as they navigate the IEP process. After a review of literature, it was determined that a gap in research exists in understanding the needs of parents of children with ASD, specifically relating to the needs of parents through the lens of Maslow's (1943) *Theory of Human Motivation*.

Findings from this study help close the gap in literature by identifying the needs of parents as they navigate the IEP process. Results from participants indicate that parents need to be understood in their roles and prior experiences; they need to be valued as equals in their

child's education. However, noticeable findings revealed that parent's needs are most satisfied when they make the choice to be active participants in the IEP process.

Additionally, noticeable theoretical contributions were made to extend the understanding of Maslow's (1943) theory to parents of children with ASD. While acceptance was a significant need for respondents, all agreed that self-acceptance or self-respect was the most significant need noted for improvement and reducing stressful situations. Additionally, three participants described having a drive to advocate for others and increase awareness within their community. This finding is also notable as it contrasts previous research that people in stressful situations are not likely to reach their full potential. In Billy's words,

God prepared me to have a son with special needs. He also provided me with the ability to speak out for others. Now I am in a position to help others, and it is my mission to help other families who are facing the same challenges we went through.

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APPENDIX A

Invitation Email sent to Possible Participants

Dear Families,

I am a Special Education Teacher at Teasley Middle School in Cherokee County. As an educator, it is my belief that it is essential for parents and teachers to work collaboratively to meet the educational needs of children. Currently, I am conducting research as a doctoral candidate in the School of Education at Liberty University on understanding the needs of parents of children with Autism spectrum disorder (ASD).

The purpose of the research is to provide valuable insight into the unique needs you have as a parent and how to better support you as you work through the Individualized Educational Plan (IEP) process for your child. As a parent of a child with ASD, you are an expert and can provide valuable information to this study.

If you decide to participate in this study, you will be asked to complete a questionnaire, construct a timeline of significant events in your life, complete an interview, and participate in a focus group. It should take approximately 2.5 hours total for you to complete the procedures listed. Your identity and any information you share will be kept confidential in this study. Additionally, you may choose to withdraw from the study at any time. If you have any questions or concerns, you may contact me anytime at 770-241-9141 or jreynolds18@liberty.edu

Please use the link below to access the informed consent and questionnaire.

Thank you for your time and support,

Jennifer Reynolds

Link to Questionnaire

APPENDIX B

The Liberty University Institutional
Review Board has approved this
document for use from
5/7/15 to 5/6/16
Protocol # 2183.050715

INFORMED CONSENT

A View of Parents of Students with Autism Spectrum Disorder through Maslow's Hierarchy of
Needs: A Phenomenological Approach
Jennifer Reynolds
Liberty University

You are invited to be in a research study investigating the needs of parents of children with ASD as they navigate the IEP process. You were selected as a possible participant because you have a child served in a special education program with an exceptionality of autism. I ask that you read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by Jennifer Reynolds, a doctoral candidate in the School of Education at Liberty University.

Background Information:

The purpose of this study is to provide a voice to parents of children with ASD as they advocate for their child through the IEP process.

Procedures:

If you agree to be in this study, I would ask you to do the following things: Complete a background questionnaire, compose a timeline of significant events in your life, participate in a focus group session, and participate in 1 personal interview. Interviews and focus groups will be audio taped for accuracy. The location and time of the focus group will be determined based on convenience of members as identified in the questionnaire. Since your time is valuable, an estimate time for each procedure is included below. You may use additional time on each procedure if you chose to do so.

- Questionnaire (15 Minutes)
- Timeline (30 minutes)
- Interview (45 minutes)
- Focus Group (1 hour)

Risks and Benefits of being in the Study:

Possible risks related to this study are very minimal and are no more than participants would encounter in everyday life. A possible risk may include emotional distress as you are asked to share experiences which may provoke an emotional response or memory. In the situation that

you experience significant distress or discomfort while in the study, you may choose to stop participating at any time.

The benefits to participation include an overall benefit to the field of education, particularly improving knowledge of special education practices and how to meet the needs of parents. While your participation may have a potential benefit on society, you may not receive a direct benefit from participating in this study.

Compensation:

This study is completely voluntary and there will be no monetary compensation provided.

The Liberty University Institutional
Review Board has approved this
document for use from

5/7/15 to 5/6/16 Protocol # 2183.050715 **Confidentiality:**

The records of this study will be kept private. In any sort of report I might publish, I will not include any information that will make it possible to identify a subject. Research records will be stored securely and only the researcher will have access to the records.

Ethical considerations will be addressed to ensure the safety and confidentiality of people and documents. Pseudonyms will be used for all names and locations to protect participant identity. Security of data transcripts will be ensured by locking up all paper documents. Also, electronic documents will be backed-up electronically and protected with a password. Sensitivity of information will be considered.

Voluntary Nature of the Study:

Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with Liberty University or Cherokee County School District. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships. You may withdraw from the study by contacting Jennifer Reynolds by email. If you do chose to withdraw, all data and documents you provided will be deleted and not used in this study.

Contacts and Questions:

The researcher conducting this study is Jennifer Reynolds. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at 770-241-9141 or jreynolds18@liberty.edu. Dr. Lucinda Spaulding is the faculty advisor overseeing this study. You may contact Dr. Spaulding at lsspaulding@liberty.edu or 434-592-4307.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the Institutional Review Board, 1971 University Blvd, Suite 1837, Lynchburg, VA 24515 or email at irb@liberty.edu.

You will be given a copy of this information to keep for your records.

Statement of Consent:

___ I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

___ I understand that interviews and focus groups will be audio recorded.

Signature: _____ Date: _____

Signature of Investigator: _____ Date: _____

APPENDIX C

Questionnaire

I have read and understand the description of the study and contents of this document. I have had an opportunity to ask questions and have all my questions answered. I hereby acknowledge the above and give my voluntary consent for participation in this study. I understand that I must be 18 years or older to sign this informed consent and participate in this study. I understand that should I have any questions about this research and its conduct, I should contact one of the researchers listed above. If I have any questions about rights or this form, "I should contact the Institutional Review Board, 1971 University Blvd, Suite 1837, Lynchburg, VA 24515 or email at irb@liberty.edu. *Required By selecting yes, I consent to participate in this study.

- Yes
- No

I am a parent/guardian of a child with ASD who is currently served in a Special Education program in CC.

- Yes
- No

Please identify your gender

- Male
- Female
- Other:

Please identify your marital status

- Single
- Married
- Divorced
- Widowed
- Other:

Please identify your ethnicity

- African-American
- Asian
- Caucasian
- Hispanic
- American Indian

- Other:

Please identify your age range

- Under 20
- 20-29
- 30-39
- 40-49
- 50-59
- 60-69
- 70-79
- 80 or older
- Other:

- Option 1

Please identify your highest level of education

- Did not complete school
- High School Diploma or GED
- Associate's Degree
- Bachelor's Degree
- Graduate School
- Other:

Please identify your employment

- Full-Time
- Part- Time
- Student
- Other:

Please identify your occupation

Have your educational or occupational opportunities been limited by your responsibilities as a parent of a child with ASD?

- Yes
- No
- Other:

Please identify how many children you have.

How many of your children have been identified as having ASD?

At what age was your child when he/she was diagnosed with ASD?

At what age was your child when he/she began receiving special education services?

Please identify your current level of stress associated with factors of your child's disability (e.g. behaviors, symptoms, providing daily care, etc.)

1 2 3 4 5 6 7 8 9 10

Least amount of
stress

Greatest amount of
stress

Please identify your current level of stress associated with advocating for your child in the IEP process (e.g. communicating to teachers, meetings, level of support).

1 2 3 4 5 6 7 8 9 10

Least amount of
stress

Greatest amount of
stress

Are you interested in participating in a study to provide educational professionals with insight on how to better support your needs?

- Yes
- No
- Other:

Thank you for your willingness to participate. The next part of this study consists of completing a timeline of significant events in your life, participating in focus groups, and personal interviews. To participate in the next part of this study, please complete the following:

Name

Email address

Phone number

Best dates/ times to contact you for an interview:

APPENDIX D

LIBERTY UNIVERSITY.
INSTITUTIONAL REVIEW BOARD

May 7, 2015

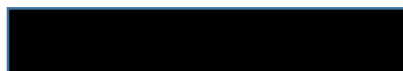
Jennifer Reynolds
IRB Approval 2183.050715: A View of Parents of Children with Autism Spectrum Disorder
through Maslow's Hierarchy of Needs: A Phenomenological Approach

Dear Jennifer,

We are pleased to inform you that your above study has been approved by the Liberty IRB. This approval is extended to you for one year from the date provided above with your protocol number. If data collection proceeds past one year, or if you make changes in the methodology as it pertains to human subjects, you must submit an appropriate update form to the IRB. The forms for these cases were attached to your approval email.

Thank you for your cooperation with the IRB, and we wish you well with your research project.

Sincerely,



Fernando Garzon, Psy.D.
Professor, IRB Chair
Counseling

(434) 592-4054

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APPENDIX E
Permission to Conduct Research in School District

1

[REDACTED] COUNTY SCHOOL SYSTEM
REQUEST FOR PERMISSION TO CONDUCT DATA COLLECTION ACTIVITIES WITHIN THE SYSTEM

Name Jennifer DeBord Reynolds

CCSD Employee: Yes No If *NO*, list employer: _____

College/University Supervising Activities Liberty University

Degree in Progress(Level/Area) Doctorate of Education

Locations for Data Collection off campus locations TBD

Date of Request 11/11/14 Requested Date(s) for Data Collection 1/15/14-2/15/14

Professor's Name Dr. Lucinda Spalding Phone #/Email lsspaulding@liberty.edu

Include with this request:

- A letter from your supervising professor on college or university letterhead indicating support for your research and his/her confirmation of data collection validity.
- A brief summary of the issues being researched and the type of data collection you are requesting to conduct. (Page 2 of this form).
- Method of data collection assessment (Page 2 of this form); Number of respondents, etc.
- Copy of interview questions, surveys, etc. that will be used. If student data/videos are used, a notarized "Release of Educational Records for Research Purposes Confidentiality Statement" and a copy of a letter requesting parent permission to use the data will be required.

I, Jennifer Reynolds do hereby submit to not hold the [REDACTED] liable for any findings, or commentary involved in this research. I understand that without the express written permission of the [REDACTED], I am not authorized to conduct any data collection involving system employees or students and/or any other information that is protected by Federal or State Law. **Furthermore, a copy of all findings and data collection instruments will be made available to the [REDACTED]. All research is to be sent to the Office of Assessment upon completion of the project.**

Signature [REDACTED] Date 12/5/14

Signature of Principal (if applicable) [REDACTED] Date 12/5/14

Send completed form to: [REDACTED] Director, Office of Assessment, ESA, Building G

Staff Use Only

Office of Assessment [REDACTED] Permission given Permission denied

Conditions of Permission: _____

Denied due to: _____

Revised 01/2012

APPENDIX F

Timeline Prompt

Thank you for choosing to participate in this study. The first piece of data is a timeline of significant events in your life. By creating a timeline, you will help me understand which events are particularly significant and guide me to understanding the events and how you experienced the events. The time- line can be wither typed in a narrative format such as a journal entry or hand created. Along with significant events, you may include any personal, professional, or academic achievements and how each may have prepared you for your role as a parent. Please be as detailed as possible in your entries. Also, please include how you felt at each event and the overall impact each event had on you.

APPENDIX G

Focus Groups

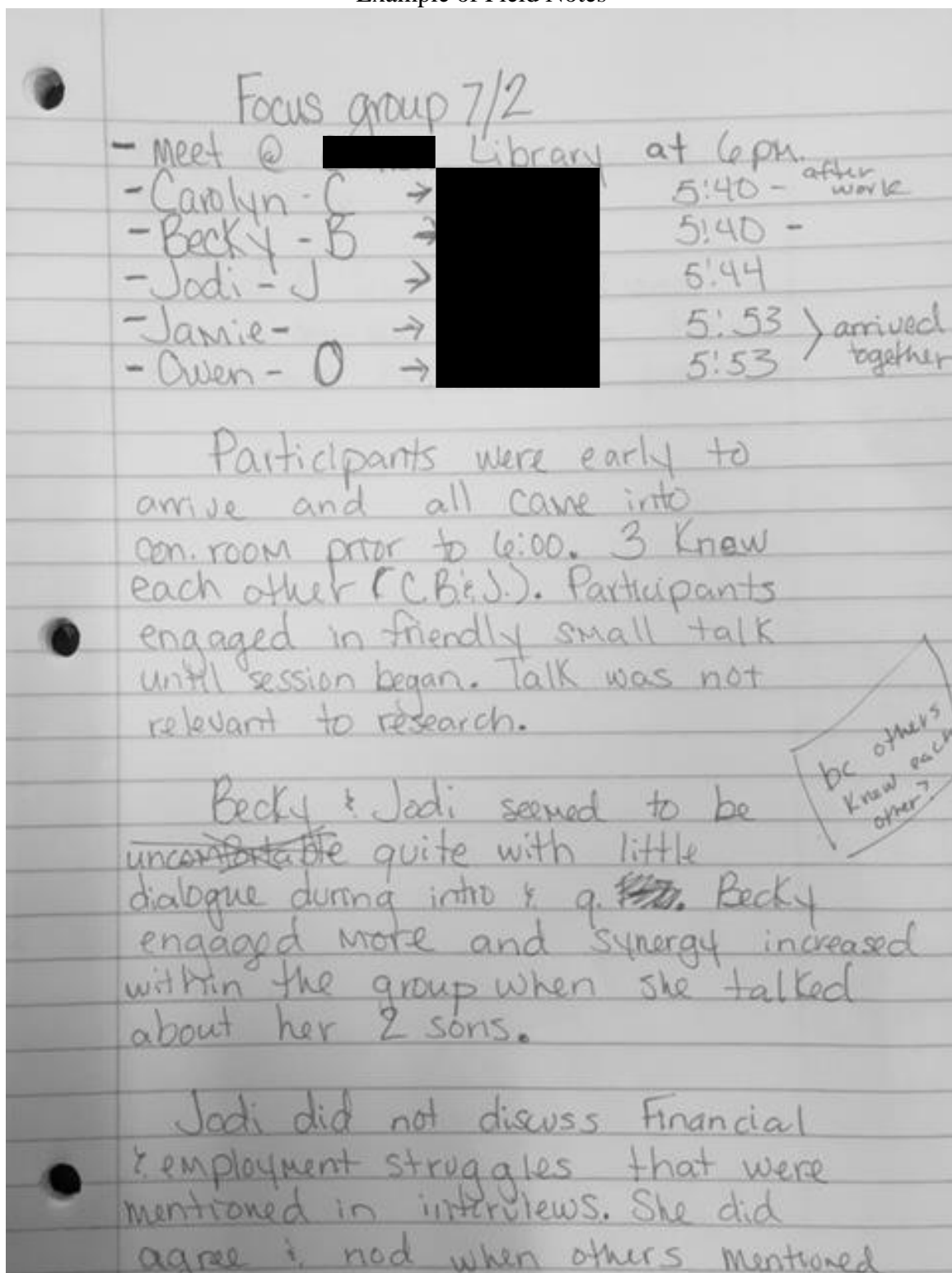
Introduction:

The purpose of this focus group is to gather additional information that may be beneficial to the study. Focus groups create discussion among members and allow extra ideas to be shared through conversation. Therefore, I would like to encourage each of you to join in the open discussion with anything you would like to share. Because this focus group will be audio recorded and transcribed, please state your pseudonym name prior to sharing. This will help maintain confidentiality and ensure the transcripts are transcribed correctly.

1. What is the most challenging aspect of having a child with ASD?
2. What is the most rewarding aspect of having a child with ASD?
3. What is the most challenging part of advocating for your child's educational needs?
4. When have you felt most successful as a parent advocate in educational settings?
5. What do you wish educators understood about you role as a parent of a child with ASD?
6. How can educators better meet your needs in the IEP process?

APPENDIX H

Example of Field Notes



APPENDIX I

Confidentiality Agreement

**A VIEW OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER
THROUGH MASLOW'S HIERARCHY OF NEEDS: A PHENOMENOLOGICAL
APPROACH**

Jennifer Reynolds

Liberty University School of Education

By signing this, I agree to maintain confidentiality of all participant information, documents, and findings in this study.

Research Assistant

Signature

Date

Researcher

Signature

Date

APPENDIX J

DEBRIEFING STATEMENT

A VIEW OF PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER THROUGH MASLOW'S HIERARCHY OF NEEDS: A PHENOMENOLOGICAL APPROACH

Jennifer Reynolds
Liberty University
Education

You recently participated in a research study of *identifying the needs of parents of children with ASD*. You were selected as a possible participant because *you currently have a child with ASD served in a special education program in CC*. The purpose of this debriefing statement is to inform you that the

Background Information:

The purpose of this study is *to understand the needs of parents of children with ASD who are currently served in a special education program in North Georgia*.

Confidentiality:

The records of this study will be kept private. In any sort of report we might publish, we will not include any information that will make it possible to identify a subject. Research records will be stored securely and only researchers will have access to the records.

Ethical considerations will be addressed to ensure the safety and confidentiality of people and documents. Pseudonyms will be used for all names and locations to protect participant identity. Security of data transcripts will be ensured by locking up all paper documents. Also, electronic documents will be backed-up electronically and protected with a password. Sensitivity of information will be considered and participants will be allowed to withdraw from the study at any time.

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