PARENTAL CONCERNS SURROUNDING THE CARE AND EDUCATION OF MILITARY DEPENDENT CHILDREN WITH AUTISM:

A PHENOMENOLOGICAL STUDY

By

Charles W. Tidwell

Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

Liberty University

November, 2016
PARENTAL CONCERNS SURROUNDING THE CARE AND EDUCATION OF MILITARY DEPENDENT CHILDREN WITH AUTISM:

A PHENOMENOLOGICAL STUDY

By Charles W. Tidwell

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

Doctor of Education

Liberty University, Lynchburg, VA

November, 2016

APPROVED BY:

Department of Doctoral Programs and Research, School of Education, Liberty University
ABSTRACT

Autism continues to be a growing concern in America and there is indication that the rate of autism among the sub-population of military dependent children is potentially higher than the general public. This hermeneutic phenomenological study focused on the concerns and experiences of parents of military families raising and educating their children with autism. Data was collected from nine military families across the United States. Six fathers and seven mothers participated through an initial questionnaire, interview, and a written reflective timeline. Findings demonstrated the stress, strain and sacrifice of families serving in the military with children with autism. Continuity of care and education was a significant concern. Participant parents stressed advocacy as a crucial key to success. Parents have wealth of knowledge and experience to share. Findings provide valuable insight to education professionals, support providers, policy makers, as well as other parents,

Keywords: Autism Spectrum Disorder, military dependent, Individuals with Disabilities Education Act, Individualized Education Program, Exceptional Family Member Program, phenomenology.
Dedication and Acknowledgments

This dissertation is dedicated to three caring and compassionate warrior moms. Two who are no longer with us, but are forever home in the presence of Jesus and one who is still running the race and fighting the good fight.

Dr. Jill Jones – She left this life too soon when she and her son were killed by a drunk driver. She was my most demanding professor at Liberty University. But with her “tough love” came just as much care and compassion. She was a prayer warrior who was on her knees before our Heavenly Father lifting her students up each day. Her words are still an encouragement and source of inspiration.

A military wife and mother of a little girl with autism – I will pretend her name is “Violet” because that was her favorite color. She too left this life too soon. She was a warrior mom in the battleground of Autism. Her love for Jesus and her family is still impacting lives today.

My Navy wife and mother of our son with autism – Heather is a prayer warrior. She continues to a champion and advocate not only for our child, but also for the many other families traveling life’s road with autism. She is a “Proverbs 31 Lady.” Our children are blessed to call her Mom and I am blessed to have her as my wife and best friend.

I would also like to acknowledge several people whose help and support helped make this possible.

First and foremost, I want to thank my Lord and Savior Jesus Christ for sustaining me along this long road called dissertation.

I would like to express my love and appreciation to my wife and children who have sacrificed much family time to allow me to pursue this calling on my life.
I would like to thank my parents and brothers and all my extended family and friends who have encouraged me throughout this dissertation process.

I would like to acknowledge my Chair, Dr. Lucinda Spaulding. She is an incredible compassionate professional in the education field. I am very blessed to have her on my team and have her wisdom and insight as a guiding light along this research path. She took me under her wing during a critical point in this dissertation journey and helped restore some faith I had lost along the way. I am forever grateful to her.

I want to also acknowledge Dr. Roland DeRenzo for his example of leadership and encouraging me to stay the course on this endurance race. Thank you to my Committee Team for their time and commitment to help me reach the finish-line.

I want to say thank you to Dr. Scott Watson and Dr. Deanna Keith for their encouragement in the early stages of my proposal development to combine three passions in my life (military service, education, and helping children with special needs) into what would eventually become this research study. And additionally, to Dr. Keith for her passion and dedication to helping the special needs community, especially children with autism.

I am also appreciative of my fellow military and education professionals who reviewed, critiqued, and edited my work and offered valuable feedback. Thank you to Dr. Karen Delbridge, Dr. Jamilla Mufdi, Dr. LeAnn Bunch, Mrs. Heather Tidwell, M.Ed., and Lieutenant Commander Christopher Tidwell, U.S. Navy.

I want to express my gratitude to my Academic Advisor, Patrick Shaw. To put it in military terms, he was my battle buddy, my wingman, he always had my back and covered me in prayer. I am forever grateful to him.
Last, but not least, I want to say thank you to all the participant families who gave so generously of their time as they volunteered in this study. You will never know how much your words meant to me on a personal level. Throughout this dissertation journey I have had seasons of adversity and discouragement. Your words directed toward other parents of children with autism were an inspiration to me when I needed it the most. Thank you reminding me to persevere and never … never give up!
# Table of Contents

ABSTRACT ............................................................................................................................. 3  

Dedication and Acknowledgments ......................................................................................... 4  

Table of Contents .................................................................................................................. 7  

List of Tables ......................................................................................................................... 12  

List of Figures ......................................................................................................................... 13  

List of Abbreviations ............................................................................................................. 14  

CHAPTER ONE: INTRODUCTION ..................................................................................... 18  

Overview ............................................................................................................................... 18  

Background ............................................................................................................................. 18  

Problem Statement ................................................................................................................ 25  

Purpose Statement ................................................................................................................ 27  

Significance of the Study ....................................................................................................... 27  

Research Questions .............................................................................................................. 31  

Research Plan ...................................................................................................................... 32  

Delimitations ........................................................................................................................ 33  

Researcher’s Biography and Motivation for the Study ......................................................... 34  

Summary .............................................................................................................................. 47  

CHAPTER TWO: LITERATURE REVIEW ........................................................................ 48  

Overview ............................................................................................................................... 48  

Review of the Literature ....................................................................................................... 49  

- Historical Background ......................................................................................................... 49  

Theoretical Framework .......................................................................................................... 86
## Summary ................................................................. 89

### CHAPTER THREE: METHODOLOGY ................................................................. 91

**Overview** ........................................................................................................... 91

**Researcher’s Role** ............................................................................................... 91

**Research Design** ................................................................................................. 93

**Participants** .......................................................................................................... 94

**Setting** ................................................................................................................ 96

**Data Collection Procedures** .................................................................................. 97

- **Questionnaire** .................................................................................................... 98
- **Interview** ............................................................................................................. 98
- **Reflective Essay / Timeline** .................................................................................. 109

**Data Analysis** ...................................................................................................... 109

**Trustworthiness** .................................................................................................. 113

**Ethical Issues** ...................................................................................................... 114

### CHAPTER FOUR: FINDINGS .............................................................................. 115

**Overview** ............................................................................................................ 115

**Description of Participants** .................................................................................... 115

- **Alpha Family** .................................................................................................... 116
- **Bravo Family** .................................................................................................... 117
- **Charlie Family** .................................................................................................. 118
- **Delta Family** ..................................................................................................... 119
- **Echo Family** ...................................................................................................... 120
- **Foxtrot Family** .................................................................................................. 121
Appendix D: Interview Procedures .......................................................... 268
Appendix E: Timeline / Essay .................................................................... 273
Appendix F: Bronfenbrenner Coding Sample .......................................... 275
Appendix G: Interview Transcription Coding Sample ............................ 276
Appendix H: Master Theme Quote Spreadsheet Sample .......................... 277
Appendix I: Theme Organization Sample .................................................. 278
Appendix J: Audit-Decision Trail Sample .................................................. 279
Appendix K: Reflective Journal ................................................................. 280
Appendix L: IRB Approval ................................................................. 281
List of Tables

Table 1- EFMP Categories and Descriptions................................................................. 64
Table 2- Objectives of Ohio State Project ........................................................................ 76
Table 3- Conclusions of Ohio State Project..................................................................... 78
Table 4- Family and Child Pseudonyms......................................................................... 96
Table 5- Research and Interview Questions ..................................................................... 99
List of Figures

Figure 1. My Child has Autism Card................................................................. 23
Figure 2. Bronfenbrenner’s Ecological Systems Model........................................... 87
List of Abbreviations

Applied Behavior Analysis (ABA)
Active Duty for Training (ADT)
Attention Deficit Hyperactivity Disorder (ADHD)
Air Force Base (AFB)
Area of Responsibility (AOR)
American Psychiatric Association (APA)
Autism Research Institute (ARI)
Autism Spectrum Disorder (ASD)
Board Certified Behavior Analyst (BCBA)
Base Realignment And Closure (BRAC)
Centers for Disease Control and Prevention (CDC)
Continental United States of America (CONUS)
Central Screening Committees (CSC)
Defeat Autism Now (DAN)
Department of Defense Education Activity (DoDEA)
Department of Defense Dependents Schools (DoDDS)
Domestic Dependents Elementary and Secondary Schools (DDESS)
Defense Enrollment Eligibility Reporting System (DEERS)
Department of Defense (DoD)
Dropped On Request (DOR)
Evidence Based Practice (EBP)
Extended Care Health Option (ECHO)
Exceptional Family Member Program (EFMP)
Electrocardiogram (EKG)
Environmental Protection Agency (EPA)
Every Student Succeeds Act (ESSA)
Free Appropriate Public Education (FAPE)
Functional Behavior Assessment (FBA)
Federal Drug Administration (FBA)
Gluten Free Casein Free (GFCF)
Hyperbaric Oxygen Therapy (HBOT)
Home-School Legal Defense Association (HSLDA)
Identification Card (ID)
Individuals with Disabilities Education Improvement Act (IDEA)
Individualized Education Program (IEP)
Individual Family Service Plan (IFSP)
Internal Review Board (IRB)
Intelligence Quotient (IQ)
Limited Duty Officer (LDO)
Mea’ Alofa Autism Support Center (MASC)
Military Family Life Consultant (MFLC)
Military Interstate Children’s Compact Commission (MICCC or MIC3)
Military Officers Association of America (MOAA)
Military Treatment Facility (MTF)
National Association of Child Care Resource and Referral Agencies (NAACRA)
Navy Family Accountability & Assessment System (NFAAS)

No Child Left Behind Act (NCLB)

Non-commissioned Officer (NCO)

National Football League (NFL)

Naval Medical Center (NMC)

U.S. Northern Command (NORTHCOM)

Northern Utah Autism Project (NUAP)

Organization for Autism Research (OAR)

Obsessive Compulsive Disorder (OCD)

Officer Candidate School (OCS)

Occupational Therapy (OT)

Primary Care Manager (PCM)

Permanent Change of Station (PCS)

Pictures Exchange Communication Systems (PECS)

Program for Persons with Disabilities (PFPWD)

Physical Therapy (PT)

Social Communication, Emotional Regulation, and Transactional Support (SCERTS)

Speech Language Pathology (SLP)

Specialized Training of Military Parents (STOMP)

Traumatic Brain Injury (TBI)

Transient Lodging Facility (TLF)

United States Marine Corps (USMC)

Vaccine Adverse Events Reporting System (VAERS)
Ventricular Septal Defect (VSD)

World War Two (WWII)
CHAPTER ONE: INTRODUCTION

Overview

It is estimated that 14.6% of military families have a family member with a disability (Jacobsen, 2014). The Centers for Disease Control and Prevention (CDC) now lists the rate of autism as one in 68 (CDC, 2016a). Raising and educating a child with special needs in any environment is difficult; however, the complexities of educating military dependent children with autism is especially challenging. This qualitative phenomenological study was designed to capture the unique experiences of military families who have a child with autism with a focus on the efforts and processes parents take to ensure an appropriate education for their children. This chapter introduces the study and ties each of the significant areas together, particularly the military and autism. This chapter also includes the statement of the problem, purpose statement, research questions, as well as a section describing the motivation behind the study.

Background

The United States of America is a unique country. It is a relatively young nation, but also one of the world’s oldest democracies. Established in 1776 as a free nation, many patriots and members of the original 13 state’s militia gave their lives in her defense. The families of these early American soldiers sacrificed much as do the military families of today. Over 235 years later this country still stands. It has grown to include 308,745,538 citizens residing in 50 states and several U.S. territories (United States Census Bureau, 2010). The sovereignty of the nation has been challenged throughout its history, first by the British in the Revolutionary War and War of 1812. The first words of the Marine Corps Hymn, “From the Halls of Montezuma to the
shores of Tripoli…” speak of battles against Spain and the Barbary pirates during the 1800s. During the twentieth century, the United States of America fought in two world wars against multiple enemies. Presently the nation is still at war against terrorist organizations worldwide including those responsible for the deaths of thousands of Americans in the 9-11 attacks. The life of a soldier, sailor, marine, or airman is unique as well. Each member of the service takes an oath to “support and defend the Constitution of the United States of America against all enemies foreign and domestic” (United States Code, 1962). They are prepared to give their life in its defense. Most of those who serve in the military will never have to make the ultimate sacrifice; however, there will be many hardships and other difficulties.

The spouses and children of military members also endure many hardships and make many sacrifices. When military members deploy to combat areas around the world, it is the wife or husband left at home who becomes both mom and dad for their children. They are forced to step into roles and responsibilities that would normally be handled by their spouse. Sometimes this may require the dependent spouse to single handedly plan and coordinate a permanent change of station (PCS) move hundreds of miles across the U.S. or from continent to continent. There is an empty seat in the audience at music recitals, sports games, and school events when military parents are deployed. Military families live with the uncertainty of knowing their loved one may often be in dangerous situations or in harm’s way.

Every move brings on new challenges. Transfers take place in every season and often affect the school year. For example, a military dependent student may start the school year in a public-school classroom in Norfolk, Virginia and finish it at a Department of Defense school in Naples, Italy the following June. Children in military families will often attend several different schools before graduating from high school. Each transfer is demanding on the military family,
but even more so for those who have children with special needs. There are numerous types of special needs. Some are more severe than others, but all require extra care.

The rate of autism in America continues to be not only concerning, but alarming. The Center for Disease Control (CDC) held the rate to be one in 88 in 2008 (CDC, 2013a). Using a study from 2012 the CDC now lists the rate of autism as one in in 68 (CDC, 2016a). Autism is complex. It is sometimes referred to as a disorder and at other times it is referred to as a disability. It has also been referred to in other ways, such as an “epidemic on the floors of Congress. The CDC says, “Autism Spectrum Disorder (ASD) is a developmental disability that can cause significant social, communication and behavior challenges” (CDC, 2016b). The American Psychological Association stated “Autism is the most severe developmental disability (APA, 2016). Autism is a brain disorder that affects a person’s ability to communicate, to reason and to interact with others. Federal law defines autism as a developmental disability significantly affecting verbal and nonverbal communication and social interaction (Wright & Wright, 2006). It is a spectrum disorder that affects individuals differently and to varying degrees of severity and is often found in combination with other disabilities. Autism Spectrum Disorder (ASD), is more commonly referred to as “Autism.” Within the spectrum there are three categories: Classic Autism, Asperger’s Syndrome and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) (Blumberg et al., 2013). Going forward all spectrum categories are addressed as autism or ASD.

Prior to the movie, Rain Man (Guber, Peters & Levinson, 1988), starring Tom Cruise and Dustin Hoffman, many Americans had no concept of the term autism. Cruise played the role of a younger brother taking care of his older sibling with severe special needs. Hoffman played the character of the brother with autism and was recognized for his performance by the Academy of
Motion Picture Arts and Sciences later that year with the Best Actor award. The film was a box office hit and brought to light the neurological disorder of autism to the general public; however, it is important to note the vast majority of people with autism are not savants like the character Hoffman played in *Rain Man* (Autism Society, 2006). Autism is a spectrum disorder. Since the movie was released in 1988, the rate of autism in America has climbed exponentially. It rose from one in 2,500 children to about one in every 300 in 1996 (Geier & Geier, 2003). In 2008, the CDC estimated that one in 88 children are diagnosed with ASD (CDC, 2013). The CDC now lists the rate of autism as one in 68 (CDC, 2016a).

More than twenty years after the debut of *Rain Man* it is still unclear exactly what causes autism. There are several theories. Some people believe autism is passed through genetics while others claim the environment plays a critical role (Hertz-Picciotto & Delwiche, 2009; Mutter, Naumann, Schneider, Walach, Haley, 2005). Others point to vaccinations as the culprit (Austin, 2008; Kirby, 2005). There is also research that suggests that both genetics and the environment play a part where some children are predisposed to the condition and something such as a neurotoxin entering the human body causes a trigger mechanism and launches the neurological disorder of autism (Mutter et al., 2005; Wakefield, 2002). Researchers are focusing on how the different genes interact with each other and environmental factors to gain understanding on why they increase the risk of autism (NIMH, 2013). This is type of research is termed epigenetics. Mercola (2013) reported that while certain genetic expression or activation of many genes is found in the majority of autism cases they are not alone. Multiple epigenetic and environmental factors work together, culminating into autism. Autism knows no boundaries and has no borders. It affects children from all ethnicities and nationalities.
While each child is different and may not exhibit the same behavior, each possess a number of similar characteristics that are used in diagnosing Autism Spectrum Disorder (ASD). In May 2013, the American Psychiatric Association (APA) published the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Under the DSM-5 the diagnoses of Autism, Asperger Disorder and PDD-NOS were eliminated and one umbrella type diagnosis of Autism Spectrum Disorder was created. In the previous DSM-IV autism was characterized by delays or abnormalities in three domains: (1) social interaction; (2) communication; and (3) restricted, repetitive, and stereotyped patterns of behavior interests, and activities. The DSM-5 reduced the diagnostic criteria domains down to two: (1) social communication; and (2) fixated interest and repetitive behavior or activity (Loranger, & Kaufmann, 2012). A couple of the criteria are lack of social or emotional reciprocity and persistent preoccupation with parts of objects (Centers for Disease Control and Prevention, 2013b).

While it is not an exhaustive list of criteria found in the DSM-IV or DSM-5, an outstanding description in laymen’s terms of some of the characteristics of children with autism comes from a card printed in 2010 by the Talk About Curing Autism (TACA) organization. Many parents use this card to hand to others when their child is in a social setting. The front side has a picture of the back of a little boy standing on the shore looking out across the water with the words “My Child’s Behavior May Be Disturbing To You. My Child Is Not Spoiled or Misbehaving.” “MY CHILD HAS AUTISM.” The back side explains that autism is a devastating biological and neurological disorder and describes five different areas where individuals can be affected:
1. TROUBLES WITH COMMUNICATION (Both verbal and non-verbal, including the possibility of no speech, or appearing deaf)

2. SOCIAL AND LEARNING SKILLS (Unable to understand social cues & situations, including waiting in lines, or unplanned changes)

3. STRANGE OR ODD BEHAVIORS (Such as tantrums, hand flapping, repetitive sounds, yelling out, or obsessive behaviors)

4. SENSORY ISSUES (For example hypersensitive hearing and vision, or aversion to being touched)

5. MEDICAL PROBLEMS (Including severe headaches, gastro-intestinal problems, sever food allergies, & many others)

The card also has a couple of statistics, the TACA website and gives the message “Thank You for Your Support & Understanding, And For Being A Friend To A Family With Autism” (My child has autism card, 2010).

Figure 1. My Child has Autism Card

The hope is that by reading this card it provides information about autism and helps a person be able to recognize the special attention and significant needs of a child with autism and be more tolerant and understanding of the child and more supportive of the parent(s).
Once an individual is diagnosed with autism, the next course of action is important. There are numerous therapies and interventions found beneficial to children diagnosed with autism. Some children have actually recovered from the neurological disorder and had the ASD diagnosis removed. In a study published by Kogan et al. (2009), almost 40% of children previously diagnosed with ASD no longer had the disorder. Autism Research Institute in a letter dated October 6, 2009 stated; “This finding supports recent research that children diagnosed with autism can recover from the disorder with appropriate interventions, both medical and behavioral” (p. 1). Bradstreet (2009) a medical doctor and parent of a child with ASD pointed out, “Most can become far healthier, experience less abdominal pain, and gain a better quality of life. Some can recover to the point where they fully integrate into life and go onto productive lives” (p. 11). Conversely, Meyers, and Johnson (2007) said that like other neurodevelopmental disabilities, autism is generally not curable and chronic management is required. They state further that regardless of intelligence, children with ASD continue to experience problems with social relationships, employment and mental health, continuing to remain on the spectrum as adults.

The United States military is in many ways a cross section of society. Autism affects many families serving in the armed forces. There is indication that the rate of autism among military dependents may actually be higher than that of the general public (Kirby, 2005). In 2007 the CDC reported the autism rate to be one in 150 (CDC, 2007). Statistics that were released by the Office of the Assistant Secretary of Defense through the Freedom of Information Act (FOIA) on June 23, 2008 found the rate to be one in 88 among active duty military families (Yazbak & Gallup, 2008). While the DoD has not released current statistics for the entire
military recently, one of the Army’s largest bases in Kansas, Fort Leavenworth, had an autism rate of 1.28 on post while the state average was .47 (Bower, 2010).

The education of each one of these military dependent children with autism is important. Prior to the Individuals with Disabilities Education Act of 2004 (IDEA) most children with autism were segregated and educated in separate schools or classrooms where they had little or no interaction with children in the general classroom without disabilities. The IDEA ensures that all children with disabilities receive a free and appropriate public education tailored to their specific individual needs in the least restrictive environment (Autism Society, 2006). This is to be done to the greatest extent possible among their age-appropriate peers. Each state has an educational system that operates independently of the others. While the federal laws such as (IDEA) and Every Student Succeeds Act (ESSA) Act of 2015 govern certain educational aspects across the nation, there are still many differences and disparities from school district to school district even within the same state. With each PCS move, every military family must navigate through an array of new networks of information and policies. All military families with children having disabilities, including autism, face a unique set of challenges.

**Problem Statement**

The rate of autism in America continues to soar. The CDC now lists the autism rate at one in 68 (CDC, 2016a). Following intellectual and developmental disabilities and cerebral palsy, autism is the third most common developmental disability (Autism Society, 2006). These climbing rates are staggering and pose a very real threat to families, schools, the military and America and are seen by some, including United States congressional leaders, as an epidemic (Kirby, 2005).
It is estimated that 14.6% of military personnel has a family member with a special need or disability (Jacobsen, 2014). Raising and educating a child with special needs in any environment is difficult; however, the complexities of educating military dependent children with autism is especially challenging. The military family endures frequent geographic relocations and forced adaptations to new schools and communities with PCS moves. In a survey of active duty families, 47% reported three or more moves in the past five years (Flake et al., 2009). High tempo of mobilizations and deployments bring increased challenges for parents and children. Sometimes the actual departure is a relief to all because of the months of training and frequent higher priority given to deployment preparation over routine family activities (Davis, Blaschke, & Stafford, 2012). Cozza et al., (2005) stated, “to assume either widespread pathology or uniform resilience to the stresses of wartime deployments would be superficial and harmful to children and their families” (p. 371). Flake et al. (2009) found over one-third of school aged children with a deployed parent had increased psychosocial morbidity. In other words, there was an increasing unhealthy state of mind. Educating children with autism in a stable environment can be challenging enough, but the stresses of military life with constant change combined with uncertainty can often be overwhelming. There are more than two million children in families serving in the United States military (Davis et al., 2012). Applying the most current autism rate of one in 68 would mean that around 30,000 children with autism are being raised and educated in military families. There is some limited data that has been collected on the parental experience; however, it is rare to find a peer reviewed study on the subject that has been conducted with established research methodology. Phenomenological research approaches are effective at surfacing deep issues and making voices heard (Lester, 1999). Military parents have a strong voice which, to a limited degree, has even been heard on Capitol Hill in
congressional hearings concerning autism. As the autism rate continues to climb and the demands of the military to deter threats at home and abroad increase, it is very important to know the challenges military families face in raising and educating children with autism. Research on the thousands of military families nurturing and educating their children with autism is extremely limited. More research is needed to fully understand the unique experiences of military parents of children with autism.

**Purpose Statement**

Several thousand United States military dependents have autism. The purpose of this phenomenological study was to describe the unique experiences of military families in the US who have a child with autism in grades K – 12, with particular focus on the efforts and processes parents take to ensure an appropriate education for their child(ren). Education and development is vital to each child’s life and plays a significant role in family readiness which directly affects operational readiness in the military. The purpose and end goal of this study was to document the voices of military parents relating their experiences, expressing their concerns, and sharing their successes raising and educating their child(ren) with autism.

**Significance of the Study**

The long-range intent of this study is to generate findings that can be used as a valuable resource for parents, teachers, school administrators, service providers, and military support personnel seeking to provide the best possible education for military children with autism. The significance of this study falls into three major spheres of influence. The first is the United
States Armed Forces. The second is the education profession. The third, equally as important as the other two, is parents and families of children with autism.

The United States of America is one of the world’s leading super powers. To maintain the security of this nation the United States must maintain a strong military with the highest state of readiness. The military must be able to deploy at any time anywhere on the planet to protect its citizens and keep rogue nations and terrorist/militant groups in check. Readiness is a degree of measurement used to determine, define and measure how quickly and efficiently soldiers, sailors, marines and airmen can be on station around the world to deter threats, execute missions and defeat the enemy, or in many cases provide humanitarian aid to victims of tsunamis, earthquakes and other natural disasters. The dedicated men and women in uniform are the United States military’s greatest asset. The readiness of these service members is crucial to mission success. The family readiness of military members is a large part of the overall operational readiness and directly impacts the effectiveness of our Armed Forces. Military members are concerned about their families on the home front. Being miles and miles away without the ability to solve a problem or help a family member in need can increase stress. In critical operations, all military members must remain focused. Issues that arise at home can often become problems for soldiers and sailors at the battle front. Major distractions can be the difference in mission success or defeat, or the difference in life and death. The military values the families of those who serve and has implemented many programs to support those families. Sometimes the resources for assistance and services are adequate and at other times they are not. There are support organizations and agencies ready to help, but they do not always know how to effectively meet the needs of the families with children diagnosed with ASD. The Department of Defense (DoD) is continually looking for ways to improve family readiness.
The education profession is involved at many levels across the country. School systems are in the business of providing the best possible learning environments for all children regardless of race, ethnicity, or socio-economic status and by law must provide a free and appropriate public education (FAPE) while adhering to the Every Student Succeeds Act (ESSA, 2015). School systems are also charged with educating children with disabilities (IDEA, 2004). These disabilities range from physical impairments to intellectual and cognitive development limitations. Schools located in communities near military installations have an increased interest in learning more about the unique needs of children from military families requiring special education.

Parents are typically the strongest advocates for their children with ASD (Johnson, 2008). Teachers may work with a child in the classroom for a school year and therapists may provide services for a season; however, it is the parents who will endure the lifelong hurdles, obstacles and challenges along with their child. These precious children are their parents’ responsibility twenty-four hours a day, seven days a week, and 365 days a year. They work tirelessly to provide the love and support their unique child’s needs, seeking out new therapies and researching articles as they search for ways to help their child. As a medical doctor, father of a child with autism and former Air Force officer, Bradstreet (2009) described his views candidly:

“Autism is a war. It is a war being waged against your child and your family. Unless you fight back you are guaranteed more casualties and greater destruction” (p. 8). Bradstreet (2009) compared autism to the London Blitz of WWII in which the German planes dropped munitions relentlessly:

Day after day of bad news is piled on top of bad news. The bombs keep falling. The school fights you over the education plan, your insurer refuses to pay for your child’s
medical care, your spouse feels neglected, your other children feel abandoned, and your career suffers. (p. 9)

For many military parents fighting in the war against terrorism there is a private war being waged on the home front. It is the battle against autism.

Autism is often a misunderstood condition. Experts in the field have made progress in learning more about the disorder; however, the cause or the cure has not been found. As a result autism continues to puzzle medical and scientific experts. Conducting this research will help identify the unique educational experiences of military families of children with autism and hopefully provide insight to meet the challenges brought on by frequent PCS moves, high operation tempo and family separation periods common with military life. Additionally, this study will hopefully encourage more studies on this disorder that ranks third among developmental disabilities, following mental retardation and cerebral palsy (Autism Society, 2006). More quantitative and qualitative studies about the subject need to be conducted. Qualitative reports tend to have a heavy narrative of rich descriptions (Ary, Jacobs, Razavieh, & Sorensen, 2006). Interviewing parents about their experiences will provide an intense description and analysis of a phenomenon and will aid in the research of ASD (Merriam and Associates, 2002). Dey (1993) relates writing a qualitative report to telling a story that unfolds into some resolution. Sharing the stories of parent’s experiences in raising and educating children with autism will provide insight for military leadership, education professionals, and other parents.
Research Questions

The general focus of inquiry of this study was understanding the parent’s perspective of caring for, raising and educating a child with ASD. The following questions guided this study:

1) What does it mean to have a child with autism while serving in the military? The military profession can at times be very demanding. Raising a child with autism can also be very difficult. This question sought to find meaning in the context of a military family.

2) What are the challenges a military family of a child with autism experience during deployments and permanent change of station (PCS) moves? Children with autism typically do best in a structured environment with set routines and familiar surroundings. The military is in a state of constant change and at times a state of uncertainty. This could cause increased strain and require additional adjustments for those families with special needs.

3) How do military parents respond to the educational challenges of children with autism? Parents must make decisions about which schools their children will attend and whether they will be mainstreamed or in a self-contained classroom. Some parents may choose to home-school their children or create a blended program between the public school and at home. Sometimes military PCS moves take place in the summer, yet often they take place during the traditional school year thus requiring a new school system to implement an IEP with minimum advanced notification. Children may be placed on a waiting list if support services are not readily available at the new duty station. Each state has different graduation criteria and proficiency requirements which could become an issue as military dependent children transfer from one school to another.
4) What are the lessons gleaned from the real-world experiences of military parents of children with autism? Parents have a perspective that is unique. They have lived and breathed the life of juggling a military career with parenting a child with ASD. This question focuses on drawing out information by entering the conceptual world of the participants (Geertz, 1973).

These four research questions were derived from sensitizing concepts from the review of literature. Charmaz (2003) found sensitizing concepts as a way of viewing, organizing and understanding experience. Glaser (1978) and Padgett (2004) viewed them as interpretive devices to be used as a starting point for qualitative studies.

**Research Plan**

This qualitative study followed a hermeneutic phenomenological design (van Manen, 1997). Narrative research methodologies along with their unique languages are shaped by a view that the world is subjective and ready to be expressed (Nash & Bradley, 2011). The complete detailed strategy is outlined in the methodology section in Chapter Three. Multiple forms of data were collected to allow for data triangulation. The first leg of data collection was an initial form which captured basic demographics info such as branch of service and some initial feedback on experiences using several open-ended questions. It was followed by an in-depth interview guided by the research questions developed through the sensitizing concepts gained in the literature review. The third leg or component of data collection was a reflective timeline/essay.

With the CDC rate now at one in 68, autism is viewed by some as an epidemic (CDC, 2016a). There are many theories and positions on the subject taken by medical doctors,
educational professionals, law-makers, specialists, and other support personnel in the field. Each of these has a perspective taken from a particular discipline. These may have merit and should be examined; however, none of these are as likely to tie things together as well as the perspective of parents of children with autism who are often the link between all the professionals, specialists and support personnel trying to help their child. van Manen (1997) said the goal of the phenomenological strategy is to “transform lived experience into a textual expression of its essence” (p. 36). The objective of this type of research is to construct an animating, evocative description of human actions, behaviors, intentions, and experiences as met in the real world (Ajjawi & Higgs, 2007). The end goal of the research was to produce findings about the unique experiences of military parents raising and educating children with autism which may be used as a valuable resource for parents, education and support professionals and the military.

**Delimitations**

The geographic area from which the participants will be drawn is the entire United States. Participants for phenomenological research projects are typically selected with different criteria than those used for quantitative studies. The aim in selection of participants in hermeneutic phenomenological research is to identify participants who are willing to talk about their lived experience which is the focus of the study (Polkinghorne, 1989; van Manen, 1997).

The participants were parents of a military family having a least one child with autism. Only one parent needed to have served and dual military couples were welcome to participate. Both active duty and reserve personnel were included in the study; however, their children must have been in grades K-12 during the time they were in the military. This delimitation allowed
for more feedback on the experience in regards to education. Nine families were chosen using purposeful selection to provide information rich cases for detailed study (Patton, 2002).

**Researcher’s Biography and Motivation for the Study**

My goal for this research was to find truths through other family’s stories. As the human instrument in this qualitative inquiry, it is important to tell my family’s story and shed light on my motivation to conduct this study. As a naval officer and father of a child with autism, I have had almost two decades of experience with autism spectrum disorder while serving in the United States Armed Forces.

My first-born child, Joshua (pseudonym) was born in 1998. I was fortunate to be home for his birth. I left for deployment on the USS Eisenhower aircraft carrier when he was eight weeks old and returned when he was eight months old. Joshua was always a very happy and responsive baby and toddler. He would smile and laugh at you and interact well with us. However, we noticed when he was around 12 months that he was not developing quite as quickly as other children his age. He was slow to sit (8 months), slow to crawl (12 months), and slow to walk (14-15 months). The pediatrician never noticed any significant delays and all milestones were reached within the normal range; however, just toward the tail end of that range. Joshua was also talking with a few words such as dog, Rebel (the name of one of our dogs), Mama, Dada, No, and a few other words by about 15-18 months. Soon after getting several immunizations around 18 months, Joshua experienced a complete loss of vocabulary. Not long after that he also began spinning. He would spin forever while cutting his eyes to the side. He never got dizzy. He sometimes toe-walked, but did not do this for long.
Due to my wife and I having the RH factor it was necessary for her to receive the Rhogam shot while pregnant. This was our first child and we were completely dependent and reliant on the knowledge of the doctors; therefore, when they gave her a second Rhogam injection with the explanation that the first was a bad batch we were not alarmed and continued to trust in their expertise. My wife’s pregnancy went smoothly, however her delivery at the Jacksonville Naval Hospital was very difficult. Her water broke and she was admitted to the hospital, but due to the doctor’s interpretation of her due date she was given medication to stop her contractions and put on bed rest with only ice chips to eat or drink. Forty-eight hours later she was given medication to reverse the process and restart the contractions. After almost twenty-four hours in labor and three days without food or proper nourishment, she delivered Joshua. I question the doctor’s decision and the amount of time Joshua was in the birth canal. Looking back now after discovering much research on the subject, I question the safety of the thimerisol in the vaccinations which were given to my child. Thimerisol is a preservative containing mercury used in many vaccinations. Mercury is a neuro-toxin known to cause harm in the human body. There are so many questions as to “why” and I know that I may never get those answers, but I will continue to do whatever I can to help him.

We contacted Tennessee Early Intervention when Joshua was about 22-24 months. They conducted a full evaluation and recommended only speech therapy. They brought a private speech therapist into our home two days a week. When he reached three-years old and we were pushed into the public-school system by Tennessee Early Intervention, we supplemented with private therapy. It was the private therapist who gave us our first diagnosis of Verbal Apraxia of speech. In retrospect, I look at the Tennessee evaluation and am frustrated with the inadequacy of services they provided. Joshua was found delayed in all areas, including fine and gross motor,
receptive and expressive language, and cognitive, although we were only provided speech therapy. He was our first child and we did not have any point of reference with which to compare his development. I am disappointed that I did not recognize the need for more services and push the issue at the time, especially since early intervention has been found to be highly beneficial (Read Their Stories, 2012).

Joshua continued to receive speech therapy and we moved to Colorado when Joshua had just turned 4 years old. We were in the suburbs of Denver and we went through Child Find. The school district assessed Joshua for preschool and performed the Autism Diagnostic Observation Scale (ADOS). They concluded that Joshua did not fall on the autism spectrum. They felt that his social awareness was too advanced to fit that criterion. They did, however, feel like he had Sensory Integration Disorder and put him in preschool with his peers, but provided an aide to work with him and a couple of other children in the classroom.

Around the same time, we took Joshua to a clinic called the Center for Inner Change, directed by Dr. Ron Minson, a neurologist and psychologist. He implemented a technique called Listening Therapy that was started by French physician, Dr. Alfred Tomatis. After spending a couple of hours with Joshua, Dr. Minson also told us he did not think Joshua was on the autism spectrum because of his interaction with the doctor during the evaluation. He engaged in play and initiated sitting on Dr. Minson’s lap. Dr. Minson said that he thought Joshua had Sensory Integration Disorder. He had no knowledge of what the school system had told us. We began a listening therapy there. We saw some imaginative play and drawing while undergoing this therapy that we had not seen in the past.

While Joshua was in preschool, his occupational therapist recommended a book to us called The Out of Sync Child by Carol Kranowitz (1998). While reading this book, my wife said,
“Why are we just now getting a diagnosis when there are stories about my son in black and white on the pages of this book?” Joshua did well in preschool but often demonstrated inappropriate behavior such as sprawling out in the middle of all the children during circle time. I mentioned the spinning and a time of toe-walking. Joshua also always enjoyed lining up toys, books, and other items, all the same theme. Like the experiences from other new parents who have been through the same thing, we just thought, “Wow, we have such a bright and organized child.” We still say that he will be the BEST librarian one day. He absolutely loves books. They are his favorite things. He organizes them and carries groups of them wherever he goes. One day he might carry all Disney books and another day all Bernstein Bear books, and then the next day pick a different theme.

Joshua went on to mainstream kindergarten there at the same school where he received Pre-K/early intervention. He had a child-specific aide with him always and did well with the other kids socially but was pushed to have social appropriateness and to succeed academically. We implemented another therapy while he was in kindergarten called sound and light movement at the Sensory Learning Institute in Boulder, Colorado.

Joshua was six years old when we moved to Vermont, where our educational battles began. Joshua started the school year about eight weeks late because of our PCS move and he was placed in the self-contained classroom “temporarily” so they could evaluate his specific needs. This placement became comfortable and we then had to push to get Joshua mainstreamed. Finally, around March, at the end of his 1st grade school year, Joshua was moved to the general education classroom where he completely flourished. Even the special education staff were amazed. I still remember meeting with the new principal going into our second year in Vermont and explaining how important it was for Joshua to be with his peers in the general
education classroom. He looked me in the eyes and made a profound statement I will never forget. He said, “You’re right, and it is just as important for the other students to have Joshua in class with them!”

Joshua then went on to 2nd grade in this same inclusive setting. He did absolutely amazing and participated in every way with his peers, from President’s Council on Physical Fitness to all school productions in the classroom and auditorium. He did have an aide who worked with him but he really flourished that year and he had different friends over to the house to play quite a bit. As a matter of fact, we still laugh remembering his eight-year-old birthday party (21 kids at a pool party). Needless to say, Joshua is a likable kid who reaches out socially to interact with his peers.

Joshua continued testing at Dartmouth Hitchcock Medical Center across the river in New Hampshire. He was given the diagnosis of Persuasive Developmental Disorder Not Otherwise Specified (PDD-NOS). His pediatrician at the local hospital in Windsor, Vermont was also one of the well-respected physicians teaching and training new doctors at Dartmouth. She was a wonderful member of Joshua’s support team and the only medical doctor I know who attended a child’s Individualized Education Program (IEP) meeting. The best description is one given by his pediatrician in Vermont, in which she said that Joshua was like a puzzle that we can’t find some pieces to. I remember well what she said about Joshua, that he was a special boy who met many of the characteristics of autism, yet had atypical traits of children on the spectrum. She concluded that Joshua was just . . . Joshua.

We were re-stationed in New Orleans less than a year after hurricane Katrina devastated the area. We enrolled both our children in the charter school on base at Belle Chasse Naval Air Station. We decided to move my wife and children down a month earlier than my orders had me
reporting, to allow the children to start school on time. We had just arrived in time to start the school year in August and had not fully unpacked all the boxes when already on the first day of school the teacher at Belle Chasse Academy decided Joshua did not belong in her class and fought to have him removed. We fought back and after many intense meetings with the principal and educational team over the course of the semester decided our children would receive a much higher quality education if we home-schooled them. We pulled lessons from different curriculums. We used ABEKA™ for language and math, and a combination technique for reading. Joshua’s memory is amazing, so we used EdMark™ reading program which is a sight word program and we also used a phonics program, so he received both. Joshua progressed academically; however, regressed some socially, not being in school with his peers.

During this time, Joshua underwent a routine tonsillectomy that was intended to be an out-patient procedure. He started hemorrhaging during surgery and ended up in the ICU with a life support machine breathing for him for an entire week. When we finally got him home, he walked aimlessly through the house, sitting down here and there for a second or two with a blank stare on his face. This post-traumatic stress was scary to watch and we feared he had slipped back into a deeper state of autism. I remember the words from the Neurologist at the Children’s Hospital, “How soon can you leave?” When we told her we just moved there, her response put my wife in tears, “Why did the Navy move you down here to New Orleans? We don’t have the services to provide for the care he needs. Most of our doctors never returned after Hurricane Katrina.”

Our second year stationed in Louisiana we moved to Picayune, Mississippi. Joshua was eight years old at the time. It was a charming southern town with a great family atmosphere. The daily commute to work was about 50 miles (one-way), but worth it to be out of the crime
ridden city area. The education system however was not much better in Mississippi. The school district was found in violation of five IDEA regulations the previous year, most of them regarding mainstreaming. We did not even attempt to put Joshua in school there. We did try the public school with his younger sister, but after a month felt she too would be better off being home-schooled with her brother. We did our best to keep Joshua involved with peers. He participated in Boy Scouts and AWANA at church and learned his memory verses like all the other kids. Game time was a bit wild though! Joshua’s biggest struggle was how to behave appropriately in an environment that is less structured. We lived in our camper for about six months at a campground with a nice family atmosphere. There were several FEMA trailers located on the grounds which were occupied by Hurricane Katrina evacuees. Getting to know these other residents really gave us an appreciation of how blessed we were.

Over the Christmas holidays that year we choose to try a new plan. I took the camper back down to Naval Support Activity New Orleans and lived at the family camp on base just across the river from the French Quarter and Lower Ninth Ward. My wife and children moved to Monroe, Louisiana where Joshua enrolled in Einstein Academy, a special school for children on the autism spectrum. This school specialized in Applied Behavioral Analysis (ABA) therapy. This school was very expensive and after one month we began discussing the value to cost ratio. Each Friday I would leave work and drive five hours to northern Louisiana to spend the weekend with my family, and then get up about 0200 in the morning on Monday to drive back to New Orleans to start work at 0730. One evening in February there was a knock on the door of our camper. My wife and kids were outside. They had had enough of the family separation and felt that our family being together was more important than any educational endeavors. We spent the next four months home-schooling in our camper on base in downtown New Orleans.
In May of 2008, just after Joshua turned 10 years of age, we conducted our ninth “official” Permanent Change of Station (PCS) move and our 14th move overall since 1995. My wife joked when we were unpacking boxes in the master bathroom of our new home in Colorado that it was almost bigger than what we had been living in for the previous ten months. The town in which we choose to live was Castle Rock. We chose this location for two main reasons: First, I was hopeful for a follow-on assignment at NORTHCOM in Colorado Springs after my tour at Buckley AFB in Denver, so I could commute south vice north and our family could remain more stable with regards to school and community. Second, we felt that the Douglas County School District would provide a comparable level of education to Cherry Creek School system in which we had been so pleased with several years earlier.

Our children were part of the first class to attend a brand-new school in Castle Rock. The special education team at the school was amazing. Joshua excelled and the IEP goals and objectives had to be re-written and raised several times. The special education director at the school said, “Joshua’s progress has been nothing short of a miracle.” For the first time in my career I could have a three-year tour of duty instead of the typical two. The stability during Joshua’s fourth, fifth, and sixth grades were a blessing and a key ingredient to his success.

In September of 2011, we conducted our tenth PCS move with the military and relocated to Cheyenne, Wyoming. We were excited to be going to a state which had its financial affairs in order. While Colorado and most of the country were cutting educational programs and services in their schools, Wyoming was expanding. We opted for a home-school/public school blended program and the local school system was very supportive. Joshua continued to be successful and made great strides of success. Back in Colorado, he participated in Special Olympic sports, but in Wyoming he competed in sports at junior high to include cross-country, swimming, plus track
and field with his peers during those two school years. The other student athletes were an encouragement to him and his cross-country coach called him “The heart of this team.”

Joshua continued to thrive as he transitioned into high school in Cheyenne, where he completed ninth grade with a blend of public and home-school. The theatre teacher sought him out to be in the spring play, the *Hobbit*. This was an amazing teacher who incorporated students with special needs into her theatrical performances. Some of her special needs students have gone on to study theatrical arts on the colligate level. In September of 2014, I turned over command and we were transferred to Gulfport, Mississippi. We continued to home-school; however, Mississippi is a state which is not very friendly toward home-schooling. Our house was very close to Keesler AFB in Biloxi. There was a large home-school population on the base and their home-school prom night on the installation had over 70 students in attendance. The church we attended had a large home-school co-op group that our children were part of and my wife taught there as well. When we sought out services from the public school for Joshua we were told “it is all or none.” This was a disappointment to us, especially since Joshua had thrived in Wyoming which worked with special needs students to provide a free and appropriate public education with the best blend of home-school and public school for each child. We found an alternative theatre resource in the way of WINGS, a nationally recognized performing arts program at Lynn Meadows Discovery Center. Joshua joined the program and participated in Disney’s *Tarzan* musical/theatrical performance. He also participated in *Dreams*, a production highlighting several musicals from the year. The *Dreams* production was held at the Beau Rivage Casino and Hotel on the Gulf Coast and attended by the current governor, the former governor and many other dignitaries. For Joshua, that really did not matter much; he was more interested in seeing the many family, friends, teachers and youth leaders who came out to
support him and cheer him on. While we did not receive a single bit of support from Mississippi, our 2014/2015 school year in the Deep South was still a success. This was a tribute to my wife and the teachers at the home-school co-op, as well as the director and staff of the WINGS program, who had great compassion for children with special needs like Joshua and included them in the performances as valuable members of the cast and stage crew.

About 10 months into my tour the position/billet I held was re-aligned and moved to Norfolk, Virginia. My detailer gave me the option of moving with the position or relocating to another billet elsewhere. God provided a position back in Colorado and our family was blessed to have the opportunity to live in the Rocky Mountains again.

In the summer of 2015 we made our 12\textsuperscript{th} PCS move. Joshua had just turned 17. Because of our great experience in Castle Rock previously, we decided to move back into our old house. It was good to be back in a state that valued parents’ involvement in education and worked well at accommodating the needs of the child. Joshua once again participated in a home-school public school blend with around 80\% spent in public education and 20\% in a home environment. The school district had a “Best Buddies” program which paired volunteer students without any disabilities with special needs students. Joshua’s “best buddy” was an extremely intelligent and very caring senior who made the world of difference in his junior year. She would sometimes pick him up to attend games or school functions together. They had a special friendship. We tried to get Joshua into the theatre department, but we were met with some resistance. He did participate in chorus and did well in all the school events. He did have advocates there at the school who watched out for him and he did have a good school year.

We again reached outside the public schools to allow Joshua to continue pursuing theatrical and performance acting. Joshua had a dream come true when he and his mother
became part of the cast of the *Thorn*. The *Thorn* is a passion play production which has been in existence for 20 years and been attended by thousands of people. Joshua became a joyful and encouraging member of the cast which affectionately called themselves “Thorniacs”. He put a lot of smiles on people’s faces during the many practices and the hours spent back stage.

Throughout Joshua’s junior year he continued to express that he wanted to go back to attend Central High School for his senior year. While he had a few friends in Castle Rock, he still remembered the friends he left behind in Cheyenne and the wonderful experiences he had there. Hearing our son’s heart and having concerns with recent changes in the administration and special education department, my wife and I began to explore the option of moving back to Wyoming. We researched graduation requirements as well as follow-on transition services after high school. The officials in Wyoming answered all our questions fully and with genuine concern. After much prayer and research leading us to believe Cheyenne would be a more beneficial environment for not only Joshua, but his siblings as well, we decided to move back to Cheyenne.

On August 1st we put a for-sale by owner sign in the yard. The first couple who visited our house bought it and we closed September 23rd. In the meantime, I moved the family up to Cheyenne the second week of August so they could start school on time. My wife and children stayed in our camper on F. E. Warren AFB in the Family Campground, while I moved our household goods into storage. Being in the base campground and getting to know many of the other families who were themselves in the middle of a PCS move or waiting for military housing to become available was a reminder of how transient the military lifestyle is. When the water was shut off for winterization, I moved my wife and children into the TLF (temporary lodging
facility) while I took the camper back to Denver for a place to sleep in at Buckley AFB. We closed on our new home in Cheyenne on Oct the 21st and started to move in immediately.

This was our 13th and last PCS/retirement move. This move was conducted while I was still working full time for the Navy and as I was in the middle of finishing this dissertation study. This recent experience has reminded me how demanding and stressful the entire moving process can be. I retire in May after 22 years of service and look forward to being back with my family full time. Fortunately, Cheyenne is only two hours from Denver and I get to be home often. Family separation is not ideal, it is a sacrifice, but when we see how well our children are thriving and hear Joshua say, “Thank you Mommie … Thank you for moving me back home,” then it makes all the sacrifice well worth it. Joshua received the warmest welcome home from friends, teachers, coaches and principals. Joshua is currently performing in the school’s fall play, a highly-edited version of *Little Shop of Horrors*, which is being co-directed by two students with special needs from the local community college theatre department.

Many people have asked us why we made this move and what the difference in the schools was. I believe my wife said it best when she said, “In Castle Rock, Joshua was a special education student who sometimes spent time with the regular education students; in Cheyenne, Joshua is a student of Central High School who sometimes spends time in the special education classroom.”

This summary of our experiences provides a necessary sense of the perspective I hold as the researcher, the human instrument in this qualitative study. To tell all the unique detailed stories would be a book in itself. Joshua’s education has been a mix of both positive and negative. Frequent moves from state to state and starting from square one with another school
district, battles with school administrators, strides of progress with certain types of therapies are all woven treads of the tapestry of our journey with Joshua’s education.

Like many other parents who have researched the subject of autism, the information I have learned has led me to certain conclusions and developed my personal paradigm. Bogdan and Biklen (2007) describe paradigm as a “loose collection of logically related assumptions, concepts, or propositions that orient thinking and research” (p. 24). Every parent has a paradigm based off their experiences. “Epistemologically, phenomenological approaches are based in a paradigm of personal knowledge and subjectivity, and emphasize the importance of personal perspective and interpretation” (Lester, 1999, p. 1).

While I have great personal knowledge on the topic and acknowledge approaching this study with subjectivity given my own perspective and experiences, I entered this research anticipating a paradigm shift through the research process. Covey (2000) described a paradigm shift as learning to view the world through the lens of another person. My goal was to have a paradigm shift, to see into the hearts and minds of military parents and understand their feelings about the challenges of serving in the armed services while at the same time securing an appropriate education for their children with autism. Knowing my strong feelings, I resolved to remain as neutral as possible when conducting the research as well as in the analysis of the information collected. I was ever mindful to differentiate any personal bias from the study by reflective journaling and using the member checking technique. However, there are many research experts who emphasize the importance of “making the researcher visible in the frame of the research as an interested and subjective actor rather than a detached and impartial observer” (Lester, 1999, p. 1). Being passionate and having strong feelings should not disqualify or discourage a researcher from pursuing such an endeavor. Passion is a compelling force not only
in the athletic arena but in the academic field as well. Denzin and Lincoln (2000) viewed the investigator as a passionate participant linked with the investigated in the creation of findings.

My passion to learn more about ways to help families of children with autism and share that information with others is straight from God and should be used to its fullest. As Maykut and Morehouse (1994) stated, “the human instrument is the only data collection instrument which is multifaceted enough and complex enough to capture the important elements of a human or human experience” (p. 27). I used a reflective journaling and decision trail to help me examine my own biases and assumptions. I worked to foster an atmosphere that encourages participants to expand and elaborate on their recollections of the experience (Ary et al., 2006). I also simply and humbly asked my Lord, who is the source of all wisdom, to help me remain as neutral as possible and guide me in all facets of this study.

**Summary**

Autism continues to be a concern. There are thousands of military families serving in the Armed Forces, while also raising and educating children with autism. Education and development is vital to each child’s life and plays a significant role in family readiness which directly affects operational readiness. Research is needed to explore the experiences of these families. The purpose and end goal of this study was to share the words of military parents expressing their concerns, and sharing their experiences and successes that might further autism research and help others.
CHAPTER TWO: LITERATURE REVIEW

Overview

The purpose of this phenomenological study was to describe the unique experiences of military families in the US who have a child with autism in grades K – 12, with particular focus on the efforts and processes parents take to ensure an appropriate education for their child(ren). This review of the literature chapter introduces the theoretical framework for this study and highlights the knowledge that exists on the topic of autism. It begins with a brief description of the history of the term *autism* referencing the work by Dr. Kanner, and Dr. Asperger. It then moves forward to discuss potential causes of the disorder such as genetics and environment and how this begins to affect the field of education. After establishing the definition of autism, the areas of concern and the controversy surrounding them, the review begins to address the issues and questions at hand such as providing children with autism the best possible education and supporting parents struggling to find answers. Several therapies and interventions are introduced to demonstrate the diversity of strategies available. The review discusses the current trends like the drastic increase in autism and the higher rate among military children. It incorporates the unique perspective of life in the military and sheds light on the challenges military service poses for families with a child on the autism spectrum. Several experiences from military parents are shared to give a rich description of obstacles they face and battles they fight. The chapter concludes with a summary that highlights areas where there is limited knowledge and areas where additional research is needed.
Review of the Literature

Historical Background

In 1943 Dr. Leo Kanner first described autism. In the article, Autistic Disturbances of Affective Contact, he described 11 children suffering from an “extreme autistic aloneness” (Blacher & Christensen, 2011). Across the Atlantic Ocean working separately from the Americans, Dr. Hans Asperger of Germany, described a similar group of children the following year in 1944 (Yazbak, 2003). All this research was being brought to light in the mist of WWII. Asperger and Kanner independently coined the terms autistic and autism respectively. Both terms come from the root word autos, which is the Greek word for self (Kirby, 2005).

Autism is a complex developmental disorder that causes issues with communication and social interaction. Children have very different symptoms and vary in their degree of severity. Individuals fall on a broad range; thus, causing the developmental disability to be considered a spectrum disorder. Today the terms Autism and Autism Spectrum Disorder (ASD) are commonly used interchangeably. The Autism Spectrum Disorders are classified as Classic Autism, Asperger’s Syndrome Disorder and Pervasive Developmental Disorders Not Otherwise Specified (PDD-NOS) (Autism Spectrum Disorders, 2011).

Possible causes. For several decades, autism was considered a psychological abnormality and was believed to be caused by poor parenting or more pointedly, refrigerator mothers, where mothers were perceived or assumed to not be providing their children love and nurturing (Gore, 2008). Genetics, environment, and vaccinations are three of the wider spread theories that are currently being considered and debated as potential causes of autism. It is important to point out and clarify that to this date there is no known cause for ASD. It is also important to be familiar
with the knowledge and research that is available to parents as each one of them will have a theory to why their child has autism.

Genetic factors are important in the causation of autism (Schettler, 2004) however, they are not fully explanatory. There have been several studies done on twins. If one monozygotic (i.e., identical) twin has autism, then the other twin has a 70-90% chance of having the same disorder, although the severity may differ considerably (Bailey et al., 1995; Folstien & Rosen-Sheidley, 2001; Steffenburg et al., 1989). The rate drops to 5-10% in dizygotic twins (i.e., fraternal twins). The chance of autism in siblings who are not twins is only slightly lower at 3-8% (Ruter et al., 1997). One study found that children of men 40 years and older were 5.75 times more likely to have autism than children of fathers under the age of 30 (Reichenberg et al., 2006). The researchers concluded that possible biological mechanisms include de novo mutations associated with advancing age or alterations in genetic imprinting.

While researchers think there is a genetic component to autism, they also believe environmental factors play a role in its recent increase (Investigating the Environmental Origins of Autism, 2008). Environmental mercury and other heavy metal exposure, pesticides and contaminated water may be factors. Palmer, Blanchard, Stein, Mandell, and Miller (2006) found a correlation between higher mercury levels and increased special education population. Many children with autism suffer from digestive diseases and seem to have a genetic disposition in which they are unable to naturally rid their bodies of toxins. Researchers are also focusing on the impact food has on the body. MacFabe (2008) studied autism triggers in rats and found improvements by diet modifications such as removing dairy and wheat (gluten). “To nail down the causes, scientists must unravel a mystery: What in the environment has changed since the early 1990’s that could account for such an enormous rise in the brain disorder?” (Cone, 2009, p.
1. Hertz-Picciotto, an epidemiology professor at the University of California, Davis, argued, “It’s time to start looking for environmental culprits responsible for the remarkable increase in the rate of autism in California” (Cone, 2009, p. 1). Dr. Bernard Weiss, a professor of pediatrics and environmental medicine agrees that the environmental causes should be getting more attention (Cone, 2009).

Due to the nature of the business in fighting wars, the military has a considerable amount of hazardous materials and toxins on bases. The military has a long history of working with the Environmental Protection Agency (EPA). With the Base Realignment and Closure (BRAC) rounds in 1988, 1991, 1993 and 1995, many military installations had to be “cleaned up” before ownership of the real estate property could be transferred over to state and local authorities. According to the Congressional Research Service, the total cleanup costs of the BRAC rounds using Department of Defense (DoD) data have been estimated at $3.6 billion (Cowan & Webel, 2005). A large number of military children live on base. Of those who live off post, many of them spend part of their day on base at school or attending other activities such as little league games, or at swimming pools, or child care centers. There are many different chemicals on military bases and it is not fully known the exposure level military dependents have to these harmful chemicals that likely include neuro-toxins. It is conceivable that exposure to chemical toxins may contribute to the higher rate of autism among military dependent children. It is interesting that the bases had to be “cleaned up” before turning them over to the community even though they were deemed safe for military families. To what degree the environment of military installations may or may not factor into the rate of autism is something that should be researched further.
Many researchers have theorized that autism is triggered by a pregnant woman’s exposure to chemical pollutants such as metals and pesticides which may be altering a baby’s developing brain structure (Cone, 2009, p. 1). Additionally, developing babies in and outside the womb might be exposed to a new infectious microbe, such as a bacterium or virus which may be disrupting the immune system. Hert-Picciotto addressed the complexity of the issue: “I don’t think there’s going to be one smoking gun in this autism problem. It’s such a big world out there and we know so little at this point” (Cone, 2009, p. 2).

The most controversial and highly debated theory is vaccines as a possible cause. Immunizations have become a cornerstone of western medicine theory and are widely held to be an important preventive health resource and accepted to be part of the basic health strategy throughout the United States of America and the western world. All states have rules in place concerning immunizations and public school attendance. There has been a trend across the nation in recent years in which many states are showing an increase in vaccination waivers or exemptions. Part of the rise in home-schooling is due to vaccination concerns (Olmstead, 2005, p. 3).

Some researchers say there is evidence that a relationship exists between thimerosal and autism (Bradstreet et al., 2003; Geier & Geier, 2003; Kaye et al., 2001; Thompson et al., 2007). Thimerosal is a mercury-based preservative used in vaccines. It is also a neurotoxin believed by many to be a contributing cause or at least a catalyst in pushing America’s autism rate to about one in 68 children (CDC, 2016). Thimerosal is a cream-colored, water-soluble, crystalline powder that is 49.6% mercury in weight. It was developed by the Eli Lilly pharmaceutical company in the 1920s. Autism was not identified by Kanner and Asperger until the 1940s, a few years after thimerosal was introduced in vaccines. Because thimerosal was widely marketed as
safe, it was grandfathered onto the list of approved list of medical additives by the Federal Drug Administration (FDA) which was established after the preservative was invented. Thimerosal never underwent the rigorous safety testing required for FDA approval (Kirby, 2005).

There are some smaller groups of the population that seemed to be immune to autism. The Homefirst Health Services in Chicago, Illinois has a diverse group of white, black and Hispanic families. Their approach to medicine is more naturalistic and thus they tend to attract families who have concerns over immunizations. The medical director who founded the practice in 1973, Dr. Mayer Eisenstein said, “We have a fairly large medical practice. We have about 30,000 to 35,000 children that we’ve taken care of over the years, and I don’t think we have a single case of autism in children delivered by us who never received vaccines (p. 1).” Eisenstein continued, “We do have enough of a sample. The numbers are too large not to see it. We would absolutely know … it’s not something that anyone would miss” (Olmsted, 2005, p. 1). Dr. Paul Schattauer has been treating about 100 children a week for 20 years with Homefirst and agrees with Eisenstein, “All I know is in my practice I don’t see autism.” (Olmsted, 2005, p. 2).

Schattauer stressed that more research on autism needs to be carried out independent of political or business pressures, “In no way would I be an advocate to stand up and say we need to look at vaccines, because I don’t have the science to say that, but I don’t think the science is there to say that it’s not” (Olmsted, 2005, p. 2). There seems to be the same phenomenon of an absence of autism in the mostly unvaccinated Amish communities of Lancaster, Pennsylvania. The CDC director Dr. Julie Gerberding said, more studies could and should be done in more representative unvaccinated groups, because the Amish “have genetic connectivity that would make them different from populations that are in other sectors of the United States” (Olmsted, 2005, p. 2).

There may in fact be another diverse group. Dr. Jeff Bradstreet, a pediatrician in Florida who
treats children with autism from around the country, mirrors Eisenstien’s observations and has found virtually no autism in home-schooling families who decline to vaccinate for religious reasons. “There was this whole subculture of folks who went into home-schooling so they would never have to vaccinate their kids. There’s this whole cadre who were never vaccinated for religious reasons.” In that subset, Bradstreet said, “unless they were massively exposed to mercury through lots of amalgams and /or big-time fish eating, I’ve not had a single case” (Olmsted, 2005, p. 3).

A few years ago, the rate of autism within the general public was one in 150 (CDC, 2007) children while the military subgroup was at one in 88 (Yazbak, 2003). Now, in 2016 the general public rate according to the CDC is one in 68 (CDC, 2016a); however, the DoD has not released any official rates of autism in recent years. The military is one of the most immunized groups in the world. Military members are conditioned to receive multiple vaccines and all at one time whether wanting them or not. Hundreds of members of the service have been disciplined and administratively separated from the military because they refused the mandatory anthrax vaccinations (Holguin, 2009). The Department of Defense (DoD) is one of the largest buyers and consumers of vaccinations (Drug Pricing Program, 2011). Lobbying groups push the importance of immunizations to those making the health care decisions for the entire force. Pharmaceutical companies that can obtain those contracts make millions in revenue each year. Northwestern University and the Center for Public Integrity teamed up on a joint project examining 22,000 travel disclosure forms by DoD personnel. Between 1998 and 2007, the private health care industry funded 8,700 trips by DoD personnel at a cost in excess of 10 million. An example is the $7,800 GlaxoSmithKline, one of the world’s largest drug manufacturers, paid for Dr. D. Heppner (Lieutenant Colonel and the Chief of Walter Reed Army
Institute of Research’s Department of Immunology) to attend the company’s 2006 symposium on malaria in Paris. The DoD prescription drug budget rose from $1.6 billion in 2000 to over $6 billion a year by 2006 (Pell & Metha, 2009). DoD employees who prescribe, purchase, and recommend the use of drugs to military personnel and their families are an attractive target for the drug companies and device manufactures. Pell and Metha (2009) found a correlation between perks bestowed on physicians and increased probability, that although usually unknowingly, physicians would prescribe a company’s drugs. Medical ethics experts have pointed out the serious conflict of interest issues. The head of the DoD’s pharmaceutical program, Rear Admiral Thomas McGinis, banned his own staff from taking trips funded by private companies; however, other military pharmacy staff went on hundreds of trips.

The concern about the financial ties to pharmaceutical companies of those making policy decisions about children’s health is not just limited to the military, but affects the public as well. In 2009 Senators Herb Kohl (Wisconsin - D) and Chuck Grassley (Iowa –R) introduced bipartisan legislation that would require medical device manufactures and drug companies to disclose to the public all gifts valued at more than $100 given to physicians. The ethics concerns will continue to be an issue for the military as the Government Accountability Office forecasts the DoD spending on pharmaceuticals to reach $15 billion by 2015 (Pell & Metha, 2009).

The medical community is divided on its views about immunization and vaccine safety. There have been studies conducted that show no causal relationship exists between the thimerosal in vaccines and autism (Kaye et al., 2001; Thompson et al., 2007) as well as those that show there is indeed a correlation (Bradstreet et al., 2003; Geier & Geier, 2003). Thompson et al., (2007) found no link between early thimerosal exposure and neuropsychological outcomes at 7-10 years, and neither did Kaye et al., (2001) in a trend analysis of mumps, measles, and
rubella vaccine and the incidence of autism. Geier and Geier (2003) investigated thimerosal in childhood vaccines, neurodevelopment disorders, and heart disease in the United States and found there was a correlation. Bradstreet et al., (2003) conducted a case-control study of mercury burden in children with ASD and found that there is indeed a link between mercury and autism. The financial backing of studies can cause undue influence. It appears more research is needed by independent researchers.

The government does acknowledge the risk of vaccinations and has paid out over $1.5 billion dollars in damages to families for injuries and deaths related to vaccine reactions. Each year the Food and Drug Administration receives between 12,000 to 14,000 reports of adverse vaccination reactions resulting in hospitalization, injuries, and deaths to the Vaccine Adverse Events Reporting System (VAERS). It is also estimated that 10% of vaccine injuries are not reported (Klicka, 2007).

In 1986 Congress created a federal claims court to compensate damages for vaccine injuries or death. In November 2002, the Homeland Security Act received a last-minute rider which funneled all thimerosal related vaccination lawsuits into what had become known as the Vaccine Court. This piece of legislature shielded drug makers from liability by having awards paid out of a taxpayer-funded account, rather than the companies themselves (Kirby, 2005). The two-paragraph provision that slipped into the massive legislative document dismissed hundreds of civil suits filed by parents against drug manufactures such as Eli Lilly for allegedly producing dangerous levels of mercury into their children’s vaccines. The rider was championed by Republican Senator Bill Frist of Tennessee, a medical doctor with strong ties to the drug industry. On November 18, 2002, fellow Republican Dan Burton, a Congressman from Indiana, went to the House floor and demanded that the rider be removed arguing the newly added
provisions did not belong in the bill, arguing, “This is not a homeland security issue. This is a fairness issue” (Kirby, 2005, p. 6). Burton saw firsthand the adverse reaction to vaccinations when his grandson became gravely ill after receiving multiple vaccinations containing thimerosal in a single day. Within days after receiving the shots the boy began flapping his arms and banging his head against the wall as well as scream indiscriminately while wandering aimlessly around the house. The doctor’s diagnosis was delivered – autism. In a statement released the same day, Burton warned,

We have an epidemic on our hands. More and more parents believe that the autism affecting their children is related to a mercury preservative used in numerous vaccines given to our children. These provisions in the Homeland Security Bill will cut off their recourse to the courts, and that’s just wrong. Instead of passing legislation to take away the rights of families with vaccine-injured children, we should be passing legislation to try to help them (Kirby, 2005, p. 6).

Senate Democrats agreed with Burton and offered a motion to eliminate the piece of legislation which had become known as the Lilly rider after the pharmaceutical giant Eli Lilly. They were opposed by Frist, however, who said, “We are a nation at risk. The threat of liability should not become a barrier to the protection of the American people” (Kirby, 2005, p. 6). Kirby (2005) in his book Evidence of Harm wrote, “The implication was that thimerosal liability protection was essential if companies were going to develop vaccines against bioterrorism weapons like smallpox and anthrax. But Frist failed to mention that these vaccines contain no thimerosal whatsoever (p. 6).” The same day the bill passed, lawyers from the Bush administration quietly filed a motion in the Federal Vaccine Court to seal off the records
regarding all thimerosal-related material handed over by the government. Many observers were left wondering why this backdoor legislation was rushed through so quickly (Kirby, 2005).

Court cases concerning the autism-vaccine link continue to be decided in jurisdictions across America. The government has paid out more than $900 million for vaccine injuries in the last two decades (Kotz, 2009). Forty percent of the vaccine triggered autism cases have been decided in favor of the families (Kirby, 2009). A highly-publicized case decided February 12, 2009 did not favor the families. The Special Masters in the case “inferred that the vaccine-autism theory was the stuff of Alice in Wonderland fantasy and virtually accused the children’s physicians of medical malpractice” (Kirby, 2009, p. 3). It is interesting that the court would make this reference since the Mad Hatter was more than just a fantasy character from Disney’s *Alice in Wonderland*. Hat-makers throughout England in the 1800s were exposed to the toxic vapors given off from the mercury-based compound used to stiffen top hats. The conditions caused by inhaling mercury became commonly known as Mad-Hatters disease and are very similar to characteristics of autism today (O’Shea, 2001). Pink disease (infantile acrodynia) is also a disorder that was prevalent at the turn of the 20th century. Infants were given teething powder that contained mercury as an active ingredient. Many of the children developed symptoms and characteristics very similar to children with autism today. Approximately one in 500 children exposed to the neuro-toxin through teething powder developed the condition (Shandley & Austin, 2011). A recent study, which targeted the potential link between pink disease and autism, found the prevalence of ASD among the grandchildren of pink disease survivors to be one in 22 (Shandley & Austin, 2011). This rate is substantially higher than the CDC reported rates for the general public and suggest that mercury sensitivity may be a risk factor for ASD.
Again, it is important to discuss the topics of autism however controversial they may be. Something is causing this autism explosion. It is helpful to understand some of the concerns and theories parents have about the subject. While this study will not answer those questions regarding the causes of autism, this review echo the words of many physicians calling for more studies to find out what is causing this epidemic. In conclusion, the following words from Aaron Liebowitz’s (2008) in the forward of his book, Voices of Autism are very applicable: “Finally, it is hoped these stories will remind researchers who are seeking answers for the causes and cure for autism, that a child is waiting [emphasis added]” (Gore, 2008, p. xii).

**Costs.** While the debate over the safety of vaccines and root causes of the disorder appear to be far from over the rate of autism has continued to rise and there are not any immediate signs of it decreasing. Ten years ago, the Harvard School of Public Health (Harvard, 2006) found the cost of caring for a person with autism over his or her life to be $3.2 million. They broke down the cost per year into two components. Direct costs included medical costs such as behavioral therapies and physician services and were estimated at $29,000 per person per year. Indirect costs were non-medical costs such as special education and child care and were estimated at $38,000 to $43,000 per person per year depending on the level of disability (Harvard, 2006). The soaring rate of autism is also a concern to school districts as it increases the number of children on Individualized Education Programs (IEPs). The required extra assistance is causing the cost of special education to continue escalating. Special services can cost a school system $30,000 or more per year for each child with autism (Yazbak, 2003).

**Current trends.** The U.S. Department of Health and Human Services (2007) surveyed 78,000 households to estimate the prevalence of ASD. The survey found the prevalence rate to be 110 per 10,000 children between the ages of 3 and 17. The rate continued to increase with
some studies indicating rates as 1 out of 91 children to 1 in 57 boys when the numbers are broken down by male and female (Kogan et al., 2009). Some other interesting findings from the study were:

- Those living in the Midwest and Northwest had higher odds of having ASD.
- Children whose parents had less than 12 years of education had twice the odds of not having an ASD child.
- Non-Hispanic black and non-Hispanic multiracial children had 57% and 42% lower odds of having ASD than non-Hispanic white children.
- Children born between 99-01 were 54% more likely to have ASD.
- Children born between 96-98 were 83% more likely to have ASD.

It is worth noting that the older birth cohort of 9 to 11 year olds was exposed to larger amounts of ethyl mercury than the 6 to 8-year-old group. There was one glimmer of hope in an otherwise depressing study. The health survey, for the first time, asked if the child diagnosed with ASD currently has the disorder. Over one third (38.2%) responded no. This is truly the bright spot of the study and supports recent research that recovery is possible for children diagnosed with autism (Kogan et al., 2009). Since this study in 2007, the CDC has increased the rate of autism from 1 in 110 based off the 2006 surveillance year to 1 in 88 based off of the 2008 surveillance year. Based off the 2010 and 2012 surveillance years the CDC currently has the rate of autism listed as 1 in 68 (CDC, 2016a).

**Intervention and therapy.** If it is possible for a child to recover from autism as some research suggests, the next question becomes, how? Regardless of how the child developed autism, once a child has been diagnosed with the neurological disorder, it is vital to determine the next step. The strategies for treating or reaching recovery of autism are almost as
controversial as the causes. There is a broad range of opinions and emotions regarding how professionals and parents view the outlook and future of children diagnosed with ASD. At one extreme are those who believe institutionalizing children is the best solution, while the other extreme believes with intense intervention that recovery and removal of the diagnosis is possible. Most parents are somewhere in the middle and continue to utilize various strategies to help children accomplish their full potential.

There are many interventions and therapies developed to help children with ASD. A few educational accommodations and modifications are Handwriting Without Tears, SRA Reading Mastery Program, and Touch Math. Two established behavioral interventions include Applied Behavioral Analysis (ABA) and the Social Communication, Emotional Regulation and Transactional Support (SCERTS) Model. Speech therapy and occupational therapy are a couple of functional interventions. Another form of therapy that shows promise is nutritional/dietary intervention. This type of therapy falls within the larger umbrella of Bio-Medical Interventions. Defeat Autism Now (DAN) started by Autism Research Institute (ARI) and Dr. Bernard Rimland is an approach dedicated to exploring, evaluating and spreading the news of scientifically documented biomedical interventions for individuals within the autism spectrum. This is promulgated through the collaborative efforts of clinicians, researchers and parents. Autism Research Institute and DAN believe recovery from autism is possible and plausible. This is accomplished beginning with the gut using the 3 R’s method which is: (a) Remove – through a GFCF diet, (b) Replenish – through probiotics and (c) Repair and Restore – using enzymes, multivitamins rich in B complex and B6. Other biomedical interventions include Hyperbaric Oxygen therapy (H-BOT) and Chelation therapy. Through many types of interventions children with ASD are continuing to improve and lead better lives.
Military concerns. The military community is a cross section of society. It is made up of members coming from every state and U.S. territory. There are even a few members serving in the US armed forces from other nations who have not yet obtained American citizenship. There are members of almost every ethnicity and race represented in America currently serving in uniform. Soldiers, airmen, sailors and marines also come from a multitude of religious backgrounds. Just like the United States of America, its military is a melting pot made up of people from many different walks of life. One common bond that all servicemen and women share is their love of country. They are all united in one clear purpose: “to defend the Constitution of the United States against all enemies foreign and domestic” (U.S. Code, 1966).

Unfortunately, many military families also share another common bond – raising and educating a child with autism. For many this involves loving and caring for a child who cannot show appreciation and love in return. Of the sub groups within the general population the military has one of, if not the highest rate of autism, with numbers as high as one in 88 when the general population rate was one in 150 (Yazbak, 2003). The DoD has not released any official autism statistics recently. In 2010 the Army’s Fort Leavenworth school district reported the percentage of students with ASD on post to be 1.28 while the state average was .47%. Why military dependent children seem to have a higher rate of autism is a research question topic in itself.

The Department of Defense has identified a concern about the number of military dependents with autism and the special considerations it brings to the service member’s career. Each branch of the service has a program designed to identify and help families having dependents with special needs. These include physical impairments such as blindness and missing limbs. It also includes medical conditions such as cerebral palsy and chronic heart
disease, as well as other disorders such as autism. The Exceptional Family Member Program (EFMP) was initiated in September 1987 by the U.S. Army in efforts to ensure compliance with public law that mandated a Free and Appropriate Public Education (FAPE) be provided for eligible pre-school and school-age children with disabilities at overseas locations within DoD areas of responsibility (Cummins, 2010). Soon after its creation, the EFMP was adopted by all branches of military. Commander Cynthia Chargois Granby, who oversaw the EFMP while assigned to Navy Personnel Command in Millington, Tennessee, described the program as a multidisciplinary assignment initiative interfacing civilian and military agencies to coordinate comprehensive medical, education, community and personnel support to military families with special needs (Cummins, 2010). Family members are enrolled in the program once a medical, mental health or special education requirement of a chronic nature (six months or longer) is identified. Special needs are usually identified during routine visits to a Tricare health provider or medical treatment facility (MTF); however, some children’s needs go unreported for various reasons. Master at Arms Second Class Petty Officer Emily Buster discovered this process through her child’s pediatrician. In October 2008, at one year of age, her son was diagnosed with autism spectrum disorder (ASD) and macrocephaly (an abnormally large head). Buster explained how the doctor helped them fill out and sign paperwork verifying his condition and indicating the type of treatment he required. She said, “The proper forms were then submitted to the EFMP to be reviewed and accepted. It is a fairly simple process. Before the birth of my son, I had heard of EFMP, but only as something next to somebody’s name” (Cummins, 2010, p. 24).

Regional central screening committees (CSC) at Naval Medical Center (NMC) Portsmouth, Virginia, NMC San Diego, California, and U.S. Naval Hospital Yokosuka, Japan review the enrollment paperwork forwarded from the MTF EFMP coordinators scattered
throughout the Fleet. The CSC recommends a category code for the family member and then forwards all documentation and recommendations to the Navy’s EFMP office. It is there that the category code is confirmed and entered into a data-base where assignment coordinators, called detailers, for each community within the Navy, can ensure resources are available before assignments to various duty stations are made. The process is very similar in all service branches.

There are six assigned categories within the EFMP. Family members are placed into one of these based on the type of medical and educational interventions the individual requires. The diagnosis of autism is an automatic category V (Cummins, 2010, p. 27).

Table 1

*EFMP Categories and Descriptions*

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category I</td>
<td>Needs do not generally limit assignments. Enrollment is designed for monitoring purposes for medical or educational needs.</td>
</tr>
<tr>
<td>Category II</td>
<td>Limited overseas assignments. Care is usually available with some exceptions. The family must successfully pass an overseas screening.</td>
</tr>
<tr>
<td>Category III</td>
<td>Limited or no overseas assignments due to non-availability of medical / educational services at most overseas locations. Must successfully complete overseas screening.</td>
</tr>
<tr>
<td>Category IV</td>
<td>Medical / educational condition requires assignment to billets near major medical treatment facilities inside the continental U. S.</td>
</tr>
</tbody>
</table>
### Category V
Multiple/severe disabilities or highly complex educational/medical requirements. Assigned to geographic areas with heavy military concentration where service member can homestead and fulfill both sea and shore duty requirements.

### Category VI
Temporary category where medical/educational condition requires stable environment for six months to one year for treatment of diagnostic assessments. At one year member is either dis-enrolled or given a permanent category.

---

The U.S. Navy streamlined its Exceptional Family Member Program (EFMP) enrollment on September 1, 2011. It launched an EFMP enrollment and tracking application on the Navy Family Accountability and Assessment System (NFAAS) website (Wheeler, 2011). The NFAAS website was developed as a tool to help keep the most complete and current data on their employees and family members. It is used to contact and account for dispersed personnel in natural disasters like hurricanes and tsunamis, like the one which hit the coast of Japan on March 11, 2011 and caused a sizable evacuation of military dependents back stateside to America. Commander Carl Chaffin, the program management officer for the Navy’s EFMP, believes this will benefit sailors by expediting the process, saying “Case liaisons can track the member’s non-medical information and referrals more effectively and electronically log individualized service plans” (Wheeler, 2011, p. 1). The new features are based on feedback and input from the Fleet and replaces the old paper-based enrollment system.

**Military health insurance.** Military families are blessed to have outstanding medical benefits. Tricare is the name of the health service program used by the armed forces. To access
Tricare, individuals must have a valid uniformed services or military identification (ID) card and be registered in the Defense Enrollment Eligibility Reporting System (DEERS). DEERS is the database of uniformed service members (sponsors), family members, and others who are entitled under law to Tricare benefits (TRICARE, 2004).

The financial costs of treating children with autism are staggering. Tricare offers optional plans; however, the greater the flexibility, the more out of pocket expense is required of the member. Tricare approves and covers a portion of occupational therapy and most laboratory tests ordered by regular physicians and Defeat Autism Now (DAN) doctors; however, not all autism treatment therapies or interventions are covered. For instance, hyperbaric oxygen therapy (H-BOT) has been found to be very beneficial to children on the autism spectrum because it increases the oxygen in the blood stream which supplies the brain (Rossignol et al., 2009). This treatment, however, not covered by Tricare for ASD patients. This is very disappointing, especially considering there are so many hyperbaric chambers on naval bases which use H-BOT for soldiers with severe burns and Traumatic Brain Injury (TBI) (Rupe, 2009).

The military provides an additional health benefit for children with severe disabilities called the Extended Care Health Option (ECHO). The ECHO replaced the Program for Persons with Disabilities (PFPWD). Enrollment in the EFMP is required to access benefits through ECHO. These benefits allow up to $36,000 per year, per child. The monthly cost share per family is between $25 and $250 according to rank. Each eligible family member is limited to $2,500 per month (TRICARE, 2011). One method or way the funds are used is for in-home respite care services; however, most parents with children on the autism spectrum use ECHO funds for Applied Behavioral Analysis (ABA) therapy.
ABA, formerly known as behavioral modification, is a type of therapy in which the principles of the analysis of behavior are systematically applied to improve socially significant behavior. It is widely recognized as an effective treatment for autism and is endorsed by a number of states and the U.S. Surgeon General (“Applied Behavior Analysis,” 2013). One of the major limitations of the program is that the person that works hands on with the children must be a Board-Certified Behavior Analyst (BCBA). There is a shortage of BCBAs across the country and they are usually the supervisors training those college graduates that are studying for their BCBA exams and logging their clinical hours by working hands-on with children with autism. Many families pay out of pocket for ABA therapy; however, most families could not afford that option. In 2009, a Congressional inquiry was filed to study autism services at Camp Lejune, North Carolina, the largest Marine Corps base on the East Coast. It was found that of the 106 children diagnosed with ASD, only 11 were enrolled in ECHO. There were no TRICARE network ABA providers available. There were 200 children on the waiting list for ABA therapy. According to 2008 statistics, only 10% of military dependents with autism were enrolled in ECHO. About 11,000 children with ASD are not enrolled either because their parents are not aware of the program or there are no ABA providers available. In Norfolk, Virginia, the most concentrated area for naval personal on the East Coast, one military mom saw a need and went into action. The Mea’Alofa Autism Support Center (MASC) now provides ABA services to over 40 children, many from military families. The founder and military mom, Keri Peko, said, “I realized that if we weren’t able to afford to provide our daughter with what she needed, surely those of a lower rank or those with multiple children affected by autism wouldn’t be able to” (Rupe, 2009, p. 104).
Legislative issues. In 2011 military families filed a motion for an injunction to mandate that Tricare cover medically necessary care needed by children with autism. The case, *Berge v. United States of America, et al.*, is moving through the court system (Wrightslaw, 2011). The ECHO program is only available to certain qualified active duty members. A recent estimate from the Congressional Budget Office shows only 700 of the approximate 8,500 active duty dependent children with autism are enrolled in ECHO.

In 2008 bipartisan legislation was introduced in the U. S. House of Representatives by Virginia Congressman James P. Morgan (D) and Florida Congressman Jeff Miller (R). The “Military Family Autism Equality Act,” HR 3690, called for broader coverage to include children with autism of military retirees. Department of Defense data indicates almost 9000 retiree families would benefit from this legislation. Representative Miller said,

This bipartisan bill to extend needed medical coverage for children of military retirees with autism is long overdue and I’m pleased that Congressman Morgan and I were able to address this issue together. Autism is an insidious disease inflicted upon our children and we should live up to our obligation to serve the children of those who have served this nation (Miller, 2008).

Caring for children with autism is expensive. Military families are already stretched thin by the high costs associated with the autism and long deployments overseas. Representative Moran went on to say that parents are often left with a choice no parent should face, “provide expensive treatments for their child or keep their family clothed and fed. This legislation will eliminate that painful decision” (Wrightslaw, 2011). The bill has yet to make it through Congress.
Military life. One of the major challenges to any family in the military is the constant and consistent moves that take place every two to four years. On one hand this is an exciting way of life as families get to experience new regions and cultures. There is also a more difficult side many do not take into consideration. Every move means finding new schools, new doctors, making new friends and establishing a new routine. While the military provides assistance to physically move their employee’s household goods, the family logistical preparations can be stressful. Often the families are split up temporarily as the military member moves to the new duty station to establish a footprint and the family catches up later after housing becomes available. Many military installations have long waiting lists for base housing. For the families having children with special needs the move is usually harder on everyone. One Army wife said,

We are on our third move and third deployment in four years. I struggle supporting my husband’s battalion and both my sons. Suicide rates and divorce rates are up for the Army, and add special needs to the mix, and it is bad. Bottom line, we need help and we are not getting the support we need. (Rupe, 2009, p. 103)

The Centers for Disease Control and Prevention (2011) found the 2009 average rate of divorce in America at 3.5% compared to the average marriage rate of 6.8%. Statistics show that many children with autism live in split families. The divorce rate is even higher in the military. Since 9-11 and the start of Operation Enduring Freedom the divorce rate for military increased from 2.6% in 2001 to 3.6% in 2009 (Bushatz, 2010). Between 2001 to 2004, the divorce rate among Army officers almost tripled to 6%. In 2004 there were 3,325 Army officers that saw their marriages come to a crashing end. During that same time period the divorce rate among the Army’s enlisted soldiers more than doubled (Burgess, 2005). The deputy director of government relations for the National Military Family Associations, Kathleen Moakler, speaking about the
Army’s divorce rate said, “It is not surprising.” Repeated deployments to places such as Iraq and Afghanistan “take a toll on family life. Military families are being asked to make enormous sacrifices and unfortunately, not every family structure is up to the challenges.” Due to the incredible stress and emotional burden, according to a study by the University of Wisconsin-Madison, couples in the general public with a child with autism are twice as likely to get a divorced as those without the disorder (Ghose, 2010). Unfortunately, it stands to reason that the divorce rate among military families with children having autism would be higher as well.

Military home-schooling. One of the recent trends in education is home-schooling. With numbers increasing as much as 12% in recent years, experts estimate there are two million home-school children in America. A 2001 Army survey found that 2.7% of military children were home-schooled, a rate twice the national average. If the rate within the military continued to climb at the same pace as the nation, the rate in 2007 would have been around six percent equating to about 70,000 military children learning at home (Anderson, 2010). A study released in 2016 based off data from 2012 found the national home-schooling rate to be 3.4% (Redford, Battle, & Bielick, 2016). The DoD has not released statistics on military dependent home-school rates. If the trend within the military continued to grow proportionately to the national rate, then the prevalence rate would be about 7%. The constant moves and need to resettle into a new school is very difficult for military children. For home-schoolers, the school travels with them. New opportunities for unique learning and field trips get refreshed with every new duty assignment. Home-school veterans cite local co-ops, church groups, and home-school groups as indispensable supports while also helping their children socialize (Anderson, 2010). Many families choose to home-school, but for many parents such as dual military couples or spouses
who have a civilian career, this may not be an option. Children with special needs may also require greater resources than what parents can provide at home.

**Moving with the military.** Children on the autism spectrum typically have a more difficult time adapting to change. For the military change is a way of life. There is constant change, PCS moves, positions and assignment changes, work and watch standing changes, promotions, and deployments to areas of responsibility (AORs) around the globe. Deployments are stressful on all families. Major adjustments happen when a father or mother leaves for a three month to year-long assignment. Having children with autism only magnifies and intensifies the level of stress during deployments periods. When talking about her son’s regression during deployments, one Air Force spouse said, “He would shut down for a while, regain ground, and regress again when Dad would return” (Rupe, 2009, p. 104).

When families move to a new area, they are often on the waiting list for months and sometimes years before services are available. An updated Individualized Education Program (IEP) will need to be created as the child begins school in a new state with different guidelines and regulations. Continuity of care is one of the most crucial issues affecting military families.

Kelley Cotton, a Military Officers Association of America lobbyist specializing in family issues is also a parent of an eight-year-old child with special needs. She says, “Ask any military family their number one frustration, and you’ll hear the word transition” (Rafferty, 2011, p. 52). High school students have to worry about whether educational differences such as course requirements between the states will prohibit them from graduating. Most military children will attend six to nine different school systems by the time they reach 12th grade (Rafferty, 2011, p. 54). The average military student will face transition more than twice during high school. Seventy percent of military dependents attend schools off military installations and are affected by
differing policies between school districts. Parents of children with special needs usually have a short window of opportunity to line up educational plans and medical support before relocating. “The biggest frustration is starting over with a new doctor and defending the care my child has received”, says Cotton, “I’m always looking for someone to get to know my child, the history of the condition, who understands the things we’ve done and ways we’ll go forward. And you don’t often find that” (Rafferty, 2011, p. 55). Former Navy lieutenant Jeremy Hilton, whose wife is on active duty with the Air Force said, “It takes me six months (after moving) to reestablish a support system because of all the things you have to get done. Special education for military kids is tough” (Rafferty, 2011, p. 55).

**Department of Defense schools.** Almost 200 years ago, in 1821, Congress first established a law allowing the operation of schools on U.S. military post. It was after WWII that the current Department of Defense Education Activity (DoDEA) really began to take shape. With the defeat of the axis powers and a return to peace, parents began to organize small schools for dependent children in foreign occupied countries. In 1946 the Department of the Army established the first dependent schools, both on and off base, in Japan, Germany and Austria. Within a few years there were around 100 schools on foreign soil operated separately by the Army, Air Force, and Navy. The three separate school systems were combined into the Department of Defense Overseas Dependents School System in 1964. In 1979 the Office of the Overseas Dependents Education changed to the Department of Defense Dependents Schools (DoDDS). In 1992 the U.S. based Domestic Dependents Elementary and Secondary Schools (DDESS) was combined with the DoDDS to form the Department of Defense Education Activity (DoDEA) (DoDEA, 2011).
Today, about nine out of ten military children are educated through public schools, many of which are on military installations. The Department of Defense (DoD), through the Department of Defense Education Activity (DoDEA), operates 167 schools serving 72,869 students on bases around the world (DoDEA, 2016). Another 159 schools are operated by local school districts onboard stateside military installations. Total, about 150,000 children attend these schools. Because many of these were established shortly after WWII they are typically old and have structural deficiencies. Local school districts are having difficulty finding money to replace inadequate facilities. The Pentagon has placed 78% of its schools in the two worst categories; poor or failing, in terms of its facility standards. A 2010 report showed almost 40% of schools run by local public systems on Army bases also fall in the worst categories. Onboard the Marine base in Quantico, Virginia, Russell Elementary School has old air units, busted water pipes, and only one handicapped-accessible bathroom, which is too small for some children to navigate in their wheelchairs. Another DoD school, Boeblingen Elementary School, located on an Army post near Stuttgart, Germany was built by the Nazis and used by Field Marshal Rommel as a barracks for his tanker troops. This is the DoD’s oldest school and it needs modernization. Some improvements like fire escapes were added only after the school was cited for nine fire safety violations in 2006. A former Representative from Texas, Chet Edwards said, “I would feel disrespected if I were on my second or third tour of duty and my kids were in a school that was so dilapidated and too small or falling apart…there are a lot of serious problems” (Lombardi, 2011, p. 12).

The 1978 Defense Department’s Education Act, U.S. Code Title 20 Chapter 25A, 921 requires “academic services of a high quality” be provided to children of military members on active duty. The law also directs that “the Secretary shall provide programs to meet the special
needs” of these children (Cornell University Law School, 2011, p. 1). The federal government spends about 30 million dollars each year in “impact aid” to 120 local school districts that educate many military children. Sometimes the money does not directly go to the benefit of those students. Unfortunately, the students lose when local school systems and military installations differ over who is financially responsible and how funding priorities fall in place.

“Some schools have spent the money on counseling and special education that benefits military children, but others have made general purchases” (Lombardi, 2011, p. 13). When speaking about Fort Riley, the massive Army post in Kansas, Charles Volland, communications director for Geary County Schools, said “The local tax-payer says, ‘Why should we fix or build new schools there?’” (Lombardi, 2011, p. 13) The school liaison officer at Fort Sill, Oklahoma summed up the jurisdictional debate like this: “People in Lawton, Oklahoma say, ‘Hey, those schools are Fort Sill’s,’ and Fort Sill says, ‘Hey, they’re not our schools’” (Lombardi, 2011, p. 13). In Fort Riley, on May 19th, 2011, at a groundbreaking ceremony of a new 29-million-dollar elementary school funded by the Army, Secretary of Defense Robert Gates spoke of a commitment he made the previous year when identifying the very unfortunate and bad situation.

“It was a little over a year ago, that I participated in a town hall at this post with many military spouses,” he said, “Thanks to their honesty and directness, I heard firsthand about the deficiencies with public school facilities here, and I made a commitment to those spouses to address these problems, and today deliver on that commitment” (Dix, 2011, p. 1). On May 7, 2011, Army Undersecretary Joseph Westphal visited Fort Sill and pledged, “To help rebuild our schools on this installation” (Lombardi, 2011, p. 13). The elementary school built before General Dwight D. Eisenhower ran for president was scheduled to be replaced by 2016. The Fort Riley schools were 35 percent overcapacity and the problem had become a major retention
issue for the Army’s 1st Infantry Division, which was on its fourth deployment since 2003.

Secretary Gates, speaking in general about the problem facing the entire nation said, “As an initial step, Congress has appropriated $250 million for the Department of Defense to directly assist school districts in revitalizing the neediest on installation public schools. Going forward would be the responsibility of all stakeholders including local, state and federal governments.”

He went further to emphasize the commitment stating,

> While local school districts should and will remain ultimately responsible for the public-school facilities located on military installations, the Department of Defense will always remain ready to intervene when it has the ability to improve the educational opportunities of our military children. We owe nothing less to our men and women in uniform and their families who have sacrificed so much in order to serve their country. (Dix, 2011, p. 2)

**Department of Defense efforts.** The departments of education at the federal level and in each state are concerned about the increase in autism. The Every Student Succeeds Act (ESSA) (2015) and Individuals with Disabilities Education Improvement Act (IDEA) (2004) stipulates that each child should receive a free and appropriate public education (FAPE). Children with disabilities and special needs are usually put on an Individual Education Program (IEP) that modifies and makes accommodations to curriculum and is designed to ensure the child receives the help and assistance needed to be successful in school.

The combination of Military Officers of America Association (MOAA) and many other organizations raising awareness and several parents testifying to the House and Senate Armed Forces committees led to Congress and DoD establishing the new Office of Community Support for Military Families with Special Needs. Traci Norris, the wife of a Marine stationed at Camp LeJeune, N.C. and mother of a ten-year-old boy with autism is grateful for the creation of the
new office but not convinced. “Here we go with something great, but it’s difficult to create this branch when we’re talking about an individualized experience … you can’t broad-brush that across the country” (Rafferty, 2011, p. 76). Norris refers to the Stomp Project and the grass roots approach as being a more effective family resource. “Stomp has a special-needs committee for every state. That’s more helpful to me in an as-needed crisis than another bureaucratic entity.” Norris said, “A lot of times as parents we’re given contact information … the last thing we want is another phone number for someone not versed with our family needs” (Rafferty, 2011, p. 76).

The DoD continues to look for ways to help parents and recently teamed up with Ohio State University to review the access and availability of evidence-based educational practices for military dependents with autism. The project team researched developments nationally and specifically in the states of California, Georgia, North Carolina, Texas, and Virginia which have the highest concentration of military personnel. School districts were surveyed about the educational services they provide to children with autism between the ages 3 to 21. The objectives of the project are in the table below (Ohio State University, 2011).

Table 2

Objectives of the Ohio State Project

<table>
<thead>
<tr>
<th>List of Objectives of the Ohio State Project</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Assess the local availability of educational services for children with ASD on and near military bases and installations.</td>
</tr>
<tr>
<td>2. Develop a review of evidence-based, best practices in educational services for children with ASD and vet this review with national experts.</td>
</tr>
</tbody>
</table>
Create a set of recommendations for the provision of ASD educational services to military dependent children.

Prepare a final report for the Secretary of Defense.

On the national level the project found that the children with autism served by public school special education programs almost tripled between the 2001-2002 and 2007-2008 school years. Between 2006 and 2008 the number of military dependents with autism rose more than 35%. Service groups at the national and state level are working together to identify service gaps and duplication to more effectively utilize resources. There is research funding for autism, but it is focused mainly on causes rather than educational services. Applied Behavior Analysis (ABA) is the most researched of the evidence-based practices (EBP’s) which are those supported by research findings or demonstrated as being effective through a critical examination of current and past practices. No state requires ASD certification; however greater attention has been given to the professional qualifications of school personnel serving children with ASD (Ohio State University, 2011).

The State overview found that in California the third largest disability service category is ASD. Most states use regional agencies that provide support and related service to school districts. Some states have established ASD task forces. Of the five states, Georgia was the only one that had not joined the Military Interstate Children’s Compact Commission (MICCC or MIC3). The compact directs the uniform treatment of military dependent children transferring between school districts and states (Ohio State University, 2011). Eventually, all states including Georgia joined the MIC3.
On the local level within states, 93 school districts responded to the ASD services survey. Children with ASD made up 1.1% of the total enrollments (Ohio State University, 2011). Fifty-five percent reported having a BCBA on staff or access to ABA services. ABA, Functional Behavior Assessment, Augmentative/Alternative Communication Devices and Picture Exchange Communication Systems (PECS) were the most frequently used ASD training topics. The largest cohort paraprofessionals received 1-5 hours of ASD annual training while the district professional staff received 15 hours each year. The two most common placements were the regular classroom with support and a setting removed from the regular classroom for more than 60 percent of the day. Mediation was the dispute resolution most often used to resolve issues related to a child’s IEP and placement. The most common resources provided to families with ASD by districts were parent training and parent support groups. Local school districts cited the rapidly increasing number of children with ASD and the limited resources available to serve them as a serious challenge. Some specific issues related to military children are the frequent moves, incomplete educational records, disruption of services and the difficulty implementing individual education programs as written (Ohio State University, 2011).

The following table describes the Ohio State University research team’s conclusion to the corresponding objectives.

Table 3

Conclusions of the Ohio State Study

<table>
<thead>
<tr>
<th>List of Conclusions from the Ohio State Study</th>
</tr>
</thead>
</table>

1. Military children have access to EBP’s at school districts servicing military installations; however, not necessarily the type or amount of services desired by parents.
Creation of the *Education Directory for Children with Special Needs* which provides resources and useful strategies to help assignment personnel assisting families in preparing for a duty assignment in any of the fifty states.

The DoD should enhance the assignment process for military families of children with ASD to include more specific information about the needs of each individual child. Additional family supports should be infused into the EFMP. ASD content should be added to the disability clearinghouse being developed at Penn State University. The potential for overwhelming a single school district exists and therefore the number of families with children with ASD assigned to a specific district must be monitored to ensure resources are not overstretched.

Phase I is complete and report filed. Ohio State University and the DoD will continue to move forward in Phase II. Ten additional states with a high concentration of military families will be added to the study. Early intervention services in all 15 states will be reviewed as well. The second phase is expected to be completed in the Fall of 2011 (Ohio State University, 2011).

The second phase from Ohio State made a point that while the CDC reported the ASD rate based on 2006 data to be one in 110 children, the Kogan (2007) study reported the rate as one in 91. Both of these rates were using the same data. ASD was found to be the fifth largest disability category and that ASD expenses total at least $35 billion per year. The study highlighted tension between the medical field and the education field, “While children diagnosed with conditions such as ASD are frequently determined eligible for special education services, this issue has resulted in disagreements among medical professionals, school staff, and families”
The study also noted, “The number of military-connected children with ASD is not publicly documented although the Organization for Autism Research (OAR) reported a ratio of one in 88 based on its review of 2005 data obtained from the DoD (Ohio State University Project Team, 2011 p. 9). For the overall general public during this time frame, the CDC reported a rate of one in 125 for surveillance year 2004 and a rate of one in 110 for surveillance year 2006 (CDC, 2016c).

Parent experiences. Many books and articles have been written about parents’ experiences dealing with autism. Several of these have been mentioned earlier in this chapter to lay a foundation of knowledge. There is not much research by way of peer reviewed studies of military parents, which is another reason why this research is needed. There are however some personal accounts from parents which have been shared in congressional briefings that are available.

What does it mean to have a child with autism while serving in the military? Karen Driscoll, wife of a Marine Corps Colonel, and mother of three said, “This was my first child and I didn’t know what to expect. I look at periods of time that are dark and ugly.” Karen recalled the intense stress she first felt dealing with her son’s condition: “It’s that grieving period when you give your life up and your expectations for your child’s life…that for me was a dark period” (Johnson, 2008, p. 36). The family has not been on a vacation since their son with autism was born and she joked that she is way overdue for a hair coloring appointment. Rachel Kenyon’s husband, a Connecticut Army Reserve Platoon Sergeant, was on his second tour of duty when she gave him the news that their daughter had been diagnosed with autism. “What does this mean?’ he said, ‘Please tell me that she isn’t going to fall down the deep dark hole of autism.’ But I had no hope to offer” (Military Families Tell Their Stories at Congressional Briefing, 2012,
For the families of Hunter and Jacob, autism means “waiting.” For Hunter’s family, the Tricare authorization took over five months and then only covered one third of the prescribed therapy. Jacob was diagnosed with autism at age two after a five-month delay waiting for an appointment. Jacob’s family now has less than half the prescribed 25 hour a week ABA therapy covered after waiting another five months for authorization (Read Their Stories, 2012). Military mom Melanie Pinto-Garcia testifying before Congress said, “There is almost nothing more stressful than the combination of military life and a child with special needs” (Military Families Tell Their Stories at Congressional Briefing, 2012, p. 2).

What are the challenges a military family of a child with autism experiences during deployments and permanent change of station (PCS) moves? One family of two boys, Nathan diagnosed with autism in 2004 and Isaac in 2006, received no assistance from TRICARE. The family could not afford the expense of the prescribed treatment. In 2006 the father was sent home from deployment on emergency leave because Nathan was hospitalized for harmful and self-injurious behaviors (Read Their Stories, 2012). Kayla Doyle, wife of a Marine Master Sergeant faced many obstacles taking care of their youngest daughter with autism while her husband was deployed to Iraq. She was concerned if she told him everything they were going through back on the home front, “he wouldn’t have been able to focus on his job. And when you’re getting shot at, you need to focus” (Johnson, 2008, p. 37). She chose not to use those precious moments of conversation to complain or vent. “I knew that what he needed to hear was that we were o.k., so he could continue to focus on his mission and keep himself safe (Doyle, 2008, p. 3). She remembered the day she emailed her husband a video of their daughter’s progress in her therapy session, “He called me on the satellite phone, practically in tears. It was the first time he had ever heard Kate’s voice in conversation with another human being. He
begged me to send more video; he knew he was missing his little girl’s transformation with each passing day (Doyle, 2008, p. 3). Her husband’s third deployment was cut short when he was wounded by a sniper. Surviving and healing from a gunshot wound added stress to the family already struggling to get the care their daughter needed. Buck Doyle often joked that “it is his wife who should be earning combat pay since, at least for all the battles he faces, he has been highly trained and properly equipped (Doyle, 2008, p. 1). After recovery Master Sergeant Doyle was given short notice orders to a duty station that had virtually no services for children with autism. Doyle speaking of her husband’s honor said, “This is one guy who would give his life for his country. The one thing he won’t do is give his kids’ lives” (Johnson, 2008, p. 37). He got pushback from the service for refusing the new assignment, but later received a different set of orders to a duty location able to meet the family’s special needs.

One Air Force family in California has two physicians currently serving in uniform was planning on getting out of the service due to concerns about relocation and disrupting their son’s therapy. Major Nirvana Kundu said, “I can either have a lot of uncertainty, which is bad for my son, or I could have no uncertainty” (Johnson, 2008, p. 38). Jeremy Hilton, a Navy veteran whose wife is in the Air Force shared frustration in their efforts to provide care for their daughter through frequent re-deployments and duty stations in locations with a shortage of providers (Military Families Tell Their Stories at Congressional Briefing, 2012, p. 2). Another family whose son is named Paul had four different duty stations by his sixth birthday. Paul was diagnosed at age three and made excellent progress with ABA services received briefly in California before moving from coast to coast. In Virginia, the school did not provide ABA services and refused to fund a home program. Paul was placed on the wait list for services
through the state’s Medicaid office which is expected to take ten years (Read Their Stories, 2012).

How do military parents respond to the educational challenges of children with autism? Many of these families already mentioned have first-hand experience dealing with the educational challenges. The Kundu family’s son is in a 35 hour a week therapy program. Enrolled in the TRICARE demonstration project the family receives $2,500 a month to cover about one fourth of the expenses. The family has financed the remainder of the monthly $8,000 bill, saying, “We knew we had to spend the resources now or our kid would be broken forever. It would be like telling a kid with cancer we’re only going to give you a quarter of what works” (Johnson, 2008, p. 38). TRICARE has increased coverage to $36,000 annually but some families still have a difficult time getting the military’s insurance provider to pay. One family whose daughter Julia had been prescribed 15 hours of ABA therapy was denied services by TRICARE because her father is a disabled Army retiree (Read Their Stories, 2012).

Currently, military members lose autism service benefits for their children when they retire, even if they are medically retired due to injuries in combat. Congressman John Larson from Connecticut who sponsored the Caring For Military Kids With Autism Act (HR 2288) called the treatment of military families raising children with autism “immoral” in a recent briefing on Capitol Hill (NBC’s Andrea Mitchell Examines Plight of Military Families Raising Kids with Autism, 2012, p. 1). “To a parent with a child who can’t speak, being told they won’t pay for speech therapy…that’s hard to swallow” (Johnson, 2008, p. 37). The Doyle family waited months on the “stand-by” list before receiving services at a new duty station. The doctors prescribed 25 hours of ABA therapy a week. Tricare picked up six which left the Doyle’s to come up with the rest. Unlike the Driscoll’s and the Kundu’s who are officer families, the
Doyle’s are an enlisted family and their income is substantially less. After three years of therapy the Doyle’s faced a $100,000 bill. The family of four moved in with Kyla’s parents to help save money. At the same time the Doyle’s were also faced with legal bills for suing their daughter’s school to ensure she had the appropriate classroom placement (Johnson, 2008). Many parents feel the school districts play a stall game and try to wait them out until they receive orders and are transferred to another duty station rather than provide the services their children require under federal law.

Another family with two boys, J.W. and Joshua, who were diagnosed with autism in 1996 and 1997 respectively, hired an attorney for battles with the public-school system that lasted over a three-year period. In 2002 they reached a settlement with the school officials and received partial funding for a home-based ABA program, however this covered less than half the expenses. The family was on the waiting list for Medicare for several years and finally received assistance in 2006. Between the years 1999-2007 J.W. and Joshua’s family paid $363,012 in out of pocket expenses (Read Their Stories, 2012).

What are the lessons gleaned from the real-world experiences of military parents of children with autism? Patrick, the son of an Army Special Forces soldier, was diagnosed at three years of age while the family was stationed overseas. The father was blessed to be reassigned stateside to ensure the family’s special needs were met. Patrick had an amazing response to ABA therapy, but unfortunately the therapy expenses exceeded TRICARE limits. The family’s accumulating debt became a security clearance issue for the soldier. Patrick regressed in North Carolina public schools thus causing his mom to quit her full-time job and implement a home-school program with ABA modifications (Read Their Stories, 2012). The Driscoll’s used the equity in their home as a resource to pay for therapy not covered by TRICARE. Driscoll said,
“Our family is in debt because of TRICARE limitations on ABA therapy. We are struggling, and my husband is a Colonel” (Military Families Tell Their Stories at Congressional Briefing, 2012, p. 2). Karen Driscoll knows the burden is greater for the families of enlisted service members and sometimes their children are forced to do without. Driscoll has become a passionate advocate for these families. “It should not be so hard to fight for treatment. That’s the reason I keep going,” she says. These stories “bring on an emotional response for me personally. How can I help that family get to a better place?” (Johnson, 2008, p. 37). The rising out-of-pocket expenses not covered by TRICARE are causing some service members to consider volunteering for additional combat tours where they will receive imminent danger pay and all compensation in a tax-free status. Service members understand their duty to go anywhere their nation may need, but back-to-back deployments often put additional stress on families. The financial challenges are causing some to leave the military. Officials warn this trend is harming military capabilities. The Navy’s Surgeon General, Vice Admiral Adam Robinson, wrote, “The assurance of family care is critical for mission readiness” (Johnson, 2008, p. 37). The Air Force Vice Commander, Major General Thomas Deppe, said, TRICARE’s treatments policies affect “the morale, readiness, and retention of the all-volunteer force” and the quality of life for families in the Air Force is “compromised by the lack of services and supports” (Johnson, 2008, p. 37). Driscoll has some “lessons learned” from being a voice on Capitol Hill for military families raising children with autism.

While military leaders want to care for the families of their service members they are often at the mercy of Congress. Driscoll recalls the harsh reality of Washington D.C. when a legislative staffer told her the military leadership was lying to her about their intentions to pressure congressional leaders for TRICARE system changes. The words brought her to tears,
“As a mom working tirelessly to advocate for reform, this was a difficult blow, and I took it hard. I guess it was my awakening to the coldness of a very bureaucratic system” (Johnson, 2008, p. 38). Because of Driscoll’s valiant advocating efforts, the U.S. Marine Corps has made changes to support these families. They now offer 40 hours per month of respite care to allow parents to go grocery shopping, attend IEP meetings, or perhaps even relax and go on a much-needed date with their spouse.

Marine bases have also employed school liaisons and case managers to help families navigate to the services and continue their children’s treatment. Driscoll increased the awareness of autism’s impact on military families according to Annette Conway, a former special education teacher and wife of the Commandant of the Marine Corps, General James Conway (Johnson, 2008). She looked at the problem “and said, you know this is not the way it should be. She really went from being a mother struggling with the school system to a mother that ended up going to the Hill and winning legions of advocates” (Johnson, 2008, p. 38).

Another success story is the son of a four-time combat deployment veteran. Jake was diagnosed with severe autism in 2005. The family valued their son’s treatment even though the Hawaii Department of Education denied ABA services. On Father’s Day 2008 Jake’s autism diagnosis was removed. The recovery came with a hefty financial price tag though as the family paid $359,000 in out of pocket expenses for ABA therapy (Read Their Stories, 2012).

**Theoretical Framework**

Bronfenbrenner’s (1979) Ecological Systems model served as the theoretical framework for this inquiry. Dr. Urie Bronfenbrenner was born in Moscow, Russia and immigrated to America with his family at a young age. Immediately after graduating from the University of
Michigan with his Ph.D., he served as a psychologist in the United States Army Medical Corps. This was during WWII at the same time Dr. Kanner and Dr. Asperger were doing their original autism research. Following the war, he also worked briefly in the Veteran’s Administration as an Assistant Chief Clinical Psychologist for Administration and Research. He also co-founded the Head Start Program which many believe to be a successful strategy in the early intervention for children with autism (U.S. Department of Health and Human Services, 2013; Zieglar, 1999). It is fitting that the work of a man experienced as an educator, medical professional and war veteran would be used in a study combing the areas of education, medicine, and the military. Bronfenbrenner (1979) first developed the ecological theory to explain how a person’s development is reflective of five environmental systems: (a) microsystem, (b) mesosystem, (c) exosystem, (d) macrosystem, and (e) chronosystem.

*Figure 2. Bronfenbrenner’s Ecological Systems Model*


The *microsystem* is the system in which the individual lives. A person is actively engaged and influenced by this system. Family, friends, school, church, sports teams and workplace are all part of this system. For children on the autism spectrum this microsystem may also include therapists, medical clinics, and special education classrooms.

The *mesosystem* is the system that includes all the interactions of the individual’s microsystems. These interconnections may take place with or without the knowledge of the individual. Friends at school may talk to teammates at a sports practice. A teacher or pastor may
talk to a parent about the individual child. For children with ASD, their parents most likely have the greatest awareness and understanding of all of these microsystems and how they interrelate.

The *exosystem* is the system of institutions that indirectly affect a person’s microsystem, even though the institutions do not directly interact with the individual. Military detailers/placement officers who assign military members to new duty stations are part of the exosystem as are the local school boards which decide policy matters including those concerning special education.

The *macrosystem* involves the culture and subculture where the individual lives. The city and state where an individual with autism lives can vary greatly. The ideologies, attitudes and behaviors of those in the world around the individual make up the macrosystem. Some communities value education more than others. A city that is pro education may be more inclined to pass an increase in taxes to fund more schools and special programs. Attitudes and ideologies can also change over time. This is evident in the shift of schools educating children with special needs in the general education classroom as opposed to teaching them in a resource classroom or even institutionalizing them. For military parents with children with autism, this macrosystem can be quite different from one duty station location to another.

The fifth system is called the *chronosystem* and is the evolution of the four other systems over time. The chronosystem includes environmental events such as earthquakes and hurricanes, transitions over the life course like divorce and death of a friend or family, and sociohistorical circumstances which are main events in a person’s life. For military families, every PCS move is a socio-historical event. Many military families were forced to evacuate for Hurricane Katrina in 2006 and also during the Japan Tsunami of 2011. This would be a major event in their
chronosystems. A transition is a life altering event. A substantial transition for military parents may be receiving the news that their child has been diagnosed with autism. The ecological theory (Bronfenbrenner, 1979) is an excellent lens in which to view this study and organize the research. The child with autism is the individual at the center of the model, however it is the parent who is in the best position to understand and describe these five environmental systems in the context of the education of their child.

**Summary**

Autism is a national issue for Americans as well as a world problem, particularly in wealthier developed countries, and it is drawing more and more attention as the rate of this disorder continues to soar. There is much data being collected and analyzed about this neurological disorder. The results of research remain largely inconclusive. There are opposing theories to what causes ASD. There are political and business interests at play. There is literature that supports an array of intervention treatments and therapies. Some interventions are backed by much more in-depth research while others have a very narrow knowledge base. Certain therapies are covered by insurance, yet others that appear successful are not approved. In a broad sense, much more research is needed on autism as a whole. The cause for the higher autism rate among military dependents is a question that needs to be addressed.

This elevated rate in autism in military families is particularly alarming given the array of challenges associated with raising a child with autism, compounded with the specific challenges of military life. All children, but specifically children with ASD, need stability and consistency and thrive within clearly established boundaries and systems. However, change is the one thing that is consistent in military life. While previous research has investigated the experiences of
parents with children with autism, no studies have addressed the unique experiences of military families who have a child with autism with a specific focus on the efforts and processes parents take to ensure an appropriate education for their children.

The words of parents are collectively a powerful voice and arguably the best advocate for children with autism. Mrs. Driscoll, wife of a Marine Colonel, is an excellent example of the positive change the experiences of parents can bring about. There are many more individual personal stories that need to be told. Much can be learned by the insight these military parents are willing to share. That is the heart of this research study – to close the gap in what is known about the experiences of military parents in regards to raising and educating their children with autism.
CHAPTER THREE: METHODOLOGY

Overview

The increase in autism over the last several decades is a critical issue facing America. The purpose of this phenomenological study is to describe the unique experiences of military families who have a child with autism with particular focus on the efforts and processes parents take to ensure an appropriate education for their children with autism in grades K-12. This chapter outlines the steps that were taken in the execution of the research throughout this study. This chapter explains how I as the human instrument am in a unique position to conduct research on the topic of autism in the military. The chapter continues with the research design, restatement of the research questions, then moves on to discuss the participants and the setting. The data collection and analysis are explained, and the chapter concludes by addressing ethical issues and methods to increase trustworthiness. As stated earlier the intent of the research is to produce findings that can be used as a valuable resource for parents, teachers, school administrators, service providers, military leaders and support personnel.

Researcher’s Role

In qualitative studies, it is the researcher who functions as a human instrument interacting with the environment and the participants. I single-handedly conducted the fieldwork and research guided only by the dissertation committee and the extant literature on the topic. This is sometimes termed Lone Ranger research (Bogdan & Biklen, 2007), however it should not be confused with a maverick type mentality where the researcher is a one man show. On the contrary, in this study I humbly operated solo in the field collecting data, but relied heavily on
the wise counsel of subject matter experts throughout the dissertation process. While my experience level in educational research is minimal, I have experience conducting interviews during investigations that have greatly affected lives and careers within the military. Throughout my commanding officer duty assignments, I have learned to be an effective communicator. Because of my level of exposure and experience dealing with autism I was in a perfect position to conduct field work and research on this topic. Lester (1999) stressed that “the establishment of a good level of rapport and empathy is critical to gaining depth of information, particularly where investigating issues where the participant has a strong personal stake” (p. 2). As the father of a child with autism and 22 years of military service I could relate and empathize with the struggles my participants’ experienced.

As a naval officer over the past 22 years I have strived to live up to the U.S. Navy’s core values of honor, courage and commitment. With my Heavenly Father’s help, I continued to practice these principles in the academia world. I did my best to protect the participants, to give credit where credit was due in terms of contributions to knowledge and information, and to produce a document with the utmost integrity.

Woven intricately into the fabric of ethics is the word truth. I, as the researcher, pursued truth from the beginning through the completion of this research project. I believe that absolute truth exists, that God created this universe and is master over it. Like the Apostle Paul, I am firmly “convinced that neither death nor life, neither angels nor demons, neither the present nor the future, nor any powers, neither height nor depth, nor anything else in all creation, will be able to separate us from the love of God that is in Christ Jesus our Lord” Romans 8:38-39 (New International Version). Nothing, certainly not autism, can separate us from God’s love. My approach to life and education, including this dissertation, is with a Christ-centered worldview.
It can be summed up in the words written on my wife’s framed diploma from Regent University, “Acknowledging God as the fountainhead of all wisdom and His Son Jesus Christ as the source of all truth.” This guiding principle directed all my educational endeavors.

**Research Design**

The research methodology is qualitative and I employed a phenomenological research design. The phenomenon was military parents raising and educating children with autism. The purpose of this phenomenological study was to describe the unique experiences of military families who have a child with autism in K–12 with particular focus on the efforts and processes parents take to ensure an appropriate education for their children. A phenomenological approach to inquiry has the goal of gaining understanding from the perspective of the participants (Bogdan & Biklen, 2007). The subjective experience (Ary et al., 2006) of parents of children with autism was at the heart of this inquiry. Phenomenology is the ideal method because it is concerned with the lived experience. Once the experience of phenomena is identified, a deeper understanding of the meaning of that experience is sought (Smith, 1997).

The phenomenological approach utilized was Max van Manen’s work (1997) called hermeneutic phenomenology. It is a method that incorporates philosophies in both hermeneutics and phenomenology. Hermeneutic research is interpretive and focused on historical meanings of experience and their developmental and total effects on both individual and social levels (Laverty, 2003). This emphasis on the individual and the social was important as the significance of this study falls into three main systems of influence; the United States Armed Forces, the education profession, and individual parents of children with autism. Hermeneutical
phenomenological researchers seek to develop a rich description of the phenomenon being investigated in a specific context (van Manen, 1997). Military parents have unique challenges and experiences while serving in the Armed Forces and simultaneously raising and caring for a child with autism while ensuring their child’s educational needs are met. They have rich, powerful stories to tell and the hermeneutic phenomenological design provided a fitting vehicle explore these narratives.

**Participants**

The participants were parents of children with autism in families where one or both of the parents served in the military. The purposive sampling procedures and snowballing technique were employed to find families with rich stories to tell. The sample included six fathers and seven mothers. Four families had both mother and father participate. The military also has many single parent households who also were welcomed to volunteer and participate. There was one participant father who was widowed. The main requirement was the families must have been serving in the military on active duty for a minimum of one year during the time that their child with autism was school age (3-18 or early intervention program through high school). No families were considered if the military member fell under the leadership and direct chain of command to the researcher as this could have created a conflict of interest.

Participants were solicited for participation through personal relationships (see Appendix B). The solicitations had the detailed guidance, instructions to participate and required consent forms included (see Appendix C). I employed the snowball sampling technique through my personal contacts to ask for referrals for potential participants. Volunteers were contacted via
phone and email to arrange an interview that was a convenient time which worked well with their schedule. Pseudonyms were used to protect the identity of all participants.

The number of families involved in the research was nine, with 13 participants in total (6 men, 7 women). Morse (1994) believed phenomenological studies should have a sample population of at least six. Creswell (1998) recommended five to 25 (p. 64). Green and Thorogood (2009) stated that “in interview studies little that is new comes out of transcripts after you have interviewed 20 or so people” (p. 120). Atran, Medin, and Ross (2005) suggested “as few as 10 informants were needed to reliably establish a consensus” (p. 753). Boyd (2001) felt saturation could be reached with two to 10 participants. Saturation is the point where responses are consistent and the researcher is not hearing or seeing any new information. The voices of 13 participant parents were heard prominently throughout the research and it was at this number that saturation was achieved.

Anonymity of the individuals participating in the study was paramount. Every effort was made to protect the privacy of the parents being interviewed as well as their child(ren). Coding of the participants was sequential in the order in which they volunteered. For coding purposes, each family was considered a participant. At least one of the parents were interviewed. The participants were coded using the phonetic alphabet. The first participant was coded “Alfa” family Dad/Mom, the next, “Bravo” Dad/Mom, and so forth, eventually ending with “Julia” for the tenth family, which actually ended up being the ninth family when the seventh family, the “Hotel” family was unable to continue volunteering in the study. Pseudonyms for the interviewees were given corresponding with the coded family name i.e. Mr. Alfa, Mrs. Bravo, and so forth. The child(ren) of each family were also be given pseudonyms that started with the same first letter of the pseudonym last name such as Alex or Allison for the Alpha family or
Donna or David for the Delta family and so forth. The real point-of-contact information on the families was written on a separate sheet and kept isolated away from the field notes in a secured container. The only link connecting the actual families to the research was in the mind of the researcher. Table 4 includes an overview of the final sample.

Table 4

*Family and Child Pseudonyms*

<table>
<thead>
<tr>
<th>Family Pseudonym</th>
<th>Parent Pseudonym</th>
<th>Child Pseudonym</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alpha Family</td>
<td>Mr. and Mrs. Alpha</td>
<td>Alison, Alex and Avery</td>
</tr>
<tr>
<td>Bravo Family</td>
<td>Mr. Bravo</td>
<td>Britany</td>
</tr>
<tr>
<td>Charlie Family</td>
<td>Mr. Charlie</td>
<td>Colin</td>
</tr>
<tr>
<td>Delta Family</td>
<td>Mrs. Delta</td>
<td>David</td>
</tr>
<tr>
<td>Echo Family</td>
<td>Mr. and Mrs. Echo.</td>
<td>Eli</td>
</tr>
<tr>
<td>Foxtrot Family</td>
<td>Mr. and Mrs. Foxtrot</td>
<td>Ferris</td>
</tr>
<tr>
<td>Golf Family</td>
<td>Mrs. Golf</td>
<td>Greg</td>
</tr>
<tr>
<td>India Family</td>
<td>Mr. and Mrs. India</td>
<td>Isaac and Isaiah</td>
</tr>
<tr>
<td>Juliet Family</td>
<td>Mrs. Juliet</td>
<td>Jared</td>
</tr>
</tbody>
</table>

**Setting**

The setting for the study was the United States of America. My network of fellow military personnel with children with autism spectrum disorder spans the entire country. There are fleet-concentrated areas where the Navy has numerous ships and sailors. Each military
branch has large bases with high populations of service members scattered across the different states. There are also smaller military installations and facilities such as the National Guard and Reserve Centers in all 50 states. With the rate of autism at 1 in 68 children, unfortunately there were plenty of participants to consider. During the course of this research study I moved to three different duty stations in three separate states. The participant families literally spanned the country from coast to coast with one family residing in Florida and another in Washington State. Several of the families had spent time in Colorado or Wyoming; however, all the participants had several other states and even foreign countries they had been stationed in. Due to the vast geographical spread and the miles between the researcher and the participant families, all the interviews were conducted via phone conference.

Data Collection Procedures

All necessary documentation was submitted to the Institutional Review Board (IRB) in accordance with regulations and university policies (see Appendix L). Once approval was granted I proceeded with solicitation in the manner described in the participant section of this chapter. After the informed consent (see Appendix C) from participants was obtained the data collection commenced with the initial data collection form. I worked directly with each family to set up an appropriate time to conduct the interview. Lastly, after returning interview transcriptions for participant member checks I collected the reflective timeline/essay from each family.

Rigorous and varied data collection techniques are an integral part of qualitative inquiry. Triangulation of methods was a critical aspect of this research. Thus, three methods were used: (a) questionnaire, (b) interview, and (b) a reflective timeline / essay.
Questionnaire

The initial tool of inquiry was a researcher created questionnaire. This form (see Appendix D) was developed to gain demographic and baseline information. There were 30 total questions. Several were demographic in nature such as “what is the sponsor’s branch of service?” and “what age was your child diagnosed with ASD?” Other questions were open ended and asked questions like “how satisfied are you with Tricare support of your family member’s special needs requirements?” and “how would you rate your local school support?” The questionnaire was sent either electronically by email or mailed to the participant family through the post office with return postage enclosed. Whichever was easier and more convenient to the participant was the method of delivery and recovery/collection. The Bravo and Golf families preferred email and scanning. All other families opted to return the hard copy via the postal service.

Interview

The process of interviewing parents to gather information was labor intensive but elicited detailed responses. The personal interview was conducted on at least one of the parents in each participant family. The interview was conducted at a safe, comfortable, and convenient location for the participant via the phone. The interviews lasted approximately thirty minutes to two hour in length and were conducted in a professional manner using a framework script (see Appendix E). The table below lists the four research questions and five interview questions corresponding to each research question.
Table 5.

*Research and Interview Questions*

<table>
<thead>
<tr>
<th>Research Questions &amp; Alignment with Interview Questions</th>
</tr>
</thead>
</table>

**RQ 1.** What does it mean to have a child with autism while serving in the military?

1. How did it feel to learn that your child was diagnosed with autism? Was it during a deployment? What did you do first?
2. Which services or resources were made available to you by medical providers or by the military health insurance (TRICARE) when the autism diagnosis was presented?
3. How did you find out about the Exceptional Family Member Program (EFMP)? What was the enrollment process like? How effective is the EFMP in supporting your family?
4. Describe your experience with detailers / placement officers when negotiating orders?
5. How supportive is the military of families who have children diagnosed with autism?

**RQ 2.** What are the challenges a military family of a child with autism experiences during deployments and permanent change of station (PCS) moves?

1. How effective are the support systems (military or other) in place during the transition times? (i.e. MFLC, Military One Source, School liaisons)
2. How does your child react to change and uncertainty during these transition periods?
3. How do you overcome the challenges associated with PCS moves and deployments? What strategies were effective in assisting your family with deployments and PCS moves?

4. What are the two major concerns / challenges of moving with a child with autism?

5. What are the two major concerns / challenges to deployments and family separation due to military assignments?

RQ 3. How do military parents respond to the educational challenges of children with autism?

1. Has your child’s education been smooth and easy, difficult and challenging, or a mix of both good and bad experience?

2. Please describe your two most challenging experiences?

3. Please describe your two most successful experiences?

4. What are your experiences in IEP meetings? Are there significant differences in your experiences between different school districts? How about different states?

5. Which programs have been most beneficial? (ABA, SCERTS, Hand Writing Without Tears, etc.)

RQ 4. What are the lessons gleaned from the real-world experiences of the military parents of children with autism?

1. What do you know now that would have helped you when your child was initially diagnosed with autism?

2. What are two things you would advise other parents to do or not to do?
3. What changes would you like to see in the support systems provided by the military? Educational support systems?

4. Please share your most difficult story raising and educating your child with autism while serving in the military?

5. What is your most successful story?

The purpose of the research questions concerning autism and the military was to formulate a framework upon which to gather information. Heidegger (1962) believed that to be human was to interpret and emphasized that every encounter involves an interpretation influenced by a person’s background. Phenomenology asks, “What is this experience like?” as it attempts to uncover meanings as they are lived out in everyday existence (Laverty, 2003). Similar to another study (Hall, 2010), all interview questions were designed to allow parents to express concerns related to raising and educating a child with autism and to discuss strategies to meet those challenges.

RQ 1 (What does it mean to have a child with autism while serving in the military?) was developed to put the experiences of having a child with autism into the context of the military. As described in the literature review in Chapter Two, parents go through multiple phases, a grieving period, hopelessness, a dark and ugly period, waiting, stressful and costly are a few (Johnson, 2008). The goal of this research question and corresponding interview questions was to understand what it is like to walk in their shoes. Bogdan & Biklen (2007), Lester (1999) and Covey (2000) each talk about the importance of paradigm. The goal was to view the parents’ paradigm through their own eyes.
The first interview question under RQ1 (What did it feel like when you received the news that your child was diagnosed with autism? Were you deployed? What did you do first?) fell in Bronfenbrenner’s (1979) micro and mesosystems. It was designed to take the parent back to step one of their journey with autism and start building the foundation of their experiences. It was the first stage in capturing these rich personal narratives.

It has been said that knowledge is power. Information is crucial in each parent’s decision making process. The second interview question (Which services or resources were made available to you by medical providers or by the military health insurance (TRICARE) when the autism diagnosis was presented?) falls in the exosystem and sought to find out the accessibility and advertisement of services provided by the military insurance.

Interview question three (How did you find out about the Exceptional Family Member Program (EFMP)? What was the enrollment process like? How effective is the EFMP in supporting your family?) was on the micro and meso level. Statistics show 14.6% of military families have a family member with a disability (Jacobsen, 2014). The question was designed to pull out the parent’s personal experience with the program the DoD set in place to track and assist families with special needs. Kelley (1994) found that military-induced separations caused disruptions in families’ ability to maintain supportive relationships.

The fourth interview question (Describe your experience with detailers / placement officers when negotiating orders?) fell in the exosystem level. Very rarely does a soldier or sailor see their detailer face-to-face. Sometimes a service member will be given a choice between a few options and other times they will not be given a choice on next duty assignment. Detailers / placement officers have a critical role trying to ensure the manning requirements for the military’s missions are met while also looking out for the military member and their family to
find the best possible placement. The detailers also work through the EFMP office as a check and balance measure to ensure the family member enrolled in the EFMP will have their needs met at the proposed new duty station.

There are currently more than two million children in U.S. military families. Additionally, 90,000 babies are born into these families each year (Davis, Blaschke & Stafford, 2012). In a report released by the CDC, Pringle, Colpe, Blumberg, Avila and Kogan (2012) found that the median age of school aged children first diagnosed with ASD to be five years. In 1988 the DoD Office of Family Policy was established to critically evaluate and address evolving military support requirements (Davis et al., 2012). Interview question five (How supportive is the military of families who have children diagnosed with autism?) was on the macro level and was designed to find out parents’ opinions about how the DoD is doing supporting families on the larger scale.

RQ 2 (What are the challenges a military family of a child with autism experiences during deployments and permanent change of station (PCS) moves?) was designed to try to extract information on one of the most challenging aspects of military life for any family and put it in the perspective with autism as a significant factor. There are additional measures which families must take concerning autism. Special consideration is given to each duty assignment. When a military member deploys, the other spouse is left to handle the home and the kids by themselves. Military members have at times been sent back home on emergency leave to help out when things have deteriorated on the home front. Gorman, Eide, and Hisle-Gorman (2010) found that “families experience multiple stressors associated with military service by a parent, frequent moves, prolonged absences of a parent during military deployment, and the risk of a parent’s death are examples of such stressors” (p. 1059).
The first interview question under RQ2 (How effective are the support systems (military or other) in place during the transition times (i.e., MFLC, Military One Source, School liaisons)? fell in the exo and macro systems. There are support systems in place during transition times, however their effectiveness in the eyes of parents may be positive or negative. “Coordination between the different services like the EFMP, the receiving school district, the Parent Training and Information Center, doctors and specialty clinics become key to a successful PCS” (Jacobsen, 2014).

The second and third interview questions both addressed the microsystem. Interview question two (How does your child react to change and uncertainty during these transition periods?) asked specifically how children with autism handle the change and uncertainty. Innocenti, Huh, and Boyce (1992) asserted that the stress in families with children having disabilities is not necessarily greater than other families. Dyson (1993) suggests that all families experience stress and adapt to change and stressors over time. Fallon and Russo (2003) also noted that like most families, military families raising a child with disabilities learn to adapt to new responsibilities and demands. When compared to other military families with children attending the same childcare centers, Schonfeld (2008) found that parents and children in the family of a deployed service member had significantly higher levels of depression and distress.

Interview question three (How do you overcome the challenges associated with PCS moves and deployments? What strategies were effective in assisting your family with deployments and PCS moves?) asked what strategies parents use during transition periods. The STOMP (Specialized Training of Military Parents) project was a grass roots movement started and directed by parents. The goal of STOMP was to “to empower military parents, individuals with disabilities and service providers with knowledge, skills and resources so they might access
services and create a collaborative environment for family and professional partnerships, without regard to geographic location” (Jacobsen, 2014, p 6).

Both the fourth and fifth interview questions had responses that intersected several of Bronfenbrenner’s (1979) systems. For example, almost two thirds of outpatient care for military children is provided by nonmilitary pediatricians (Gorman et al., 2010). Providers and policy makers on the exo and macro levels should continue focusing on supporting military families in all phases of deployment.

Question five (What are the two major concerns / challenges of moving with a child with autism?) asked for two specific concerns with moving and question six (What are the two major concerns / challenges to deployments and family separation due to military assignments?) asked for two specific challenges to deployments. This is important information to gather because of the stressors. Gorman (2010) found that “separation of a child from a parent because of the parent’s military deployment was associated with an 11% increase in the rate of outpatient visits for mental and behavioral conditions (p. 1064). When controlling for caregiver’s stress and depressive symptoms, Chartrand, Frank, White, and Shope (2008) found that children aged three and older with a deployed parent had increased behavioral symptoms. In a review of nine U.S. based studies, White, de Burgh, Fear and Iversen (2011) found an increase in emotional and behavioral problems for children during the deployment of a parent.

RQ 3 (How do military parents respond to the educational challenges of children with autism?) was specifically geared toward education. It was a lead question which started the exploration of a parent’s experiences with ABA therapy, special education, working on IEP’s and dealing with insurance. It built on the previous two questions and addressed more specifically the educational aspects of raising a child with autism. Chandra et al., (2010),
examining children across social, emotional and academic domains reported that older boys and girls of all ages had significantly more school related difficulties when a parent was deployed. Paris, DeVoe, Ross and Acker (2010) found this type of separation may compromise optimal child growth and development.

All the interview questions corresponding with RQ3 focused in the micro and mesosystems. The first question (Has your child’s education been smooth and easy, difficult and challenging, or a mix of both good and bad experience?) started to get at the root of the experience of educating a child with autism.

The second interview question (Please describe your two most challenging experiences?) sought to pull out some powerful stories of difficulties in educating military children with autism. The third interview question (Please describe your two most successful experiences?) was very similar to the second and sought to highlight the positive stories.

Interview question four (What are your experiences in IEP meetings? Are there significant differences in your experiences between different school districts? How about different states?) had multiple parts. The personal experience is in the microsystem, but the follow-on component fell in both the mesosystem and exosystem as it covers a much broader area. Moving from state to state can be challenging for any student, but even more so for those with special needs. Ninety four percent of children with autism have special needs requiring health or related services beyond those generally required by children (Pringle et al., 2012). The Military Interstate Children’s Compact Commission (MIC3) is a national organization put in place to help transitioning military students with the widely varying policies they face. The goal is to use a comprehensive approach and provide a consistent policy in each school district in every state that chooses to join. All states have joined the MIC3.
Interview question five (Which programs have been most beneficial? (ABA, SCERTS, Hand Writing Without Tears™, etc.) focused in the microsystem. Paris et al., (2010) suggested, home-based family focused interventions warrant the most serious consideration. Pringle et al., (2012) found that nine out of 10 school aged children with special health care needs and ASD use one or more services to assist their developmental needs with social skills training and speech therapy the most common. Parents have a unique perspective that an individual special education teacher or ABA therapist do not always have. Parents usually have a broader view of all the interventions that their child is involved with and they can observe their children in multiple settings.

RQ4 (What are the lessons gleaned from the real-world experiences of the military parents of children with autism?) was a capstone question which sought to find out what could be learned from these experiences. Feedback from parents has caused changes and additional support services to be brought online in the military, including increased insurance coverage. Parent’s voices are powerful instruments in the hermeneutic interpretive process and bring understanding and disclosure of phenomena through language (Annels, 1996).

The first interview question under RQ4 (What do you know now that would have helped you when your child was initially diagnosed with autism?) fell in the microsystem. Hindsight offers a unique perspective and it has been said that personal experience is often the best teacher. Responses captured by this question may offer parents of newly diagnosed children a head start with strategies to help their child.

Interview question two (What are three things you would advise other parents to do or not to do?) was mainly from the mesosystem and sought specific guidance on things the parent
can be pro-active about as well as things to be on the guard against. This was an opportunity to hear from veterans in the arena.

The third interview question (What changes would you like to see in the support systems provided by the military? Educational support systems?) dealt with the exosystem. Chartrand et al., (2008) expressed that “information is necessary to provide clinicians serving the military families with evidence-based anticipatory guidance” (p. 1014). Black (1993) highlighted the unique stressors brought on by military-induced separation and gave guidelines to help social workers in designing interventions to assist military families. Chandra et al., (2010) concluded after research that in families where caregivers experience poorer mental health may benefit from programs focused on supporting the caregiver and child. Parental feedback is vital to forming programs and policy. Many different agencies and organizations are concerned with methods that work. They are continually seeking ways to improve the systems for all children including those with special needs. Noting that autism care and treatment is evolving, Assistant Secretary of Defense for Health Affairs, Dr. Jonathan Woodson, said a newly launched pilot program would yield great insight and identify best practices (Cronk, 2013).

Question four (Please share your most difficult story raising and educating your child with autism while serving in the military?) and question five (What is your most successful story?) focused in the micro and mesosystems but also highlighted items in the exosystem and macrosystem. Personal stories are powerful and bring out the truth (Nash and Bradley, 2011). The Assistant Secretary of Defense for Health Affairs said there is an expanding need and recognition of military families with children who have autism (Cronk, 2013). The DoD is very interested in issues that affect recruitment and retention of an all-volunteer military force. Davis,
Blaschke, and Stafford (2012) bring it through a full circle when they stated “Military policy can affect national policy regarding children, families, and communities” (p. S7).

**Reflective Essay / Timeline**

The third and final phase of data collection was the detailed timeline/essay completed by the parents. van Manen (1997) felt that writing in a reflective journal forces individuals into writing about themselves in a deeply collective manner. Heidegger (1927/1962) saw the reflective journal as an illustration of the hermeneutic circle with knowledge moving back and forth between the parts and the whole. The reflective timeline /essay allowed the participants to really think through their experiences without being rushed, thus providing a richer more detailed history. Each family was asked to put together a timeline/essay of important dates and milestones in their child’s life as it relates to autism and education. Parents were asked to provide a detailed description corresponding with each event listed on the timeline. After the interview, they were given a sample timeline/essay that could be referenced and used as an example template (see Appendix E). The sample illustrated the life of Helen Keller where Heidi was substituted as a pseudonym for Helen. Parents were given the liberty to put whatever dates, events, therapies, etc., they felt were important in this timeline. Emphasis was on the rich detailed stories and experiences that will be able to be used by others. The parents completed this independently and delivered it back to me and I asked for clarification as needed.

**Data Analysis**

Qualitative analysis has some mechanical aspects but is mainly interpretive. Koch (1995) suggested hermeneutics engages participants in a continuous conversation without providing a set methodology. Allen (1995) stressed interpretation comes from pre-understandings and
dialectic feedback between the parts and the whole and therefore the interpretive process cannot be bound by a finite set of procedures. While a very rigid set of rules was not followed, organization was a key ingredient in the successful processing of this research. Using van Manen’s (1997) methodology the data analysis was broken down into six components: (a) immersion, (b) understanding, (c) abstraction, (d) synthesis and theme development, (e) illumination and illustrations of phenomena, and (f) integration and critique (Ajjawi & Higgs, 2007).

Immersion is the initial familiarization of the data. The initial data collection forms were organized by pseudonym last names using the phonetic alphabet, Alfa family, Bravo family, etc. Using Bronfenbrenner’s (1979) ecological model the open-ended survey responses were recorded categorically into the appropriate system. The remaining stages of data analysis followed. The audio recordings of all interviews were transcribed along with notes that described other information such as tone, tears, and silence. Kvale (1996) emphasized the importance reading between the lines of not only what was said, but how it was said. The third method of the data collection triangulation was the reflective timeline/essay. Like the surveys and interview transcriptions, each of these were organized by corresponding pseudonym last names. The time line /essay reflected the chronosystem found in Bronfenbrenner’s (1979) ecological systems model, which is the other four systems over time. During this stage the preliminary interpretation began to take shape. The aim was to get a sense of what is being expressed from the participants. At this point in the data analysis process my insights were the predominate force working through all data collected in each collection method to get a sense of the whole.
The second stage is understanding. The data was initially organized by Bronfenbrenner’s (1979) ecological model and then coded into the themes as the big picture began to emerge. This first order of constructs was the participant’s ideas expressed in their own words which captured in greater detail what they were trying to share. The participant’s ideas were coded into the microsystem, mesosystem, exosystem, or macrosystem. To ensure the themes were aligned and correct, a process of validation called member checks occurred when the themes were returned to the participants for their agreement (Colazzi, 1978). I conducted member checks with all participant families. Most participants looked over the material and gave their concurrence with a “perfect” or “absolutely correct” type comments. A few participants gave concurrence and offered some rewording to texts. All correspondence was on target with participant’s thoughts and ideas and met with their agreement. Gadamer (1960/1998) believed hermeneutics as a partnership between participants and researchers, in which the discovery of meaning occurs through a circle of readings, interpretations, and reflective writings.

Abstraction was the third stage in the data analysis. This involved constructs which were developed from the researcher’s theoretical and personal knowledge. This second order of constructs was then grouped into concrete sub-themes. Bowen (2006) found themes gradually emerge as a researcher becomes intimate with the data and ties together what was learned from the literature review and logical associations with the interview questions.

The fourth stage was synthesis and theme development. (See Appendix G, H, I). The sub-themes were grouped and organized into themes. Padget (2004) found that the ultimate survival of a sensitizing concept used in the initial conceptual framework is dependent on where the data leads and emergent concepts may augment or replace them all together. These themes were compared across all three data collection methods and further elaboration of themes took
place before finalization. This was an intense stage as the data was read multiple times to clarify relationships. There was a continuous moving back and forth between the research texts, the literature, and earlier analysis as part of the hermeneutic circle. Morse and Field (1995) found that because themes are concepts often found in the data rather than directly and specifically described by the participant, a theme may at times lie just beneath the surface of an interview, but then appear obvious once it is finally identified.

Illumination and illustration of phenomena was the fifth stage. The themes developed in the previous stage began to be linked back to the literature for further development and discussion in Chapter 5. The interpretations were reconstructed back into stories by theme using the participant’s own words to illuminate their experiences and highlight key points.

The final stage of the data analysis is integration and critique. The literature was reviewed one last time to consider any developments that could impact the understanding of the phenomenon. During stage six peer reviews with educational/military professionals were also used to help ensure the themes were on target and aligned with the data. Total, four peer reviews were conducted during the study. Two were done in the initial stages of the study and covered Chapters 1-3. These were done by Dr. Karen Delbridge and Dr. Jamillah Mufdi. Two individuals were asked to critique and give feedback on Chapter Four. My wife, Heather Tidwell, M.Ed., gave an in-depth review highlighting areas that needed clarification and offering suggestions for theme consolidation. As an educational professional, military spouse, and mother of a child with autism, her knowledge and experience made her the ideal candidate to review Chapter Four. My brother, Lieutenant Commander Christopher Tidwell, a Navy SEAL and military professional volunteered to review and critique my work as well. His perspective came from a military leader. His feedback was almost verbatim to the feedback offered by my
Committee Chair. He recommended reorganization and consolidation of the themes and a realignment of the chapter with a smoother transition between themes. After stage six, the final phase included a total analysis and yielded a synthesis of all meaning units into a consistent summarization of the participant’s experiences (Giorgi, 1985). The concluding interpretation of the research findings were then being reported and documented in the study.

**Trustworthiness**

It was important to implement methods to increase the trustworthiness of findings. Steps were taken to address the credibility, dependability, confirmability, and transferability of findings. Credibility deals with how believable the results are. In other words, to what degree of confidence exists regarding the truthfulness of the study’s findings. According to Hammersley (1992), “an account is valid or true if it represents accurately those features of the phenomena that it is intended to describe, explain or theorize” (p. 69). The credibility of a qualitative study is improved by triangulation methods. It is also improved by the peer review method. Professionals with experience in the field of education who have completed a post graduate degree were the criteria used for determining peers. Member checks were a method where I shared interpretations and asked for feedback from the participants. This ensured accuracy, cleared up any misunderstanding and demonstrated professionalism and courtesy toward the volunteer participants. Each interview was recorded using an audio recorder which captured verbatim the many low-inference descriptors used to provide very rich detailed information to the study. Several member checks were done after all data was collected and transcriptions were complete.
Researcher bias was a concern and kept in check by the method of reflexivity in which I used self-reflection to be ever mindful of my own personal bias and assumptions and ensure that they did not skew the findings. A reflective journal (see Appendix K) was used throughout the process. This also provided an audit / decision trail, which documented rationale, outcome and evaluation of all actions and engagement with the data (Creswell, 1998). Schwandt and Halpern (1988) found that an audit trail (see Appendix K) can increase dependability and credibility in terms of whether the results were a logical conclusion from the collected data.

Transferability refers to the possibility that what was found in this study is applicable to another context (Ary et al., 2006). Participant families represented the Air Force, Army and Navy thus transferability was enhanced across the DoD. The disorder of autism and service in the military are not exclusive to any state or region of the country. The research provides a thick, rich description about the participants, the setting, the procedures and the findings. Readers must discern the degree of transferability between the findings of this study into other settings including their own.

**Ethical Issues**

The Liberty University IRB procedures were adhered to in a strict manner. The major ethical concern of the study was maintaining the confidentiality of the participants. This was accomplished mainly using pseudonyms. Under no circumstances were volunteers selected or even considered to participate if they fell in my direct military chain of command. No pressure was applied to the participants and they could withdraw from the study at any time. Another step to protect the participants was to allow each participant to review and approve any transcriptions before they were included in the data analysis and representation of findings.
CHAPTER FOUR: FINDINGS

Overview

The purpose of this hermeneutic phenomenological study was to describe the unique experiences of military families who have a child with autism with particular focus on the efforts and processes parents take to ensure an appropriate education for their children with autism in grades K-12. Data were gathered via questionnaires, personal interviews, and timeline essays. All data were analyzed in accordance with Bronfenbrenner’s (1979) ecological systems model and van Manen’s (1990) procedures for conducting a hermeneutic phenomenology. The end goal of this study was to produce a rich description of the voices of military parents expressing their concerns, and sharing their experiences and successes. Chapter Four begins with an introduction of the nine participant families as their voices resonate throughout the following sections where their experiences are presented thematically, with the answers to the research questions presented in the concluding chapter summary.

Description of Participants

Nine families participated in this study. Those families that volunteered their time and efforts to provide this valuable data are extremely appreciated. Their lives are difficult and sometimes overwhelming. Their free time is precious. They often go on little sleep and are in survival mode. Several families initially agreed to participate and had to step back due to the demanding pace of life raising a child with autism. Two participant families were from the Army, four from the Air Force and three from the Navy. It was a very experienced and seasoned group with the years of service ranging from eight to 28 with 20.3 being the average. Five
families were currently on active duty and four had recently retired. The families on average had 10 years of experience raising a child with autism. On average, the children had attended 4.5 schools (not including home-schooling). The following section is introduction of participant families.

**Alpha Family**

The Alpha family recently retired from military service. Mr. Alpha retired as a field grade Naval Officer after 24 years in uniform. His career was a blend of active duty and reserve time. After becoming a reservist, he could keep his family in one location for a longer time period; however, he was mobilized overseas and spent several assignments back on active duty. Three out of five of Mr. and Mrs. Alpha’s children have autism. Their daughter Allison has severe autism. Their two youngest sons, Alex and Avery, also have autism. Each of the children attended four different schools and are now in high school. Mr. and Mrs. Alpha have their hands full. The following is a quote from Mrs. Alpha which describes the level of stress they have been under during this journey with autism, “I almost vomited over it from the stress … crying because I couldn’t believe this was happening” (A2, p. 39). Both the husband and wife work outside the home to make ends meet. The Alpha family had been under duress during the data collection phase of this study and was unable to complete the third leg of the research. They were in the process of being forced to relocate from the military installation on which they were living. The military privatized on-base housing. To keep 100% occupancy, the civilian housing companies have opened up base housing to retired military families; however, they can be bumped for active duty personnel being stationed at the local base. This has led to situations where retired military families have been forced to scramble and relocate off the military installation. This put even more stress on an overwhelmed family with three children on the
autism spectrum. The Alpha family shared an example of life in transition, using the illustration of hotel room doors which are designed to keep people out not keep people in, Mrs. Alpha said, “Basically one of the parents has to sleep across the doorway like a Roman guard, or one of your children or both could be running like down the hallways causing issues … our daughter was the “great Houdini” (A2, p. 15). Despite their challenges, they seemed to always keep a good positive attitude with a sense of humor, sharing a new definition of the acronym Individualized Education Program (IEP), in which they said, it really means “Initiating Explosive Parent.”

**Bravo Family**

The Bravo family suffered the loss of a wife and mother when Mrs. Bravo passed away in 2013. No one can truly understand the enormous amount of strain and pressure military spouses are under or the burden families feel living without the love and support of a primary caregiver. Mr. Bravo is a high ranking senior officer who has spent his entire Air Force career of 26 years on active duty. He is now a widowed Dad raising three daughters (one in high school and two in elementary school) on his own. The youngest daughter, Britany, has severe and significant needs related to her autism diagnosis. At almost six years of age, Britany had attended three different schools. Mr. Bravo was very clear and distinct with his answers. He approached every question in a logical and sincere way. His answers were very well thought out and delved into the legal aspects concerning autism and leadership within the military. Mr. Bravo was selected to become the commanding officer of one of the nation’s military bases; however, he never assumed command because the at-home responsibilities increased dramatically after his wife died. He is an outstanding leader and patriot. He has suffered career restrictions due to enrolling his daughter Britany in the military’s required Exceptional Family Member Program (EFMP). He said, “It's like anything else in life, you cannot measure what you
do not know. When they put a Q-Code on your career as an officer and people make judgments about your career, it's without knowing why” (B2, p. 11). Mr. Bravo was not able to complete the third leg of the data collection due to time constraints after moving to a new duty station and the demands of another high-level position. He did not always feel that he had the support of his chain of command surrounding his family’s special needs situation. He explained, “As long as it doesn't impact required duties it is not; but always becomes a negative factor, especially since the death of my spouse” (B1, p. 4). He was very generous with his time and insight in the other two legs of the data collection including the interview which was the longest of all interviews lasting about two hours and providing a rich database of knowledge and understanding to draw from.

Charlie Family

The Charlie family served in the U.S. Navy. Mr. Charlie retired recently with the rank of Chief Petty Officer. He served within the medical community of the Navy as a hospital corpsman. Throughout the interview that passion in his voice was evident. The Charlie family has an adult son, Colin, who has severe autism. The strain and difficulties raising and caring for Colin took a toll on their marriage. After divorcing, Mr. Charlie went on to remarry, but he and Colin’s mom continued to care for their son jointly. Colin was born and spent 14 years of his life while Mr. Charlie was on active duty. He attended three different schools. The final part of Mr. Charlie’s career, however, was spent in the Navy Reserve. He fulfilled several assignments on active duty as a reservist including mobilization. Mr. Charlie has been an advocate for his son. He was still very concerned about the well-being of both his son and ex-spouse (Colin’s birth mother) who chose not to participate in the study. Mr. Charlie described his son as happy-go-lucky individual. He said Colin “requires the care that he requires but by the same token has the
ability to live life without misery and well, I guess when you take a look at all the forms of severe handicaps, that’s probably a blessing” (C2, p. 18).

**Delta Family**

The Delta family is an Army family currently serving on active duty. Mr. Delta is a non-commissioned officer who has 14 years of service. His wife, Mrs. Delta, has served as a trainer / educator with a nationwide special needs support program where she has facilitated over 93 workshops during a three-year period. She is an incredible advocate for families and all children with autism, including their son David who was diagnosed at age two. By age five, David had attended four schools. Mrs. Delta highlighted the issue of continuity of services with each military move. You must see your military treatment facility or your primary care manager to get referrals. You then must wait for that appointment and then you have to wait for the referral to go through. You then hope the service providers have spots available. The first available time slot is used as an evaluation. You then wait for the results of the evaluation. After that, you schedule therapy sessions where there are openings in the future. She said, “So, it becomes two, three, four months between the time that you get … to your new installation and the time that they actually will able to see your child” (D2, p. 11). This can be a lengthy process that eats up precious time during a child’s formative years. Mrs. Delta was careful not to speak of other people’s experience when rating services of support. The passion and love in her voice for helping families was evident. She shared one of their most successful stories, “Our son is talking all the time now. He may not effectively communicate as well as we’d like, but the fact that he’s talking, he’s potty-trained … we’re extremely thrilled with that” (D2, p. 21). Mrs. Delta’s son, David, is in a general education kindergarten class almost fifty percent of his day, which allows his mom to help other families. Mrs. Delta said, “That is definitely a success story and because
of him, I am able to do the job that I have been awarded because I have a son with a disability” (D2, p. 21). Without his success, she said, “I would not be able to effectively do my job or be able to help other military families and professionals gain the understanding that I gained throughout the years” (D2, p. 21).

Echo Family

The Echo family currently serves in the Air Force. Mr. Echo is a high ranking senior officer in the Air Force who has been serving on active duty for 23 years. Mrs. Echo is a very involved military spouse with the experience of several PCS moves. They have two sons. The older son, Eli, was diagnosed with Asperger’s Syndrome, a very high functioning form of autism at age 11. This was by far the oldest to be diagnosed of all participant families. Eli has been a student at six different schools. You could hear the passion, excitement and emotion in Mrs. Echo’s voice as she shared and relived some experiences during the interview. She shared this advice with other parents, “Be prepared to be the parent that goes to everything, volunteers for everything, gets to know all the teachers and doctors at the clinic” (E1, p. 7). She does her best to be both an advocate for her son but also support the teacher. She tries to listen to the teacher's frustrations with her child and help correct behaviors while also looking to help them make accommodations. She advised, “Make sure to have face-to-face appointments as it is much harder to ignore people after you have met them” (E1, p. 7). She mentioned it is hard after being at one duty location where you knew everyone and they all knew your child, and then you move. She commented, “It’s starting back at square one and it is exhausting for both mom and child. Be prepared and don't beat yourself up; the older the kids get, the harder it gets” (E1, p. 7). She recommended using Skype to let children have needed social time and keep in contact with old friends from the previous duty station. She wrote, “I have many friends with "regular" kids that
can move every year and their kids just pick up and flourish effortlessly, that is not my life as I know it” (E1, p. 7).

**Foxtrot Family**

The Foxtrot family recently retired from active duty in the U.S. Air Force where Mr. Foxtrot flew aircraft and held the rank of Lieutenant Colonel. Their youngest of three sons, Ferris, has autism. He was diagnosed at age seven and has attended three different elementary schools. They are a very active family with three boys in elementary / middle school. Mrs. Ferris is constantly on the go between schools, sports, and extracurricular activities. Ferris’s older brothers are very supportive and often help their parents by watching out for their younger brother with autism. The Foxtrot family was unable to complete the second and third leg of the data collection due to the transition period they were in as they moved several states away to be closer to extended family and start their next chapter of life after the military. This was a very exhausting endeavor and it took a while for the family to get settled. Their participation was appreciated. In describing overall general support across all schools where her child has attended, Mrs. Foxtrot said this, “The best support we had was at Freedom Elementary in Cheyenne. We had exceptional help. I feel at our current school, that Ferris is not” (F1, p. 6).

**Golf Family**

The Golf family is currently an active duty family in the U.S. Army. Mr. Golf has served for eight years. His son Greg was diagnosed with autism at 19 months and is now six years old. Mr. Golf is a Non-Commissioned Officer (NCO) who left active duty for about one year due to concerns over his son’s well-being. Mrs. Golf is an ABA therapist and advocate for their son, Greg, and works on a professional level with many other families raising children with autism. She wrote the following insight to share with other parents, “Try to get everyone on the same
Hang in there. You need to be your child’s advocate” (G1, p. 7). Her voice cracked and she started to cry while talking about their most difficult story. Her emotion and passion were very evident. Mr. Golf was also pursuing his Master’s degree with ABA certification and planned to leave military service to work helping children with autism along with his wife. Mrs. Golf explained that not all ABA therapy is equal and the quality of service can vary greatly between companies and between therapists. While Mrs. Golf believed in ABA, she shared, “I have to say though that has to depend on the company you use” (G2, p. 19). They first used ABA when their son, Greg, was two and it was horrible. It was so bad that they stopped services within two months and Mr. Golf stopped pursuing his degree in it. Now they work with a different company that has made a world of difference. Mrs. Golf said, “He’s been in ABA for four days a week for over two years and they’ve made the biggest adjustments and that’s caused me to finish my master’s degree and my husband to start his back up” (G2, p. 19).

**India Family**

The India family recently retired from active duty with the U.S. Air Force. Mr. India reached the rank of Colonel. His retirement came just two years shy of three full decades of service in uniform. Mrs. India had experience working as a professional in schools before raising her own children. She offered a unique perspective in regards to IEPs. She has sat on both sides of the table, both as a speech therapist on the educational team and as a mom of a special needs child. She said, “I was on the SLP side of the IEP table talking to parents about their children and then eventually I became the parent and was on the mom’s side of the table” (I2, p. 17). She had a benefit most parents do not have, “Because I was so already aware of parents’ rights and what the IEP process was all about, I could go into these meetings and know
exactly what was going to happen so it wasn't as overwhelming for me” (I2, p. 17). She was very thorough in all three legs of the data collection methodology. They have twin boys who were both diagnosed with autism at age six. Isaac has attended eight schools and Isaiah has been a student at 10 schools. Mrs. India commented about the diagnosis of autism and their boys not being verbal, “I can remember being very sad like when they were three and they were doing a lot of echolalia where I would say ‘what is your name’, and they would just say, ‘what is your name’” (I2, p. 7). This was very difficult for a mother. She said, “I use to think, wow, are they ever going to be able to say mom? Will they ever say I love you … and I was very sad” (I2, p. 7).

**Juliet Family**

The Juliet family is a Navy family currently on active duty. Mr. Juliet is a Lieutenant who started his career in the enlisted ranks before moving into the officer corps. Mrs. Juliet has had experience as a command ombudsman, a position representing the commanding officer and functioning as an advocate for the military units’ families. During her tenure in this position she was amazed by how many support services were available out there that families do not know about. Their son Jared has a very high functioning case of autism. He was diagnosed at age five. They have worked with the Navy’s EFMP staff to reduce Jared’s category ranking to allow greater flexibility with order assignments and duty locations. They have sought out the best educational environment for their son which has included home-schooling. They wrote, “June 2011 - Our first home-school year is under our belt. We look back at our progress and are astounded at the amount of growth that has taken place. There is no turning back at this point” (J3, p. 5). Mrs. Juliet also shed tears during the interview. There was much passion in this mother’s voice as she shared her heart.
Findings

Following van Manen’s (1997) methodology for hermeneutic phenomenology, I initially immersed myself in the data using Bronfenbrenner’s (1979) model to systematically code the data (see Appendix F). As I re-read through the material several times and I moved through the stages of understanding, abstraction, and synthesis themes began to develop (see sample Appendix G). It was during the fourth stage, synthesis, where every single document of research was systematically broken down by theme and placed into a spreadsheet. All the spreadsheets were then combined into a master spreadsheet with multiple themed tabs (see Appendix H). As the themes began to develop they were initially organized in accordance with their correlating research questions that guided this study (see Appendix I). They were then arranged into main themes and sub-themes sections. In the following pages as the themes are discussed and the voices of the parents become clear. Starting with the theme of diagnosis and finishing with the theme of perseverance, the stories of Alpha family through Juliet family were woven together in a narrative of the parents’ personal words. The participant families have traveled and are still traveling the road of autism. Their experiences and life stories are invaluable. The findings describe the phenomenon of military parents raising and educating children with autism. The following section address in the parents’ words what is unique and challenging about military life with autism. They have much insight and knowledge to share.

Experiences With Autism Diagnosis

Two specific events in the chronosystems of the participant families were the events of birth and autism diagnosis. Parents shared their experiences openly. The sub-themes related to the theme of Experiences with Autism Diagnosis that emerged were: (a) Participant families’
children with autism were considered healthy at birth; (b) Parents experienced a spectrum of emotions with diagnosis.

**Healthy at Birth**

The birth of a child is a special event highly anticipated by parents. While not specifically solicited, five of the parents commented about the birth of their child. Eli was born at Ramstein Air Force Base, Germany. He was 10 pounds and seemed perfectly fine at birth. Mrs. Echo said, “He met all his milestones and was actually a super easy baby. He was happy and very easy going” (E3, p. 1). Three families mentioned children being brought into this world via C-section. Ironically, the India twins, Isaac and Isaiah were actually born on the ‘Labor Day’ holiday in 1998 at 38 ½ weeks with no significant issue during labor/birth. Mrs. Delta wrote, “Our son was born via emergency C-section as I was induced with Pitocin and his heart rate dropped during contractions. Despite level of emergency he was said to be delivered healthy” (D3, p. 1). Mrs. Juliet wrote, “30 June 2004 – Our son Jared was born in Monterey California. At 28 weeks, I began having preterm labor and with bedrest and medication was able to stop labor. Jared was born at 37 weeks” (J3, p. 1). Colin was born just at the beginning of the third trimester premature in Cherry Hill, NJ. He hit all the milestones through the first year of life. At about age 13 to 14 months the Charlie family said, “we were concerned that he wasn’t progressing any further from those milestones in the first year” (C3, p. 1).

Despite some complications parents reported healthy children meeting milestones during their first year of life. At different stages in their children’s development parents began to see delays and differences. The earliest a child in the study was diagnosed with autism was at 18 months of age. Two groupings of diagnostic age emerged. Five of the families reported diagnosis at 18 months to two years of age. Three families reported the age of diagnosis between
five and seven years of age. One family’s child was very high functioning and was not diagnosed until age 11.

**A Spectrum of Emotions With Diagnosis**

For families, the news of this magnitude can be overwhelming. Parents go through many emotions with the autism diagnosis. Mr. Charlie said, “Well, it felt like we went through all five phases of change; anger, denial, bargaining and all of that. It’s a traumatic life experience” (C2, p. 1). In the timeline essay he described his son’s diagnosis as “initial shock and awe” (C3, p. 1). The Alpha family was already experiencing life stressors when they received the news. Mr. Alpha said, “We learned that our child was diagnosed with autism while I was preparing to separate from active duty and try to transition to a second career and also determine where we were going to relocate” Mrs. Alpha interjected “panic” … and Mr. Alpha agreed, “Ah panic, panic is a good word” (A2, p. 1).

The India twins’ special education preschool program teacher was one of the first to notice autism characteristics. Mrs. India described what a teacher said to her, “I'm only a teacher. I'm not a doctor, but my son has it and I can see some similarities in the way that your boys are, their speech, just from different ways that they play” (I2, p. 6-8). Mrs. India expressed, “I would say I was in denial when I first heard that because my background wasn't Special Ed. It was in Speech Therapy” (I2, p. 8). She had taken one class on autism. Her sons did not exhibit stemming. She said, “There's something definitely going on, but it's not that” (I2, p. 6-8). She commented that the doctors were on the fence about autism and many felt, “Let's wait and see” (I2, p. 6-8).

Mrs. Delta’s son was two at diagnosis. David had six different evaluations over a six-month period. All the evaluators, up to that point, said it was probably just a speech delay.
David was referred to Vanderbilt Children’s Hospital where he was seen by the child psychologist for about an hour. Mrs. Delta described their emotions after the doctor came into the room and told them their son had Autism, “It was a shock because we were just expecting what everyone else had said prior to that which was speech delay or PDD-NOS” (D2, p. 1-2).

Mr. and Mrs. Delta cried and then went back to their pediatrician at Blanchfield Army Community Hospital on Fort Campbell, Kentucky. The doctor read the report and said, “We are going to run with the diagnosis if that is alright with you both” (D2, p. 2).

Mrs. Echo described an event which happened at a play group in 2002 in which a woman came up to her and said, “You know your son is Autistic, right?” (E3, p. 1) She said, “I found that so offensive and my girlfriend and I were shocked and really upset that some stranger would come up and say that to me.” (E3, p. 1). Mrs. Echo commented in hindsight that the other mom must have been clued in better than her. Eli never wanted to leave play group, she said, “It was embarrassing and sometimes I would have to pick him up kicking and screaming to leave” (E3, p. 1). Years later, what Mrs. Echo referred to as the bus stop event happened. This pushed her to the library where she checked out a book on Asperger’s Syndrome. Her husband was adamant that Eli did not have any issues. She made an appointment with the Pediatrician who knew her son from Cub Scouts, basketball, other base events in addition to being his doctor for a year. After the appointment, which lasted a couple of hours with the doctor and child therapist, Eli was diagnosed with Asperger’s. The therapist told Mrs. Echo on the first home visit that Eli was so high functioning that he ‘might’ move out and get a job someday. Mrs. Eli said, “I have to admit that that sent a bolt of fear into my heart. We have joked that he would live in our basement playing video games his whole life but had hoped it was just a joke” (E3, p. 2-3). This reality hit the Echo family for the first time. She described the diagnosis, “It was actually a relief, because
I kept saying this is not normal to have fits like this, you know, not making eye contact, all the random weird things, it just didn’t make sense” (E2, p. 1). She went on to say, “It’s not ADHD, it’s not, you know, all these other things that the teachers and everyone would say, it was finally Asperger’s, so it was a relief” (E2, p. 2).

The Golf family described this story on the road to diagnosis. Their son Greg was born in July 2008 at Lackland Air Force Base in San Antonio, Texas. The next year their son was lacking in joint attention, not holding his cup, and very fussy. The doctor had placed ‘flags’ on his medical chart and talked about the possibility of autism, but to wait on a diagnosis until he was two. The Army transferred them from San Antonio to Fort Drum, New York. The doctors in New York identified that something was not right, but it was a specialist from Walter Reed Army Hospital which diagnosed their son with autism. Mrs. Golf said, “At that time my husband was getting ready to deploy to Afghanistan and I was super stressed” (G2, p. 2). Mrs. Golf expounded about their compassionate reassignment request in her timeline essay, “My husband’s unit becomes angry stating no matter what he will go overseas with this unit and they ‘do not care if he is on the ground for a day, he will go!’ (G3, p. 1).

The Juliet family described Jared’s behavior leading up to diagnosis. He withdrew from the group. He did not participate with the other kids. Because autism is a spectrum, not every child with autism displays all the characteristics or behaviors associated with the disorder. Mrs. Juliet explained that Jared was very loving but almost seemed to crave their touch. This was one of the things that threw them off. Mrs. Juliet said, “I had never considered autism because he was such a love bug, I had been told that children with autism didn’t like hugs or to be touched. I just didn’t know much about it. Autism wasn’t on our radar” (J3, p. 3-4). While in Kindergarten on Whidbey Island, Jared started throwing tantrums after school. He was
aggressive when frustrated and could not seem to de-escalate. She talked to the doctor about celiac and his behavior. In 2009 after a four-hour evaluation with the Developmental Pediatrician, Jared was diagnosed with autism. Mrs. Juliet said, “For us there’s a sense of relief in that we understood what was happening. Also, just kind of feeling you got hit with a brick wall because I knew what was going on but I hadn’t expected that” (J2, p. 1). She shared that it was a weird feeling. She felt validated because she knew that something more was going on with him, but she did not have a word or direction for it until that moment. She was also kind of ‘dumbstruck and sad’ because up to that point her limited view of autism had taught her that it was so bad. She wrote, “On the way home I stop at Barnes and Noble and get Temple Grandin’s book called The Way I See It. It was the best book I could have picked for that moment” (J3, p. 4).

Mr. Bravo also shared a feeling of relief with Britany’s diagnosis; “To be perfectly honest, in a way it was a relief because we had suspected that she had autism for a while or that something was ‘wrong’ with her” (B2, p. 3). He tells people now that it was a relief mainly because of the ignorance he had at the time. He and his wife had studied and read up on it and thought in their heads this is what it must be. He had no idea how that would impact their life. They were relieved and could start getting Britany the help that she needed, but he said, “We had no idea about the road we were about to travel” (B2, p. 3).

Families shared the spectrum of emotions with autism diagnosis. Parents talked about the initial “shock” of autism diagnosis and the “relief” of having a name and condition associated with the behavior and symptoms their child was displaying. As families began their journey with autism, they soon discovered it was a hard road to travel.
Challenges and Difficulties of Autism and Military Life

Military families live a unique life with many challenges and difficulties. Autism brings challenges to military service and serving in the military creates difficulties with raising and educating children with autism. Autism is a dynamic condition with health and behavioral considerations which create difficulties for any family. The military life combined with autism increases stress and strain on parents as well as the sacrifice of families. The sub-themes identified were (a) health and behavior concerns and challenges; (b) Autism and military increases stress, strain and sacrifice.

Health and Behavior Concerns and Challenges

Both health and behavior are interrelated and are issues that parents face. The health issues are physical cognitive and emotional. Parents shared experiences and concerns.

Health concerns. Another challenging area involves the health concerns accompanying autism and overall health of the child. Charlie family wrote about Colin’s under nourishment due to his inability to handle texture and solid meats and vegetables. Feeding is still a constant battle; Colin wanted pureed food well into his grade school years. Mr. Charlie said, “Mastering bathroom potty training continues to this day in adulthood” (C3, p. 3).

The Juliet family shared experiences with gastrointestinal issues which were consistent with many other children on the autism spectrum. At age two Jared was having problems with bowel movements and was always constipated. His pediatrician suggested using Baby Lax to help him through the constipation, but soon this became necessary for a bowel movement almost every time he needed one. Jared was diagnosed with chronic constipation by a Gastroenterologist at Wake Forest University Medical Center who told them that Jared’s constipation could be resolved when he was older by teaching him to relax his muscles but for
the time being they should give him a stool softener. During this time, Jared met most
milestones on time; however, he did not speak well until age three. He was able to learn a little
bit of sign language and used a lot of gestures to get what he needed when he needed it. He also
did not have the ability to draw anything recognizable. When using a crayon, he would make
random marks. When the family moved with the military from North Carolina to Virginia the
constipation issues worsened; however, their new family pediatrician in Virginia would not
prescribe the stool softener that Jared was given at Wake Forest. Jared’s new pediatrician did
not feel it was necessary and so he went several months without it. Jared could not have a
normal bowel movement without pain and straining. He was in the 3rd percentile for weight.
Mrs. Juliet commented, “He resembles a starving child from a third world country. You can see
his ribs and his tummy is so bloated it looks like a pregnant belly” (J3, p. 1).

The Juliet family called their former Gastroenterologist at Wake Forest who renewed the
prescription for Jared over the phone. Jared’s constipation continued getting worse even with
taking stool softener. Mrs. Juliet returned to the pediatrician and voiced the same concerns that
she had previously and was again told that Jared’s bowel movements were normal. She insisted
on a referral to a Gastroenterologist in Virginia. An x-ray and examination by the
Gastroenterologist found that Jared’s rectum had stretched and created a pocket of stool. His
stool had not completely blocked yet, but was close to causing an emergency situation. The
doctor prescribed doubling the dose of stool softener and an enema each night for a week. Mrs.
Juliet heard from her cousin who had started her son on a gluten/casein free diet because of
ADHD. She researched ‘gluten free’ and the first thing that came up is information about Celiac
Disease. She said, “When reading the symptoms, I feel like they are talking about Jared; it is so
spot on” (J3, p. 1-2). They put Jared on a Gluten/Casein free diet and within days the
constipation is gone, but not only that, his behavior improved immensely. He was calmer and less aggressive. Mrs. Juliet wrote, “Seems like he has come out of a fog. The next few days and weeks are HUGE. Jared draws something recognizable for the first time, a smiley face, it is a masterpiece in my eyes” (J3, p. 2). Soon after Jared potty-trained himself. He began to gain weight and his belly began looking less bloated. He started looking healthy. The next year the Juliet family saw Jared’s health improving and continued the gluten/dairy free diet. Mrs. Juliet shared, “It is hard in that we are learning to eat a completely different way, but we see the benefits right in front of us and it’s an easy choice to make” (J3, p. 2).

During the research, participant parents shared several other diagnoses their children received. Several children were identified as having a speech delay. At age three Mrs. India’s twins were enrolled in a special education preschool program designed for children with speech / language delays in Colorado Springs. She wrote, “They only had five words each in their repertoires and were diagnosed with a profound speech delay” (I3, p. 2). In 2009 the Golf family’s son was diagnosed with ventricular septum defect (VSD) and required a heart specialist. Mrs. Golf wrote, “In 2014 - Finally got back to see the developmental doctor after being on a waiting list for 3 months, and my son is diagnosed with ADHD too, medication is referred to him” (G3, p. 2). Mrs. India described another diagnosis, “Overall, this past year (2015) for both the twins, their OCD (Obsessive Compulsive Disorder) is more severe. The OCD is more challenging for us than autism” (I3, p. 14). Mrs. Juliet wrote, “In 2006 – at 2 we took Jared to a Gastroenterologist at Wake Forest University Medical Center who diagnosed Jared with chronic constipation” (J3, p. 1). He was diagnosed with chronic constipation.

There may have been more diagnoses, but the research questions were not targeted toward other conditions or diagnoses. Sometimes other diagnoses are given leading up to an
autism diagnosis, yet other times a separate condition can be diagnosed afterwards. Many children on the autism spectrum have additional conditions or medical diagnoses. This often complicates the challenges and difficulties.

**Behavior challenges.** The behavior of children with autism is quite different than typical children (Autism Spectrum Disorders, 2011). Autism is complex. Often the mannerisms and way in which children with autism go about their world is odd, peculiar, disruptive and sometimes even offensive. Mrs. Golf explained it like this, “Well he does not look retarded” (G3, p. 1). This is one of her favorite lines given by complete strangers trying to make her feel better about having a child with autism. Occasionally, she has a snappy comeback but most days she simply walks away. She wrote, “Autism Spectrum Disorder or ASD is a wide-ranging array of disorders relating to troubles with social interaction, verbal and nonverbal communication, and repetitive behaviors (AustismSpeaks.Org 2012). Many people do not learn or know about ASD until someone they know has some form of it” (G3, p. 1).

Behavior is a challenge. Mr. Bravo put it in perspective from a military leader and a father. In the military, there is an expectation of a certain behavior and compliance both for him and those around him. “I have to let that go with children to a degree, have to let it go even more because I have all girls, and have to let it go even more when I expect Britany to do something” (B2, p. 45).

The Alpha family shared a couple of scenarios their family experienced, “One of my children if I went into a Starbucks would plaster herself on the pastry case like a starfish and we had to peel her off and it causes a scene and it’s exhausting … it’s not fun” (A2, p. 41). They also described staying in a hotel during their last PCS move. Their daughter could open the door, even with the security bar lock. They had to devise a way to keep the door closed and
locked. They wrote, “Dealing with the consequences of security breaches like a naked child running down the hotel hallway after an escape, or meltdowns and head banging in a public area like a hotel was especially wearing and stressful” (A1, p. 3).

Mrs. India described her twin boys, “One of the things I use to say about them, they were like Curious George. They would look into things. They could climb and they were so active. I would say they are like, I mean, hyper on speed” (I2, p. 28). She described it “like herding cats” (I2, p. 28). It was just very difficult to keep them together. She would have to find a fenced park because they would run and not come back.

Mr. Charlie described behavior challenges as the children increase in age, “Adolescence presented a young adult who could cause harm to himself and others” (C3, p. 3). He illustrated it like this, in childhood, Colin would be vocally crying or perhaps slouch or kick but as an adolescence he had more reach, power, and could be aggressive in a manner greater than that of a child. For instance, pounding on a car window, but not having any understanding that it could break. Mr. Charlie also commented that as the level of frustration increases sometimes self-destructive behaviors appear.

Mrs. India also described difficulties as their boys entered adolescence, “Isaac went to an adolescent treatment In-patient facility for four days after becoming very escalated at home, was verbally aggressive with siblings and became physically aggressive, needing to be restrained and then taken to the ER for evaluation” (I3, p. 14).

The India family also shared an event when local authorities had to be called in. In February 2012, an incident happened at the younger twin's school. Isaiah's Obsessive Compulsive Disorder (OCD) was getting more severe. If he was brushed on the shoulder for example, he would say that he needed to be brushed again backward to make him 'normal' again.
One day the principal touched Isaiah’s shoulder and caused Isaiah to feel 'abnormal.' When Isaiah asked the principal to re-touch his shoulder, the principal refused. Mrs. India said, “I was there to pick him up early so I told the principal to go ahead so we could leave the school. The principal still refused saying that he was 'uncomfortable' (I3, p. 15). Mrs. India reassured the principal that she was okay with him touching Isaiah's shoulder and to please do it so they could leave. The principal still refused. Isaiah told the principal calmly that his initial tap on the shoulder caused him to have a disturbing image appear in his brain and started to plead with the principal to tap his shoulder. She said, “I started to plead too. The principal still refused and then locked himself into his office when Isaiah started to ask him louder to help him get the image out of his brain!” (I3, p. 15). Mrs. India ended up calling 911 to get Isaiah removed from the campus. She said, “Needless to say, it was a very traumatic event for us as a family and his teacher at the school. When I called the twins psychiatrist later that day, he was livid and was ready to confront the principal!” (I3, p. 15). As a result of the incident, Isaiah was removed from school and put in an alternative Adolescent Day Treatment program.

**Autism and Military Increases Stress, Strain, and Sacrifice**

Raising a child with autism in the military increases the basic challenges and difficulties of child-rearing. Several families commented about the extra stress and sacrifice. Mr. Bravo said, “The aspects that Autism brings to your family, most of those increased challenges do not come with increased help or increased benefit” (B2, p. 2). Mrs. Golf said, “It’s also very challenging … having a child with autism and being in the military, it is a whole new world” (G2, p. 1). Mrs. Golf also wrote, "One of the hardest challenges for my family has been in my husband’s army career" (G3, p. 1).
**Stress.** Mrs. Golf explained that other families do not really understand the struggle they are going through. She said, “It’s, I would say, very different and very challenging” (G2, p. 1). They tried to help their son adjust to moving and new situations but to use her words, “most oftentimes he freaked out” (G2, p. 1). She also shared that he had tantrums and “reverted back to pooping in his pants” (G2, p. 1) for the change that occurred. This was very difficult and increased stress on the parents.

Mrs. India wrote, “Parents need to get involved. This is the difficult part because some parents are so overwhelmed they don't know where to begin” (I1, p. 6). Mrs. Golf said with emotion, “I actually ended up going to a psychologist because I was severely depressed between my son’s diagnosis and the fact that my husband was going to leave me and I had nowhere to turn to, no help” (G2, p. 24). With her husband about to deploy with his Army unit she described being in a new place and not knowing anyone. She had no idea how she was going to drive six hours one way to the closest specialist in Vermont who could see her son, in the snow in the dead of winter for a three-hour doctor’s appointment, then turn around and have to drive six hours back home, all in one day with a child with autism.

Sometimes life can present many challenges all at once and increase the stress level as in the case of the Juliet family. Mrs. Juliet shared this story. In addition to autism their son Jared was having gastrointestinal complications. The doctor told them to double the dose of stool softener and Jared was to have an enema each night for a week. He had accidents everywhere he went. This was the same week that her husband put on “Khaki” (a certain uniform worn by Commissioned Officers and Chief Petty Officers). He was gone most of the week for Chief’s induction training. Mrs. Juliet described the stressful week. She was eight months pregnant and hosting her husband’s parents for the weekend. She said, “To add insult to injury one of the
daycare kids came in with lice and I had to de-lice my kids, myself, and my house before our guests came in. It was an awful week” (J3, p. 2).

**Marital strain.** Within a family, the relationship of marriage can be strained because of autism. Mrs. Delta talked specifically about the added stress on marriage, “Every marriage has ups and downs and when your child has a disability, especially autism … it can put stress on a marriage and a military marriage is already fragile because we deal with deployments” (D2, p. 20). She also said, “There is emotional strain on the marriage because you always try to take care of your child if you’re a good parent and sometimes there is not enough that you’re giving to your spouse” (D2, p. 20).

**Financial strain.** As mentioned in an earlier section, often the diagnosis of autism is accompanied with other medical conditions. The health of their children is important to military parents. Medical care is expensive. She described the monetary financial strain on the marriage, “Not having enough money because the other parent cannot work because someone has got to be there to take the child to all of their therapy appointments and all of their medical appointments” (D2, p. 20). The military has an extensive medical insurance program which helps cover a lot of expenses; however, it does not always cover all of them. Autism is a multifaceted disorder. The behavior of children with ASD is targeted with many types of medical intervention and therapy with high medical costs. Mr. Bravo explained, “Because she requires 24 hr. care, $24,000-$36,000 a year; she also requires medications and other supplies not considered in most programs” (B1, p. 3). Mrs. Juliet stated, “I cannot afford to pay out of pocket for therapy or medical. This isn't an option” (J1, p. 3).

Mrs. Golf talked about her husband leaving active duty and then rejoining for Tricare benefits, “My husband actually got out a year after being here. So, we went home for a year.
And my husband did the reserves, but we couldn’t make it on our own with our son needing the insurance” (G2, p. 4-5).

Mr. Bravo talked about the cost of medical care and the financial burden, “The big challenge that I've seen is the financial. All the states have different Medicaid waiver programs and processes. The military has absolutely no equalizer” (B2, p. 23). He commented about how he was given military orders to go to a new duty station in accordance with the EFMP program; however, the military has no Soldier’s Relief Act for special needs children nor is there an Education Compact for Special Needs Kids to help with the continuity of care with this program. He explained they were getting about $36,000 a year in health benefits from a state fully funded on the Medicaid waiver. The funds covered expenses such as caregiver wages and items like diapers that are not typical for an eight-year old girl. They moved with the military to a different state that did not fully fund the Medicaid waiver and therefore he was placed on a ten-year waiting list and had to make up the difference of $36,000 out of his own pay in order to have the same level of care that Britany required 24 hours a day, seven days a week. Each military move to a new state means going to the bottom of a list and starting over.

Mr. Bravo went on to comment about the recent legislative changes to health care where he had learned that the Affordable Care Act had limited the benefits of normal insurance companies to special needs children. If a government program covers a particular item as mandated by law by the Affordable Care Act, the insurance companies will not pay for it. He said, “It doesn't matter if you're on the government program or if you're waiting for ten years because the state in which you're in doesn't fund that program, that does not matter” (B2, p. 24). He concluded, “So you can see where a service member would want to leave their family in one
location where they got the immediate services of a particular program…and I understand that happens more and more because of these challenges” (B2, p. 24).

Family sacrifice. Family sacrifice was a theme throughout the research findings. The challenges are difficult in supporting a child with autism. Both the parents and other children are affected in profound ways. Sometimes it is a difficult burden for both parents and siblings living in a home with a child with autism. Families often sacrifice in many different ways. Service in the military brings a heavy burden for any family. These family sacrifices come in multiple forms and fashions. Mr. Bravo shared his perspective, “From my point of view, I think that having a child with autism in the military it opens your eyes to the challenges that other folks with other disabilities have” (B2, p. 1). He mentioned the difficulty of serving your country and performing the requirements. He said, “Performing those duties without bringing in your family situation has shed the light … on how much of an expense the military service is to family life. It exacerbated that or demonstrated that to me gravely” (B2, p. 1).

Sibling sacrifice. The brothers and sisters of children with autism also sacrifice. Mr. Charlie said, “I was mobilized and upon departure for my mobilization, it was very difficult leaving my son. Moreover, it was even more difficult for my spouse at the time because my son was acting up in ways that were self-destructive” (C2, p. 17). He described how Colin would bang his head against the wall. Colin would rock incessantly and grab a picture of his father. It was very difficult to calm him down when he got in emotional temper tantrums because he did not understand or have the ability to calm down. The whole family unit had to manage that behavior and deal with those situations. It is an added burden when the military member was serving away from home. Mr. Charlie said, “I feel as though it was especially difficult to his
sister who is just three or four years older than he is and she had to also get involved to help settle him down” (C2, p. 17).

Often there is so much attention directed toward the special needs member of the family that there is little left for them. Mrs. India talked about this, “Well, the boys were five and our youngest was three. I never really had any time alone with her, not much” (I2, p. 35). After explaining to the school that she was a “burnt out mama” (I2, p. 36) they accommodated her needs by picking up both her boys separately to take to two different schools, which allowed her about three hours one-on-one with her youngest daughter.

The India twins have grown into adolescents, but their behavior still impacts the family. The impact of autism and OCD in their daily lives became very intense and traumatic for them and for the entire family. The boys would get ‘stuck’ in public places and attempts to get them to walk out calmly were barely successful. Mrs. India said, “We are not able, as a family, to live a life with enjoyable activities to participate in because of the twins. The toll on our other two children has been a heart-breaking experience to witness” (I3, p. 15). She shared that they were beginning to look at residential options for the twins, both for education and for living skills experiences. Mrs. India wrote, “I would love to take our kids to Disneyland one day but the reality is that we would not be able to take the twins and really enjoy the experience” (I3, p. 16). She expressed her hope to one day have some fun memorable guilt-free experiences with her two neuro-typical children.

Solo parent. Raising a child with autism can be extremely hard for two married parents, but when one spouse is gone because of deployment, divorce or death the challenges and level of sacrifice increases. Mrs. Delta said, “So, it becomes very difficult when you’re the only person at home because your active-duty service member is deployed” (D2, p. 1). Mr. Bravo had this
perspective, “A lot of these considerations that I’m talking about sometimes are not even thought about by the military because you have a spouse. If you have spouse, then the military doesn’t worry about it” (B2, p. 35). Mrs. Echo said, “I’m mostly a single parent anyway because of the military life, the hours” (E2, p. 11). She went on to say “At least I do have somebody there to support me and to step in when I need a break, and you don’t have that when you have a spouse deployed” (E2, p. 11).

Mrs. Delta wrote, “It very well may be, partially, my husband’s sense of duty and responsibility, but he is rarely home to provide any assistance to/with our son” (D1, p. 4). She also shared in the interview, “So, if it were him trying to get time off or be there for the IEP meetings, it probably wouldn’t work out too well because he’s expected to do his job no matter what” (D2, p. 9).

Mrs. Juliet described the biggest challenge with the deployment as being so far away from family and the people who can really be a support to you. She expressed it is nice to have friends and the support of medical professionals, but being far away from family and not having her spouse there while dealing with those hard moments when there is a behavior problem, she said, “That’s difficult in deployments” (J2, p. 4). Mrs. Golf stated, “Our biggest challenge that we have is just trying to get our son to understand that daddy is gone and so it’s only mommy here and mommy can’t do all the things that daddy does” (G2, p. 13). Mrs. Delta also spoke of her son handling the challenge of Mr. Delta traveling for military assignments, “So, we have dealt with my husband, ‘Dad’, being gone … and it gets difficult because our son doesn’t understand that daddy is just gone for a while” (D2, p. 13). She explained that, “After a couple weeks, he’ll like, cry for him, ask for him and that’s the hardest part is that he doesn’t understand that daddy is just gone for a little while. ‘He’ll be back!’” (D2, p. 13).
Being a solo-parent on the home front managing the household and keeping the family together causes the stress level to rise. Mrs. Alpha commented, “My experience is considerably different from my husband’s because he was at work or deployed for a good percentage of the time we’re discussing so I’d have to do the hands-on frustrating stuff” (A2, p. 8). She said, “Honest to God there are sometimes I don’t know how I survived it. I was working two jobs and I have three special needs kids and we had battles going on that were legal and social” (A2, p. 14).

**Deployed parent.** The perspective of the parent deployed and away from home was also noteworthy. Mr. Alpha explained, “Ah, additional stress of worrying about how things are going and not being able to really assist to resolve issues like the problems that were encountered with the schools with our son while I was in Iraq” (A2, p. 16). He talked about trying to help, but felt he really could not do anything about it except try to provide emotional support and locate resources that might help.

Mr. Bravo also commented about the challenge of being the military parent away serving, “One of the other challenges for me that I would say with me being gone is that I cannot intervene for her” (B2, p. 35). He said, “When I am here, I can intervene for her at any moment if I need to, and that vulnerability for her, an already vulnerable person that vulnerability goes up” (B2, p. 35).

Mr. Bravo spoke about the sacrifice of being widowed and raising a child with autism while serving in the military, “Well, all those things increase now and are different now with a child with Special Needs and having no spouse” (B2, p. 36). He explained, “It just takes a heck of a lot more planning, and it takes a heck of a lot more out of you when you do that and the sacrifice to me is much greater” (B2, p. 36).
Career sacrifice. Having a child with special needs can be a restricting factor in career progression. It is also a limiting factor in regards to duty assignments and locations. PCS moves are tough on families. Having a child with special needs increases the challenges and stress level. In an attempt to help these families, the military has inadvertently placed some obstacles in careers of the military member. The military has established the Exceptional Family Member Program (EFMP) to help. The program is designed to help ensure that a child or spouse gets the help that they need when the service member is transferred. Sometimes; however, the program has an adverse effect on service members’ careers.

Mr. Bravo explained that once they got the diagnosis for their child, the military registered him, not his daughter, in the EFMP, “They didn't put her, they put me, and that's a key thing to realize in the military system. Even though she is the reason for being on the Exceptional Family Member Program” (B2, p. 9). He described getting on the program as not being difficult at all. He said, “I had heard from other guys that getting on the program is not tough. Getting out of it is extremely hard” (B2, p. 9). In the Air Force, they have what is called a Q-Code which is an assignment limitation code. He said, “Once you get on the EFMP program, you get a Q-Code which means everybody sees in your record, everybody” (B2, p. 9). Mr. Bravo explained that even those who do not have a need to see it still see that there is some limitation on your ability to PCS. He said, “That Q-Code is not explained in your records, but it's put in your records anyway” (B2, p. 9). He shared further in the interview, “I got to tell you that the limitation that they put on your career -- it's like anything else in life, you cannot measure what you do not know” (B2, p. 11). When a Q-Code is placed on your career as an officer people make judgments about your ability and commitment to serve without fully knowing all the details. He explained, “The officer mentality, especially the more senior you
become, is that if there's any reason to have a limitation in the service of your country, then you are not fully a member of the Officer Corps” (B2, p. 11). Mr. Bravo admitted he was part of that culture. He is still surrounded by that culture, and must be careful now because he sees that some people do not make those choices. He said, “I've dealt with that in a lot of ways where people will make those comments about the limitations and what not, and it's very interesting to live in that world” (B2, p. 11).

Mr. Bravo spoke openly and often about the career restrictions, “Every time we move or get orders, I have to prove again she's autistic” (B2, p. 17). He described going from point A to point B, where once he got the orders to go to point B, the system would flag that Q code on his record. That Q code does not tell anybody whether he can go or not. It just says that he must go through this painful process which the military says every point B that he gets might be a no. If the system says he cannot go to point B because of his daughter, he has two choices: he can retire or he can wait for the system or the process to select another area. The more senior in rank the less flexibility a member has to request a certain duty station. Mr. Bravo explained the selection system, “They do it in kind of draft manner, if you will, NFL draft. They put you on a list, and the General Officers get to pick you to go to where they think you should go next” (B2, p. 17). Because the selection team does not have the time nor the inclination to worry about it, the Q code is a limitation code. The officer drops to the bottom of the list to be selected out right. In Mr. Bravo’s words, “The limitation code basically says, ‘Hey if you pick this guy, the answer may be no, if you pick this guy, he comes with conditions” (B2, p. 19). He explained, “The military is not made, especially at the senior officer level, to accept those kinds of conditions. So, that's the challenge and even before you get orders” (B2, p.19).
Mr. Bravo shared from personal experience that he was not able to take a certain duty assignment because of its location. The individual who took his spot in filling that assignment is now a Brigadier General and about to be made a Major General. This was a huge career opportunity he missed. While his superiors seemed to be understanding of the situation, the reality was tough. He felt, “In my particular case, I think that the code has been a huge detriment because of the perception that you can't give your all which is what they expect at the senior officer level” (B2, p. 13). In fact, he was told that matter-of-factly by one of his superiors. It was a very clear if-then statement in which the senior officer told him, “‘You know, if you didn't have this daughter with autism, then this is where you would be or what you would become’” (B2, p. 14). Mr. Bravo said, “In a way, I understand it, and in another way, I think it's a shame” (B2, p. 14). He explained that the institution within the military is “If you are different or you are a slight bit of a drag is to cut you off or to get rid of you. No matter what they say in Washington, that's the position” (B2, p. 53).

Mrs. Golf echoed concerns about career restrictions on the enlisted side, “Because when you start moving around, you have a lot more challenges and also like for us, we’ve had to do two compassionate reassignments” (G2, p. 21). She explained that means her husband does not get points when they are only stationed at a post for a few months. She said, “That causes the scoring that they give you to be really low and that’s unfair” (G2, p. 21).

Because of concerns about career restrictions some military families are hesitant to enroll in the EFMP. The Echo and Foxtrot families did not enroll in EFMP. Mrs. Echo’s son has very high functioning autism. She explained their reasoning as such, “Because there is no need to announce it. I don't hide it, but he skirts the line of needing any help” (E1, p. 4). The India family was also hesitant. Mrs. India wrote, “My husband, if asked, would give information
about our children's special needs. He's not one to just volunteer info about our unique situation” (I1, p. 4). She also shared, “We knew about EFMP program for quite a few years before we signed up (to be honest). My husband was concerned that he would not be able to get certain assignments in the Air Force if he signed our family up for EFMP” (I1, p. 1). She wrote, “I had tried to talk my husband into signing up for EFMP but he was apprehensive that he would be able to get the position he wanted at a different Air Force Base!” (I1, p. 1). Mrs. India explained, “My husband was concerned about not being able to get certain positions that he knew he was very qualified for, that he would be automatically disqualified from being a contender for a really good position somewhere (I2, p. 11). She remembers getting a lot of information about EFMP and hearing her husband just say, “I'd like to be able to get that position. I know I would be really good in that position, and I don't want to kind of disqualify myself by doing that” (I2, p. 12). On the decision to register their twins on the EFMP she said, “We did kind of go back and forth on that topic” (I2, p. 12).

Mr. Bravo said, “My experience with others and being on the EFMP program was all negative” (B2, p. 10). He had supervised hundreds of military members on the EFMP program. Not just for autism, but for everything from epilepsy to breathing disorders to cancer. Mr. Bravo said, “I have never seen a positive experience from the EFMP program when it came to the members” (B2, p. 10). Mr. Bravo had witnessed the sacrifice families made firsthand. He shared, “I was reluctant to be on it, but the only way my daughter could receive services through Tricare was to be on it so I enrolled as soon as I could … to give her that help” (B2, p. 10).

Once the India family was enrolled in EFMP they made adjustments and modifications to how they approached new assignments. Mrs. India indicated her EFMP experience was not necessarily bad. She said, “I didn’t really have a lot of control to tell my husband, oh, let's try to
move here, try to get this job here because they have this and this and this” (I2, p. 14). Mr. India would identify jobs at certain bases with the right opening timeframe. He felt that he had to go and do the research on his own because of the "Q" code. Sometimes the assignment personnel would tell them they were ineligible because there were no services that their sons would need at a base or community. Mr. India would go and start researching it and if he found that the community did have services there, he would then go back and tell that assignment personnel that he did the research and there were these types of services or therapies, therefore everything that their boys needed they would be able to get in that particular community.

The Juliet family also shared about their career limiting experience. They moved once since receiving an autism diagnosis and were getting ready for the next PCS. The detailer (placement officer) knew quickly where Mr. Juliet was planning to go. Everything was going smoothly and then brought to a halt when the detailer saw their EFMP status. Mrs. Juliet explained, “They told us that ‘no we could not go to Mississippi’ because they didn’t have the services that we needed” (J2, p. 3). The Juliet family felt that was a little weird for their situation because Jared was high functioning and they did not feel that they needed special hospitals or medical facilities nearby which was the main issue for the EFMP category five. Mrs. Juliet said, “We were just really surprised because we felt like we didn’t need a lot of those things and yet you know we’re being held back from certain places” (J2, p. 3). The Juliet family talked to their doctor and showed where they would be able to receive all the services they felt their son needed at their proposed new duty station. “I think that was the hardest thing for us with this is when they told us that we would be a category five and we knew from prior experience the restrictions that came with that as far as getting orders” (J2, p. 3). The doctor signed off and all the required documentation was forwarded to the EFMP headquarters office which worked with the detailer
to issue the military orders. Mrs. Juliet wrote in her timeline essay, “January 2013 – We stop all therapies in preparation for our next move. We are also able to get our EFMP status changed to Category 4 in hopes of getting orders to Fleet Survey Team in Mississippi” (J3, p. 6).

While career restrictions may not be intentional from the military, they are real. Because of these military members are hesitant to enroll in EFMP even though it is mandatory. Once registered in the program, families do a lot of research on their own to ensure their children’s needs will be met at potential new duty assignments. Families also try to work with detailers and placement officers to find the right fit for the military member and their children with special needs. Parents have a lot of experience to share. Stability and continuity of care are areas of concern that arise with career progression and new duty assignments.

**Challenges and Difficulties Related to Change**

The military can be a demanding profession for the soldiers, airmen, sailors and marines who serve in uniform. It can be equally demanding on the non-military spouse and the family. There are many aspects of military service which are challenging and cause difficulties for families. Two sub-themes that emerged were (a) Military life means change and transitions; (b) PCS moves are difficult.

**Military life means change and transition.** Change can be good or bad, positive or negative. People react to change differently; some handle it better than others. Individuals on the autism spectrum struggle with change. Change caused by military commitments and requirements can be a difficult for any child, but specifically for a child with autism. Mrs. Echo said, “Every change is just a little bit more difficult, every PCS, every school change, every house move, every starting over with friends is just more difficult” (E2, p. 1).
Mrs. Juliet talked about the disruption caused by change, “I think for us we feel it, it screws with our, the way we do things and the schedule … it messes with our, I don’t know what the word is, the way we do our day” (J2, p. 6). The Alpha family wrote about their experience with the frequency of change regarding military assignments, “1 year-long mobilization and deployment; 1 period overseas on ADT orders for 6 months, and several periods of ADT duty in CONUS for periods of 2-4 months. This was between January 2007 and March 2012” (A1, p 4).

The Alpha children have come a long way in their development. Mrs. Alpha said, “But there were stages in each of their development where any change, whether it was something major like a move or something minor like putting on their clothes in a different order, was cause for trauma and meltdowns” (A2, p. 11). Mr. Charlie described his son’s reaction to change, “Colin does not understand uncertainty” (C2, p. 6). He explained that since Colin is on the severe end of the autism scale that he is not cognitively able to process the uncertainty part. He said, “But he does understand the change and he’s confused by the change. He doesn’t understand why the change is happening. There is no ability for him to grasp that. Therefore, the change becomes more dramatic for him” (C2, p. 6). Mr. Alpha shared, “In terms of deployment … the younger, definitely with the younger child my being gone was very disruptive for him and unsettling” (A1, p. 11). Mrs. Alpha interjected, “Which led to a whole huge trauma at school and ended up involving the CPS, but it was major and our other daughter who is profoundly autistic was also impacted” (A2, p. 11). She said their other daughter was just unable to articulate it, and they probably didn’t pick up on her “angst” as clearly as they did their son.

**Regression.** Regression is a common term in the autism community. Mrs. Delta saw this on multiple occasions, “Children with Autism will typically regress and we knew that our son had regressed from the move from Tennessee to Utah” (D2, p. 7). They believed he would
regress at least mildly again, because during that move he had completely stopped talking again after several months of successful therapy that was getting him to start communicating. She went on to say, “Every time we move, I think he actually likes the adventure a little bit. He is out of sorts. He is not able to do all the things that he had done when we left. So, the regression occurs” (D2, p. 11).

Mrs. Golf’s comments were similar about behavior when ‘Dad’ is gone for military service. She said, “And so my son starts to get really anxious. Why isn’t he calling us? Where is he at? What is he doing? When is he going to be home? (G2, p. 13). Then he starts to once again revert because a change happened. She explains, “He’ll start pooping in his pants, throwing a lot more tantrums around the house and then it becomes harder on me” (G2, p. 13). Mrs. Delta emphasized the issue, “Well, the major thing is the regression that occurs. No matter how much you believe you prepare for it, the regression still happens. So, that’s a huge problem” (D2, p. 10).

Mrs. Echo talked about her son Eli and the change with PCS moves, “When they do connect it makes it even harder when you leave because it’s almost like they regress because they’re just missing what they had and they don’t know how to form it at the next place” (E2, p. 1). She described Eli’s feelings when she told him they were moving, “‘But mom I’m so comfortable here’, you know, it’s just so hard when they’re so comfortable and I was too, you know, we had our little groove and honestly we haven’t found a groove here” (E2, p. 31). Mrs. Echo also highlighted adaption differences between children with autism and neuro-typical children. When moving to a new place it is very hard to feel included; it takes a very long time. She said, “We’ve been here eight months and he’s just now saying he feels comfortable” (E2, p. 6). She shared this story about missing old friends, “When we go to Boy Scouts he still gets on
my phone and calls his other friends while he’s at Scouts with the new kids because he just notices so keenly how much he misses them” (E2, p. 7). Because of Eli’s need to keep in contact with old friends Mrs. Echo drove him from Florida to Virginia. The other military family traveled all the way over to Virginia from Wyoming so the boys could go to Scout camp together. She said, “You know, and I’m like all right, I’ll do it because it’s that important to keep him having his friends” (E2, p. 7).

**Change is a way of life in the Armed Forces.** The military is in constant motion. All around the globe the military men and women stand watch. Around the clock someone is on duty. Military members are coming and going from training evolutions and deployment cycles are being adjusted based upon world threats and other factors. Military members are also being relocated from duty assignment to duty assignment as they serve, increase their skills and move into positions of greater responsibility. Change is a way of life in the Armed Forces. For single military members, the changes may or may not be as demanding. For military families, it can be extremely difficult, especially for families of children with special needs. Mr. Charlie commented, “I would also have serious concerns with relocation every two or three years. For a low-functioning autistic child, that’s just way too much upheaval” (C2, p. 16). He also said, “It would be a deal breaker, no matter how much I then were committed to serve, loved to serve, wanted to serve, enjoyed the job or the team … for the needs of my son … I would have to leave the service” (C2, p. 5).

Mrs. India shared her frustrations with last minute changes in duty assignments, “At the last minute, my husband’s orders got cancelled and we ended up going to a place that was just kind of starting to get some services, but it wasn't like the other place” (I2, p. 4). She said her husband was really excited about that move, but she was very disappointed. She said, “You kind
of get that carrot, you know, dangling in front, like about something that could have been offered to your kids, and then it gets taken away” (I2, p. 4).

Mrs. Juliet also wrote about challenges with sudden order changes, “We prepare for a move and find out three days before pack out that my husband has been selected as LDO (Limited Duty Officer) and will be commissioned and that we must stay where we are for a year” (J3, p. 3). Orders can be cancelled at the last minute and can also be issued with short notice or lead time.

Mr. Bravo explained a personal experience with this. He was selected to be the Vice Wing Commander at a Missile base; however, the people who wanted him to report to duty had absolutely no concept of EFMP or the legal requirements to move with EFMP. He said, “The insinuation was that I should essentially pencil whip all the paperwork so that I can report to my duty station in an expeditious manner, which was in two days” (B2, p. 13). He explained that there is barely enough time to handle EFMP requirements within the standards of normal Air Force or military PCS moves, “much less two days” (B2, p. 13).

Clearly military careers can be difficult on families. Many families seem to find themselves in a constant state of transition. The military life has a great deal of change and moves from duty station to duty station are very common and expected; however, they bring about many challenges and hardships.

**PCS moves are difficult.** Like birth and autism diagnosis, the permanent change of station (PCS) move is a major transitional event in the chronosystem for families, especially for families with children with autism. Mr. Bravo said, “Most people don't remember their moves with a great sense of glee and happiness” (B2, p. 32). Mrs. Golf wrote about the frequency and challenges, “Throughout the 8 years he has been in services we have moved a total of 8 times”
Mr. Bravo said, “Once you get your orders, it is a continual almost exhausting process to now make all of these things official” (B2, p. 19). He went on to add, “And, of course, a PCS changes that exponentially and so you always suffer the unknown when you PCS” (B2, p. 23). The Juliet family wrote, “This last move was the most challenging. We had all of our services set up and it was a feat to get those services” (J1, p. 3). Mrs. India described the back and forth that sometimes happens where the military member would move the family out in advance and then go back for a month or so to finish responsibilities at the previous command and then join up with the family later. She said, “It was a lot” (I2, p. 25). Delta family wrote, “We sold our home because my husband was leaving for Recruiting School. To keep receiving services my son and I moved into a hotel for eight weeks prior to PCS’ing” (D3, p. 2). Mrs. India shared, “We kind of have a thing where we say ‘sumiper gumby’ is one of our sayings, like always be flexible” (I2, p. 30). Participants have learned over the years from experiences such as having PCS orders cancelled after they already had a home picked out and deposit paid for, but instead had to go back and get their rent money back and find a new residence at a different duty location, often with little notice.

There is an expectation when a service member reports for duty at a new duty station that the member’s spouse will coordinate and handle all the move-in arrangements. Mr. Bravo said, “For senior officers, there's always a huge pressure to as soon as you get to where you are going, that you begin work immediately, whether your household goods are there, it falls to your spouse to handle all that” (B2, p. 31). In a previous position, they came and brought his Blackberry to him the first day he arrived. In another one, they issued it to him before he arrived. Regarding the military’s expectations, he said, “And even if they say you're not at work, you're at work” (B2, p. 31). Mr. Bravo explained the tough part is everything that is tough about military life,
the moving around, orders, duty, deployments, family requirements, expectations, all those things are multiplied. He said, “Because a move is -- with a child with autism, a move is a hundred times worse than when you don't have a child with Autism” (B2, p. 1).

Disruption of routines. Military moves or PCS’s are major disruption to the flow and routine of families with autism. This involves education and support services. Mrs. Echo stated, “Now PCS is where everything is cut, all ties are cut, that is more difficult” (E2, p. 6). Mr. Bravo described his daughter’s first PCS, “First move that she was a part of she had a horrible reaction. It was violent and she also had to be hospitalized due to her reactions to this” (B2, p. 27). The Alpha family also experienced difficulty, “We were slipping through the cracks so badly and we were scrambling to move and relocate and starting over and it just really cost her a lot of precious time and it took us quite a while before we got any services for her whatsoever” (A2, p. 34).

The Golf family commented, “Our journey has been difficult, PCSing with a child with autism means that it takes us twice as long as other families to travel” (G3, p. 1). They described making more stops, pre-teaching their child and dealing with the fall out and stress their child encountered such as sleeping only about two hours a night, more tantrums and increased sensitivity to light and sound plus “starting to poop in his pants again” (G3, p. 1).

The Delta family experienced times when they were not able to get certain therapies continued during transition due to Tricare needing to do a new referral. Mrs. Delta explained the process. You have to see your military treatment facility or your primary care manager in order to get those referrals. Then you have to wait for that appointment and then you have to wait for the referral to go through and then you have to wait for those services to have spots available to do the evaluation’s, then you have to schedule all the therapies. She said, “So, it becomes two,
three, four months between the time that you get somewhere like, to your new installation and the time that they actually will able to see your child” (D2, p. 10).

*Positive outcomes of change.* While change is clearly difficult, change can also have positive outcomes. Mr. Bravo explained how a recent PCS move experience helped his daughter get over some of her adjustments to unexpected people, unexpected visits, unexpected everything, and where she grew more tolerant. He said, “I think that probably, more than anything, helped her adjust to some of the things that happen when you PCS, the non-routines and the meeting different people, the staying in the different houses” (B2, p. 28). Mr. Bravo talked about minimizing the uncertainty, “Moving directly from one house to another was very helpful … we basically did a door-to-door move where we were not in temporary quarters for an extended period” (B2, p. 30). He made efforts to ensure success, “To make sure she was settled, to make sure we were settled and to get the heck out of the boxes as quickly as possible so that all the stuff and all the things that look familiar to her were out as soon as possible” (B2, p. 32). He outlined the quick journey going from their old house to a hotel to another hotel, to a military temporary living facility (TLF) to their permanent house. He said, “Because that was able to happen so quickly, and she was able to see her things so quickly, I believe that also helped” (B2, p. 31).

Overall, Mr. Bravo was pleased with his family’s most recent PCS move. The entire Bravo family worked together to support Britany during the transition. He said, “She really did well. I was very proud of her for her ability to kind of look past a lot of the things that before, she would have 4 or 5-hour temper tantrums over” (B2, p. 29). “A lot of what she was experiencing,” Mr. Bravo said, “we just had to kind of put up with it. So, it's just an added or an additional stress to the normal things you go through when you move, but she really did well”
(B2, p. 29). He went on to say, “You know, everybody in the family, we worked very hard at being positive the whole time” (B2, p. 29).

Managing expectations was a strategy parents discussed Mrs. Juliet shared, “Transitions are so difficult and for Jared it’s all about his expectations. He gets in his head what is going to happen next and if it doesn’t happen then that can cause a huge disruption in our plans” (J2, p. 5). There are so many changes that happen that can throw the whole schedule off. She said,” We try really hard to make sure that he has a good idea of what’s going to happen and that he’s not getting too anxious and rigid with his expectations” (J2, p. 5).

The Golf family also shared their positive approach. They do a lot of coaching. They have countdowns, this many more months are left, this many more days are left. This is how it is going to be when they arrive at their new home. The big motivating seller on one of their PCS moves had been that Grandpa was going to be there. They said social stories worked well. They showed him pictures of the area and talked through what he should expect. They try to always keep it positive, “Yes, always doing that positive. Yes. I mean, for any child really, especially that is with autism, if you mention something negative, it stays with them” (G2, p. 11-12). The Golf family has taken Greg to Mount Rushmore, Wall Drug Store and Great Wolf Lodge during one military move. Mrs. Golf said, “We’ve taken him there or hotels that have pools and stuff, just things that are going to make it fun for him and be like, hey this is what we have to look forward to though, when we’re moving” (G2, p. 11-12).

The Juliet family also tries to make the moving process fun while outlining the schedule, “I think we did a lot of like just preparing Jerod and all of my kids really for what’s going to be there, what to expect during the pack-out” (J2, p. 5). They plan lots of activities for the kids in route to their next assignment so it feels like they are just taking a vacation before arriving at
their new place. Mrs. Juliet said, “So that’s something that we try to do and it kind of soothes the hectic chaos of it all when we can take those little breathers in between and say let’s take a field trip today” (J2, p. 5). After the family arrives at their destination and begins the moving-in process, Mrs. Juliet has a plan to keep it fun on the tail end of the move. She explained how she has a ‘dress-up box’ due to her kids being fanatical about dressing up, “So that’s the first box we opened and then they spend the rest of the time while I’m unpacking, playing dress-up and, you know, climbing through boxes and things like that” (J2, p. 5).

Mrs. India offered her perspective on the benefits of change. She had friends who had children on the autism spectrum who spent their whole life in one town. When they had to move because of a job transfer it was very difficult because they had never experienced that magnitude of change. She felt that her boys built up resilience with their experiences growing up in the military. They became accustomed to the moving and to the changes. She said, “There's still changes that happen every year and I think that with their experience, I think that they're able to cope with things because of that” (I2, p. 25). She said now that they are verbal they will reminisce and talk about things that happened during PCS moves and things that happened at different places they lived with the military.

**Parents Offer Valuable Insight for Support Services and the Education Field**

Parents spoke very openly about their experiences with support services and the education field. They ranged from very negative to positive and many had a mix of experiences, often starting off negatively then getting better. Two sub-themes emerged: (a) Need for continuity of care and education; and (b) Organizations, communities, and people who have compassion make a difference.
Support service experiences. Both support services and education are closely related and often interconnected therefore there was sometimes cross-over in the parents’ feedback. The section illustrates negative experiences as well as positive ones and then discusses the more direct detailed sub themes. Support comes from multiple organizations which can be military or civilian. They can be educational, behavioral, medical or a blend of each.

Negative experiences with support services. Mr. Bravo described the lack of help from several organizations, “We weren't provided anything; not a single thing arrived at our door because she was diagnosed with autism. Not a single call, help, no switch, no light switch went on!” (B2, p. 4-6). He explained that if they had not sought it out, nothing would have happened. They could have lived the rest of their lives without telling a soul. Mr. Bravo said, “We would have gotten nothing and that’s from the medical, from the pediatric side, that's from the state, that's from the county, that's from the military, that's from the insurance, nothing. Everything we had to seek out ourselves” (B2, p. 4-6). Sometimes they even had to convince the people that they were seeking the help from that their daughter had autism. Usually everywhere they went they had to prove Britany had autism.

At one of his previous duty stations, Mr. Bravo said it was like pulling teeth trying to make the support service personnel learn their own requirements and regulations and then force them to do the job they were expected and required to do. After Mr. Bravo’s wife passed away it took the Commander of that base looking at those support personnel and saying, “You need to figure out how to comply with the rules” (B2, p.54). Without the Commanding Officer’s intervention, Mr. Bravo said, “We would not have had that opportunity at that base either” (B2, p. 54). He found the attitude of those people to be immeasurably important. “In fact,” he said, “I didn't notice until after I left, that at my previous station, someone had actually filed a complaint
against someone who was actually complying with the rules for my daughter” (B2 p. 55). A complaint was filed saying that the support personnel were giving Mr. Bravo special treatment because of who he was. When the claim was finally resolved, it found that the entire system at that base had not been complying with the rules and that Mr. Bravo, in fact, was not getting special treatment; the problem was everybody else was getting ignored.

Mrs. Golf shared an experience they had when they arrived at an army post and his unit learned they had a special needs child. From her perspective, the command basically said, “This is your fault. You’re here. So now you’re ours and I don’t care about your family and this is how it has to be” (G2, p. 23). She said, “They were not supportive at all and it was a horrible time” (G2, p. 23). She also shared this personal story. While they were trying to get services set in place for Greg, they found out that Fort Drum did not have any services for their child. Describing the nearest available services, she said, “The waiting list in Syracuse was over two years long and the place that Tricare was trying to send me, it was a six-hour drive to Vermont one way” (G2, p. 23). Because of the lack of services for a newly diagnosed child with autism the Golf family requested a compassionate reassignment. She said, “His unit was extremely angry with us because and I quote ‘I don’t care if you have to step one foot in Afghanistan, you’re going’ was their mentality at that time.” The higher authority within the Army decided that a reassignment was in the best interest. Mrs. Golf described her husband’s command’s reaction, “So, they wanted to send me to a new post and my husband to Afghanistan … and so, my husband’s bag went overseas and we received it back two years later” (G2, p. 2).

Mr. Bravo gave these sentiments about his disappointment with the military “All of the services love to pronounce how much they help families and they help this and that. I believe …
without trying to be disloyal, I believe that is one notch above lip service in my experience” (B2, p. 51).

Mrs. Golf shared this story about her friend who had a child with autism. The military member was a junior ranking soldier. Their son was going through brain scans, MRIs and surgery. Someone from his unit showed up at their house to tell his wife how to run things in her household and how her husband needed to be at work and they should not expect there to be help. Mrs. Golf said, “So, in my words the Army does not care about families with special needs!!!” (G2, p. 7).

Mr. Bravo said, “It depends on the rank of the person, some things in the military are easier to walk away from than to question … nobody in the military is promoted because they make waves, nobody” (B2, p. 56). He believed the reason why the military has been slow to recognize the special needs of families with autism is because it is easier for people to go back home. It's easier for people not to say anything. It's easier for people to get out. It is easier for people to PCS the primary military member and leave the family where they are accustomed to getting the benefits they are receiving from the civilian side, not from the military side. Mr. Bravo stated from his experience, “If a Senior Airman’s spouse starts to advocate too loudly, the Senior Airman is going to be under an immense amount of pressure to tell his spouse to be quiet to accept their lot in life” (B2, p. 56).

Mixed experiences with support services. Mrs. Juliet shared their family’s experience which was mixed. They found out about EFMP from the doctor the day she diagnosed their son with autism, “She initiated us getting enrolled. She, after diagnosis, kind of pushed us in the right direction” (J2, p. 2). The process of getting enrolled was simple on the front end, “The EFMP counsellors and things like that were very helpful in getting everything set up” (J2, p. 2).
The difficulty came with the school and Tricare working together to get services because the school did not feel that Jared needed an IEP, however Tricare would not provide services without one. Mrs. Juliet said, “So that was the difficult part. Getting enrolled in the EFMP went very smoothly, but getting services did not go smoothly” (J2, p. 2).

Mr. Bravo gave this assessment of services the military provides, “In my estimation, if I had to give them a grade, I would give them a D minus” (B2, p. 26). He said the only reason they get a passing grade is because recently the Air Force has started a program where they have a nurse that helps with Special Needs families and EFMP families and that has added a great degree of helpfulness to the program. The Alpha family wrote, “I think the landscape is changing, but it's happening as we are out the door” (A1, p. 6). The Foxtrot family responded about receiving services, “I feel we got help right away - but at our pushing” (F1, p. 6). Mrs. Juliet expressed, “I think the supports out there are just abundant; it’s finding them that’s hard” (J2, p. 4). When she took on the role of command ombudsman she was amazed at how much support there is for families in the military and how little she had taken advantage of it. She does not even recall calling or talking to the ombudsman before she became one. She said, “But, I think there’s so much for them, but you know, it’s not really utilized and maybe . . . I don’t think families are as aware as they should be about what they have” (J2, p. 4).

Even though Mr. Bravo still has negative thoughts of EFMP limitations and what it has done to him and his family, he said, “If EFMP is a requirement to get ABA therapy for my daughter, then that’s been worth and that’s been a positive” (B2, p.12). In the data collection form Mrs. Juliet wrote, “We knew what to expect beforehand as we had friends who were enrolled. That said, we weren't expecting the automatic category 5 enrollment” (J1, p. 2). She felt like the EFMP premise is a good one but that the program takes some rights away from the
families. She commented, “So far though everyone we have worked with in EFMP has been very kind and helpful” (J1, p. 2). She added later that while good, it could use some changes. She wrote, “The ABA therapy that we were provided through ECHO was a God send. Our tutors were fantastic. The respite care was also wonderful. Though once again I did find both to need some tweaks” (J1, p. 6).

Mr. Bravo went on to share about his expectations for his daughter Britany’s care and his experience during one PCS move, “She was the first child that someone expected them (military support services) to do what they were required to do” (B2, p. 52). He thought based on the way the support service teams were acting that that they had coordinated services for a million children like this before. He didn't know that his daughter was the first one. “I had an opportunity to ask questions for which people can't blow me off!” (B2, p. 52). Because of his rank and position in certain places he has had the ability to ask questions in a way that invokes action instead of getting ignored. “I've been able to hopefully make it better for folks after me” (B2, p. 53).

**Positive experiences with support services.** Mrs. Juliet shared one of their most successful stories is home-schooling. She said, “It’s been really hard, it’s been a really big challenge to learn how to do that” (J2, p.8). She commented about the support services that have helped, “I have to say that, you know, some of those services the military provided us, the ABA therapy taught me so much and being able to have that in my home was huge for us” (J2, p. 8). She talked about seeing first-hand the successes Jared had made one after another. His behavior and his learning improved drastically, “We had a huge success with reading comprehension learning with him, he couldn’t get through half a sentence with understanding what the sentence was about to being able to read a page and tell you what it was about” (J2, p. 8). She said, “So
seeing that happen was big for us” (J2, p. 8). The Alpha family wrote, “We have dealt with one medical installation Naval Hospital Bremerton, and one AFB (Buckley), the services provided were good, although not specific for special needs children / families” (A1, p. 5).

**Specific feedback for support services.** Parents have a lot of experiences across many duty locations in different states. They have seen and coped with differing policies across state lines and have worked with many types of support organizations. The following statements are some specific feedback for support services.

**Outreach.** Parents stressed the importance and need for greater outreach. Mrs. Alpha explained, “If the diagnosis is new, they are most likely in shock, bowled over, and not really sure what to do next!” (A1, p. 5). She wrote, “Be open to the variety of needs that families of kids with special needs can have; no two families will be alike. Be prepared to assist families with locating resources” (A1, p. 5). Mr. Bravo wrote, “Become involved instead of providing endless lists of brochures and websites” (B1, p. 5). Mrs. Juliet said, “You got handed a pamphlet and oh, you can have this, but there was, there was no outreach, you know, and I think that would be good” (J2, p. 11). Mrs. Golf shared frustration, “When a family like that is transitioning and stuff, you would think that they would reach out to them.” She said her husband marks a category when they are PCS’ing that asks ‘Do you have an EFMP family? Would you like more information?’ She said, “My husband always marks yes and nothing ever happens” (G2, p. 9). Mrs. India shared, “I would say that these support groups need to continue to reach out to families with special needs situations and attempt to engage with family members to help empower them” (I1, p. 5). She said there were times when she was feeling very overwhelmed, but strived to be proactive, “I was older (in my 30's) when I had children. I can only imagine the feelings of being overwhelmed to a young teen or 20 - something aged parent!”
(I1, p. 5). Mrs. India suggested, “We're not moving but …how do you get the word out to people when they're moving, they're coming in every couple of years and leaving. You know, how do you get them in right away?” (I2, p. 69). She suggested activities like setting up tables at the Base Exchange (BX) which is similar to a department store, or somewhere very visible to families, at least a couple of times a year or quarterly to just try to get the word out, “Like hey, we are here to help you” (I2, p. 69).

**Institutional change.** A need for policy change was called for by participants. Mr. Bravo said what he would like to see is institutional or bureaucratic change both on the governmental and the military side to provide these vulnerable children and their families the services that they deserve without having to go to great extremes. He found it deplorable that his country would allow him to deduct from his taxes insurance and interests on a home loan, but that he has to meet some percentage of his income in order to start deducting for his special needs child. He stated, “I think that's morally reprehensible!” (B2, p. 59).

**Counseling.** Parents emphasized the need for counseling support. The Alpha family said that the family service centers and support programs that offer assistance should look at offering specific programs to support special needs families. “The number of special needs kids is only growing and they need education” (A2, p. 50). Mr. Charlie saw the need for counseling. He commented, “I believe faith in the Lord, whatever your religion may be, is something that should be also looked at especially as its available” (C2, p. 15). He felt it should be one of those things that the military goes out of their way to make available to families who have children like his son Colin. He also expressed that psychological counseling should be highly encouraged and readily available for the military member as well as the family members.
Educational experiences. The study participants had a range of experiences with their children’s education. There are too many to write them all down. A few will be used to illustrate some critical points, but then the section will progress to positive experiences.

Negative experiences. Mrs. Golf started out, “I would say so far we’ve only had bad, negative experiences” (G2, p. 15). Mrs. Juliet wrote, “Our experiences with the school systems regarding special needs has been horrid. Getting services and keeping services has been dependent on school support and schools don't understand that” (J1, p. 6). Mrs. India said, “I don't have much positive to share when it comes to junior high and high school. It's been more challenging now with things going on than elementary school” (I2, p. 44). Mrs. Echo said, “I am not a fan of our current state's school system” (E1, p. 6). Mrs. Golf was also displeased with their son’s current school district, “I think the education, where we’re at right now currently for my son it’s a huge joke. He’s has so many issues this year with school that it has been ridiculous” (G2, p. 14).

Mr. Bravo shared a story about his initial interaction with special education in Virginia. When his daughter was first diagnosed with autism, he and his wife did not agree with the way the school was working with their child. On paper, it looked like a wonderfully enlightening program; however, the way it was practiced resembled an old-school program from the 1940's. They withdrew her because they believed that it was negative and counterproductive. Mr. Bravo said, “I thought I was in a totalitarian country. When we decided to take her out, we were treated as if goons were going to come to us at night because we were questioning the way they were doing business” (B2, p. 41). The school basically turned from very warm to very cold when they decided to withdraw Britany. He said, “They didn’t like that. They didn't like any disagreement
with their procedures or policy. So, we found that to be challenging as well as that bureaucracy being inflexible” (B2, p. 41).

Mrs. Juliet described Jared’s first IEP meeting, “Our first experience with IEP meeting was horrible, but I think that was expectations on my part, I just I thought here I have an answer, I know what’s causing his problem and I know he’s just been diagnosed” (J2, p. 8). She thought she could tell the IEP team her thoughts and requests and they would help her, but that is not what happened. The meeting was very quick with the educational professionals saying, “Well we don’t see that in the classroom and we don’t think that he needs any help with this at school” (J2, p. 8). Mrs. Juliet said, “When it was over with, I felt like I just had whiplash” (J2, p. 8). She also wrote about the experience, “The teacher Jared had didn't recognize there was a problem even after diagnosis. They initially refused further evaluation and wouldn't write an IEP. I had to request a speech evaluation 4 times” (J1, p. 5). The Juliet family finally ended up with an IEP, because without it Tricare would not approve services. In the timeline essay Mrs. Juliet wrote, “Both of my children are floundering in the public school. Although promised more communication from the school/teacher as well as a speech evaluation, I have yet to receive either” (J3, p. 4). She pulled both of her boys out of the public school during spring break and started to home-school. She continued to pursue a speech evaluation. The same day that she decided to home-school, she said, “We received a letter from TRIWEST saying that our ECHO referral is being closed because it has been open for more than 30 days without receipt of documentation required for program eligibility” (J3, p. 4). She continued to push hard and eventually got Tricare to provide services. She also wrote in the survey form about continued difficulties in the state of Mississippi, “We currently have no support from the school system.
We are home-schooling and the state we are currently in does not support home-schoolers. They have no experience with special needs home-schoolers either!” (J1, p. 6).

Mrs. Golf also spoke about her experience attending the autism hearings at the Washington state capitol building. She shared that a gentleman got up before the assembly and spoke about his child receiving unfair and cruel treatment. She commented about how frequently this happened in the first part of the school year, “So, they weren’t even at 100 days yet and his son had been isolated, placed in isolation 103 times for more than 30 minutes. Yes, this is just a room, nothing in there’’ (G2, p. 26). The child was stuck in the room not because he was violent, but because he had no means of communication. The family brought in behavior specialists who were willing to share functional communication training and ways that the child could communicate better with the school, however the school “Just said no, we don’t have time right now. We don’t have time!” (G2, p. 26). Mrs. Golf said, “The school never did the functional behavior assessment and writing their plans based off that. Instead, they isolated the child… horrible!” (G2, p. 26).

**Mixed experiences with education.** Parents have many negative feelings toward the public education system and they have the stories to back up why they feel the way they do. Even in their difficult experiences, there are silver linings of hope. For many families, their educational journeys have been a mixture of both positive and negative experiences. Mrs. India said, “We've had some really good experiences, and we've had some not so good experiences” (I2 p. 34). Mrs. Alpha said, “It’s a mix of good and bad, but it’s been incredibly difficult” (A2, p. 6).

There are several factors and variables which cause the disparity throughout the education field. Teachers, curriculum, and school districts are just a few. The Alpha family
wrote, “Acceptable, to mediocre to horribly inadequate. Allison and Avery have both had, upon occasion good teachers, but often flawed policies / services rendered inadequate and sometimes detrimental outcomes” (A1, p. 6). The Foxtrot family wrote, “The best support we had was at Freedom Elementary in Cheyenne. We had exceptional help; I feel at our current school that Ferris is not” (F1, p. 6). The Echo family wrote, “Montana was fine although just wanted to label him ADHD and give him medication. California was very dependent on teacher. Wyoming was wonderful” (E1, p. 6). Mr. Charlie wrote, “Colorado was insistent that the member could serve a positive role with 'non-effected' students. This was a false theory as it caused meltdowns … since transferring to a specialized school for autism this has since been resolved” (C1, p. 6).

**Positive experiences with education.** Almost all the families had at least something positive to say about education. Mr. Bravo said, “My experiences are completely different in different school districts or different states” (B2, p. 45). He did not feel he had been one of those parents that severely disagreed with what the educational professionals have said. He commented, “I thought in most cases that they've done a very good job in what they were required to record and to assess” (B2, p. 45). Mrs. Delta wrote, “They try and care about children with disabilities” (D1, p. 6). Mr. Charlie wrote, “Very good to outstanding: limitation is by Colin's capacity not school support” (C1, p. 6). The Alpha family wrote, “Excellent at the current schools that our daughter and son attend. The programs they are currently in have been very beneficial, especially for our daughter” (A1, p. 6).

**Specific feedback for the education field.** Parents have seen a spectrum of policies and procedures from many different states as they moved and served at various military locations. They have experiences with many separate school districts. The participants in this study felt
that every organization involved in supporting / educating a child with autism has room for improvement. The following direct feedback is in regards to the field of education.

**Funding.** Funding is an issue and comes in the form of not having enough support services / personnel in the school. Mr. Charlie wrote, “Figure what can be done within budget. Finally, get the word out to those that something outstanding can be done for children in handicap situation” (C1, p. 6). The Alpha family wrote, “Look at funding. So many times, therapies were offered - in NON-Therapeutic Doses! (A1, p. 6). She explained if a child was prescribed and needed several hours of one-on-one speech therapy, “It isn't helpful at all to offer, instead, a few minutes in a group setting, with 15-25 other students” (A1, p. 6). Mrs. Delta explained, “Follow the child’s IEP. If a child needs a 1:1 tutor/aide, then provide it to/for that child so they are able to be in their least Restrictive Environment” (D1, p. 6). Mrs. Delta wrote about how children learn from their peers, “Let them be included with their typically developing peers as much as possible” (D1, p. 6).

**Communication with compassion.** Within the field of education, there is the crucial piece called the Individualized Education Program (IEP). It is essentially the rule book and game plan for each child. Good communication is vital for the development of each IEP and preparing for successful IEP meetings. Mrs. Juliet shared this story about her first IEP meeting, “When you are a parent of a newly diagnosed child and you walk into a room full of professionals it is completely nerve wracking” (J1, p. 6). She talked about only just wanting her child to have all the help he needed to be successful. She said, “You anticipate these meetings and worry over them. For a teacher, it is just another long meeting and there isn't anything special about it, but for the parent everything is riding on it” (J1, p. 6). Through her experience, she offers this, “Listen to the parents, let them talk, don't rush it, hear their concerns and what
they need for their child. They know that child better than anyone. Listening is the first step to finding the best plan for the child” (J1, p. 6).

Mrs. Juliet talked in the interview about how she is currently attending college and learning a lot about special education and how to conduct an IEP meeting. She felt that it was important for teachers to have ongoing training and practice scenarios to help when talking to actual parents about what it is like raising and educating children with autism. She said, “So that it’s not just another meeting for everybody else, and they understand that the kids . . . that this is a person and a family going through something” (J2, p. 11). IEP meetings can stir emotion and bring tears. Mrs. Juliet said, “But when your child is first diagnosed that meeting is just huge, you know. Sorry, I’m getting emotional, but . . . It’s just, it just means so much and it’s hard to go in and just get wiped out” (J2, p. 11).

Mrs. Echo summed it up, “I would ask the schools and teachers to try and understand the kids, understand they have this different way of thinking but also the added stress of the military life - be it PCS or deployment” (E1, p. 6). These children do not have the security of going to school with kids they have known their entire lives. There are so many pressures they are coping with. She wrote, “Administration / teachers need to be more willing to communicate with parents. Then the schools need to be willing to listen to the parents” (E1, p. 6).

**Need for continuity of care and education.** The continuation of services and support is vital to the well-being of children with autism. The military is in constant motion with many changes which affect military families. Each change that occurs has the potential to disrupt the continuity of care at every level, from support services to education.

Change is a fact of life, but even with the difficult changes in the world of a child with autism there can be positive outcomes. Parents’ efforts in pre-teaching, coaching and managing
expectations help keep regression that occurs to a minimum. Pro-activeness by parents helps children be more secure and settled. Within the world that is changing there can still be continuity; however, while this consistency is possible is often not the reality for families raising and educating children with autism. Mrs. Echo said with laughter, “Yeah for our life we don’t get that continuity very often (laughter)” (E2, p. 4). Mr. Charlie said, “Well, having a child while serving in the military that is, a child that is severely autistic, that presents a challenge” (C2, p. 1). He said, “The constant moving around and the constant flux of change makes things tremendously more difficult and challenging” (C2, p. 1). Parents shared concerns over having to prove their child has autism with each move, the waiting lists for services at new duty locations and basically starting over each time. The continuity of care is important in the medical clinics, but equally as important in the classrooms. Mrs. Golf described these concerns about continuity well, “Starting medical care over. Finding new doctors, being placed on waiting list, medication refill issues, just really starting over. IEP process nightmares!!” (G1, p. 3).

**Referrals.** A large hinge in the continuity issue is the referral process. Parents made many comments about referrals. The Delta family wrote, “Upon PCS’ing there are extremely long periods where referrals are not utilized due to moving” (D1, p.2). They explained further, “Extended wait times once arriving at gaining duty station for PC (Primary Care) appointment to request referrals” (D1, p. 3). Mrs. Echo wrote, “I believe that in our situation it is dependent upon the doctor you get and how proactive or willing to listen he/she is and if they are willing to allow referrals” (E1, p. 6). She commented about the need for continuity, “I would like when you have a referral that the referral should be able to continue when you move to a new duty station, that you don’t have to start from scratch again” (E2, p. 25). She stated, “Because like the gap can be six months…it can take forever” (E2, p. 25). Mrs. Echo explained, “If you had the
same referral for the doc at your current location, you could just get it transferred to a new place and then you can make that appointment before you left and still continue the care” (E2, p. 25).

Mrs. Juliet commented, “If diagnosis will automatically enroll me in EFMP it should also automatically qualify us for supporting services” (J1, p. 5). Mrs. Delta suggested this to the support system from the military for helping continuity, “Better effectively communicate with the other EFMP and even possibly the medical side and get the parents the information they need to get their children to the right places before they even do a PCS move” (D2, p. 19). Mrs. Golf also touched on PCS moves, “There needs to be an easier process with transferring families. Families that are PCS'ing should be given doctor names and referrals before leaving to speed up the process. Military member should be given time off for their child's appointments” (G1, p. 5).

Mrs. Delta continued highlighting continuity and pro-activeness, “It would be extremely helpful for parents to get their kids right into the therapies again.” She said, “I wish that they had updated lists of those providers or give you a more effective way to go about it rather than just waiting to see how they can help at some point down the road” (D2 p. 20). Speaking of therapies Mrs. Delta stated, “We weren’t able to get them to be continued due to Tricare needing to do a new referral” (D2, p. 10). Mrs. Delta wrote, “When a child receives specific services at one installation through referrals (ex. Speech therapy, OT, PT, and ABA) have new referrals made prior to that move so the child may continue those services” (D1, p. 5).

**Waiting lists.** The lack of continuity is often manifested in waiting lists. Parents were consistent in their concerns over the lengthy wait times for their children to receive support services. Mr. Bravo explained that there are often extensive wait times to get your child into needed services. He said, “You have a level of care in which you had become used to or dependent upon, and then now you're in a new system … when we moved here, it was about five
months before we were able to get in to see the developmental pediatrician here where we are now” (B2, p. 21). He also said, “I mean, basically, once you get to point B, you have to re-establish everything. You have to re-establish all the care for the child, all the services” (B2, p. 22). Mrs. Golf explained, “When we move, a lot of the challenges that we face are …because for some reason nothing ever transfers the way it should” (G2, p. 8). She explained that the families should be set up in advance, but the Army doesn’t do that. Mrs. Golf elaborated, “When you move to another post…it can be two, three, four months before you’re even able to see one (doctor), and sometimes your medication runs out. That causes back steps in a child’s life” (G2, p. 22). Mrs. Echo said, “You shouldn’t have to start from scratch and try to convince this doc that you need to start all of this stuff all over again” (E2, p. 25).

Mrs. Golf explained that when first moving to a new post with a child who has special needs, it means there will be numerous appointments. There are a lot of new assessments to fill out, which require both parents. Some are medical appointments while others are educational appointments. On the educational side, she commented that Functional Behavior Assessment (FBA), Individual Education Program (IEP) and Individual Family Service Plan (IFSP) all need to be done, as well as setting up any other services the child may need. In regards to medical appointments, their son does ABA, speech therapy and occupational therapy which also means he needs an evaluation from each of those specialists. The medical and educational pieces go hand in hand as schools provide occupational and speech therapy and occasionally ABA therapy. She wrote, “Every place has waiting list or takes months to get into these specialists. This waiting list has delayed medication refills and delayed childcare forms being filed in a timely manner” (G3, p. 1).
**IEP continuity.** Mrs. Golf said, “Every time I move into somewhere else, they want to basically re-diagnose him and to me, it almost feels like they don’t care what the doctor has said. They don’t put any preventative measures out there” (G2, p. 14). She explained that the school would have to see it for themselves and that would lead into huge problems on its own. She would tell the school what her son’s reaction would be to different situations but the school would reply, “Oh, well it doesn’t matter, we have to see it for ourselves” (G2, p. 14). Mrs. Golf shared her frustration, “This year actually led into them restraining my son, and my son doesn’t like to be touched, and they actually left bruises all over his arms from it” (G2, p. 14).

Mrs. Alpha explained she had requested a service for one of her children and the school response was, “Oh we can’t do that because then well have to do it for all the children” (A2, p. 30). She said, “I looked at this person and said that is what the I in IEP means, individualized education program, and yes you can” (A2, p. 30). The IEP must follow the federal IDEA guidelines. Discovering the least restrictive environment (LRE) is a crucial part of writing and implementing the IEP. The LRE looks different for each child and is based on the individual and specific needs of that child.

Mrs. Golf said, “Oh ideally, it would be amazing if the IEP process was uniformed or at least transferrable to where I could take the IEP that I got in Texas and it could be usable in Washington” (G2, p. 23). Mrs. Delta shared thoughts about the continuity of IEP’s. So many children do not have measurable goals written due to moving every two to four years. Parents just move from one place to the next thinking that their child’s IEP is fine when in fact, there has never been a goal that the child has been able to accomplish due to never having an effective one written. She said, “I wish … schools would adhere to those IEP’s because there are so many schools that don’t even follow the IEP for the children” (D2, p. 20).
Status changes when moving from state to state can disrupt the education of each child. Mrs. Echo spoke about her son Eli, “Well, here he doesn’t have an IEP, his grades are too high” (E2, p. 19). The Foxtrot family wrote, “Ferris' IEP was taken away in third grade. He did not meet Washington State's qualifications. His IQ, reading and PT were way too high” (F1, p. 5). Mrs. Alpha said, “Fast forward a few years, he started in junior high to need help and because he no longer had an IEP we (sigh) we were seeing him struggle” (A2, p. 32).

**Consistency.** Parents shared frustrations and the need for a high standard to increase consistency and enhance continuity. Mr. Bravo commented about the services from one installation to another installation, “Very inconsistent. Wide ranging gaps in knowledge and commitment” (B1, p. 5). Mrs. Echo wrote, “Definitely some installations and states are more accommodating than others” (E1, p. 5). Mrs. Delta also conveyed, “Consistency varies due to population and installation size. We have been in one state that did not have ABA who could come into the home near where we resided. We had to do without during that time” (D1, p. 5). Mr. Charlie talked specifically about the continuity of ABA, “The thing about ABA is that you’ve got to do it constantly, continually in all environments that he’s in and you have to do it unmercifully, if you will” (C2, p. 12). He emphasized the need for consistency, “It takes an extended commitment. You can’t just do this for a month or a day or a year … You’re going to want to break and those are the times where you really need to keep strong at it” (C2, p. 13).

Mrs. Echo expressed frustrations with medical support consistency, “Just standard medical care here is very, very difficult. So, I can’t imagine that autistic type care would come easily. Just getting an appointment for regular stuff is difficult here” (E2, p. 5). She commented how during the fourteen years of her son’s life, there was only one place that they saw the same doctor, “We have been here eight months. Our PCM has changed three times and now they are
down to just one pediatrician in the clinic, so you literally can’t be seen” (E2, p. 26). Mrs. Echo shared her exacerbation, “Knowing how difficult this medical clinic is I just don’t have the energy to do it” (E2, p. 20).

Concerning continuity of the military’s health insurance program, Mrs. Foxtrot wrote, “A lot of providers do not take Tricare because it does not pay them well and it is a lot more ‘paper’ work” (F1, p. 3). Mrs. Alpha wrote, “Most providers accepted Tricare, and I don’t recall any that did not, but virtually all specialty doctors were unable to accept Tricare” (A1, p. 3). Mr. Bravo explained inconsistencies with other medical coverages, and shared frustrations with the effects on his daughter Britany. He wrote, “Must prove she has autism each time - States have varying degrees of support Medicaid Waiver - Re-establish caregivers / medical services at each station - Change of surroundings / routine is major disruption in her needs” (B1, p. 3).

The education of each child with autism is affected with every move. Mr. Charlie speaking on military moves and the need for continuity of care said, “Well, if and when and how that takes place, the number of variables needs to remain constant” (C2, p. 7). Moving in the middle of the school year adds a variable which leads to inconsistency. Mrs. India explained, “So, then the kids were kind of accustomed to having that whole school year and leaving during the summer and then when things would happen where well, we have to leave in March instead of June. It's very hard” (I2, p. 30). Mrs. Echo said, “The teachers don’t communicate, especially if you haven’t met them and if you’re in a new place they don’t know him, they don’t know their little quirks” (E2, p. 13). Mr. Bravo summed up school district inconsistencies, “They have different policies. They have different ways in which they interpret those policies. Sometimes they're better. All the time they're different…so there are advantages and disadvantages. Those occur though at every single move” (B2, p. 23).
The disruption in education is an area of concern for military families. Mrs. Golf shared one the biggest challenge with each move is what school system their son is going into. She said, “Is there going to be proper care there for him. . .are they going to treat him any differently and how is he going to react to everything? I think I have panic attacks about the school” (G2, p. 12). Mrs. Echo expressed, “It is becoming more and more difficult to get established, make good friends, get into solid groups, feel comfortable at another new school” (E1, p. 3). Mrs. Juliet expressed a big challenge with each move, “Really trying to figure out, you know, what the best option is for, Jared” (J2, p. 7). Mrs. Juliet shared, “We found a consistent . . . great school where they were just doing exceptionally and really learning a lot and then we got to this place where I didn’t feel like they were moving at all” (J2, p. 7).

**Flexibility and choice.** Parents gave feedback to the continuity issue. They would like to see better flexibility and choice to increase continuity. From a medical and civilian point of view Mr. Bravo said, “I guess I would like to see a more active and a more flexible system to help your child when your child is found to be a certain way” (B2, p. 63). Mr. Charlie said, “Evaluating a case-by-case basis to find out what is really necessary for that family unit, I think is a worthwhile thing that can be done for these families” (C2, p. 16). Mr. Bravo went on to add that the biggest thing that he would like to see is “Flexibility in that system because every child is not the same” (B2, p. 64).

Mrs. Juliet spoke of the medical continuity, “Medically, it is frustrating. We have struggled with doctors believing us with Jared’s Celiac issues. Then we find someone who is completely onboard and we trust and we have to move” (J1, p. 5). She felt there should be more choice instead of just being assigned medical providers. Mrs. Juliet wrote, “Locating doctors isn't the issue” (J1, p. 3). More concerning to her is that you do not have a choice which doctor
you get. Mrs. Echo said, “Going to someone they are familiar with … it does make a huge difference!” (E2, p. 27). Mrs. Juliet wrote about their Primary Care Manager (PCM) who kept insisting that Jared's constipation was normal, even though he had been seen by a specialist at their previous duty station, “After months of returning to him, I finally refused to leave without a referral. At which point we found we were days away from a medical emergency” (J1, p. 4).

Exercising flexibility and choice the Juliet family found a positive solution to some of the continuity challenges by home-schooling. Their children were thriving in a public school, but after relocating to a new duty station they had a very negative experience with the new school system. The Juliet family evaluated their options “Very quickly after that happened we decided to home-school and that was purely so that we could keep, our school, the education consistent and so that we could address the challenges that he was having consistently” (J2, p. 6). They did not want to start over every time they got to a new school system and explain about their son repeatedly. Mrs. Juliet said, “Home-schooling felt the best option for our family” (J2, p. 6).

Since Mississippi is one of the states which does not allow home-schoolers any access to public education activities the Juliet family sought out other options. As part of their home-school curriculum Mrs. Juliet enrolled their son in the Wings Performing Arts program while stationed along the Gulf Coast. Through this community sponsored theater program, Jared’s confidence and social skills were greatly enhanced. He played the role of Tiny Tim in a Christmas Carol production where he had to improv’ when a fellow cast member forgot her lines. Mrs. Juliet described being in the audience and losing her breath twice. The first time with the glitch in the script when it looked like her son might get frustrated and have a melt down on stage and then seconds later as he put all the ABA training into practice and adjusted beautifully to continue with his lines. Mrs. Juliet contacted their ABA therapist that very night to share the good news
story. She described this performing arts program as an intricate part of their home-school strategy.

Education is an important part of a child’s life and development. This includes both public and home-schools. States differ in their levels of education as do school districts within each state. Each relocation into a new school district brings additional challenges. Fitting in and feeling comfortable in school contributes to the overall health of a child with autism. Extra effort is often required to help these children be as successful as possible. The continuity of education is challenging; however, it is crucial for success.

**Organizations, Communities, and People Who Have Compassion Make a Difference.**

Parents are consistent in their words about the need for continuity. Continuity is a challenge; however, it is a possibility through parental advocacy and pro-activeness. Children with autism need more than just their parents as advocates. Children need advocates at every level of Bronfenbrenner’s (1979) ecological model. Support personnel who have compassion and give the extra effort can increase continuity and make a difference in the overall success of each child with autism in the micro and meso systems. Parents had a great deal to say about the positive support they received from an array of service and education organizations which affect the exosystem. Comments were made about military chain-of-command, medical providers, and educational support professionals. Several success stories emerged from the parent’s feedback.

**Family.** Family is a support system at the micro level. It is often a wonderful resource for parents during transition times. Mrs. Juliet took her kids coast to coast from California to North Carolina and moved in with her parents during one of Mr. Juliet’s unaccompanied overseas tours to Bahrain. Mrs. Delta wrote about the support of family, “Soldier (aka
Daddy/my spouse) was deploying in a few days to Iraq. We decided to rent out our home and drive from TN to OR for son and I to live and have support from my in-laws” (D3, p. 2).

**Special needs community.** The special needs community becomes a support system not only for the individual with special needs but for the entire family. In some ways, it functions as an extension of the family on the exosystem level. Mr. Bravo shared specifically about the special needs community, “One of the other successes I think I’ve seen in that same kind of light, the patience that many folks have that are in the special needs community” (B2, p. 45). Britany has learned to comply with the demands and requests, but she has her own time and she has her own definition of things. He gave this illustration about telling his daughter to throw something away, “Ever seen the Family Circus cartoon, where they have like the dotted line where the mother tells the kid to go home, and the kid like runs all over the neighborhood, and then eventually gets home. That's exactly her!” (B2, p. 45). He explained that if you tell her to throw something away, she may wonder through the bathroom and go to the bedroom and go through other areas, but she will throw it away in the specific garbage receptacle she was told. People in the special needs community exhibit tolerance and acceptance when things do not always follow a standardized normal pattern of behavior.

**Special advocates.** Special advocates are those support providers who often bridge the gap and liaison between the exosystem and the micro and meso systems of the family. Mrs. India said about seeking out those whose job is assisting families, “I would always look to see if there was either like an agency in town or sometimes they have a family advocate who actually works for the school district” (I2, p. 46).

Mrs. India shares this story of a school administrator referring an advocate, “When we were first getting ready to move here, a principal mentioned this advocacy organization, like an
agency, and they told us … here's the phone number. Call when you get here” (I2, p. 19). Once moved into their new house she called right away. Her husband has since retired from the military but she is still a client with this agency, “I am assigned an advocate that comes to every meeting and whatever appointments, whatever I need, I just call them. Even if it's just with questions, I get a lot of support through that particular agency” (I2, p. 19). Mrs. India was thankful for this principal’s caring foresight, “Some administrators and some teachers really get our children, really understand that if you meet one child with autism, you have met one child with autism and how we really don't fit” (I2, p. 32).

Mrs. Alpha shared how support in the form of legal help was instrumental. While homeschooling they were assisted by Home-school Legal Defense Association (HSLDA). She said, “If it weren’t for the brilliant work of Mr. Klika I would have lost my son and, and the rest of my kids too. He has since passed away, but I am forever grateful for that man” (A2, p. 45).

**Schools, administrators and teachers.** Despite the many negative experiences parents have encountered there are many success stories of extremely positive experiences with schools. At the center of these positive experiences are people who truly care. Education professionals who have compassion make a positive difference at the micro system, mesosystem, and exosystem.

Mrs. Golf speaking as Mom and as a therapist said, “I have been through a ton of IEP meetings and every single one of them is completely different. You have some schools that are willing to work with you and really value what the parents are saying” (G2, p. 18). Mrs. India described educational experiences as, “Again some good, some bad. Hills and valleys” (I1, p. 6). She wrote, “Some school administrators and / or teachers work well with special needs of students and really 'get them.' Not all staff 'gets' the kids with special needs. Some teachers /
administrators seem annoyed and don't want to be bothered.” (I1, p. 6). Mrs. Golf said, “This year, my son has been switched from a teacher that couldn’t handle him at all to a teacher who has been a lot more understanding of his situation” (G2, p. 17). Mrs. India said, “I have to wonder why some people teach Special Ed. It just doesn't seem to be their niche, yet other teachers that the boys have had and paraprofessionals and principals and other staff … we've had some wonderful experiences” (I2, p. 33-34). She explained the disappointment of having to move after a positive educational experience, “Then we're sad, especially if they're in a class where the teacher is just so wonderful and we know that we're leaving that state” (I2, p. 33-34).

Mr. Bravo said, “My experience has been that almost in every case, they adjust to what I asked them to do within their resources” (B2, p. 47). Mrs. India credited the administration even though they did not see eye to eye, “With that one principal, I mean I felt like she was really wrong for what she was doing. Even though I think her philosophy was different than mine and she was doing what she thought was the best thing” (I2, p. 61-62). Mrs. Golf talked about administration having a positive impact. The director of special education she explained, “He actually came in and sat in a meeting with us and we were able to really talk to him and he was able to basically tell the school where they were messing up” (G2, p. 16).

When parents have a positive experience with teachers they let it be known. Mrs. Echo said, “And then he got a male teacher and that was like oh my God school can be fun … it was like a lightbulb went off in Eli’s head and it was the best year” (E2, p. 17). Foxtrot family wrote, “Ferris' teacher is really accommodating. She lets him email his homework in so he can type it” (F1 p. 6). Mrs. Juliet wrote about a wonderful teacher, “February–May 2009 – We move to Whidbey Island, WA. I home-schooled during this time, before our move Jared attends public school preschool. He thrived with his wonderful teacher there and learned to read early” (J3, p.
3). Mrs. Echo also spoke of a teacher who made a difference, “His 6th grade teacher was really wonderful. She helped him to love school and he became a much happier child” (E3, p. 3).

Mr. Bravo shared similar thoughts, “The successes have been where the teachers in the classroom accept the individuality of the child and realize that every Special Needs Kid, like every child, like every typical child, is different and has different requirements” (B2, p. 43). He felt success had come where teachers had treated his daughter in a manner consistent with her personality. He said, “I believe that the bureaucracy, the IEP, the rules, they kind of forget, there's no such thing as Special Needs. There is no such thing as Special Needs Children. There is a Special Needs Child” (B2, p. 43). Society often looks at those differences as things that have to be overcome, fixed, repaired, ignored, silenced or water downed. He said, “We forget sometimes that those ‘isms’ are the personality of that child” (B2, p. 43). He shared that the biggest success in his daughter were where the “Teachers and the professionals have realized this is a part of her individual personality, and it is something that I need to capitalize on and utilize in the teachings of these other requirements” (B2, p. 43). He illustrated in this story, “Britany loves to throw leaves up in the air, she likes to do things with plants like pull the dirt out” (B2, p. 43). She had a teacher in their last assignment that saw this all the time, so then she changed this training of Britany into teaching her how to water a plant every day and care for a plant. He said, “So it was really cool seeing this transition. Now, it wasn't easy or pretty, and it wasn’t clean. We had to clean up a lot of water” (B2, p. 43). Instead of saying ‘stop throwing leaves in the air or stop dirtying up this carpet with this dirt’, the teacher channeled unique behavior of a child with autism into a very positive learning experience.

Mrs. Alpha praised Allison’s teacher, “She’s been her angel, she had challenged our daughter in ways we never even dreamed of” (A2, p. 24). The teacher made all the difference
between their child curled up in a miserable ball on the floor and barely getting out of her head banging mode to a young lady they could drop off at the door of the school. Mrs. Alpha described being able to watch Allison walk into school and “know that she will go from class to class in high school with a little bit of prompting and her IPad and that’s all she needs with this lady. Just incredible!” (A2, p. 24). She went on to add, “If you ever find a great teacher for goodness sake bring them coffee, bring them flowers, tell them you appreciate them because this lady is making all the difference for our girl” (A2, p. 26).

Mrs. Echo said, “It’s amazing what a teacher can do to your life. Parent and child, you know, a good teacher, a good teacher is worth so much for all kids, but especially to Asperger’s kids” (E2, p. 18). Mrs. Alpha described successes of two of her children, “It’s amazing what a good teacher that really cares can do for kids. And that’s what our daughter needed is someone who really could see that she had potential” (A2, p. 25). Concerning her son Mr. Alpha said, “And specifically his fifth-grade teacher, you know, really worked with him and, and started to bring out his strengths. And now, he’s got a really great team at the school he’s in, I’m very happy with them” (A2, p. 27).

The military parents were very thankful and appreciative of the successes in the classroom. They sang the praises of the teachers and other education professionals who care and work hard to help their children grow and be the best they can be. The influence of compassionate educational teams is far reaching. The parents also showed gratitude to all the other support service organizations and personnel who have made a positive impact on their children with autism.

**Support Services.** Support services is a broad category which includes organizations in the exosystem and individuals in the micro and meso systems. Mr. Charlie said, “Well, I think as
a reservist, the support systems are strong” (C2, p. 16). The Alpha family described support services as “Excellent. We have had good support from community-centered boards, and the local police. Since moving onto a military base, we have received good support for our son” (A1, p. 5). Mrs. Echo reflected to a previous duty station, “He’s only been officially diagnosed for around four years, and we had such a great support system, wish I would have appreciated the support system I had before we left (laughter) more” (E2, p. 20).

Mrs. Echo commented, “We were fortunate to be at a base and a state that was very supportive of the whole family during deployment - the last year long deployment” (E1, p. 4). Mr. Charlie wrote about two different state’s support, “Outstanding. New Jersey was where Colin received initial care and Colorado has done a more than adequate job in assisting what can be done” (C1, p. 5).

Mrs. Delta shared the positive impact the assignment personnel had on their family. Delta family requested a compassionate reassignment to Joint Base Lewis-McCord because they knew of all the services that were available there. Educational support services are important to any child with special needs, but they are crucial to those children of military families who move every 18-36 months. Mrs. Delta said, “I had reached out and contacted every school in a 50-mile radius or every district at least, to see which ones had autism-specific programs” (D2, p. 8). She found out which ones utilized speech therapy and ABA as well as teacher to student ratio and teacher aide to student ratio. She said, “We found a couple great districts and that’s what brought us to buy a house in a specific town so he could go there and without having done that, I don’t know where we would be” (D2, p. 8).

Mrs. Alpha shared the positive impact of the base youth center on their son. “The youth center on the base is the biggest God send you can ever imagine.” (A2, p. 28). It has art, it has
music, it has events, it has gardening, they bring in baby goats and chickens that hatch and they have a gym with a basketball court and they have a ballet room and trampoline and Ping-Pong and a computer room and games and a whole lot of cool stuff. But Mrs. Alpha clearly stated what she felt was the best aspect, the people, “And what’s more importantly is a staff that is fabulous, that care about him and work with him” (A2, p. 28). The other military kids were friendly “So there’s been no hostility, nobody’s picked on him, we haven’t had to worry about bullying or anything like that” (A2, p. 28).

**Medical providers and insurance.** Medical providers and insurance benefits are vital to the experience families have and level of care that they receive. Both make a profound difference. The insurance has implications in the macro and exosystems and filters down to the microsystem. The individual medical providers have face to face interaction with patients and their parents and influence the micro and mesosystems. The Alpha family said, “Well, we got good support from Tricare for what they could do” (A2, p. 5). Mr. Charlie wrote concerning his son Colin, “He is severely handicapped that whatever is not covered by primary insurance is paid up through Medicare / Medicaid” (C1, p. 3). Mr. Charlie went on to say, “While mobilized, Tricare stepped up and took care of expenses that were at that time” (C2, p. 2). Mrs. Juliet wrote, “August 2011 – We began getting Respite Care through NAACRA (National Association of Child Care Resource and Referral Agencies). For my well-being, this is HUGE” (J3, p. 5). She explained the demands of raising three kids, home-schooling, work, and going to college part-time plus her husband working long hours and being away for training. She expressed gratitude, “Respite therapy became a need. I am so thankful that we were approved for this” (J3, p. 5). Mrs. Delta commented about the speed in which David received assistance, “Son evaluated for speech therapy, OT, and ABA. Started receiving services within two weeks” (D3,
She wrote in her timeline-essay about the steady progress once starting services, “Oct 2011 – Started going to Northern Utah Autism Project (NUAP). Jan 2012 – Son started speaking real words. Aug 2012 – Son was potty trained. Vocabulary had increased” (D3, p. 2).

Medical support providers, especially doctors make a big impact in both diagnosis of autism and leading parents in the next steps. They are the first link in helping families get the support they need. Mrs. Echo said, “Where we were last was fabulous and the doc, like I said, it so much depends on the doc I think, and maybe the Tricare office in the state” (E2, p. 5). Mrs. Delta believes their son did not fall to the wayside like some do because of a doctor who cared and got them started on the right track. She said, “I think that we were very blessed in how we were able to receive services so quickly and have those resources at our fingertips” (D2, p. 5). She explained, “Had we not been active-duty, had we not been to that particular doctor, we may not have had the diligence put into our son’s diagnosis” (D3, p. 4). Reflecting back Mrs. Delta was thankful, “The pediatrician said we will run with this diagnosis. We’re going to put you in through ECHO and there you will be enrolled into the exceptional family member program and we said okay” (D2, p. 4). Mrs. Juliet shared her excitement about her son’s doctor helping them get set up to receive services through the Extended Care Health Option (ECHO) program, “One of the first things that the doctor talked to us about was ABA therapy and I was really excited to find out about this and she talked very highly of it” (J2, p. 1). The doctor explained they did not have to worry about the cost because that was something that could be provided for them through the ECHO Program. Additionally, they were provided occupational therapy, private speech therapy and respite care.

The Golf family had experienced some tough circumstances at different locations, but they shared a positive story about one of their duty stations, “When we got here at Fort Lewis,
the developmental pediatrics were really good with setting us up with EFMP and making sure that we had all the right documentation for everything” (G2, p. 3). Mrs. Golf expressed her gratitude for the support team, “Actually, the really nice thing was here, the developmental place actually took care of everything. They filled out all the necessary paperwork for us and we just had to wait for about a month to get confirmation” (G2, p. 3). Mrs. Delta commented, “If I have ever needed assistance and contacted EFMP, they have helped; however, if I could take care of it myself I would” (D1, p. 2). Mrs. India appreciated “Being a part of the ECHO Program and getting somebody calling me monthly to kind of see how things were going and having that support” (I2, p. 11). She also wrote, “We did get more support through EFMP (i.e. questions answered, learned about additional resources). Now that my husband recently retired we still get support via phone calls from assigned ‘family support' person through Tricare ECHO program” (I1, p. 2).

Mrs. Echo spoke highly of Eli’s support providers, “But it was her therapist that really did a lot . . . Tricare paid for therapy and where we lived she came to our house, which was amazing … it was very comfortable for him” (E2, p. 3). She went on to talk about the continuity of care and consistency of providers. While her husband was deployed, the family stayed a third year on base which made a huge positive impact on their son with autism, “The fact that we had been somewhere for two years already, he was very connected. We had great docs, the therapist, it was not a problem, it was a breeze, I had no problems” (E2, p. 6).

Chain-of-Command. For a family raising a child with autism, the military member’s chain-of-command is a crucial element in their experience. Those that have supportive leadership have a more positive experience. The military operates as an institution in the macro and exosystems; however, the commanding officers and direct-line supervisors impact families
at a more personal level in the micro and mesosystems. The Alpha Family wrote, “The
commands were accommodating when the sponsor had to take time away from work for
appointments, or take our daughter to therapy sessions” (A,1 p. 4). The Foxtrot family felt the
sponsor's immediate chain of command has been accommodating of their family's special needs
situation. Mrs. Foxtrot wrote, “The time we were in yes” (F1, p. 4). Mrs. India wrote about her
husband, “He feels that leadership overall was very supportive over the years. If things came up
(medical, school mtgs, etc.) during the work day, the chain of command was supportive” (I1, p. 4).
She felt the support was dependent on the person, their position and their chain of command.
Mrs. India indicated her husband was more private with his family situation and did not
volunteer a lot of information, but he would re-arrange his schedule to fill in on the home-front if
something came up where she could not be the one to take the boys to appointments. She said,
“Whenever a situation came up, my husband did feel overall very supported while he was active
duty from his superior officers. He felt pretty positive about it” (I2, p. 16-17).

Experiences and Knowledge of Parents Offer Encouragement to Other Parents

Having already traveled down the road of autism, the parents in this study have a wealth of
knowledge and experience to share not only with the support services and the educational
field, but also with other families. While the section is geared toward military parents there are
still many things that are applicable to non-military families as well. Along with the specific
feedback parents shared, two sub-themes emerged; (a) Advocacy is crucial to success, and (b)
Perseverance – Never Give Up. The participant parents care and want other families raising
children with autism to thrive. Mrs. Delta started off with this advice and emphasized, putting
the child in the best place for the child, not for the parent, “It’s not about what the parents’ needs
are when you have a child with autism. It’s about the child” (D2, p. 19).
Feedback from lessons learned. The following comments were gleaned from participant parent feedback and were geared to help other parents. While they did not emerge as major themes, they are important points made by parents. Parents gave feedback on three specific topics: research and record keeping, proactive preparation, and communication, networking and teamwork.

Research and record keeping. Research and record keeping were emphasized. Mrs. Golf said, “First thing I would say is keep records of everything. Because most oftentimes, you move to another post and they lost something or they will state that they never signed something when they did” (G2, p. 21). She also advised, “Once you find a place that’s really helpful to your child, stay there because the grass isn’t greener at another post. It may be worse” (G2, p. 21). Mrs. Delta shared, “I would advise them to do their homework and actually get their ducks in a row if they can get everything written down, do pros and cons list, anything that they believe they need to do” (D2, p. 19). Mrs. India commented, “I just think that parents kind of need to be … as aware as you can as far as what rights parents have and what rights the kids have” (I2, p. 63). She also mentioned being open to getting legal help, “That means that if you have to hire somebody to help you fight, you need to do that” (I2, p. 63). Mrs. Juliet said, “Spend time finding your resources because . . . I didn’t ever stop to see everything that was there for us.” (J2, p. 10). Mrs. India wrote, “The support programs are out there and overall are good … but parents need to get involved. This is the difficult part because some parents are so overwhelmed they don't know where to begin” (I1, p. 6).

Proactive preparation. Being prepared and pro-active and not reactive is very important and can head off many difficult situations. This was encouraged by participant families in the following ways. Parents encouraged pro-activeness and being prepared. Mrs. India emphasized
being proactive, “I think it is so important for parents to make calls to new base as soon as they find out where they are going next” (I1, p. 7). Parents should set up meetings either via phone or as soon as they arrive and get necessary releases signed and forward paperwork from old school to new school. Mrs. Alpha also stressed being prepared. She said, “Our autistic daughter went through some periods where she was extremely violent and self-injurious and she would also damage property using her hand to totally demolish doors and damage walls” (A2, p. 46). She explained how they had a video they would show any repairmen before entering the house to prepare them for what they may see. She said, “Right here’s how it happened. Nobody’s been in a drunken rage, nobody’s abusing anybody, we have a special needs child who is a little out of control sometimes and this is what you’ll see” (A2, p. 46).

**Communication, networking, and teamwork.** Parents of special needs children need each other for wisdom, for encouragement and for support. Being proactive by networking and developing a support system is another piece of advice parents stressed. Mrs. India shared this, “As a parent, you know, you're always thinking like what if? What if I would have not have done that or what if I would have allowed this and not that” (I2, p. 58). She commented about the benefits of talking with those more experienced, “To have like a mentor kind of situation where we could kind of bounce ideas off of somebody who actually walked the walk” (I2, p. 59). Mrs. Golf wrote, “Getting out and meeting other parents with children on the spectrum may be the single best first step in living a life with an autistic child and I highly recommend this” (G3, p. 1). Her first encounter was with their coordinator for school, who had a girl with autism. She and her husband quickly learned they were not alone. She said, “This is also where I met a family that handed out business cards with information about ASD for curious onlookers, opinionated elderly, and ‘mothers of the year’” (G3, p. 1). She found this idea most fascinating,
“Albeit true the majority will give a strange look and simply shrug off the unanticipated response” (G3, p. 1). She explained that most people are completely unaware of the adversity overcome by the parents of children with ASD or even more so the ability of the children themselves to succeed in a world that does not understand them. She wrote, “Predominately, people understand their own children or those they are around most often and do not stop to think that this ‘normal’ looking child sees the world differently and marches to the beat of their own unique drum” (G3, p. 1).

Mrs. Alpha expressed, “People need to get on this, they need to connect, they need to get help, they need to get educated, they need to get assistance with just navigating the waters” (A2, p. 50). She also cautioned, “Time is of the essence, but it isn’t a sprint it’s a marathon they’ve gotta remember that too” (A2, p. 50). Mrs. India recommended preparing for what is ahead, “Get hooked up with someone who's like an older parent so maybe when your kids are in elementary school, you have an opportunity to meet parents whose kids are at junior high and high school level” (I2, p. 44). Mrs. Delta commented, “What would’ve helped me would have been another parent who has gone through the same things letting me know like, what to expect” (D2, p. 18). She and her husband had no family members with autism, she said “We were walking into uncharted territory” (D2, p. 18).

Mrs. Alpha shared her thoughts on networking with other parents to tag-team and give each other a break, “And for goodness sakes hook up online with other parents who are going through the same thing. Nobody has the time to drive 30 minutes to go to a meeting because nobody has the childcare resources” (A2, p. 41). Respite care, as Mrs. Alpha points out, is not only beneficial for parents, but for the siblings of children with autism as well. She advises, “Find someone in your neighborhood or your church or something who can come give you a
break and for goodness sakes try not to lean too hard on any neuro-typical kids you have because they’re gonna break down too” (A2, p. 42). They need the support also, she said, “Try to make sure those neuro-typical kids get to have as many opportunities to be a normal kid as possible” (A2, p. 42).

Communication and teamwork were factors to success. Mrs. India said, “I think I would try to ideally kind of express attitude of let’s work together and collaborate and cooperate and not make them feel like on the defensive. I always strive to try to do that” (I2, p. 61). She also shared a win-win strategy for communication, “I would definitely recommend that parents kind of communicate a lot with the administrators and the teachers when their kids are in school but also try to pop in during their lunch or something” (I2, p. 60). She would pop in unannounced every so often and drop off snacks or something, rather than just saying “Well, I'm coming to kind of see what's happening” (I2, p. 60). She would stop by the classroom and say “Oh, you know, I thought I’d bring by some cookies for the kids” (I2, p. 60). But her main purpose was to see what was going on at school and she wanted to come in unannounced. This let her know if there was a situation where she needed to be advocating for her children.

Children with special needs often require someone to help them. They need an advocate. Additionally, there are times when parents or families need an advocate to support them. Advocacy is important in caring for and educating those who cannot speak for themselves or do not know how to advocate on their own.

**Advocacy Is Crucial to Success**

Advocacy was a word that came up often in many different forms. Children with autism need parents advocating for them. Parents likewise, need support and others advocating for their
families. Advocacy is part of the strategy parents use to help their children the best way possible.

Mrs. India shared her experience, “I can remember at first I wouldn't want to say anything” (I2, p. 73). She explained that she would see something that did not look right or something that was not handled correctly and she would remain silent and not say anything. Eventually, she just got to that point where something would just hit her, “I think, you know what, if I don't say anything, no one's going to say anything. If I think this is wrong, I need to let them know” (I2, p. 73). She said, “I think with every situation you get stronger” (I2, p. 73).

Mr. Bravo said, “Almost everybody that has a Special Needs Child will say this, is that you are the biggest advocate for your child” (B2, p. 38). Mrs. Delta said, “I’ve kind of always taken it upon myself to figure out things during transition” (D2, p. 10). Advocating for continuity was important. Mrs. India wrote, “I feel that again I was so proactive that I would make sure services stayed as consistent as I could make happen. For example, I would call months in advance to ensure smooth transitions with medical, school, etc.” (I1, p. 5).

Mrs. Delta felt confident because she had done her homework, “Our son is too important to just let anyone educate him. Like I said, when we moved from one place to another, I have researched what places, what schools, what programs will be most effective in teaching him” (D2, p. 14). She also shared a success story. They were able to get their son into a highly effective program at four-and-a-half years of age. She said, “I called constantly and I think they chose us possibly…because I was a pain. So, I WAS being persistent and they let David in and he did well, he flourished there” (D2, p. 15).

Mr. Bravo explained, “You are on your own and you must learn the requirements and rules to be a true advocate for your loved one. You must often 'force' the issue to get even the most basic services” (B1, p. 6). Mrs. Golf also stressed teamwork, “Try to get everyone on the
Hang in there. You need to be your child's advocate” (G1, p. 7). Mrs. Alpha wrote, “You need to be the advocate for your child/children, and be persistent in requesting services or accommodations. When we first heard that, back in Omaha in 98 or so we had NO IDEA want that meant” (A1, p. 7). After years of experience raising three children with autism she gave this advice, “You are human; you will find the end of your rope. Make a knot, and ask for help!” (A1, p. 7). She expressed, “You NEED some time with your spouse, this is a MARATHON, not a sprint. If you don't do maintenance and fix cracks and leaks when they are small, trust me, eventually the dam can and probably will break” (A,1 p. 7).

Mr. Bravo talked about the need for parental advocacy, “We had to learn it all on our own or by talking to other parents” (B2, p. 6). He believed that children tend to be pigeon-holed in the process or in the bureaucracy, “The tough part is that it hasn't been tough advocating for her. It has been tough getting them to change some of the rules and some of the bureaucratic things that need to be changed for Special Needs Kids” (B2, p. 39). He went on to say, “School systems appreciate the nuances that she has and the nuances of Special Needs Kids both in transportation and in the classroom, however, sometimes we've had to advocate or to push them to go beyond the bureaucratic rules” (B2, p. 40).

With regards to the military Mr. Bravo said, “Advocating or pushing on this big bureaucracy, to categorize these people in one large group and seeks to ignore the rest. If you're in the rest and you advocate for yourself or for your child, it is very difficult” (B2, p. 54). He later added, “And that's the thing that always gets me, you know, the fact that you have to advocate for the obvious means somebody is ignoring the obvious” (B2, p. 57). Mrs. Golf shared a story of advocacy in the state legislature, “I just sat at the house of education, the board
of education out in Olympia, Washington and I listened to the testimonies of a lot of parents and like, it really pulled at me” (G2, p. 26). She got emotional because she was listening to a bill that Washington was trying to pass about unlawful restraints and isolation of children that have special needs. She said, “I was in support of the bill and I hope it goes past here and I hope that many other states do pass something similar. If not, I’m going to be there fighting for it” (G2, p. 26).

Sometimes parents need someone to advocate for them and their children. Many benefits come from having a professional advocate alongside working on behalf of these families. Mrs. Juliet said, “Well that first thing that I said to do, to have an advocate, to find a professional that you can have come with you to those meetings” (J2, p. 10). She explained that a big help would have been a better understanding of the processes for getting services and what the IEP meeting was going to be like, “I think it would have been really great to know then that I could have an advocate for that meeting, I didn’t know that” (J2, p. 10). She expressed she would have benefited from somebody that could walk her through beforehand and explain what was going to happen next. She said, “That would have been huge for me” (J2, p. 10). Mrs. Alpha said, “What would be helpful is more education for parents on how to navigate the system, recognize the traps and how to advocate for their child” (A2, p. 30).

Mrs. India had a unique perspective of being an educational specialist before becoming a mother. She used to sit on the SLP side of the table of the IEP table talking to parents about their children. She said, “Eventually I became the parent and was on the mom’s side of the table hearing therapists and teachers talk to me about my children” (I2, p. 17). She felt prepared because she was already aware of parents’ rights and what the IEP process was all about. She said, “It wasn't as overwhelming for me” (I2, p. 17). However, she also commented, “Even with
my background, I still would ask advocates to come with me to IEP meetings just to have that support” (I2 p. 18). Mrs. India also stated, “Every time we moved, I would look into as much as I could with like support. Like if there was an advocate” (I2, p. 18). Mrs. Delta had experience both as a parent advocate and professional advocate for others, “My service member husband and I are open about our family. Also, I am a professional advocate for military families with children who have special needs” (D1, p. 4). Mrs. Juliet also advocated for her son and other special needs children. She wrote, “I also begin working to make our children’s ministry more special need friendly” (J3, p. 5). She worked with an occupational therapist to accomplish the task. She stated, “It makes a huge difference in Jared’s experiences in the children’s ministry as well as those of some of the other children” (J3, p. 5).

Mrs. Delta expressed the challenge of working with ‘experts in the field’ who believe they know what’s best for the child because they deal with multiple children with a type of disability. She said, “I’m under the firm belief that the parent is the expert on their own child, but not everyone is under that belief” (D2, p. 16). Mrs. Foxtrot wrote, “This is to any parent: you know your child, if you are not getting what is best for your child … keep pushing” (F1, p. 7). Mrs. India described having to advocate, “We have had situations in different places where I've had to fight for placement and for services” (I2, p.20).

Mrs. India shared a personal story about an autism mother who became an attorney to advocate for families with autism, “Sometimes you're pushed into a position where you have to fight … I didn't want to have to fight for things, but I knew that if I didn't fight for them, nobody was going to fight for them” (I2, p. 61). The attorney that they hired specialized in children with any kind of disabilities. Mrs. India shared that the attorney’s experiences and background with her own son when he was in high school was what motivated her to go to law school, “So she
knew when she was in law school that her focus was going to be kids with special needs and their families and making sure that they get what they need and what they are entitled to” (I2, p. 61-62). Mrs. India explained that advocating goes far beyond their family and makes a lasting impact on the autism community. She shared it was three years ago, that they initially hired the attorney, “But we went into it thinking like this goes beyond our kids. This community needs help. There are other families here” (I2, p. 61). She said, “We hear in general from other people like, oh yeah, you guys aren't the only ones that are going through some stuff” (I2, p. 62). There are other families here that are struggling with different things also. The India family perspective is “We need to do something today that maybe might not even help ours but it might help a child down the line, down the road, that maybe a precedent could get set now, that's going to help some other family” (I2, p. 65). Their boys are older now, almost done with high school and facing new challenges, but the parents are still persevering and fighting to get appropriate services for them. Mrs. India wrote, “We are looking at our experience as one of ‘paying forward.’ We are trying to help this community and school district become better able and willing to serve the children here and their families!” (I1, p. 7).

For the Delta and Golf families their success is twofold, with the progress of their children which has led them to be advocates for other families raising and educating children with autism. Mrs. Delta said, “Most successful story is that our son is talking all the time now. He may not effectively be communicating as we…as we’d like, but the fact that he’s talking, he’s potty-trained, he’s in school, and he is in general education almost 50 percent of his day in kindergarten and we’re extremely thrilled with that. That is definitely a success story and because of him, I am able to do the job that I have been awarded because I have a son with a disability. Otherwise, I would not be able to effectively do my job or be able to help other
military families and professionals gain the understanding that I gained throughout the years” (D2, p. 21). Mrs. Golf shared, “My most successful story is the fact that where we’re at today, my son is doing absolutely amazing and I will finish my master’s degree in July in ABA and we are at a great spot to go home and be with our family and our life has really came together and I don’t know if I would honestly be looking into the career I am looking into today if it wasn’t for my son and wanting to change people’s minds in Autism” (G2, p. 25).

**Perseverance- Never Give Up!**

Some of the synonyms for perseverance are: determination, grit, persistence, resolution, and diligence. All of these describe the parents in this study. Throughout the research their words of hope and encouragement would emerge. There was a clear message to other parents raising and educating children with autism. That message was to persevere, “Don’t give Up!”

Mr. Bravo shared, “I’m one of those guys that believe you've got to pick the two or three main things that need changing or an adjustment and go after those” (B2, p. 61). He said, “That would probably be my message and kind of the banner for that is not to give up” (B2, p. 61). The banner “Don’t Give Up” was one that resonated with the participant families. Mrs. Delta gave this advice, “Don't give up. Days are long and life is short, don't squander your time with your children because they have a disability” (D1, p. 7). Mrs. Foxtrot wrote, “Keep pushing” (F1, p. 7). Mr. Alpha encouraged other parents to keep moving forward, “Hmm well (with heartfelt laughter) put your head down and do one day at a time” (A2, p. 12). Mrs. Golf said, “Hang in there” (G1, p. 7). Mrs. Alpha shared these words of hope, “There is a way - find it. Your child(ren) are counting on you!” (A1, p. 7). Mr. Charlie wrote, “Stay strong, good luck, they must be the ones to find best services for their children. Support groups can be a very strong way to do this and receive validation on experience being shared. Never Give Up” (C1, p.
7). Mrs. Juliet shared that services kids need are there, it is just a matter of getting them, “Sometimes that feels like a fight, but it can be really, really worth it” (J1, p. 7). She wrote, “You know your child so don't give up if you hit a roadblock and don't leave the decision making up to someone who doesn't know what's going on.” (J1, p. 7). She was open and shared a personal difficulty, “My biggest hurdle was trusting myself and pressing on when I hit those roadblocks and that is still something I struggle with!” (J1, p. 7).

Mr. Bravo summed it up with this passionate perspective from a military leader and a single parent of a child with autism,

I don't mean to be critical in any way, because everybody has to fight the battle and the enemy that's put before them, and that's the way I believe God equips us, but I don't believe in running from a battlefield. I believe in, if you run from it, you run from it only to figure out how you're going to go back in at a better angle. And I believe that life, you know, the whole concept of you didn't deserve a Special Needs Child or I didn't ask for this, you got to put that behind yourself and you got to figure out how to be positive and how to make the best out of it, not just for you but for other people too. (B2, p. 62)

Summary

Several themes emerged in the research and are discussed in this chapter. They ranged from Birth and Diagnosis to Military Life and Advocacy and finished with Perseverance. The following is a summary of the findings considering the research questions I sought to answer.

RQ 1: What Does It Mean to Have a Child with Autism while Serving in the Military?

Having a child with autism while serving in the United States military means going through a spectrum of emotions with an autism diagnosis after raising a healthy child the first
year of their life. It means getting the diagnosis as one parent is about to deploy. It means dealing with the many difficulties and challenges including the health and behavior of children with autism who often have additional medical conditions and diagnoses. It means handling these challenges away from family and an established support network. It means increased stress and strain and family sacrifice. It means a life of change while serving with career restrictions.

RQ 2: What are the Challenges a Military Family of a Child with Autism Experiences During Deployments and Permanent Change of Station (PCS) Moves?

Military life means change and transition. Children on the autism spectrum struggle with change and so there is a recipe for difficulty from the start. The world is in constant motion with global threats changing daily. The Armed Forces react and adjust to meet those threats, protect a nation and keep its citizens safe and secure. Parents talked about the frequency of change and how the short notice last minute changes are demanding. When a military member is deployed, it increases the strain on the other parent holding things together on the home-front as a solo parent. Children with autism often regress with difficult changes such as a dad being gone for long periods of time. One of the biggest changes for families is the PCS move. Parents do not talk about their PCS moves with much positivity. They describe it as an exhausting process. From the moment the orders are issued, parents start making plans to move from point A to point B. There are many logistical concerns. Parents described the problems with having to set up support services and therapies at a new duty station. In addition to finding a good school and getting enrolled, parents must take additional steps to ensure the special education department has all the documentation needed to set up a meeting to discuss a new IEP. There are many moving parts to a PCS move. It is a starting over process. The continuity of care and support is delayed and gapped during the moving process and often longer due to being on the waiting lists
for services at the new duty location. PCS moves are difficult. Parents relate it to being a hundred times worse with a child with autism.

RQ 3: How do Military Parents Respond to the Educational Challenges of Children with Autism?

Parents have a wealth of experience and knowledge. They offer valuable feedback and insight to support services and the education field. There were several strategies that parents used to help with the educational challenges of their children while serving in the military and dealing with frequent transition. Parents talked about the need to be proactive. They coached and pre-taught their children during transition periods. They called ahead and did research on potential schools and support services at the new duty station that they were being ordered to. The greatest concern was the need for continuity of care and education. The greatest response to challenges was advocacy. Organizations, communities and people who have compassion make a difference. Parents shared many stories of how a doctor, or a teacher or other support provider who truly cared made a positive impact in their child’s education and development.

RQ 4: What are the Lessons Gleaned from Real World Experiences of Military Parents of Children with Autism?

The participant families have a wealth of knowledge and experience to share with support organizations and the education field, but particularly with other parents. They emphasized the importance of researching resources and good record keeping. Parents felt being proactive by networking and building a support system through good communication and teamwork were keys to success. There are thousands of children with autism who need a champion to fight for their cause. The military participant parents encouraged other parents to be the advocate for their own children and for other families raising children with autism as well. They stressed
perseverance and never giving up because the children are counting on you. They practice a mantra used in the military, “Leave no one behind.”

This summary of the research question findings concludes Chapter Four which was designed to provide a rich narrative of the voices of the participant families, the words and thoughts of parents raising and educating children with autism while serving in the military. The implications of these findings are discussed in Chapter Five.
CHAPTER FIVE: CONCLUSION

Overview

The purpose of this hermeneutic phenomenological study was to describe the unique experiences of military families who have a child with autism, with focus on the efforts parents take to ensure an appropriate education for their children with autism in grades K-12. In this chapter I summarize the findings and discuss the findings in relation to the theoretical framework and extant literature on the topic. I also discuss implications of the research on multiple levels. The limitations of the research are identified and recommendations for future research are presented.

Summary of Findings

Findings from the study were generated through a triangulation of data which was collected through surveys, personal interviews and timeline essays. The data from nine families was analyzed using van Manen’s (1997) hermeneutic phenomenological methods and with Bronfenbrenner’s (1979) Ecological Systems Model as the guiding framework. Parents shared an incredible amount of knowledge and experience on the topic. There is an old proverb which says, “Experience is the best teacher.” There is an over-arching theme throughout the study; Military parents of children with autism have a wealth of knowledge and experience to share. There is much to be learned by hearing the narratives of these parents and listening to their stories. Five main themes emerged, all dealing with experiences. The themes were identified as: (a) Experiences with autism diagnosis; (b) Experiences with challenges and difficulties of autism and military life; (c) Experiences with challenges and difficulties related to change; (d)
Experiences and knowledge of parents offers valuable feedback and insight to support services and the education field; (e) Experiences and knowledge of parents offers insight and encouragement to other parents. Each main theme had sub-themes that emerged within. Some of these sub-themes are also “major” themes. They are addressed in context of each of the research questions.

**RQ 1: What Does It Mean To Have A Child With Autism While Serving In The Military?**

*Children with autism were all considered healthy at birth.* Several children were born early and a few were delivered through C-section; however, the children were found healthy, hitting milestones and developing normally through the first year of life. Parents started seeing delays and differences at different stages of their children’s development. They began to research their concerns and sought out help for their children. Some of the diagnoses happened across time and across different duty stations. Some families received diagnoses as they were in transition with PCS moves and preparing for deployment.

**Parents Experienced a Spectrum of Emotions With Diagnosis**

Some parents were in denial before the evaluation results came back with the diagnosis. They knew something was going on with their child but when someone at the playground or school would say, “I think your child may have autism,” they would be offended. They felt there was a problem, but it was not autism. Part of that may be because autism had not been seen in a positive light. Until recently the positive and successful life experiences of people like Temple Grandin had not been widely known to the public. Mrs. Juliet, on her way home from receiving the autism diagnosis, stopped by the book store and bought Temple Grandin’s book entitled *The Way I See It.* She said, “It was the best book I could have picked up for that moment.” While there was an initial shock for some and many cried tears when receiving the autism diagnosis,
there was an overwhelming consensus from the parents of feeling a sense of relief. After much personal research, doctor’s visits and diagnostic testing, parents finally had a name to put with their child’s condition and the pattern of behavior they were witnessing.

**Health and Behavior of Children With Autism Is a Challenge**

Parents shared that their children received other diagnoses in addition to autism. Some of the other conditions were speech delay, ADHD, OCD, chronic constipation and VSD. Gastrointestinal issues are common with children on the autism spectrum. Mrs. Juliet chose a gluten free diet as an intervention for her son. While eliminating certain proteins found in most foods required diligence and extra work as well as increased costs, it was well worth it when the health and behavior of her child improved. Mrs. Juliet said, “It is hard … but we see the benefits right in front of us and it’s an easy choice to make” (J3, p. 2).

The behavior of children with autism is different than normal children. A child having a meltdown in public can cause quite a scene. This leaves parents embarrassed and exhausted. Mrs. India described controlling her boys “like herding cats.” There are safety issues when children run and do not come back. Because these children are in their own world they do not perceive the dangers in their environment. ASD is a spectrum disorder and thus children display behavior from minor social inappropriateness to violence. Some children also exhibit self-destructive behaviors when they are frustrated. Children who display more extreme behavior wear a helmet to protect their brain when they engage in head banging. As they get older all types of behaviors can intensify because of their size and strength. Adolescents’ still mastering potty-training is yet another difficulty with health and behavior of children with autism. Changing the diaper of a teenager is a hard reality for some parents doing their best to care for their son or daughter.
**Autism and Military Life Increases the Stress, Strain, and Sacrifice**

The stress, strain and sacrifice come on multiple levels and different ways. Autism makes military service hard and life in the military makes raising and educating children with autism difficult. Parents talked about the overall stress, the marital and financial strain as well as the family and career sacrifice.

The cost of caring for a child with autism is expensive. Even with Tricare insurance helping pay for medical care the financial burden can be heavy. Often the care and supervision of a child with autism prohibits one parent from working, which can increase the financial strain on a marriage.

There is an emotional strain on marriages as children with autism require much time and energy and little time and attention is left for spouses. Having a child with autism creates a burden on the parents as well as the other children living in the home. The extra time, effort and expense it takes to care for a child with autism pulls away from the family resources. Parents talked about the toll on their other children. The duty requirements of serving in the military often cause the military member to be away from the home for long periods of time which causes sacrifices to increase. When the military member deploys, the spouse left to manage the home-front becomes a single parent trying to hold it all together. Parents expressed military service is often an expense to family life. Military members have a strong sense of duty and desire to serve their country. They also have an enduring steadfast love for their families and their well-being. Sometimes it is a balancing act to meet the military missions and care for their children with autism at the same time.

Parents expressed concerns with the EFMP, to the point where some did not enroll their child in the program. Others were hesitant before registering in EFMP because they felt it would
be career restrictive. The Air Force has a Q-code that goes into the military member’s record. It requires another level of screening which can put a member at a dis-advantage in the selection process. Parents saw the EFMP as a limitation both in career progression and duty assignments.

What does it mean to have a child with autism while serving in the military? It means going through a spectrum of emotions such as denial, shock, anger, sadness and relief when an autism diagnosis is given after raising a healthy child the first year of their life. It means dealing with the many difficulties and challenges including the health and behavior of children with autism who often have other medical conditions and diagnoses such as ADHD and OCD. It means increased stress, strain and family sacrifice. It means a life of service with restrictions on career progression and duty assignments.

RQ 2: What Are The Challenges A Military Family Of A Child With Autism Experiences During Deployments And Permanent Change Of Station (PCS) Moves?

Change is a way of life for military families. The world is in constant motion with global threats changing daily. The armed forces are charged with protecting a nation and keep its citizens safe and secure. They must react and adjust to meet those threats.

Military Life Means Change

Parents talked about the frequency of change and how the short notice last minute changes are demanding. Children with autism struggle with change. Often, they regress during periods of change such as a parent being deployed. The continuity of care and support is delayed and gapped during the moving process and often longer due to being on the waiting lists for services at the new duty location. They also shared successful strategies in dealing with change. Being proactive, flexible and managing expectations helped keep the regression of their children to a minimum. The military saw the concerns and created the Exceptional Family Member
Program (EFMP) to help minimize the amount of change to families with special needs and to ensure that when military members are re-stationed that their new duty station will be able to accommodate the special needs.

**PCS moves are difficult.** Parents did not talk about their PCS moves with much positivity. They described it as an exhausting process. They related it to being much worse with a child with autism. It is a starting over process. From the moment the orders are issued, parents start making plans to move from point A to point B. Parents described the problems with having to set up support services and therapies at a new duty station. In addition to finding a good school and getting enrolled, parents must take additional steps to ensure the special education department has all the documentation needed to set up a meeting to discuss a new IEP.

There are many moving parts to a PCS move. Parents described being on their way to a new duty assignment and being re-directed enroute with order modifications to a new point B, a completely different location. Travelling cross country with children with autism also presents additional challenges. Parents described the pressure for the military member to begin work immediately at the new location while the spouse and rest of the family handle all the household goods and moving in process.

What are the challenges a military family of a child with autism experiences during deployments and permanent change of station (PCS) moves? They are many of the same challenges that any typical military family with no special needs deals with; however, as Mr. Bravo said it, “with a child with autism, a move is a hundred times worse” (B2, p. 1). The challenges are starting over, gaps in continuity of care and education, long waiting lists for appointments, therapies and support services. The challenges are family separations and
uncertainty which lead to behavior problems and regression in children with autism. The challenges are the frequency of change and the disruption to the routine of children with autism

**RQ 3: How Do Military Parents Respond To The Educational Challenges Of Children With Autism?**

Parents spoke very openly about their experiences with support services and the education field. Those experiences ranged from negative to positive. Both support services and the education field are intertwined and go hand in hand in the care and education of children with autism. Parents gave specific feedback with these experiences. To the support services they relayed that outreach was needed, but not just providing a brochure with a list of websites. There needs to be more active direct outreach to the families with a more personal approach. Counseling was suggested as one of the ways to offer more direct support and assistance to families with special needs. Institutional change was recommended on both the governmental and military sides.

**Need for continuity of care and education.** Parents continue to stress the need for continuity. Long waiting lists for services were experienced by participant families. The referral process as it currently operates causes delays. The consistency or inconsistency between bases and from state to state varies greatly. The flexibility and free choice of parents is inhibited. Parents shared that the IEPs did not transfer well or were not adhered to at all. They spoke about the moving challenges and trying to find the best options for their children. Some found home-schooling as a viable option to help with continuity.

**Organizations, communities and people who have compassion make a difference.** When taking a deeper look at the experiences of parents, a theme began to appear. Negative experiences are associated with situations where an organization or person seemed not to care or
it was perceived by the parents that they did not care. Parents gave examples of military commands and education professionals who did not foster a caring environment and the outcome was not positive. Parents also shared many positive stories. At the heart of these stories was an education team, a command, a teacher or other professional individual or organization who truly cared and had compassion for the family. Parents spoke specifically about the positive difference the following groups made in the life of their child with autism; the military chain of command, medical providers and insurance, support services, schools, administrators and teachers, and special advocates, legal and family support, and the special needs community.

How do military parents respond to the educational challenges of children with autism? They do this by working hard to overcome the problems associated with the moves and changes common with military life. Parents see the need for continuity of care and do their best to overcome the obstacles. Parents seek out schools, support services and education professionals who have their children’s best interest at heart and they work diligently to have good communication with each of these while fostering a spirit of teamwork and cooperation.

**RQ 4: What Are The Lessons Gleaned From Real World Experiences Of Military Parents Of Children With Autism?**

Parents have a great deal of experience to share. There were several strategies that parents used to help with the educational challenges of their children while serving in the military and dealing with frequent transition. Parents talked about the need to practice proactive preparation. They coached and pre-taught their children during transition periods. They called ahead and did research on potential schools and support services at the new duty station that they were being ordered to. They stressed good record keeping, as well as communication, networking, and teamwork.
Advocacy is crucial to success. The greatest response to challenges was parents advocating for their children with special needs. Advocacy emerged in a crucial way. Parents talked about the importance of parental advocacy, but also the need for professional advocates to support the child and family.

Perseverance – never give up! Parents outlined the importance of advocacy and encouraged other parents to persevere. Preserve means to continue to proceed, to continue to persist, and endure. The strong powerful message emerged from the parents to other parents, “Don’t give up!”

What are the lessons gleaned from real world experiences of military parents of the children with autism? Children with autism need their parents working diligently on their behalf. Success is reached by advocacy where parents communicate and network to build a team of support. High stakes are riding on the efforts of parents. Persevere and don’t give up.

Discussion

Thousands of military dependents have autism. The purpose of this phenomenological study was to describe the unique experiences of military families who have a child with autism, with particular focus on the efforts and processes parents take to ensure an appropriate education for their children with autism in grades K-12. Education and development is vital to each child’s life and plays a significant role in family readiness, which directly affects operational readiness in the military. The purpose and end goal of this study was to share the experiences of military parents of children with autism and let them voice their concerns.

There is an over-arching theme throughout the study; military parents of children with autism have a wealth of knowledge and experience to share. This is the heart of the study.
There is much to be learned by hearing the words of these parents and truly listening to their voices. There were five main themes which developed, each dealing with experiences. Within each of these main themes were two sub-themes.

**Participant Families’ Children with Autism Were Considered Healthy at Birth**

This is a significant finding that children were healthy at birth. To date there is no commonly agreed upon cause for autism. There is much research that has been conducted which points to environmental factors. There are studies which also seem to contradict each other. It is still a much-debated subject. During the time that this study was conducted, the rate of autism has continued to increase from an official CDC rate of 1 in 88 to 1 in 68 (CDC, 2016a). There is also a study that the CDC published in a 2015 National Health Statistics Report which found the rate of ASD to be 1 in 45 (Zablotsky et al., 2015). This finding is like a study in a 2013 National Health Statistics Report that found the rate to be one in 50 (Blumberg, Bramlett, Kogan, Schieve, Jones, & Lu, 2013). Using either statistic represents an increase in autism prevalence. Five families gave unsolicited comments about this major event in their essay timelines. Both birth and diagnosis are major events that fall in the chronosystem of each family. Three families reported C-section deliveries. Despite some complications with delivery, parents reported healthy children at birth and meeting milestones during their first year of life.

Parents experienced a spectrum of emotions with diagnosis. Parents go through many emotions when receiving the autism diagnosis. The participant families described denial, shock, anger, and sadness. From previous research, the wife of a Marine Corps Colonel said, “It’s that grieving period when you give your life up and your expectations for your child’s life … that for me was a dark period” (Johnson, 2008, p. 36). Mr. Charlie described going through five different phases. He said, “It’s a traumatic life experience” (C3, p. 1).
The CDC (2016a) states that even though ASD can be diagnosed as early as two years of age, most do not receive a diagnosis until after age four. The earliest a child in the study was diagnosed with autism was at 18 months of age. Two groupings of diagnostic age emerged. Five of the families reported diagnosis at 18 months to two years of age. Three families reported the age of diagnosis between five and seven years of age. One family’s child was very high functioning and was not diagnosed until age 11. There seemed to be a correlation between the age of diagnosis and the severity of ASD. The later the diagnosis, the higher functioning degree of ASD. This lines up with the CDC (2016a) statistics which lists median age of first diagnosis by subtype; Autistic disorder, three years and 10 months; Pervasive developmental disorder-not otherwise specified (PDD-NOS), four years and one month; Asperger’s disorder, six years and 2 months.

**Health and Behavior of Children with Autism Is A Concern And Challenge**

The health and behavior of children with autism is challenging. Children with autism see the world differently, thus their behavior in this world is different. Parents describe dealing with inappropriate behavior as “exhausting” and “stressful.” As children move from childhood to adolescence the behavior can intensify and pose increased risk of harm to self and others.

Participant families shared several other diagnoses that their children received. This aligned with CDC statistics, which stated the co-occurrence of other non-ASD developmental diagnoses was 83% (CDC, 2016a). Mrs. India described their twin sons Obsessive Compulsive Disorder (OCD) as “more challenging for us than autism” (I3, p. 14). Ninety-four percent of children with autism have special needs requiring health or related services beyond those generally required by typical children (Pringle et al., 2012). Mrs. Juliet went in-depth about the gastrointestinal issues her son had. She put her son on a strict gluten / dairy free diet, which led
to drastic health improvements and improved behavior. This type of intervention follows the Defeat Autism Now (DAN) biomedical protocol which calls for healing the gut through the GFCF diet (2011) and restoring it through probiotics and multivitamins rich in B complex and B6. From the literature review, there was a study done at the University of Western Ontario which looked at autism triggers in rats and found improvements through diet modifications such as removing dairy and wheat (gluten) (Investigating the Environmental Origins of Autism, 2008).

**Autism and Military Increase Stress, Strain, and Sacrifice**

Autism makes serving in the military hard, and service in the military makes it difficult on children with autism. Both autism and the military have challenges by themselves but when they are combined, the difficulties increase. The participant parents echoed the words of parents in the literature review. One military mom when testifying before Congress said, “There is almost nothing more stressful than the combination of military life and a child with special needs” (Military Families Tell Their Stories at Congressional Briefing, 2012 p. 2). Mrs. Golf said, “It’s also very challenging … having a child with autism and being in the military, it is a whole new world” (G2, p. 1).

There is a sense of being stressed and strained to the breaking point. Parents mentioned the word “overwhelmed” many times. Mrs. Golf described the feeling when her husband was about to deploy, “I actually ended up going to a psychologist because I was severely depressed between my son’s diagnosis and the fact that my husband was going to leave me and I had nowhere to turn, no help” (G2, p. 24). This lined up with earlier research from Schonfield (2008) who found that parents and children in the family of a deployed service member had significantly higher levels of depression and distress.
The stress and strain comes in different forms and on different levels. The high cost of caring for a child with autism is source of strain. Mr. Bravo explained that his daughter required 24-hour care at $24,000 - $36,000 annually and she also required medications and other supplies not covered in many insurance programs. Previous research by the Harvard School of Public Health (2006) estimated the costs for a child with autism were $38,000 – $43,000 for non-medical costs such as special education and child care. Further, the monetary strain on a marriage can be difficult due to increased costs associated with autism and a shortage of funds due to one of the parents not being able to work because of the time commitment caring for their child. Since 9-11 and the beginning of the war on terrorism divorce rates in the military have increased (Bushatz, 2010). Ghose (2010) found parents of children with autism are more likely to get divorced.

When so much focus and time is put on a child with autism the other parent can feel neglected. Mrs. Delta said, “There is emotional strain on the marriage . . . sometimes there is not enough that you’re giving to your spouse” (D2, p. 20). Siblings of children of autism often miss out on opportunities and quality time with parents as well. From the solo parent on the home front trying to manage everything single handily, to the deployed military spouse who wants to help but is frustrated they cannot because they are stationed overseas, there is sacrificial service. There is sacrifice from the whole family unit. Mr. Bravo said that, “Having a child with autism opens your eyes to the challenges that other folks with disabilities have” (B2, p. 1). He described how much of an expense the military service is to family life. From earlier research Gorman, Eide, and Hisle-Gorman (2010) found that frequent moves, military deployments, and the risk of a parent’s death are examples of multiple stressors associated with military service that families experience.
Having a child with autism causes restrictions in duty assignment and career progression. In the literature review, Master Sergeant Doyle received push back for refusing short-fused orders to a duty station that had virtually no services for children with autism. This was a Marine combat veteran who was wounded by a sniper in his third deployment. His wife said this about him, “This is one guy who would give his life for his country. The one thing he won’t do is give his kids’ lives” (Johnson, 2008 p. 37). Mr. Bravo was passed over for an outstanding career opportunity and told point blank “You know, if you didn’t have this daughter with autism, then this is where you would be and what you would become” (B2, p. 14). Mr. Bravo is registered in the EFMP. The Exceptional Family Member Program (EFMP) was designed by the DoD to help support and protect families. Of the participant families in this study four were not registered in EFMP. Of the other five, several were hesitant to enroll due to the reputation of EFMP and the negative impact on their careers. EFMP is mandatory and a requirement to access additional health and educational benefits through the military’s Tricare insurance. Participants described making the choice to enroll because it would help their child, even at a detriment to their careers.

**Military Life Means Life Change and Transition**

The purpose of the military naturally lends itself to change and transition. To be able to meet the threats and challenges around the world directed toward the United States of America and her citizens, the armed forces must be fluid and mobile, always ready to respond quickly. This comes through much practice and training, which is always changing. For military families, this means saying goodbye often when the military member leaves for training exercises or for real world operations. It means relocating the family as the military member attends different
training schools and fulfills different duty assignments around the country and sometimes overseas.

Mr. Charlie who finished his career in the reserves felt that relocation every two or three years was “too much upheaval” (C2, p. 16). He said, “For the needs of my son … I would have to leave the service” (C2, p. 16). Children with autism struggle with change. Parents described many stories of their children regressing during periods of change such as deployments and PCS moves. The literature review shared a story from one Air Force spouse who said of their son, “He would shut down for a while, regain ground, and then regress again when Dad would return” (Rupe, 2009, p. 104). White, de Burgh, Fear, and Iversen (2011) found an increase in emotional and behavioral problems for children during the deployment of a parent. The literature review also contained a story of a father being sent home from deployment on emergency leave, because his son was hospitalized for harmful and self-injurious behaviors (Read Their Stories, 2012). Participant families described examples of regression as loss of verbal communication and children throwing more tantrums. One participant family described “trauma at school which ended up involving CPS” (A2, p. 11). Mr. Charlie put military life in this perspective, “The constant moving around and the constant flux of change makes things tremendously more difficult and challenging” (C2, p. 1).

**PCS Moves Are Difficult**

One of the major changes with serving in the military is the PCS move. Each move falls on the family’s chronosystem (Bronfenbrenner, 1979) as a significant transitional event. The literature review described a military dependent with autism named Paul who had lived at four different duty stations by his sixth birthday (Read Their Stories, 2012). The Golf family described moving eight times in eight years of service. Mr. Bravo put it nicely when he said,
“Most people don’t remember their moves with a great sense of glee and happiness” (B2, p. 32). PCS moves are difficult. There is often an expectation that the non-military spouse handles everything so the military member can begin work at the new station immediately. Every PCS means starting over. PCS moves are a major disruption to the stability and routine of families. Mrs. Echo said, “Now PCS is where everything is cut, all ties are cut, that is more difficult” (E2, p. 6). Getting on waiting lists and setting up a whole new support system at the new duty station is challenging. The participant families described some strategies during the moving process. The main strategy was managing expectations. They accomplished this by being flexible, or “sumper gumby” as the India family put it. They pre-teach and do a lot of coaching as they prepare their children for these big transitions. A big key to their success is trying to make the moving process fun for their kids. One participant family even stopped by Mount Rushmore to make the trip more exciting for their child with autism. Fallon and Russo (2003) noted that like most families, military families raising a child with disabilities learn to adapt to new responsibilities and demands.

Parents go to great lengths to help their children and keep regression to a minimum during these change and transitions periods. Mr. Bravo described how having a child with special needs multiplies all those things that are tough about military life “…the moving around, deployments and family requirements.” He said it well when he shared, “Because as bad as a move is—with a child with autism, a move is a hundred times worse than when you don’t have a child with autism” (B2, p. 1).

**Need for Continuity Of Care And Education**

If there is one theme that stood out more than any other, it is *continuity*. Two words were consistent throughout the research; change and continuity. While these terms may appear at first
glance to be opposites, they are not. Change means things become different. Continuity means uninterrupted connection or duration. Change is inevitable. Our world is in a constant state of change. Some change is routine, like the seasons of the year. Other changes can be sudden, like earthquakes and hurricanes. In the education field, every school year brings change. The military environment is always changing as each branch of service adjusts to operational commitments to meet the threats worldwide. Often within change there is continuity. For example, when the aspen leaves start to turn a golden color each year it marks that the seasons are changing, but there is continuity and after the snows of winter begin to melt, God’s creation can count on new life budding from those same trees in the spring.

Continuity was a major theme which ran throughout the literature review and this research study. A few of the statements from the literature review were: “Ask any military family their number one frustration, and you’ll hear the word transition” (Rafferty, 2011, p. 52). “The biggest frustration is starting over with a new doctor and defending the care my child received” (Rafferty, 2011, p. 55). “It takes me six months (after moving) to reestablish a support system because of all the things you have to get done. Special education for military kids is tough” (Rafferty, 2011, p. 55). Parents from this study made these statements that mirror the literature review: “The constant moving around and constant flux of change makes things tremendously more difficult and challenging” (C2, p. 1). “Every time I move … they want to basically re-diagnose him” (G2, p. 14). “You shouldn’t have to start from scratch and try to convince this doc that you need to start all of this stuff over again” (E2, p. 25).

Deployment cycles and PCS moves are a way of life in the military. While the frequency may decrease by being enrolled in the EFMP, change will happen. Parents are crying out for help with the continuity of care and education of their children during these transition periods.
Mrs. Echo was spot on when she said, “You shouldn’t have to start from scratch and try to convince this doc that you need to start all of this stuff all over again” (E2, p. 25). A study by Ohio State University (2011) found specific issues related to military children with autism to be frequent moves, incomplete educational records, disruption of services and the difficulty implementing individual education programs (IEPs) as written. The referral process can take months to see the primary care physician and specialists at the new duty station. Once a child is approved for services at the new place, it can be months on a waiting list before they start receiving services. Mrs. Echo shared parents’ frustration, “the gap can be six months … it can take forever” (E2, p. 25). Participants overwhelmingly felt the consistency of services between installations was poor. Mr. Bravo wrote, “Very inconsistent. Wide ranging gaps in knowledge and commitment” (B1, p. 5). Parents want to see more choice and flexibility with the system. This includes medical and support services, as well as education. Mrs. Delta suggested, “When a child receives specific services at one installation through referrals (e.g., Speech therapy, OT, PT and ABA) have new referrals made prior to that move so the child may continue those services” (D1, p. 5). Mrs. Golf said, “It would be amazing if the IEP process was uniformed or at least transferable to where I could take the IEP that I got in Texas and it could be usable in Washington” (G2, p. 23). This may prevent the loss of services, like what happened to the Foxtrot family when their son’s IEP was taken away after moving from Wyoming because he did not meet the Washington State eligibility qualifications. The Echo family’s son Eli also lost his IEP eligibility status when the family moved to Florida, because his grades were too high.

Mr. Bravo described the differences between states and school systems, “They have different policies. They have different ways in which they interpret those policies. Sometimes they’re better. All the time they’re different … so there are advantages and disadvantages” (B2,
It is important for these suggestions to find their way to those who can affect change on the exosystem and macro system levels. Chandra et al. (2010) expressed “information is necessary to provide clinicians serving the military families with evidence-based, anticipatory guidance” (p. 1014). The participant parents have much to share to affect positive change. Very similar to the proactive parents from the literature review who established the STOMP (Specialized Training of Military Parents) project to empower service providers and other military parents with the tools to better access services and create teamwork and collaborative environments, without regard to geographical location (Jacobsen, 2014).

The Juliet family, like many other military families, found a positive solution to help continuity in education by home-schooling. According to Anderson (2010), home-school veterans cite local co-ops, church groups and home-school groups as indispensable supports while also helping their children socialize. The Juliet family found support through WINGS, a nationally recognized performing arts program at a local community center.

This backs earlier research which shows the number of military home-schoolers trending upwards (Anderson, 2010). Not all parents have the availability or opportunity to home-school for various reasons. The continuity in public education needs to improve. Also, the services provided by public schools to home-school students should increase and follow the intent and spirit of ESSA (2015) and other educational laws.

**Organizations, Communities, And People Who Have Compassion Make a Difference**

Another theme that ran throughout the research data was people who care make a difference. “Compassionate” is a word which described these people. The word compassion means sympathetic consciousness of others' distress together with a desire to alleviate it. People and groups of people or organizations often ban together to address a need that has been
identified. Compassion International is a Christian, humanitarian aid, child sponsorship organization headquartered in Colorado Springs, CO exemplifies this quality. They recognized the need of children living in poverty around the world and developed an outreach plan to provide care and education for these children.

From the literature review, there was a story of a military mother who saw the need for increased services because of the long waiting lists in the fleet concentrated area of Norfolk. She went into action and created the Mea’ Alofa Autism Support Cent (MASC) which expanded ABA services to over 40 children. This military mom and autism advocate, Kerri Peko, realized the struggle and financial hardship of those of lesser rank and did something to bring attention and a solution to the problem (Rupe, 2009, p. 104).

Parents told many stories of teachers and support personnel who made a positive difference in their child’s life. These professionals were genuinely concerned with the health and education of children with autism and worked attentively to help them. They had compassion. Doctors who not only made the autism diagnosis, but went a step further and helped the families enroll in EFMP and start receiving services through the ECHO program made a positive impact. Organizations, communities, and people who have compassion make a positive difference in the micro system, the mesosystem, and exosystem (Bronfenbrenner, 1979).

**Advocacy Is Crucial to Success**

Advocacy was a theme that emerged consistently throughout the research. Children need an advocate watching out for their best interest. The parent is the one best suited and able to do this. They are with their child the most and have the best oversight of the child’s mesosystem, which is where all the microsystems connect and interact. Parents also need advocates coming along to support them as they strive to give their children the best care and education possible.
Mr. Bravo said, “Almost everybody that has a special needs child will say … you (the parent) are the biggest advocate for your child” (B2, p. 38). Mrs. Juliet said, “I think with every situation you get stronger” (J2, p. 73). It is the parent that ties all the support systems together. Mrs. Delta said, “I’m under the firm belief that the parent is the expert on their own child” (D2, p. 16). The doctor usually does not interact with the teacher at school; however, the parent is the link to ensure communication flows and all the systems are in sync working together as a team. This is a hard job and very demanding on a parent. Mrs. Alpha wrote, “You are human; you will find the end of a rope. Make a knot, and ask for help!” (A1, p. 7). It is important to have advocates fighting alongside parents. Often these come in the form of other parents who have advocated for their own children and are now championing the cause to help others.

The literature review revealed parents advocating on Capitol Hill and making a difference. Karen Driscoll was such an advocate. She had a vested interest as a military spouse and mother of a child with autism. The India family, like the Driscoll family, shared a great perspective on advocacy, “paying forward” (I1, p. 7). Both families had struggles and experiences which drove them to make efforts to help some other family or child down the road. Mrs. Driscoll’s concern and compassion for others caused her to storm the Hill and as the Commandant of the Marine Corps’ wife, Annette Conway said, she won “Legions of advocates” (Johnson, 2008, p. 38). Her valiant advocacy efforts led to policy changes with the U.S. Marine Corps. Mrs. Golf shared about her experience advocating with other parents at the state legislature in Washington State and the impact it had on educational policy in that state.

At the DoD level, Secretary of Defense Robert Gates illustrated the power of advocacy. When talking to a group of military spouses during a town hall meeting on one Army post, the spouses advocated for their children and highlighted problems. About a year later, Gates
returned and said, “Thanks to their honesty and directness … I made a commitment to those spouses … and today deliver on that commitment” (Dix, 2011, p. 1). These parent advocates affected change at the macro system and exosystem, which in turn trickles down thru the meso and micro systems.

Annels (1996) found parents’ voices are powerful instruments in the hermeneutic interpretive process and bring understanding and disclosure of phenomena through language. This phenomenon of military families raising children with autism is getting more attention as parents continue to advocate. As more parents advocate, their voice gets louder and stronger, and impacts the macro level and the culture changes.

**Perseverance – Never Give Up!**

The U.S. military has a mantra by which they live that says, “Leave no one behind.” It may be ingrained in the military families because of the lifestyle which develops and enforces determination, grit, and diligence. The Navy SEALS have a slogan which reads, “TEAMWORK – failure is not an option.” Parents stressed communication, networking, and teamwork. An overwhelming theme from all the participant families directed toward other families raising and educating children with autism was “Never Give Up!” Delta family said “Don’t give up” (D1, p. 7). Foxtrot family said, “Keep pushing” (F1, p. 7). Juliet family said, “Don’t give up if you hit a roadblock” (J1, p. 7). Alpha family said, “There is a way – find it” (A1, p. 7). Charlie family said, “Stay strong … Never Give Up!” (C1, p. 7). Golf family said, “Hang in there” (G1, p. 7). Bravo family said, “The banner for that is not to give up” (B2, p. 61). This theme may seem more divergent from earlier research in the literature review.

Rachel Kenyon when relating the autism diagnosis news to her husband deployed overseas said, “I had no hope to offer” (Military Families Tell Their Stories at Congressional
Briefings, 2012, p. 2). The participant parents shared encouragement. “Do not squander your time with your children because they have a disability, life is short, take it one day at a time,” they said. So much pressure and level of success is riding on the parent. Another stated, “It may feel like a fight, but it is worth it.” “Your kids are counting on you; regroup and attack from a different angle, but keep persevering and “Never give up!”

While there were not any direct quotes from parents in the literature review saying “Don’t give up,” they were also not responding to questions about what they would tell other parents, rather they were responding to Congress about their concerns with regards to raising children with autism in the military. I believe if these parents were asked the same question as those in this study, then their responses would be similar. I believe their actions confirm this. Mrs. Driscoll and Mrs. Peko both faced difficult situations. They did not give up. Mrs. Peko saw a shortage of ABA services. She did not give up, but rather founded an autism support center which increased services to over 40 children (Rupe, 2009). Mrs. Driscoll did not give up when Tricare did not cover all their child’s therapy, instead they got resourceful and used the equity in their home to pay for needed services. This experience also motivated her to persevere and advocate for other families (Military Families Tell Their Stories at Congressional Briefing, 2002). Faced with shortage of finances, the Doyle family did not give up, but rather moved in with Mrs. Dolye’s parents to save money to pay for therapy bills (Johnson, 2008). Another family from the literature review hired an attorney to fight for services from the school system. They did not give up and after a three-year legal battle reached a settlement with school officials to cover a home-based ABA program. (Read Their Stories, 2012).

Actions sometimes speak louder than words. The parents from earlier literature and this research are speaking through their actions, “Don’t Give Up.” They are displaying perseverance.
This has a huge impact on the mesosystem. Parents are the ones that are most tied into all their child’s microsystems. They are the “glue” that holds it all together. If they do not “stick” with it and persevere, then things fall apart for the child with autism.

Implications and Recommendations

The purpose of this phenomenological study was to describe the unique experiences of military families who have a child with autism. As Ary et al., (2006) stated, the participant’s subjective experience is at the heart of the inquiry. Hermeneutic research is interpretive and focused on historical meanings of experience and their total effects on both individual and social levels (Laverty, 2003). The findings of this study addressed all levels of Bronfenbrenner’s (1979) model. The research from this study will affect the micro level through the macro level. Further, the implications from this study fall in three main spheres of influence: the military, support services and the education field, and individual parents of children with autism.

The words and stories of parents affect the change, as was evidenced in the literature review with stories of advocating parents speaking to congress in Washington D.C. This study saw participants share experiences about going to the state capitol building in Washington State to voice concerns and advocate for special needs children. It also shared stories of parents advocating locally at school districts and military installations. The exosystem indirectly affects a family’s micro system. The institutions such as the DoD or a state legislature create policy, as does local school boards. The one over-arching theme that this study produced is the need for continuity of care and education for these military children with autism.
Military

Operational readiness continues to be a high priority for the Armed Forces. The military must be ready to deploy anywhere in the world with a rapid response to threats against the United States of America or her allies. The military also has a humanitarian mission and must be ready to respond to natural disasters such as hurricanes and tsunamis. Family readiness is a crucial element of the overall operational readiness. Vice Admiral Robinson, the Navy’s Surgeon General stated, “The assurance of family care is critical for mission success” (Johnson, 2008, p. 37). Families sacrifice to enable the military member to serve. When the men and women of the military deploy, and are in operations around the world they need to be able to focus on the mission. When a military parent is deployed, children have an 11% increase in outpatient visits for mental and behaviors conditions (Gorman, 2010). The wife of one marine Master Sergeant did not tell her husband while he was deployed to Iraq about all the challenges she dealt on the home front in taking care of their daughter with autism, “He wouldn’t have been able to focus on his job, and when you’re getting shot at, you need to focus” (Johnson, 2008, p.37). It is important for military members to know that their families are safe and cared for back home. Major General Deppe, Air Force Vice Commander, warned that the quality of life for families is “compromised by lack of services and supports” (Johnson 2008, p. 37). To help family readiness, the DoD established the EFMP as a program designed to better support military families with special needs. The EFMP is a program which has many benefits. It was described earlier as a multidisciplinary assignment initiative interfacing civilian and military agencies to coordinate comprehensive medical, education, community and personnel support to military families with special needs (Cummins, 2010). Enrollment in the EFMP is prerequisite to gaining access to the ECHO program through Tricare. The ECHO program has helped many families
with autism by providing ABA therapy and respite services. Only five out of the nine families in this study were enrolled in EFMP. That means 44% of the participant families may have not been on the military’s radar for needing special attention or consideration through EFMP. A quantitative study with statistical analysis may be needed to determine how many children with autism are in military families. Also, the rate of autism within the military could be calculated and compared to the general rate of the public as identified by the CDC. Of the five families in this study that were enrolled, several expressed serious reservations about enrolling because they had heard mostly negative experiences from those already enrolled. These families also talked very candidly about the career sacrifice and restrictions the EFMP enrollment brings.

Parents in this study and from the literature review expressed disappointment and disillusionment at the bureaucracy of the DoD and the federal government in Washington D.C. They felt while the government organizations do put some policies in place, they do not follow through with a genuine commitment. One USMC Colonel’s wife advocating in Washington D.C. was told by a legislative staffer that the military leadership was lying to her about their intentions to pressure congressional leaders for Tricare system changes. She cried and said “I guess it was an awakening to the coldness of a very bureaucratic system (Johnson 2008, p. 38). The parents describe it as government lip service (B2, p. 51). This is an issue that must change at the macro system where culture is created and changed. There is hope, as it appears there are some advocates serving in the halls of Congress. Congressman Larson, referred to the treatment of military families raising children with autism as “immoral” (NBC’s Andrea Mitchell Examines Plight of Military Families Raising kids with Autism, 2012, p. 1). Congressman Burton said, “Instead of passing legislation to take away rights of families … we should be passing legislation to try to help them” (Kirby, 2005, p. 6).
Serving in the military is a very transient lifestyle. Military members are constantly leaving for training evolutions and deploying on mobilizations. Every two or three years they move and relocate along with their families to a new duty station. These changes bring the challenge of maintaining continuity of care and education for children with autism. The parents in this study as well as the parents in the literature review were consistent in their concerns over the referral process and the delays and wait times to receive services. Children regress and behavior deteriorates during periods of change. Family readiness is degraded. The lack of continuity is a problem and must be addressed by military leaders, support services and the education field. For the military, there should be a very careful look at how the EFMP enrollment affects career progression. Specifically, for the Air Force, the Q-code that is placed in a member’s record should be scrutinized to determine if having a Q-code causes biases in the selection of personnel for promotion and assignment selection. A few years ago, the military went to a blanket Category Five EFMP assignment with all military dependent children with ASD, regardless of where they fell on the autism spectrum. Some parents presented medical documentation to lessen the Category ranking and were successful in working with the EFMP office. Autism is a spectrum disorder. Each child with autism is different. As the phrase in the autism community goes, once you have met one child with autism … you have met ONE child with autism. Their needs are so different from one child to the next. The military should look at each child and family individually and assess the needs that they have and then assign the most appropriate EFMP category. The DoD should enhance the assignment process to include more specific information about the needs of each individual child (Ohio State University, 2011). When the Navy went to Category Five for all children with ASD, it caused more limitation on career assignments and caused more families to relocate to a hand-full of designated fleet
concentration areas. While this can help with more stability with a greater chance for the military member to take a follow-on assignment in the same geographical area, it can also increase the demand on the autism support services as more children arrive at the clinics and the local schools. The study by Ohio State University (2011) highlighted the concern of over burdening the resources in areas with a large military presence.

**Support Services and Education Field**

Continuity was a major theme throughout the literature review and the research. Parents shared their experiences with the difficulties and challenges of maintaining continuity for their children. This is a challenge issued to those who have the power to affect changes and bring about better continuity. The referral system with Tricare, the military’s health system, needs to be streamlined to eliminate the long waiting lists and gaps in services. The educational system and health care system needs to be more fluid across different school districts and health care regions to ensure there is a smooth transition when military children with autism relocate and transfer to new schools and to new special services/therapy with each PCS move. This includes military children who are home-schooled.

Mississippi was mentioned as a state which does not allow children with special needs to access public education if they are home-schooled. Many states across the country are very supportive and accommodating to military families who home-school. Mississippi and any state with a closed view on home-schooling should change policies within the macro and exo systems to allow military dependent children with autism being home-schooled to access programs and activities in public schools. This is part of the free and appropriate public education (FAPE) the law requires under the IDEA (2004). The Military Interstate Children’s Compact Commission (MICCC or MIC3) was a compact between states which was created to enhance continuity for all
military children/students transferring from state to state. The compact directs the uniform
treatment of military dependent children transferring between school districts and states (Ohio
State University, 2011). It took several years, but eventually all 50 states signed the document
and joined the MIC3.

The States working together to care for military children through the MIC3 are an
eexample of a partnership on the macro and exosystems. More coordination and collaboration
between the school and point A and the school at point B should take place. For example, if the
special education director at a school in Tennessee has touched base and communicated with a
special education team in Nevada where the child is transferring from, then the first IEP meeting
at the new school in Tennessee will most likely be more affective and beneficial to the child, the
family, and the new education team. The success of the Bravo family during their last PCS was
an example of the positive outcome when support providers at point A and B are proactively
working together to ensure the needs of a child with autism are met.

The Medicaid Waiver was also another area of concern. The literature view revealed
children being placed on the wait list for services through the state’s Medicaid office with an
expected wait time of 10 years. Parents in this study shared concerns over having services with
one state and then going to the bottom of the waiting list after PCSing to a new state. Davis,
Blascke, and Stafford (2012) stated, “Military policy can affect national policy regarding
children, families and communities” (p. 87). Assistant Secretary of Defense for Health Affairs
explained there was an expanding need and recognition of military families with children who
have autism (Cronk, 2013).
Parents

The implications of this study for parents is that this research can be used as a resource on the journey with autism. Personal stories are powerful and bring out the truth (Nash & Bradley, 2011). One of the biggest take-aways is the need for parental advocacy. No one ties all the micro systems of a child with autism together like the parent. The parent operates in the mesosystem where all the micro systems of their child connect. The success of each child with autism is directly dependent on the advocacy of his or her parents. To accomplish this parents must research and educate themselves about autism as well as the rights and protections their children have under the laws such as IDEA (2004) and ESSA (2015). For those just learning about autism, a suggested book is The Way I See It by Temple Grandin. As parents begin to get educated they should also network with other parents and support groups. This will speed up the learning curve and establish meaningful relationships as information and resources are shared. Parents will realize that even though they may sometimes feel isolated, they are not alone.

Limitations

This study has some limitations. First, not all the participant families were able to complete all three data collection methods. One family was unable to complete the second and third phases of data collection. Two families were unable to complete the third phase of data collection; however, the second phase of data collection, the personal interviews for these families were two of the longest, lasting approximately two hours each. Several families initially agreed to participate, but had to withdraw due to time constraints and a family schedule already overwhelmed with caring for a child with autism. The limitation was not having 100% triangulation method in data collection. There are many variables which cannot and should not
be controlled in qualitative studies. This is acceptable because as Polkinghorne (1983) stated, “there is an increasing realization of the limitations of addressing many significant questions in the human world within the requirements of empirical methods and its search for indubitable truth.” In fact, a variety of research methodologies such as grounded theory, ethnography and hermeneutic phenomenology have grown in popularity partly because of this growing difference in philosophical perspectives (Denzin & Lincoln, 2000).

Another limitation is my own. Serving as a Naval Officer for 22 years and raising a child with autism for most of those has given me a wealth of knowledge and experience to share. My knowledge and experience is an enhancement to the study; however, I still have biases. I believe it is important to acknowledge that, even though I have done everything in my power to remain completely neutral and ensure those biases do not affect the research study. Due to the vastness between participant families who were spread throughout the United States, I did not have the time nor sufficient funds to travel and conduct face-to-face interviews. In-person interviews are usually preferred because they offer many non-verbal signs and clues which add emphasis and meaning to what is being said. Several families initially volunteered but then soon after withdrew because to the demands and time constraints of raising a child with autism. It is plausible that the nine families that did participate are more adjusted to raising and educating children with autism and the sample in this study may not be representative of the population of military families with autism.

**Recommendations for Future Research**

This study points directly toward the need for more research on ways to enhance continuity for military families transitioning from state to state and school district to school
district. Certainly, with the modern technology, innovative systems and a touch of compassion, organizations can work to create solutions to the continuity issue, or lack of continuity problem.

There are many therapies that parents use to help their children with autism. ABA is one that has been scientifically established to beneficial. There is evidence that increased oxygen intake through HBOT can help not only burn victims, but children with autism as well. The effectiveness of each of these different type therapies should to be studied.

The EFMP enrollment is mandatory, yet four out of the nine families in this study were not enrolled in EFMP. A qualitative study should be conducted to explore why almost half the families having children with autism choose not to enroll in EFMP.

Since the start of this research, the CDC has reestablished the rate of autism from 1 in 88 to 1 in 68 (CDC, 2016a). Autism continues to increase. The military has one of the highest sub-rates of autism. Something is causing this increase. More studies need to be conducted determine the cause of the epidemic, and specifically, factors that influence the rate of diagnosis in military families. Research indicates that the environment toxins plays a role in causing many health-related issues, including autism. As mentioned in the literature review, why is it ok for military families to live and play on military installations, but when the base is closed, the federal government must spend millions of dollars to clean it up before it is safe to transfer the property to the local community? This is a question deserving of further inquiry.

In 10 years from the surveillance year of 2000 to the surveillance year of 2010, the autism rate increased from one in 150 to one in 68 (CDC, 2016a). Research to find a cure for autism should continue. Cancer research continues to find breakthroughs to fight the deadly disease and save lives. Autism research should continue and intensify in the same manner as cancer research.
Aaron Liebowitz (2008) in the book *Voices of Autism* wrote, “Finally, it is hoped these stories will remind researchers who are seeking answers for the causes and cure for autism, that a child is waiting” (Gore, 2008, p. xii). The purpose and end goal of this study was to produce a rich description of the experiences of military parents of children with autism. It is hoped that these findings will further autism research, help others, and encourage more studies.

**Summary**

In this hermeneutic phenomenological study parents shared concerns surrounding the care and education of military dependent children with autism. This study highlighted the challenges, successes, and concerns of nine United States military families (6 men, 7 women) who volunteered to participate in the study. I am forever grateful for their time and candidness. These families represent this phenomenon of thousands of military dependents with autism. Using Bronfenbrenner’s (1979) ecological systems model and van Manen’s (1997) methodology for data organization and analysis, the experiences of nine military families were explored. Participants shared their hearts and life stories. These findings fill a gap in research which was found during the literature review. Participants shared heartbreaks and successes with their children. They shared the challenges of serving in the military and raising and educating children with autism.

There was one over-arching theme: Parents have a wealth of knowledge and experience to share. There were five main themes that developed around their experiences: Experience with autism diagnosis; Challenges and difficulties of autism and military life; Challenges and difficulties related to change; Parents offer valuable insight for support services and education field; Experiences and knowledge of parents offer insight and encouragement to other parents.
Throughout the research there were several themes which seemed to come up more frequently and with more emphasis from the participant families; Need for continuity of care and education; Perseverance – Never give up!; Advocacy is crucial to success; Organizations, communities and people who have compassion make a difference.

The military, educational field, and support services all like to use acronyms. For instance, OCS stands for Officer Candidate School, and DOR means dropped on request. Likewise, NCLB stands for No Child Left Behind, or the reauthorization of the law called ESSA which stands for Every Student Succeeds Act. Also, EKG stands for Electrocardiogram, and OT means occupational therapy. In keeping with the spirit of using acronyms and to tie the study’s four major themes together an acronym was developed: C-pac.

*Continuity* is the first c in the acronym. One of the biggest concerns of parents is the need for continuity of care and education. The reason it gets the capital “C” is because it is still a significant need that should be addressed. The hyphen separates the need from the things that will help that need be met and create positive continuity. The remaining letters in the acronym come from the three other major themes and together create an answer to the continuity issue.

The p in C-pac stands for *perseverance*. The participant families spoke about what it means to have a child with autism while serving in the military. They shared how autism makes life hard in the military and how the military makes life with autism hard. They described in detail how difficult it is, but they all also gave this overwhelming message to other parents. The participant families in this study have walked the autism road a long time and they encouraged other parents traveling this same road to “Never Give Up!”

The a in C-pac stands for *advocacy*. Advocacy is crucial to successes. This was a major theme as participant families stressed the importance of advocating for their children. There are
two notable individuals who have incredible success stories who were named in this study. Hellen Keller and Temple Grandin. Both ladies would not have reached the level of success they did without dedicated loving parents who advocated for them. Hellen’s parents researched a story in *American Notes* written by Charles Dickens, which described the successful education of another girl who was also deaf and blind. Hellen’s father traveled to Baltimore seeking help for his daughter and through a series of referrals ended up traveling to the Perkins Institute for the Blind in south Boston, where he was introduced to a young student who would forever change his daughter’s life, Anne Sullivan.

Temple Grandin’s advocate was her mother. Her mother, through research, came upon a checklist describing autism which was published by the founder of the Autism Research Institute, Dr. Bernard Rimland. It was Temple’s mother that took her to the world’s leading special needs researchers at the Children's Hospital in Boston and refused to allow her daughter to be institutionalized. This mother was one who persevered and did not give up. It was Temple’s mother who proactively sought out the best opportunities for her daughter and laid the ground work for her future success. It was Temple’s mother who advocated for her to be placed in Mountain Country School, a private boarding school in Rindge, New Hampshire, for children with behavioral problems. It was here where her daughter would meet another advocate that would impact her life, a teacher named William Carlock.

All the parents in this study are like Temple’s and Hellen’s parents. Mrs. Juliet home-schools and keeps a strict GFCF diet to help Jared. Mrs. Echo drove across several states so Eli, who was struggling to fit in at the duty location, could go to Scout Camp with an old friend from their previous duty station. The India parents fought legal battles to ensure their children were provided adequate services. Mr. Charlie planned toward the future and went to great lengths to
establish legal documentation to ensure Colin would be cared for in case Mr. Charlie passed away. Mrs. Golf advocated with other parents at the Washington state capitol on behalf of their autistic children.

The last c in C-pac stands for *compassion*. The participant families talked much about their experiences with support services and education. Their experiences ranged from extremely negative to very positive. At the center of those positive experiences were people who cared. Organizations, communities, and people who have compassion make a difference; this was a major theme. Parental advocacy is very important, but parents need other advocates to come alongside them and their children with autism. Advocates come in the form of doctors, teachers, and other professionals or parents. These advocates not only care, they have compassion which they demonstrate through their actions. They see a need and want to help make a situation better, so they step in and start doing something about it. Annie Sullivan agreed to become Hellen’s teacher. She quickly changed her strict teachings after seeing they did not suit Hellen. She adjusted to the needs of the child and began to have much success. Sullivan had great compassion for her student, which lasted a lifetime and had a ripple effect on many other children with special needs.

Temple’s high school science teacher, Carlock, who had worked for NASA, become an encouraging and compassionate mentor. He continued pouring into Temple and he was a bridge of continuity of support, while reaching out and giving her guidance in her follow-on years at Franklin Pierce College.

Ferris had a teacher who made a positive difference. The teacher who channeled Britany’s behavior and taught her how to care for a plant created a success story in the classroom. Alison’s teacher was described as an angel who has made all the difference in the
world for Alison to be able to function at school. Mrs. Delta started as a “Autism Mom” and now she serves as a professional advocate making a positive difference for other children with autism.

The acronym C-pac is not only an acronym, it is a formula for success. When parents who persevere, and advocate for their children with autism are joined by organizations, communities, and people who have compassion, then a difference will be made and the Big C problem will cease to be an issue. Then, military children with autism will have greater positive continuity of care and education.
REFERENCES


Disorder. Retrieved from


And Schuster Audio.


DoDEA. (2011). *DoDEA History.* Retrieved from http: www.dodea.edu/home/about.cfm?print=y&cId=history


http://onlinelibrary.wiley.com/o/cochrane/clsysrev/articles/CD003498/frame.html


My child has autism card. (2010), TACA. Retrieved from


http://www.autismvotes.org/site/c.frKNI3PCImE/b.5141983/k.A9E4/Military_homepage.htm

Ohio State University. (2011). Education Services for Military Dependent Children with
Autism, Executive Summary. Retrieved from
http://www.militaryhomefront.dod.mil/12038/Project%20

Ohio State University Project Team. (2011). Education Services for Military Dependent Children
with Special Needs: Phase II


Retrieved from http://articles.mercola.com/sites/articles/2001/02/24autism-
mercury-part-two.aspx

perspective in qualitative research. In D. K. Padgett (Ed.), The qualitative research

mercury release, special education rates, and autism disorder: An ecological study
of Texas. Health and Place, 12(2), 203-209.

Paris, R., Ross, A., & Acker, M (2010), When a parent goes to war: Effects of parental
deployment on very young children and implications for intervention.
American Journal of Orthopsychiatry, 80, 610-618. doi:10.1111/j.1939-
0025.2010.01066.x


Thompson, W., Price, C., Goodson, B., Shay, D., Benson, P., Hinrichsen, V., Lewis, E.,
Eriksen, E., Ray, P., Marcy, S., Dunn, J., Jackson, L., Lieu, T., Black, S., Stewart,
G., Weintraub, E., Davis, R., & DeSteano, F. (2007). Early Thimerosal Exposure
and Neuropsychological Outcomes at 7 to 10 Years. The New England Journal of

Federal Services, Inc.

Tricare, (2011). Tricare Extended Care Health Option (ECHO) brochure. Rancho
Cordova, CA: Health Net Federal Services, Inc.


subtitleA-partII-chap31-sec502.htm

United States Code (1966), 5USC3331. Retrieved from:
subpartB-chap33-subchapII-sec3331.htm


APPENDICES

Appendix A: Individual Solicitation Form

Greetings, my name is Charles Tidwell, but I go by Chad. I am doctoral candidate at Liberty University in Lynchburg, Virginia. I am carefully conducting research and working diligently to finish all requirements for graduation. My dissertation project is entitled “Parental Concerns Surrounding the Education of and Care for Military Dependent Children with Autism: A Phenomenological Study Highlighting Challenges and Successes of Military Families” As an educator, naval officer, and parent of a child with autism I have great passion for this subject matter.

This research will focus on the unique lives of military families affected by ASD. The one criterion is that the families must have been serving on active duty in the military for a minimum of one year during the time that their child with autism was school age (3-18 or early intervention program through high school). Selected respondents will be given a short initial data collection form. Upon completion, the parents will be contacted to arrange an interview time and place at their convenience. Interviews will be recorded for transcription purposes. Names and identities of participants will remain anonymous. Codes will be used and will not be linked to any name or place. Interviewees will be given a copy of their transcription for approval prior to release. The final item will be a reflective timeline / essay in which parents outline the important dates and milestones in their journey with a child with autism (sample template will be provided). This will help establish reliability to the study through the triangulation of methods approach.
I believe parents offer the most powerful insight. This is an opportunity for you to share your experiences that may be able to help other parents, education professionals, and military support groups.

Attached is the consent form. If you wish to participate, please sign and return to me. If you have any questions, please do not hesitate to ask. My contact information is listed below.

Thank you for your consideration to participate in this research project and for being an advocate for children with autism. My prayer for this project is that it leads to successful graduation, but more importantly that it becomes a useful resource to help families raising children with autism and educational professionals teaching military dependent children.

Sincerely,

Chad Tidwell

Wk# 307 - 773 - 6451
Cell# 303 - 990 - 4816
Wk email: Charles.tidwell@navy.mil
Hm email: Tidwells4jc@gmail.com
Appendix B: Individual Consent Form

I/We volunteer to participate in the dissertation research being conducted by Charles Tidwell through Liberty University. I/We would like to contribute to the dissertation project entitled “Parental Concerns Surrounding the Education of and Care for Military Dependent Children with Autism: A Phenomenological Study Highlighting Challenges and Successes of Military Families.” I/We understand that our names (first and last, including children) will remain anonymous and we will be given the opportunity to review the interview transcript to ensure accuracy prior to release. I/We also understand at any time we may decide to terminate participation in the research study.

Printed Name/s  ____________________________________________

Signature/s  ________________________________________________

Date  _______________
Appendix C: Questionnaire

Code___________

INITIAL DATA COLLECTION FORM

Parental Concerns Surrounding the Education of and Care for Military Dependent Children with Autism: A Phenomenological Study Highlighting Challenges and Successes of Military Families

(Please use the back of this form or additional sheets as needed)

1. What is your family member status?
   Military member / civilian spouse       Dual military       Single

2. What is the sponsor’s branch of service?
   Air Force       Army       Marine       Navy

3. What is the length of the sponsor’s time in service? ______________________

4. What is the sponsor’s current status in the military?
   Active Duty       Reserve / National Guard       Retired       Other

5. What is the length of time raising a child with autism on active duty in the military and how many schools has he/she attended? ______________________
   ______________________________________________________________________

6. How old is your child and at what age was your child diagnosed with ASD?
   ______________________________________________________________________

7. Is the military sponsor enrolled in the Exceptional Family Member Program (EFMP)?
   Yes       No
   Why?______________________________________________________________
   ______________________________________________________________________
   ______________________________________________________________________

________________________________________________________________________
8. What was the time period between diagnosis and enrollment in Exceptional Family Member Program (EFMP)? ___________________

9. How did you learn about the EFMP enrollment process?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

10. Has EFMP met your expectations?

Yes       No

Why? __________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

11. Are you satisfied with TRICARE support of your family member’s special needs requirements?

Yes       No

Why? __________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

12. Have you had challenges locating medical/education specialty providers that will accept Tricare?

Yes       No
13. Have you had significant out-of-pocket expenses due to the care of your special needs family member?
Yes  No

Why?________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

14. Is the military sponsor enrolled in TRICARE’s Extended Care Health Option (ECHO)?
Yes  No

Why?________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

15. What was the time period between diagnosis and enrollment in ECHO?
______________________________________________________________________________

16. As a military family, how many times have you moved with your special needs family member during the military sponsor’s career? __________________________

17. What challenges have you experienced with PCS moves?
______________________________________________________________________________
18. Over the past ten (10) years, how many times has the military sponsor been deployed?

_________________________

19. Did you encounter special needs support challenges during times of deployment?

Yes
No
Why?______________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

20. Is the sponsor’s chain of command aware of your family’s special needs?

Yes
No
Why?______________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

21. Do you feel the sponsor’s immediate chain of command has been accommodating /
supportive of your family’s special needs situation?

Yes
No
Why?______________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
22. How would you describe the consistency of services you have encountered from military installation to military installation?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

23. What feedback would you offer the support groups (i.e., Tricare, EFMP) within the military?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

24. How would you describe local community support for your special needs family member at your current location?

______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

25. Have you had issues with your child’s school regarding special education?

Yes    No
26. How would you describe your current local school support?

______________________________________________________________________________

______________________________________________________________________________

27. How would you describe local school support overall across all schools where your child has attended or received services?

Why?_________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

28. What advice would you offer schools and education professionals?

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

______________________________________________________________________________

29. How would you describe the overall military support of families with special needs?
Why?___________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

30. What insight would you share with other military parents?
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

________________________
Appendix D: Interview Procedures

I. Preparation for the interview.

a. Review the Data Collection Form again to get a sense of each family’s experiences and feelings before the phone conference.

b. Ensure recording devices are operating properly and spare batteries are on hand.

c. Ensure the environment is quiet and that distractions have been minimized.

d. Be present and ready five minutes prior to the agreed interview time.

e. Pray and ask God’s blessing on the interview.

f. Address the interviewee by designated sequential code to protect identity subjects, i.e. Mr. Alfa, Mrs. Juliet and so on.

g. Inform the interviewee of the recording process and interview protocols.
   1. Interviewees may withdraw from the research at any time without fear or penalties.
   2. Inadvertent identification of specific persons or places that may jeopardize anonymity will be corrected in the transcriptions.
   3. Interviewees will have opportunity for final approval of transcriptions prior to release.

II. The interview.

a. Informally started by the statement to the interviewee, “First of all, let me say thank you for being willing to take part in this study”.

b. Take notes. Pay particular attention to non-verbal communication such as tone and voice inflection.

c. Do not interrupt to ask for clarification or questions.
d. Ask questions later during appropriate pauses.

e. Respond neutrally to questions the interviewee may ask.

f. Summarize the highlights at the end of the interview to make sure everything was understood as the interviewee intended.

III. The script.

a. “First of all, let me say thank you for being willing to take part in this study.

Before I turn on the audio recorder and we begin, I want you to know you that the privacy of you and your family is of the utmost concern to me. It is my responsibility to protect it. Throughout the interview I will refer to you as Mr. Alfa and Mrs. Alfa, the Alfa family and (child’s pseudo name). If any of us slip up and use a real name it is ok because a correction can be made in the transcription of the audio recording. Once the transcription is complete, I will give you a written copy of the interview to review and approve. Once the interview transcription is approved by you, I will delete the audio recording. The interview will probably take between 30 to 60 minutes. I want to be clear that the end goal of this dissertation is to ultimately further autism research and provide successful strategies from lessons learned by producing a rich descriptive study, complete with the voices of parents sharing experiences and successes as well as concerns.

Do you have any questions before we get started? (push the record button and start interview)

I. What does it mean to have a child with autism while serving in the military?

1. How did it feel to learn that your child was diagnosed with autism? Was it during a deployment? What did you do first?
2. Which services or resources were made available to you by medical providers or by the military health insurance (TRICARE) when the autism diagnosis was presented?

3. How did you find out about the Exceptional Family Member Program (EFMP)? What was the enrollment process like? How effective is the EFMP in supporting your family?

4. Describe your experience with detailers / placement officers when negotiating orders?

5. How supportive is the military of families who have children diagnosed with autism?

II. What are the challenges a military family of a child with autism experiences during deployments and permanent change of station (PCS) moves?

   1. How effective are the support systems (military or other) in place during the transition times? (I.e. MFLC, Military One Source, School liaisons)
   
   2. How does your child react to change and uncertainty during these transition periods?

   3. How do you overcome the challenges associated with PCS moves and deployments?
   
   What strategies were effective in assisting your family with deployments and PCS moves?

   4. What are the two major concerns / challenges of moving with a child with autism?

   5. What are the two major concerns / challenges to deployments and family separation due to military assignments?

III. How do military parents respond to the educational challenges of children with autism?
1. Has your child’s education been smooth and easy, difficult and challenging, or a mix of both good and bad experience?

2. Please describe your two most challenging experiences?

3. Please describe your two most successful experiences?

4. What are your experiences in IEP meetings? Are there significant differences in your experiences between different school districts? How about states?

5. Which programs have been most beneficial? (ABA, SCERTS, Hand Writing Without Tears, etc.)

IV. What are the lessons gleaned from the real-world experiences of the military parents of children with autism?

1. What do you know now that would have helped you when your child was initially diagnosed with autism?

2. What are two things you would advise other parents to do or not to do?

3. What changes would you like to see in the support systems provided by the military? Educational support systems?

4. Please share your most difficult story raising and educating your child with autism while serving in the military?

5. What is your most successful story?
b. This completes our interview, again “Thank you” for being willing to share your experiences. (push the stop button)

c. I will be back in contact soon with the transcription ready for your review and approval. In the meantime, I want to leave you with a template to use in the third part of the research. Please complete the timeline / essay with the events you feel is important in this timeline / essay. Please know you have the liberty to put whatever dates, events, therapies, etc., you feel are vital parts of your story, particularly as it relates to autism and the education of your child. Please focus on the rich life experience you can share that may benefit others.

IV. Transcription.

a. Transcribe the recording.

b. Present the draft to the interviewee for quality assurance and any needed corrections.

c. Finalize the draft with interviewee approval.

d. Submit the transcripts for data analysis and archiving.

e. Delete the recordings for privacy issues.
Appendix E: Timeline / Essay

Timeline Essay Sample Template - Please put whatever dates, events, therapies, or other items you feel is important in this timeline / essay, particularly as it relates to autism and raising and educating your child. Please focus on your rich life experiences, sharing your story that may benefit others. Please also describe any defining moments that always come to mind when you think of your experience navigating the autism diagnosis journey. Hopefully I can pick it up when I deliver the interview transcription for review and approval. The following is a sample given in another area of disability. This is simply presented to act as a guide. I used Helen Keller as an example.

27 Jun 1880 – Our daughter Heidi (pseudonym for Helen) was born in Tuscumbia, Alabama. She hit all milestones through the first year of life. At 19 months she fell ill. We thought she had contracted scarlet fever or meningitis. The doctors described the illness as “an acute congestion of the stomach and brain.” The sickness took away both her hearing and sight. She became very hard to control as she was isolated in her own world. She was able to communicate a little with the six year old daughter of the family cook. They communicated through signs. By age seven Heidi had about 60 home signs she used to talk to our family.

1886 – I read a story in American Notes written by Charles Dickens. It described the successful education of Lauren Bridgeman who was also deaf and blind. This was truly and inspiring moment and I sent my husband and our daughter Heidi to find Dr. Julian Chisholm, an ear, nose and throat specialist in Baltimore. Dr. Chisholm referred us to man who had been successful working with deaf children. His name was Alexander Graham Bell. He encouraged them to visit the school where the girl in Dickens’ story, Laura Bridgeman, had been educated. The next step
was a huge moment in our lives. My husband and Heidi traveled to the Perkins Institute for the Blind in south Boston. The school’s director asked a former student, Anne Sullivan, to become Heidi’s teacher.

Mar 1887 – Ms. Anne Sullivan arrived at our home in Alabama to work with Heidi. It was very difficult initially for both Anne and Heidi. Things were broke, tears were shed. We were about to give up hope, then one day we had a major break though….what I call a miracle. Heidi finally understood that Anne was trying to teach her the names of different things using sign motions in the palm of her hand. The wonderful moment came when she had cool water running over one hand while her teacher gave the motion for the sign of water in the other in the other hand. I’ll never forget that day….it was filled with such excitement and emotion.

May 1886 – Heidi went back with Anne to attend the Perkins Institute for the Blind. It was a sad day as we hugged our daughter good bye, but we felt in our hearts that it was the right decision. We were encouraged by the amazing progress she had made and the prospects of a better quality of life for our little girl.

1894 – Heidi graduated from Radcliffe College, becoming the first deaf blind to earn a Bachelor of Arts degree……………………………

***** This is just an example of the events and milestones one family may have experienced while raising and educating their child with special needs. Parents are at liberty to put whatever dates, events, defining moments, etc., they feel is important in this timeline. Thank you for sharing your story and life experiences that may benefit others.
Appendix F: Bronfenbrenner Coding Sample

23. What feedback would you offer the support groups (ie. Tricare, EFMP) within the military?

When a child receives specific services at one installation through referrals (ie. Speech Therapy, OT, PT, and ABA) have new referrals made prior to that move so the child may continue those services.

24. How would you describe local community support for your special needs family member at your current location?

We decided to live in a low population community off the installation due to class size and our local community is great.

25. Have you had issues with your child’s school regarding special education?

Yes

Why? JEP not being followed or revised at one year mark (annual review)
Appendix G: Interview Transcription Coding Sample
## Appendix H: Master Theme Quote Spreadsheet Sample

<table>
<thead>
<tr>
<th>Continuity</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;That from the process point of view, I think one of the positive things that I saw was at my last PCS, independently without me asking, and I can’t say whether it was because of my rank. I can’t say it was because -- in every case that we’ve moved, we’ve actually made a trip to the new location and personally met with everybody that she would have and tried to set up all the care and all that so that maybe have been a part of it, too. But I didn’t know until I got here that they folks at my new base, after they had met me and seen me and we had come around and talked with them, they talked all of their equivalent folks at the base I was at, my previous base now, they had called all of them to have conversations with them about what my daughter was like and what she needed and how she reacted and what the best way to care for her was. That was very positive because I think that’s something that has to happen for everybody, not just for me but everybody doesn’t have the time, the experience, the money to be able to go in advance and do the pre-planning that’s kind of required for that. So I think that’s one of the most positive. I was very touched in the heart by that and happy because that happened.&quot; (B2 p.67)</td>
</tr>
</tbody>
</table>
Appendix I: Theme Organization Sample

Insight & Feedback:

Advice to Support Staff:

- Offer robust feedback & support
- Create a safe environment
- Encourage open communication
- Foster a sense of community
- Build relationships

Points from Stakeholder Insights:

Advice to Educators:

- Provide clear guidance
- Foster a collaborative environment
- Encourage collaboration
- Promote continuous improvement
- Encourage professional development

Points from Stakeholder Insights:

Advice to Other Parties:

- Provide consistent communication
- Foster a sense of support
- Encourage active participation
- Promote a culture of collaboration
- Encourage continuous improvement

Advice to Children:

- Provide clear guidance
- Foster a sense of community
- Encourage continuous improvement
- Encourage professional development
- Promote a culture of collaboration

Advice to Families:

- Provide clear guidance
- Foster a sense of community
- Encourage continuous improvement
- Encourage professional development
- Promote a culture of collaboration

Advice to Staff:

- Provide clear guidance
- Foster a sense of community
- Encourage continuous improvement
- Encourage professional development
- Promote a culture of collaboration
Appendix J: Audit-Decision Trail Sample

Audit/Decision Trail (cont.)

- What I did - How I came back up a few days
- Do exercises in 2 Q's or by main themes experienced
- Keep file notes separate as their an analogy to the file, "Your main theme in January this - Register is still 2nd in the pages required each year. "Don't need speed." - "I've never been.

- How many free days 50 per 100 allowing for who to control.
- Better off if any are in left field.

- Major
- This
- Then
- From
- Another
- About
- Much
- spin
- possibly

A week to stay with
- Use 3rd of May, 1940
- How end time June, torn gone
- Impressed stay until 3rd-4th agreeing to a speech under field

Helen Keller
- For closing Mr. Anne Sullivan 1884 Braille printed. For Municipal Library
Appendix K: Reflective Journal

4/25 Up in Cheyenne Easter evening to be by for Joshua's 5th high initiation. McCormick Jr. High. Joshua was nervous, but did well. As we were up here in my cell spoke to my heart a lot, we knew this timing at having us endure another 1858 here as it am writing my dissertation. I realized I am going through the same thing again—well, I will be studying.

4/26 Kept up again about the challenges of moving when I took the kids to the dentist—our very patient and kind pediatric dentist. He has chosen of mine's playing for each child on the screen on the ceiling. When we were leaving & driving out, the assistant said...
Appendix L: IRB Approval

October 16, 2014

Charles Wesley Tidwell
IRB Approval 1899.101614: Parental Concerns Surrounding the Education of and Care for Military Dependent Children with Autism: A Phenomenological Study Highlighting Challenges and Successes of Military Families

Dear Chad,

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

Liberty University | Training Champions for Christ since 1971