

IN THE SHADOWS OF AUTISM: A COLLECTIVE CASE STUDY ON  
LIFE WITH A SIBLING WITH AUTISM IN A MILITARY FAMILY

by

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Liberty University

A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

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## ABSTRACT

The purpose of this collective case study was to understand the typically developing (TD) sibling's well-being and role in a military family with a child with autism spectrum disorder (ASD) on a military post through the parent and TD sibling perspective. The three theories which guided this research include the social cognitive theory (Bandura, 2001a), self-determination theory (Ryan and Deci, 2000), and family system theory (Bowen, 1966). These theories were utilized to evaluate and better understand the motivations, characteristics, and the social development within the family when one child has a diagnosis of ASD. The research questions were: (1) How is the well-being of a typically developing child in a military family living on a military post impacted by having a sibling with autism in the home? (2) How does having a sibling with ASD impact the roles of the typically developing siblings in a military family who lives on a military post? (3) How do parent perspectives on the experiences of TD siblings compare and contrast to the TD siblings' actual experiences and perceptions when one sibling has ASD on a military post? Each family had one sibling that had a diagnosis of ASD as well as a TD sibling. Data were collected through observations, photographs, and timelines to provide in-depth understanding of the siblings of children with autism in a military household. Interviews were conducted with four families, one parent and a TD sibling, all from the same military base. Data from interviews, timeline discussions, and photograph discussions were then coded for common themes. Eight themes were identified: protective nature of siblings over their sibling with ASD, separations create a change in lifestyle, the annoying little brother, reactions to home therapy, improvements of sibling relationships as they mature, fairness among siblings, anticipation for what the future holds for their children, and self-reflection of parent choices.

*Keywords:* autism, siblings, military, qualitative, family

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### **List of Abbreviations**

Applied Behavioral Analysis (ABA)

Autism Spectrum Disorder (ASD)

Center for Disease Control and Prevention (CDC)

Extended Care Health Option, TRICARE's autism-related benefit (ECHO)

Individuals with Disabilities Education Act (IDEA)

Institutional Review Board (IRB)

National Autism Association (NAA)

National Defense Authorization Act (NDAA)

Permanent Change of Station (PSC)

Temporary Duty Yonder (TDY)

Typically Developing (TD)

U. S. Department of Defense Military Health System (TRICARE)

## **CHAPTER ONE: INTRODUCTION**

### **Overview**

This chapter provides background information about Autism Spectrum Disorder (ASD) and the experiences that the typically developing (TD) siblings of children with ASD encounter in a military family. The purpose of this collective case study was to understand the typically developing sibling's well-being and role in a military family with a child with autism on a military post through the parent and sibling perspective. In this chapter, the significance of the proposed study is discussed. The research questions, research plan, and limitations provide the foundation for this chapter.

### **Background**

There is a global increase in the prevalence of autism, and it is approximated that four million Americans will have a diagnosis of ASD within the next decade (Casey et al., 2012). Between 2000 and 2010, the number of children with ASD in Europe and North America increased from five to nine per 10,000 people to 90 to 110 per 10,000 people (Zhange, Yan, Barriball, While, & Liu, 2015). This increase could be attributed to any number of factors from changes in diagnostic practices and increased awareness, to better access to health care (Centers for Disease Control and Prevention [CDC], 2014; Idring et al., 2015). Thompson (2013) warranted the rapid increase in autism research on technological advances and changes in practice which began in the mid-1960s. Whatever the reason for the increase in numbers, ASD is no longer a rare disorder but rather one that has the potential to impact the whole of society. The diagnosis of ASD for one individual can affect all family members; therefore, this increase in individuals with ASD indicates an increase in family members impacted by ASD.

The military population is not immune to this increase in prevalence, and even reported a higher rate of ASD diagnosis than the national average (Organization for Autism Research, 2010). As of 2013, the Army represented only about 37% of all military personnel and reported at least 8,500 cases of autism and counting (Klin et al., 2015). The indicated numbers of family members with ASD under TRICARE (the military health system) nearly tripled from 2,292 in 2009 to 6,550 in 2012 (Kline et al., 2015). With an increase this large one can anticipate a strain on the military base medical personnel and also that of the schools, but closer to home the number of military families impacted by autism has also increased.

### **Historical relevance**

The term *autism* came from Leo Kanner (1943), a Swiss psychiatrist who applied it to a subset of symptoms related to schizophrenia. Kanner first observed what appeared to be a distinct psychiatric syndrome in a group of children which he labeled as Infantile Autism (Kenny et al., 2015). Kanner's research launched a scientific study of autism (Thompson, 2013). The characteristics of the children observed by Kanner included a marked limitation in spontaneous activity, insistence on sameness, impression of serious-mindedness, and a presence of anxious tenseness (Kanner, 1943). During these observations, the children exhibited a good relation to objects and would happily play with them for hours with little relation to or interest in the people around them (Kanner, 1943). The children's desire for aloneness and sameness was noted by Kanner (1943). Although Kanner (1943) presented the idea that these children were born with the inability to effectively connect with people, misguided theories began to materialize placing the blame for the syndrome on severe parental neglect, abuse or serious mishandling (Thompson, 2013).

The cause of autism was first considered to be a result of poor parenting (Kenny et al., 2015; Thompson, 2013; Wolff, 2004). The second thought was that Autism Spectrum Disorder (ASD) was an early form of childhood schizophrenia, but this idea was abandoned in 1979 (Wolff, 2004). Within this thought was the idea that ASD was a developmental disorder, rather than a psychosis (Wolff, 2004). Wolff (2004) described the third consideration for the cause as a developmental receptive language disorder, which was later viewed as a secondary symptom to ASD. The actual cause still is unknown. Thompson (2013) explained that currently it is recognized that ASD is a cerebral dysfunction and the typical events that can lead to brain malfunctioning include genetic conditions, syndromal developmental conditions, and toxin exposures. Parents and professionals continue to question the validity of an ASD diagnosis as there is no definitive blood test, genetic test, brain scan, or biological test for autism (Thompson, 2013). The ASD diagnosis can encompass a wide variety of abilities and needs, as children can vary from seemingly typical children who might appear a bit different to those with severe disabilities (Kenny et al., 2015; Wolff, 2004).

Lorna Wing (1981) accredited Hans Asperger's work with helping to birth the idea of Asperger's syndrome while linking it to Kanner's previous account of autism (Wolff, 2004; Frith, 1991). Asperger's syndrome was associated with children identified or diagnosed with high functioning autism and having an IQ of above 70 (Frith, 1991). Children with Asperger's typically speak at a normal age; however, walking can be delayed (Wing, 1981). Wing (1981) describes the content of this speech as abnormal, either by repeating a word or phrase over and over again or by lengthy disposition about the individual's favorite subject. Nonverbal communication is also impacted as children with Asperger's may exhibit few facial expressions or gestures and in return may not be able to comprehend the non-verbal cues from others (Wing,

1981). Wing (1981) describes other characteristics of children with Asperger's as clumsiness, ill-coordination, and withdrawal from social interaction.

This neurodevelopmental disability severity can be characterized as ranging from mild to severe social, communicative, and cognitive deficits that result in a significant lifelong disability. By drawing attention to the higher functioning individuals with ASD, the autistic spectrum was born (Wolff, 2004). Still to this day, there is a lack of understanding about the nature of the ASD diagnosis as well as a wide variety to the severity of the symptoms under the spectrum that is ASD (Thompson, 2013). This lack of homogeneity, forces professionals to describe autism as a family of overlapping conditions (Thompson, 2013).

### **Social relevance**

Autism was first recognized as a medical condition, which led to its inclusion in the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III) (Kenny et al., 2015). As it was considered a mental condition and labeled as such, there was a need to fix or cure the disability (Kenny et al., 2015). However, there is no known treatment, yet some behavioral modifications and interventions have shown to improve the symptoms of ASD with early intervention but no proven effect on long term prognosis (Wing, 1981; Wolff, 2004). Over the years there has been a shift in how individuals with ASD are viewed, both culturally and politically (Wolff, 2004). This shift has been influenced both by research and cultural views on education and treatment (Wolff, 2004). The American Psychiatric Association (APA, 2013) stated that a diagnosis of ASD required the demonstration of persistent impairment in social communication and social interaction often combined with repetitive behaviors. Autism can be associated with a lack of social and communication abilities that hinder social learning (APA, 2013). Individuals with ASD may insist on routine and have aversion to change (APA, 2013).

This aversion impacts all aspects of their lives. ASD is also a social communication disorder that can present challenges to interpersonal relations such as sibling relationships (Diener, Anderson, Wright, & Dunn, 2015). A sibling relationship incorporates not only more frequent, but also more intense conflict than any other close relationship (Feinburg, Sakuma, Hostetler, & McHale, 2013). Individuals with ASD may also display levels of aggression, which can impact sibling and family relationships (Hodgetts, Nicolas, & Zwaigenbaum, 2013). Individuals with ASD require assistance in the areas of self-care, mobility, and other daily living tasks influencing family roles and responsibilities (Cridland, Jones, Stoyles, Caputi, & Magee, 2015).

### **Theoretical relevance**

Although the difficulties of raising a child with autism from the parental perspective and the impact on the siblings has been researched, military families have not been studied in this manner (Davis & Finke, 2015; Klin et al., 2015). Siblings of individuals with disabilities are often left out of research, support services, and advocacy movements, despite their critical support role in the family system (Arnold, Heller, & Kramer, 2012). The perspective of the typically developing (TD) siblings of children with ASD has been overlooked by parents and researchers alike (Arnold et al., 2012). As military life can include multiple transitions, it can lead to unique struggles for these families with children with ASD (Brendel, Maynard, Albright, & Bellomo, 2013; Davis & Finke, 2015; Davis, Finke, & Hickerson, 2016; Klin et al., 2015; McGuinness & McGuinness, 2014; Mustillo, Wadsworth, & Lester, 2016; Richardson, Mallette, O'Neal, & Mancini, 2016). These unique struggles include frequent relocations and periods of separation which may take a parent away for extended periods of time due to training or deployment (Brendel et al., 2013; Davis & Finke, 2015; Davis et al., 2016; Klin et al., 2015; McGuinness & McGuinness, 2014; Mustillo et al., 2016; Richardson et al., 2016). This

qualitative multiple case study provided in-depth understanding of the roles and well-being experienced by TD siblings of children with autism in military families. This research benefits the military families of children with autism and TD siblings by providing a voice for these siblings. In addition, this research helps professionals to understand the nature of this phenomenon of having a sibling with ASD in a military family and provides a place to begin putting in place supports for the typically developing siblings.

Theories utilized to evaluate and better understand the data from this research include the social cognitive theory (Bandura, 2001a), self-determination theory (Ryan and Deci, 2000), and family system theory (Bowen, 1966). Through the lenses of these theories, motivations and characteristics were explored and better understood in connection with the social development, roles, and well-being of the TD sibling in a military family where one sibling has a diagnosis of ASD. In the social cognitive theory, Bandura (1962) explored how individuals learn behaviors from their surroundings and through modeling within the family system and in society. This research examined how the TD sibling's family system and surroundings on the military post have shaped the roles for which they take responsibility for within the household. In the self-determination theory, Ryan and Deci (2000) examined how an individual's needs fuel his or her motivation. This theory relates an individual's needs and motivation to his or her own social development and well-being (Moller & Deci, 2009). This research examined the well-being of the TD sibling with a sibling with ASD and in doing so, expands on the SDT through discussions about motivators and goal pursuits of these individuals within their military families. The family systems theory suggests that the family relationships are a system and child behavior is directly related to the balance of the system (Bowen, 1966). When a child within the family system is presented with a diagnosis of ASD, the family balance could be thrown off which directly relates

to other family systems. This research examined the workings of the family system and the roles that the TD sibling has within the military family setting when one sibling has a diagnosis of ASD. Through the lens of these theories, this research explored how the TD siblings in a military family are impacted in the areas of their personal social development and well-being when at least one sibling is a child with ASD.

### **Situation to Self**

The motivation behind this collective case study was an interest in determining how having a sibling with ASD impacts the typically developing sibling in a military family. As a special educator, my focus is always on the child with ASD. Throughout my work as a special educator, I have been a witness to families who exhibit an intense focus on their child with a disability while often leaving their TD child to their own devices, as well as families who balance the focus and attention equally between the children. In all cases, the TD sibling had responsibilities and played a vital role in the family. Over the years, I have observed that some TD siblings accept this responsibility and thrive in their family role and others are less receptive. The voice of the TD sibling is something of interest that needs to be heard in relation to their own well-being and the roles they assume in the military family.

When conducting a qualitative study, philosophical assumptions are important to explain as they influence the research. The two philosophical assumptions considered are that of ontological and epistemological within the post-positivism paradigm. Post-positivism, in practice, views inquiry as a series of logical steps with a belief that multiple perspectives and realities exist (Creswell, 2013). The ontological assumption is that reality can take on multiple views, by multiple people (Creswell, 2013). To help present these multiple views and realities, both the siblings and the parents of the children with ASD in military families participated in the

interview process. This research explored human relationships, perceptions, and opinions (Cohen & Crabtree, 2006). These multiple perspectives were utilized as sources of information. Valuable information was provided from the insight of each participant's views of his or her life in a military family with a child with ASD (Guba & Lincoln, 1994). The epistemological assumption looked at how known knowledge is conveyed and the data includes quotes as evidence of spending time with participants in the field (Creswell, 2013). The epistemological assumption that is foundational to this research is that knowledge is known "through the subjective experiences of the people" (Creswell, 2013, p. 20). Within the epistemological assumptions, participants were interviewed in their home or a place of their choosing as to ensure their comfort. The participants were interviewed and data collected includes quotes. These quotes act as evidence to their collaboration in this research. Under this assumption, evidence was assembled based on the views of the individual participants and their reality became knowledge and data (Creswell, 2013). Holding a post-positivism paradigm, I looked at the real, presented realities and imperfections as critical realism (Guba & Lincoln, 1994). The focus of this paradigm was situated in inquiry and explanation as I discovered how events and situations impacted the participants in their specific family situations (Guba & Lincoln, 1994). Within the post-positivism paradigm, each piece of evidence builds on and provides greater understanding, forming linkages between the siblings' roles and well-being (Guba & Lincoln, 1994).

### **Problem Statement**

According to the Centers for Disease Control and Prevention (2014), the prevalence of autism increased 289.5% over the last 12 years. The prevalence of Autism Spectrum Disorder (ASD) in the military is higher (1:88) than the national average (1:110) (Organization for Autism Research, 2010). Children with autism typically have a core deficit in the area of social

development. These children often appear different from other children as they are absorbed in their own world, seemingly uninterested in what is going on around them (Huang et al., 2013; Kenny et al., 2015; Rauf, Haq, Aslam & Anjum, 2014). The responsibilities of caring for a child with ASD affect both parents and siblings, impacting each of the family members in various ways. The additional challenges of military life create opportunities for greater emotional reactions (Davis & Finke, 2015). These additional challenges include frequent relocations, gaps in health care providers, and family separations which can last as long as a year at a time (Davis & Finke, 2015; Klin et al., 2015). Green (2013) looked at multiple studies of non-military populations relating to the impact of having a sibling with ASD and findings revealed that in many quantitative studies the typically developing (TD) siblings rated their emotional and behavioral experiences well adjusted, whereas qualitative data revealed more disturbing emotional challenges that impacted the well-being of these individuals. Military families having a child with ASD are underrepresented in literature and research, despite the number of military dependents with a diagnosis of ASD reaching 23,500 (Davis & Finke, 2015). There are few studies that provide in-depth understanding into this context for TD siblings of children with autism in a military household on a military post, despite the growing numbers of individuals this phenomenon impacts. In addition, there is no research that gives a voice to the TD siblings in the military family to provide insight to their perspectives of their role and well-being. The problem is that the roles assumed by TD siblings and their well-being within military families that have a child with ASD have not been studied and are not well understood.

### **Purpose Statement**

The purpose of this collective case study was to understand the TD sibling's well-being and role in a military family with a child with ASD on a military post through the parent and TD

sibling perspective. The TD sibling's well-being or state of being happy and healthy are relative to the time of the research. The role or part the TD siblings of children with ASD played in the family varied from social role models to eventually possible care givers. The theories that guided this study were Albert Bandura's (1962) social cognitive theory, Ryan and Deci's (2002) self-determination theory and Bowen's (1966) family systems theory.

Bandura's social cognitive theory examines how human behavior and development are influenced through cognitive, behavioral, and environmental factors (Bandura, 1962; Bandura, 1979). Bandura (1962) examines how imitations and patterns of behaviors influence behavior among siblings. Ryan and Deci (2000) present the idea that psychological and physical well-being directly relate to autonomy felt by the individual and how it develops within the family unit. Finally, Bowen's family system theory (1966) connects the multiple roles an individual possesses within the family systems as being responsible for an individual's development. This study examined the parental perspective of the TD sibling of a child with autism in the home setting of a military family living on a military post in conjunction with the sibling's experiences in the home setting in conjunction with the sibling's experiences and perceptions that shaped their role in the family and the well-being of the TD sibling.

### **Significance of the Study**

The practical significance of this study lies in the examination of the roles and well-being of the TD sibling of a child with ASD within the military family. As the numbers of individuals with ASD increases, so does the number of families who are impacted (Hesse, Danko, & Budd, 2013; Nealy, O'Hare, Powers, & Swick, 2012). The impact of having a sibling with ASD on the TD siblings is often overlooked, by parents and researchers alike (Arnold et al., 2012). This research will help parents to better understand the perspective of these TD siblings while helping

them to see what roles they take on in the military family. In addition, this research could assist parents and caregivers to better understand how to meet the revealed needs of the TD sibling in the military family. The needs of the TD sibling of a child with ASD has been overlooked in research (Arnold et al., 2012). The siblings of children with disabilities are often overlooked by parents, professionals, and researchers as a group that can not only assist in knowledge in regards to their sibling with ASD but these TD siblings may also need some degree of support (Arnold et al., 2012). The voice of the TD sibling is important and by utilizing these TD siblings as informants their perspectives and social worlds can be better understood (Maguire, 2005).

The empirical significance of this study is in bridging the gap in the literature with regards to typically developing children with siblings with ASD in the military. Davis and Finke (2015) confirm there to be no peer reviewed studies about military and ASD other than their own qualitative investigation focusing on the military population. Green (2013) found mixed results from research conducted with the general population which emphasizes large gaps in the literature in regards to the TD siblings of children with ASD. Quantitatively, Green (2013) discovered that research presented siblings of children with ASD as well adjusted, based on a clinical and nonclinical rating scales. Green (2013) also found there to be some disturbing emotional and cognitive challenges for siblings of individuals with ASD through qualitative data which justified a need for further investigation into well-being outcomes. The military population is underrepresented in empirical research, despite the growing size of the population of military children with ASD (Davis & Finke, 2015). Davis et al. (2016) noted that there is little information about military children in general and even less about military children with special needs. This research addressed this empirical gap in the literature.

The theoretical significance of this research lies in the relationship of the military family to the social cognitive theory (Bandura, 2001b; Bandura, Barbaranelli, Caprara, & Pastorelli, 2001) as the TD sibling's development and well-being will be examined the environmental impact of having a sibling with ASD. As the focus is on the military family and the unique stresses that these individuals face, this study furthered the understanding of Bandura's theory (2001b) through consideration of how the TD sibling adapts and changes with experiences presented from their social system. The self-determination theory was applicable to this study in that the study looked at the well-being of the individual, with specific focus on motivation (Ryan & Deci, 2000). This research looked at the motivators of the TD sibling in a military family with a sibling with ASD and their personal well-being. This research examined what motivates the TD sibling and aides in their happiness. Finally, by connecting the research to the family system theory the roles of the TD siblings of children with ASD was better understood. The family systems theory discusses how family members can take on various roles within the family system and how these roles can impact behavior between the children (Bowen, 1966). TD children with a sibling with ASD took on many roles within the family and they exhibited some behavioral adjustments and difficulties (Green, 2013). By examining their roles in the military family, both inside and outside of the home, the TD siblings provided information about how these roles have impacted their own behavior and sense of well-being. The focus of this research on the TD sibling of military families living on a military post who also have a child with ASD provided a narrow and unique application of the family systems theory.

### **Research Questions**

The purpose of this qualitative study is to understand the TD sibling's well-being and role in a military family with a child with ASD through a collective case study design. The research

questions helped to narrow the purpose while providing the opportunity to encode and foreshadow the approach taken in the inquiry (Creswell, 2013). The following three research questions were used in this collective case study investigation.

**RQ1:** How is the well-being of a typically developing child in a military family living on a military post impacted by having a sibling with autism in the home?

Research looking at typically developing children with siblings who have ASD shows mixed results (Brewton, Nowell, Lasala, & Goin-Kochel, 2012; Chan & Goh, 2014; Cridland, Jones, Magee, & Caputi, 2013; Diener et al., 2015; Gold & McCabe, 2012; Green, 2013; Hesse et al., 2013; Tsao, Davenport, & Schmiege, 2012; Walton & Ingersoll, 2015). Some research presented the idea that siblings of children with ASD may have more internalizing symptoms, higher levels of loneliness, and increased difficulties with peers (Green, 2013; Hastings & Petalas, 2013; Tsao et al., 2012). While other research indicated that the TD siblings also exhibited high self-concepts, were well adjusted, showed family resilience, and were more accepting of others (Green, 2013; Tsao et al., 2012). Additional research discussed the notion that siblings of individuals with ASD were no more likely to have adjustment issues than comparison sibling pairs to include other disabilities (Carter, Cook, Sutton-Boulton, Ward, & Clarke, 2016; Green, 2013). Specifically, the behavior problems of children with ASD have been found to predict the psychological well-being of the TD sibling (Hastings, Petalas, Jones & Totsika, 2014). This research addressed the typically developing siblings' well-being who share their home with a child with ASD on a military post.

**RQ2:** How does having a sibling with ASD impact the roles of the typically developing siblings in a military family who lives on a military post?

Tsao et al. (2012) stated that the role of the siblings of children with ASD has been underexplored from the sibling perspective; most research has focused on the parental perspective of the TD sibling or the sibling relationship. Family roles and responsibilities are influenced by the needs of the child with ASD (Cridland et al., 2015). There are inconclusive results on how these roles and responsibilities impact the well-being of the typically developing sibling (Cridland et al., 2015). The TD sibling is situated to greatly enhance family life while not only providing influence in early development, but also assisting in the fostering of social skills for the child with ASD (Tsao et al., 2012). Question two addressed how having a sibling with ASD impacts the roles of TD siblings whose families live on a military post.

**RQ3:** How do parent perspectives on the experiences of TD siblings compare and contrast to the TD siblings' actual experiences and perceptions when one sibling has ASD on a military post?

Lam, Solmeyer, and McHale (2012) described parents as not only the instructors but also as a source of guidance; they were also noted as the primary source for socialization. Overall parental attitude was found to impact sibling adjustment (Saxena & Adamson, 2013). Tsao et al. (2012) discussed the idea that parental expectations of the sibling responsibilities were a key aspect in all parent-child relationship. In addition, the attitude of the parents in regards to support for each of their children was vital in promoting positive sibling relationships (Tsao et al., 2012). Existing literature suggested that the TD siblings of children with ASD will undertake various family roles and responsibilities within the household and at school (Cridland et al., 2015). With this question, the parental perspective was explored in relation to the TD siblings' well-being and their roles within the family when one sibling has ASD on a military post. Diener, Anderson, Wright, and Dunn (2015) found that the sibling and parent perspective differed. This research

question explored the idea how the parent and sibling perspective on roles within the family and well-being could differ.

### **Definitions**

1. *Adjustment* – Adjustment refers to the internalizing and externalizing of behavioral problems of the sibling of the child with ASD (Hesse et al., 2013).
2. *Autism Spectrum Disorder (ASD)* – Autism Spectrum Disorder (ASD) is defined by specific areas that include social/communication deficits and behavior identifiers (restricted, repetitive behaviors, and interests) (APA, 2013).
3. *Echolalia speech* – Echolalia is speech that consists of the repetition of phrases, words, or parts of words (Bernier & Gerds, 2010).
4. *Family System* – The family system is a system composed of interdependent and interrelated subsystems, such as sibling, parent-child and spousal subsystems that are all impacted by emotions and behaviors (Rasmussen & Troilo, 2016).
5. *Resilience* – Resilience is the process of encompassing positive adaptation or prevailing when faced with difficult or negative situations (Bekhet & Johnson, 2012).
6. *Role* – The role in the family indicates specific responsibilities one has within the family (Cridland et al., 2015).
7. *Well-being* – A person's well-being is an account of their overall development, adjustment, and mental health (Gold & McCabe, 2012); an absence of psychological distress (Jones, Hastings, Totsika, Keane, & Rhule, 2014).

### **Summary**

As the numbers increase in the prevalence of ASD across the United States, so do the numbers of TD siblings who are also impacted by the diagnosis. The military has not been

immune to the increase in numbers of children with ASD and, in fact, has experienced a higher prevalence than the national average. Military families face unique challenges and these challenges can multiply when combined with the presence of a child with ASD in their households. The purpose of this collective case study was to understand the typically developing sibling's well-being and role in a military family with a child with autism on a military post through the parent and sibling perspective. This chapter provided the background, problem, purpose, and significance of the study. The research plan and questions the research intended to answer were also discussed.

## CHAPTER TWO: LITERATURE REVIEW

### Overview

The prevalence of Autism Spectrum Disorder (ASD) has increased from 4 to 5 per 10,000 in 2000 to 14.7 per 1,000 children in 2012 (CDC, 2014; Wolff, 2004). The number of children identified with ASD has increased from one in 150 in 2000, to one in 68 children in 2012, and again to one in 50 in 2013 (CDC, 2014; Gill, 2013). The 2010 general census recorded that within the general population one in 42 boys and one in 189 girls have a diagnosis of ASD (CDC, 2014). The prevalence rate in the military is higher; as of 2005, it was recorded as 1 in 88 children among active duty military service members (Organization for Autism Research, 2010). ASD is described as a neurodevelopmental disorder which impairs individuals in the areas of social interaction and is typified by repetitive stereotyped behaviors and interests (APA, 2013; Casey et al., 2012; Martins, Bonito, Andrade, Albuquerque, & Chaves, 2015; Rauf et al., 2014). This disability impacts individuals across multiple domains of development and is currently the second most common developmental disability in the United States (APA, 2013; Woodman, Smith, Greenberg, & Mailick, 2015). Children with ASD may appear different from their TD counterparts in both their behavior and communication skills (Huang et al., 2013). Children with ASD typically exhibit unusual object use, have difficulty relating to people, and display limited verbal as well as non-verbal communication skills (Huang et al., 2013). Regardless of the severity of symptoms, children with autism typically have a core deficit in the area of social development as they often are described as being absorbed in their own world or appearing to be locked inside themselves, seemingly uninterested in what is going on in the world around them (Kenny et al., 2015; Rauf et al., 2014). While not exhibiting these characteristics or symptoms, family members of those with ASD are impacted in various ways.

When the demands of military life are added to the challenges faced by military families with an ASD child, the opportunity for greater emotional reactions increases while the community of care is reduced (Davis & Finke, 2015). A military life means constant transitions, and transition periods involve different issues for the child with ASD as well as for the family (Cridland et al., 2015). A military family relocates approximately three times more than a civilian family and a military child switches schools on average six to nine times between kindergarten and graduation (Davis et al., 2016). Additional challenges of a military family include war, periodic family separations, varying access to specialized health care, and an unknown level of stress that comes with the deployment of a family member (Davis & Finke, 2015; Klin et al., 2015). The periodic family separations and deployments often leave one parent available to advocate and care for the children and the household, sometimes for a year at a time, putting stress on the family system (Klin et al., 2015). With one parent away and one parent managing the household, the typically developing (TD) sibling can be expected to take some care giving responsibilities for his or her sibling with ASD. In this chapter, the theoretical framework of this study and the history of autism will be addressed followed by a review of current literature related to autism and the impact on the family when one child has a diagnosis of ASD.

### **Theoretical Framework**

Multiple psychological theories are utilized to frame this study, including the social cognitive theory (previously known as the social learning theory) (Bandura, 2001a), the self-determination theory (SDT) (Ryan & Deci, 2000), and the family system theory (Bowen, 1966). Through the lenses of these three theories, motivations, and influences can be explored in relation to the social development and well-being of siblings' relationships when one sibling is a

child with ASD. Bandura (1962) studied how individuals learned behaviors and new information through modeling. Ryan and Deci (2000) focused on the necessary components for optimal psychological development and the process which leads to motivation and well-being. Bowen (1966) argued through the family system theory that the family can be any number of systems, from social systems to a combination of emotional and relationship systems. The works of these researchers, through review of the social learning theory, the self-determination theory, and the family systems theory, established the theoretical framework for the current study.

### **Social Cognitive Theory**

Bandura proposed the social cognitive theory which he used to explain how individual's views, behaviors, environmental influences, and other personal influences as interlocking determinants influencing behavior (Bandura, 1979; Bandura, 2001b). The social cognitive theory developed directly from the social learning theory (Bandura, 1962). Both the social cognitive theory and the social learning theory look at how people learn through observing others, with the main factors of both including self-efficacy, goals, and outcome expectancies (Bandura, 1969; Bandura 2001a). However, the social cognitive theory proposes that typical siblings' experiences and exposures directly and indirectly shape their behavior (O'Connor, Matias, Futh, Tantam, & Scott, 2013). Whereas, Bandura's social learning theory (1962) explained that by imitation of behaviors and patterns of behavior a child acquires a behavior repertoire. Once acquired, these same behavioral patterns are effectively strengthened and maintained by observations and actions of modeling influences (Bandura, 1962; Bandura, 1969). These modeling influences are not limited to the parents of the family; other influential individuals that shape an individual's moral judgements and behavior include other adults and peers (Bandura, 1969).

The social cognitive theory is not only relevant to the typically developing siblings, but also the children with ASD. According to research from Lam et al. (2012), older siblings often act as socialization agents for the development of their younger siblings. Bandura (1969) found that children proved equally responsive to the influence of modeling, regardless of their developmental level. However, it is noted that the efficacy of the modeling outcomes can be affected by developmental status and interactions with other variables (Bandura, 1969). The individual characteristics of the observer may also have an impact on the efficacy of the modeling influence (Bandura, 1969). Bandura (1979) stated that human behavior is driven by goals and consequences. These behaviors can be activated and directed by “numerous environmental inducements and constraints” (Bandura, 1979, p. 440), hence the family impact. According to the social cognitive theory, socioeconomic factors, educational background, and family structure impact the individual’s behavior, aspirations, sense of efficacy, personal standards, and other self-regulatory influences greatly (Bandura, 1999; Bandura, 2001a; Bandura, 2001b; Bandura et al., 2001). Perceived self-efficacy not only occupies a central role in the social cognitive theory, but also is positioned as a pivotal factor in a human’s development (Bandura et al., 2001).

Bandura (2001a) also discussed how the concept of collective agency and a group’s shared beliefs produce the desired results in individuals. Social cognitive theory extended the idea that the collective performance of a social system, in this case a family with at least one child with ASD, involved dynamics, a level of perceived collective efficacy, and the group acting on shared beliefs (Bandura, 2001a). Bandura (2001b) explained how environmental events, such as family life, in conjunction with inner forces, help to shape people into self-organizing, self-reflecting, and self-regulating organisms (Bandura et al., 2001). The self-

development, adaptation, and changes humans undergo are embedded in the social systems they experience (Bandura, 2001b). Although this collective group efficacy is discussed, Bandura (2001a) further explained that the self-system and social structure operate interdependently and are created by human interactions, activity, and socio-structural practices. These socio-structural practices and human interactions are responsible for providing individuals, specifically the children of the family system, with resources and opportunities for personal development and function (Bandura, 2001a). This research will build on the social cognitive theory by looking at the TD siblings' views, behaviors, environmental influences, and other personal influences of living with a sibling with ASD in a military family.

### **Self-Determination Theory**

Just as Bandura examined how social modeling impacted individuals, Ryan and Deci (2000) developed the self-determination theory (SDT) which explained how specific needs must be met for optimal social development and personal well-being. The SDT began as the cognitive evaluation theory (CET) in 1980 (Deci, 2012). Ryan and Deci's CET theory specifically discusses the social and environmental factors that develop intrinsic motivation (Riley, 2016). In time, SDT started to take shape and the CET became a mini theory within the SDT (Deci, 2012). SDT maintained a full understanding not only goal-directed behaviors, but also the psychological development and well-being of individuals that directs their goal pursuits (Deci & Ryan, 2000). Deci and Ryan (2000) explained that in SDT there are three psychological needs: competency, autonomy, and relatedness. These three needs are essential for understanding and fueling an individual's goal pursuits while fostering self-motivation which directly relates to the individual's well-being as stated in the CET (Riley, 2016). Ryan and Deci (2000) presented the concept that influences from individuals' interactions with the social environment can either

fulfill their needs, which leads to growth and psychological well-being, or can thwart their needs, which leads to psychological ill-being. These needs are considered innate and universal in SDT. To maximize autonomy and intrinsic motivation, the SDT states that individuals need to maintain or enhance intrinsic motivation (Deci & Ryan, 2000). Individuals who facilitate the internalization and integration of extrinsic motivation and promote aspirations of life goals also provide a degree of satisfaction toward this basic need (Deci & Ryan, 2000). SDT also clarifies that in order to maintain better mental health the individual must pursue and attain intrinsic life goals, as well as, extrinsic aspirations at a degree of satisfaction to influence development, performance, and well-being (Deci & Ryan, 2000).

In other studies, Moller and Deci (2009) posited that psychological and physical well-being is directly related to how autonomy. Deci (2012) explained that two types of motivation exist within all people, autonomous motivation and controlled motivation. When an individual is autonomously motivated, they are doing an activity with full willingness and of their own choice (Deci, 2012). In contrast, in controlled motivation environments the individual is completing the activity because of pressure and a sense of obligation (Deci, 2009). Individuals from both autonomous and controlled environments present motivated behaviors, with very different results (Deci, 2009). Deci and Ryan (2000) discussed how autonomous environments can positively relate to the individual's satisfaction and honest, naturally occurring relationships between parents or friends. Whereas a controlled environment is positively related to defensive functioning (Deci & Ryan, 2000). Parents are identified as the primary source of socialization where they act as instructors, foster certain behaviors, and provide guidance in social exchanges (Lam et al., 2012, Ryan & Deci, 2000). In a family setting, maternal environments characterized by greater warmth and support promote less materialistic goals, and family members are not only

all in better health, but also have a greater level of community participation (Ryan, Huta, & Deci, 2008). This warm, supportive environment fosters autonomous motivation, which allows individuals to perform better, utilize flexible thinking, and demonstrate a higher level of psychological health and well-being (Deci, 2012). In contrast, those who are raised in a more controlling environment are prone to low self-esteem, anxiety, depression, insecurity, and even narcissism (Deci, 2012; Ryan et al., 2008). A controlling environment neglects and frustrates the individuals' needs for autonomy and ultimately impacts the self-determined motivation of individuals in that environment (Khalkhali, Sharifi, & Nikyar, 2013). This research will examine the well-being of the TD sibling with a sibling with ASD and in doing so, will add to the SDT through discussions about motivators and goal pursuits of these individuals within military families.

### **Family Systems Theory**

While Bandura (2001a) discussed how socio-structural factors produce behavioral effects and Ryan and Deci (2002) presented the idea that social interactions influence development, Bowen (1966) discussed the various systems that the family unit can influence. Bowen (1966) developed the idea that the family is made up of a variety of subsystems and a change in one part of the system is followed by a change in another part of the system. Within the family systems theory, Bowen (1966) looked symbiotically at the relationship between a mother and child, the relationship between the father and child, and also the sibling relationships. This triad of systems is the focus of the theory (Feinburg et al., 2013; Rothbaum, Rosen, Ujiie, & Uchida, 2002). Functions of these systems range in "levels of efficiency from optimal functioning to total dysfunction and failure" (Bowen, 1966, p. 351). When one subsystem of the family is in dysfunction, Bowen (1966) presented the idea that another family subsystem is in equal over

function to counterbalance or compensate for the other. When a child in the family is presented with a diagnosis of ASD, it can throw the family system off and individual members of the family compensate in various ways. The family system theory is concerned with communication patterns, family dynamics, roles of family members, and power relations within the family unit (Rothbaum et al., 2002). The family systems theory conceptualized that the behavior of the children in the family is not only embedded into the network of the family relationships, but also serves as an important focus within the family system (O’Gorman, 2012). O’Gorman (2012) explained that behavioral concerns are directly tied to that of the family system, be it the behavioral symptoms of ASD or that of antisocial behavior. When one child in the family system has ASD with behavioral issues, impact on the other family parts is likely (Bowen, 1966; O’Gorman, 2012). This research will examine the working of the family system, presenting roles that the TD sibling has within the military family setting when one sibling has a diagnosis of ASD.

Through the lenses of the social cognitive theory (Bandura, 2001a), the self-determination theory (SDT) (Ryan & Deci, 2000), and the family system theory (Bowen, 1966) this research will explore how the TD siblings in a military family are impacted in the areas of their personal social development and well-being when at least one sibling is a child with ASD. Bandura (1962) studied how the environment shaped the individuals. Ryan and Deci (2000) focused on the necessary components for optimal psychological developmental and the process which leads to motivation and well-being. Bowen (1966) looked at the family system as a set of subsystems all related and impacting the others in the family. The principles of the social cognitive theory (Bandura, 2001a), the self-determination theory (SDT) (Deci & Ryan, 2000), and the family system theory (Bowen, 1966) established the theoretical framework for the

current study. This research could potentially add to these theories from the examination of the TD siblings in a military family with a sibling who has a diagnosis of ASD. This study will utilize a narrow and unique application of these theories to focus on the specific environmental situation of a sibling relationship when one has a diagnosis of ASD in the military family.

## **Related Literature**

### **History of Autism**

In the 1940s, Kanner (1943) described autism as an extreme aloneness from the beginning of life. Although it was noted that few of the parents were warm hearted and that some of the marriages were failing, Kanner (1943) presented the idea that these children had an innate inability to form usual contact with people. Kanner's (1943) observations separated infantile autism from childhood type schizophrenia. This idea was not abandoned until 1979 (Wolff, 2004). In 1944, Hans Asperger, a German pediatrician, identified a milder form of autism in children who exhibited higher intelligence and still demonstrated inhibited social interactions and obsessive interests (Cook & Willmerdinger, 2015). Bruno Bettelheim, a childhood psychologist, championed the first predominate theory for the cause of ASD in the 1950s which stated that autism resulted from the mother's coldness (Bernier & Gerdts, 2010). As a result of this hypothesis, Bettelheim developed the *refrigerator mother theory* which described these mothers as psychologically cold and aloof and ultimately responsible for turning the child inward and "retreating into autism" (Bernier & Gerdts, 2010, p. 46). In the 1960s a new approach to autism research focused on the biological and behavioral mechanisms of autism (Cook & Willmerdinger, 2015). This research began with Dr. Stella Chess, who researched autism as a neurological disease (Cooke & Willmerdinger, 2015). At this time, these children were categorized as schizophrenic children who resisted change in their environment and strived to

restore or maintain sameness (Wolff & Chess, 1964). In 1964, the Autism Society of America was founded by Bernard Rimland who actively refuted the *refrigerator mother* theory (Cook & Willmerdinger, 2015). In 1981, Asperger's syndrome was identified through the work of Lorna Wing (Wolff, 2004). In the late 1980s, the idea that ASD was an unchangeable condition started to vanish and it came to be considered treatable as intensive behavioral interventions showed to be effective in some children with ASD (Thompson, 2013). Jumping to the late 1990s and early 2000s, parent groups such as National Alliance for Autism Research, Cure Autism Now, and Autism Speaks joined to help provide funding for autism research alongside the Autism Society of America (Bernier & Gerds, 2010).

### **Diagnostic Criteria**

The diagnostic criterion for autism has changed dramatically over the years. In 1952, autism was first categorized as a childhood subtype of schizophrenia in the Diagnostic Statistical Manual (DSM) (Cook & Willmerdinger, 2015). In 1974, the DSM-II was revised and Pervasive Developmental Disorders: Asperger's Disorder and Pervasive Developmental Disorder- Not Otherwise Specified (PDD-NOS) were added under the criteria of ASD (Bernier & Gerds, 2010). By adding these two subtypes, the criteria loosened and allowed for more people to meet the criteria to be diagnosed with ASD (Bernier & Gerds, 2010). In 1987 and 1994 more changes in criteria took place with the DSM-III and the DSM-IV (Bernier & Gerds, 2010). ASD has never easy to place in a single category, as those with the condition have varying degrees of language and social impairments, usually accompanied by impacted social and intellectual skills (Wing, 1981). In 1987, the DSM-III definition and diagnostic criteria of infantile autism expanded to become autism spectrum disorder (Cook & Willmerdinger, 2015). In 1994, Pervasive Developmental Disorder-Not Otherwise Specified and Asperger's syndrome were

added to the subtypes of autism through expansion of the criteria in DSM-IV (Cook & Willmerdinger, 2015). In 2013, the DSM-V was published and the subtypes were removed from the criteria for determination of ASD (APA, 2013). ASD under DSM-V is categorized as one umbrella that is defined by two categories, impaired social communication and/or interaction and restricted and/or repetitive behaviors (APA, 2013; Cook & Willmerdinger, 2015). The reasoning behind the creation of the new category of ASD in DSM-V was to recognize the shared features within the autism spectrum (Verhoeff, 2013). In the DSM-V a new category of Social Communication Disorder (SCD) was added to describe the few children who display the social and communication impairments of ASD without the restrictive and repetitive behaviors (Verhoeff, 2013).

ASD is categorized by social impairments, cognitive impairments, communication difficulties and repetitive behaviors by the National Autism Association (APA, 2013; NAA, 2016). One single symptom cannot distinguish a person as ASD, but rather a pattern of combined symptoms is required (APA, 2013). ASD is described as a family of overlapping conditions, with no single homogeneous autism disorder (Thompson, 2013). ASD represents a spectrum of complex neurological and developmental disorders and the symptoms vary in degrees of severity and are different for every person (Karst & Vaughn Van Hecke, 2012). Children with ASD are often described as having rigid, aloof personalities and are known to struggle with pragmatic language (Shivers, Deisenroth, & Taylor, 2013). Individuals with ASD are also reported to have cognitive impairments, such as seizures and mental retardation. These cognitive impairments occur in approximately 30 to 80% of children in the ASD population (Arya & Sindhvani, 2016). Other symptoms may be more severe when combined with cognitive impairments (May, Cornish, & Rinehart, 2014). In conjunction with intellectual disorders, sleep disorders, conduct

disorders, attention deficit/hyperactivity disorder (ADHD), gastrointestinal disorders, anxiety disorders and language disorders often co-occur with the ASD diagnosis (Green, 2013). This combination of deficits inhibits the individual with ASD from developing meaningful relationships outside of the family unit (Gold & McCabe, 2012). Symptom severity and expression can change throughout development, due to social demands of the environment, pubertal biological changes, and impact of psychological factors (May et al., 2014).

Social impairments include deficits in expression and gestures, as well as in social and emotional reciprocity (Arya & Sindhvani, 2016; Bernier & Gerdts, 2010; Gold & McCabe, 2012; Green, 2013). Individuals with ASD exhibit difficulties with nonverbal social behaviors and peer relationships, in addition to spontaneous seeking to share enjoyment (Bernier & Gerdts, 2010). In regards to nonverbal social behaviors, individuals with ASD have difficulty with eye contact, gestures, facial expressions, and body proximity (Bernier & Gerdts, 2010). Children with ASD can be described as detached with odd social behaviors and are known to struggle with everyday human interactions (Rauf et al., 2014). There are differences in some symptoms between male and females, as boys with ASD reported higher levels of hyperactivity and females had more symptoms of social phobia (May et al., 2014).

Communication impairments range from unusual or repetitive spoken language to lack of ability to participate in symbolic or imaginative play (Arya & Sindhvani, 2016). Imaginative pretend play may not occur or may be confined to one or two themes that the individual reenacts repeatedly without variation (Wing, 1981). Individuals with ASD are described as having difficulty maintaining conversations as well as demonstrating unusual speech patterns (Bernier & Gerdts, 2010). Many children with ASD struggle to develop a single spoken word by 24 months of age, whereas TD children develop begin developing spoken words at around 12 months

(Bernier & Gerdts, 2010). It is not uncommon for some children with ASD to not develop spoken language within their lifetime (Bernier & Gerdts, 2010). For the individuals who do develop fluent speech, their inability to maintain age and topic appropriate conversations is another noted struggle (Bernier & Gerdts, 2010). In addition, individuals may repeat phrases they have heard from adults, movies, commercials, and/or television shows and use this as a communicative manner (Bernier & Gerdts, 2010). This repetition in speech is known as echolalia (Bernier & Gerdts, 2010).

Repetitive behaviors and restrictive interests are identified symptoms of ASD. Repetitive motor mannerisms, intense interests, and compulsive behaviors are common characteristics of individuals with ASD; however, they are not sufficient to diagnose an individual with ASD (Bernier & Gerdts, 2010). The clinical diagnosis of ASD requires a triad of deficits in social interaction, communication, and repetitive or restricted interests and behaviors (Arya & Sidhwani, 2016). These behaviors, often described as self-stimulatory behaviors, include hand flapping, finger flicking, and rocking back and forth and can increase because of stress or excitement (Bernier & Gerdts, 2010; Green, 2013). Other behaviors are identified as aggression or are self-injurious in nature (Green, 2013; Hesse et al., 2013; Hodgetts et al., 2013; Tint & Weiss, 2015). Restricted interest, such as a particular video game, television show, or intense interest in a specific topic, is common among children with ASD (Bernier & Gerdts, 2010). Individuals with ASD also are known to insist on sameness in routine and may become upset when their routine is altered in any way (Bernier & Gerdts, 2010; Hesse et al., 2013).

### **Prevalence of ASD in Schools**

The Individuals with Disabilities Education Act (IDEA) was originally enacted in 1975 to ensure that children with disabilities have an equal opportunity to receive a free appropriate

public education (FAPE). Over the years this law has been revised many times. It was not until 1990 that IDEA included autism as one of its classifications for eligibility (Zirkel, 2011). Prior to this amendment, children with ASD qualified for services under another classification, such as mental retardation (Zirkel, 2011). The number of children with ASD served under IDEA increased from 20,000 in 1992-1993 to 120,000 in 2001-2002 (Zirkel, 2011). According to the National Center for Education Statistics (2016), these numbers have continued to rise to a staggering 498,000 in 2012-2013. The general census of 2010 reported that in the 11 designated sites, nearly half or more children eligible for special education had a primary diagnosis in the category of ASD (CDC, 2014).

According to the Centers for Disease Control and Prevention (2014), the prevalence of autism has increased 289.5% from 1998 to 2010, increasing to one in 68 children. This number increased to one in 50, per parent phone survey done by CDC and released in March of 2013 (Gill, 2013). According to the CDC (2014), the national average in 2006 showed a prevalence of 1 in 110 children with a diagnosis of ASD. In three decades, autism went from an almost unheard-of disorder to a widespread diagnosis across the globe (Gold & McCabe, 2012). With the prevalence on the rise, it is essential to understand the unique stresses and difficulties that having a child with autism may cause the family (Hesse et al., 2013; Nealy et al., 2012). These numbers imply that there are approximately 730,000 Americans younger than the age of 21 who are diagnosed with ASD and an estimated 36,500 more are expected to be diagnosed each year (CDC, 2014). Of these 730,000 individuals, approximately 85% present with cognitive, mobility, adaptive, and/or communication limitations which impact their ability to live independently in adult life (Gotham et al., 2015; Karst & Vaughan Van Hecke, 2012). ASD impacts across

multiple domains of development and is currently the second most common serious developmental disability in the United States (APA, 2013; Woodman et al., 2015).

### **Impact on the Family**

As much of the care is provided by the family, the families living with ASD have increased stress levels (Cridland et al., 2013). Individuals with ASD may display aggression which can have significant impact on family outcomes as well as on the daily lives of the families involved (Hodgetts et al., 2013). Up to 68% of individuals with ASD can have an increased rate of aggression at some point in their lives and the predictors for this aggression are not well understood which adds to family stress and isolation (Hodgetts et al., 2013). In addition to the struggles in with interaction, socialization, and communication, approximately one-third of individuals with ASD require assistance in the areas of self-care, mobility, and various other daily tasks (Cridland et al., 2015). The responsibility for this assistance and support falls mainly to that of family members, be it parents, siblings, or grandparents.

Composed of parent and child, sibling and marital subsystems, the family is the original social system (Griffith, Hastings, Petalas, & Lloyd, 2015; Martins et al., 2015). As presented in Bowen's (1966) family systems theory, each family has a unique pattern of systems and each system has its own unique functioning, which contains various degrees of emotional stress, communication styles, and individualized expectations of the family members (Cridland et al., 2015). Each family member is expected to behave in accordance with the expectations of the other family members (Everson & Figley, 2011). All family dynamics are complicated and family characteristics (i.e., family size, parental stress, and socioeconomic level) all play important roles in the development of the children. These family characteristics also directly relate to the well-being of the family members (Tint & Weiss, 2015). Faso, Neal-Beevers, and

Carlson (2013) state that parent coping behaviors can influence psychological adjustments. The family dynamics also change when one of the children receives a diagnosis of ASD. When a child with a disability is born into the family, new expectations emerge as do new realities for family members (Martins et al., 2015). Each member of the family is influenced by and has influence on the other family members, therefore the diagnosis given to the individual child has an impact on the whole family (Griffith et al., 2015; Nealy et al., 2012). Children develop unique ways to meet their individual needs and these unique ways evolve from the family structure and emotional processes within the family system (Everson & Figley, 2011). When one of the individual family members has a diagnosis of ASD in conjunction with military life (i.e., separations, relocations, and transitions) the stress level increases for the child with ASD as well as for the family (Cridland et al., 2015; Davis & Finke, 2015).

Just as in the military where the families are often separated, Saxena and Adamsons (2013) noted that families with children with developmental disorders are more likely to be single-parent homes and typically parents have to reduce work hours to care for the child with a disability. Parental relationships of children with ASD are associated with decreased relationship satisfaction and an increased divorce rate (Cachia, Anderson, & Moore, 2016). Therefore, the family could have a lower household income and higher costs associated with caring for the diverse needs of the child with a disability. In these situations, the child with ASD can become the central focus of the family as the remaining family members cope with the stress of the separation. Some families withdraw from social activity and in return have less support outside the immediate family and experience isolation (Nealy et al., 2012; Pollard, Barry, Freedman, & Kotchick, 2013; Tint & Weiss, 2015). When one parent is left to care for the children, the lack of support and decreased social activity, in conjunction with trying to balance the needs of multiple

children often leads to parental feelings of worry, guilt, and inadequate parenting (Nealy et al., 2012). These feelings in addition to the stress of being a single parent will impact the children within the household.

There is ample family research in the field of ASD, but more so in regards to the impact on the mother than on the father in the family. Researchers have found that it is the mother who is typically more involved in the care of the child with ASD leaving the mother with a greater potential to be affected by the child's behavior and typically reported higher levels of stress (Bader, Barry, & Hann, 2014; Banda, 2015; Cachia et al., 2016; Conti, 2015; Hesse et al., 2013; Jones, Totsika, Hastings, & Petalas, 2013; McStay, Dissanayake, Scheeren, Koot, & Begeer, 2013; Ozturk, Riccadonna, & Venuti, 2014; Zhou & Yi, 2014). Typically, it is the mothers who spend more time caregiving and playing a managerial role, whereas the fathers spend more time in play activity with the children (Ozturk et al., 2014). Over half of mothers of children with autism experience symptoms of depression (Conti, 2015). These rates are not only higher than parents of typically developing children, but are also a higher rate when compared to parents of children with other disabilities (Jones et al., 2014; McStay et al., 2013). Consequently, the behavior problems of the child with ASD have become a predictor for parental psychological distress (Bekhet & Johnson, 2012; Jones et al., 2013; Jones et al., 2014; McStay et al., 2013; Zhou & Yi, 2014). It has also been found that parental stress has a direct impact on the severity of the symptoms in the child with ASD (Bekhet & Johnson, 2012; Jones et al., 2013; Jones et al., 2014; Zhou & Yi, 2014). Parental mental health influences the level of conflict between sibling relationships, showing higher levels of conflict when parental mental health problems were present (Martins et al., 2015; Petalas et al., 2012). While parents of children with ASD have an increased risk of elevated levels of parent mental health concerns, most commonly depression

and anxiety (Cachia et al., 2016; Faso et al., 2013; Griffith et al., 2015; Hodgetts et al., 2013; Jones et al., 2013; Karst & Vaughan Van Hecke, 2012; Ozturk et al., 2014; Pollard et al., 2013; Zhou & Yi, 2014), this increased stress can have adverse effects on the children of the family (Casey et al., 2012; Martins et al., 2015)

### **Military Families**

Military families face unique challenges, such as long periods of separation. Extensive separations are a source of disruption in the family system with the absence of the family member/s altering the family's emotional structure (Everson & Figley, 2011; La Flair et al., 2015). These separations can be a result of deployment, which potentially puts the parent in life threatening situations, and/or military trainings (Davis & Finke, 2015). A parent may deploy for as long as a year at a time. Deployments can place extreme demands on all family members and there can be increased stress associated with role shifts as the family adjusts to the member's absence (Davis & Finke, 2015; Everson & Figley, 2011). The family may feel stress as a result of the change in their social support system (Davis & Finke, 2015). When a military family includes a child with ASD, the demands on the remaining parent include meeting the complex needs of the child in addition to managing the household without the assistance of the deployed spouse. Research shows that the impact of military separation varies on the children, resulting in both positive and negative outcomes (Davis & Finke, 2015; Brendel et al., 2013). A meta-analysis found that during these separations military children displayed small amounts of maladjustment (Davis & Finke, 2015). However, other research indicates that separations can have significant impact on military children. Negative outcomes include children with deployed parents being at a higher risk for psychosocial problems and being more likely to be diagnosed with a mental health problem (Brendel et al., 2013). In addition, children can experience

increased behavioral disorders, stress disorders, school related problems, and internalization of the symptoms of sadness, hopelessness, depressive symptoms, and suicidal thoughts (Brendel et al., 2013; McGuinness & McGuinness, 2014; Mustillo et al., 2016). One positive effects of parental deployments can foster resilience with an increase in responsibilities that can foster growth and maturity (Brendel et al., 2013; Richardson et al., 2016).

Military families experience more frequent relocations. While at least 60% of military families have relocated once in the last three years, a staggering 47% have relocated three or more times in the past five years (Davis et al., 2016). Whereas a non-military family can opt to move to a location with better services or remain where they are, military families do not have the luxury of choice or frequency in their relocations (Davis & Finke, 2015; Davis et al., 2016). These frequent relocations not only undermine the family's ability to secure stable school environments, but also have been related to lower marital happiness, lower retention in the military, and lower physical and psychological health (Davis & Finke, 2015; Klin et al., 2015). In TD military children, frequent relocations have been shown to affect the socioemotional well-being and cause disruptions in their educational programming (Davis et al., 2016). Since children with ASD require more interventions and specialized school services, these disruptions may be especially harmful (Davis et al., 2016). Children with ASD typically have difficulty with transitions and any changes to their routines (Davis & Finke, 2015; Klin et al., 2015). This difficulty with transitions can mean an increase in behavior problems as they adjust to their new environment (Davis & Finke, 2015; Klin et al., 2015). In addition, families may be less able to find necessary intervention services for their child with ASD (Davis & Finke, 2015; Davis et al., 2016). Limited service providers, challenges in attaining diagnostic and evidence-based treatment services, gaps in services, and a general lack of continuity in interventions can

be frustrating for the family (Davis & Finke, 2015; Davis et al., 2016; Klin et al., 2015).

Relocation requires families to find new health care providers and also time to develop new relationships with the community (Davis & Finke, 2015). The relocation may take the family away from extended family and friends. Military families typically live within close proximity to other military families, as frequent relocations place many families in post housing. The network of being near multiple other family systems within a larger social context can influence the individual family system in both positive and negative ways (Everson & Figley, 2011). This sense of community can help to teach and encourage healthy relationship skills as children and youth who are less isolated have more opportunities for relationship provisions (La Flair et al., 2015; Richardson et al., 2016). The quality, quantity, and diversity of resources in the community can impact satisfaction of the residents (La Flair et al., 2015). Social cohesion of the neighborhood and social control can have an adverse outcome on mental health and impair social functioning within a community (La Flair et al., 2015).

### **Parenting Styles**

Baumrind (1971) identified three types of parenting styles that include authoritative, authoritarian, and permissive which are still used to describe parents today. Just as parenting styles impact the children, family life with a child with autism can impact parenting styles (Conti, 2015). Further, parenting styles can also have an impact on the relationship between parental satisfaction and sibling adjustment (Feinberg et al., 2013; Hesse et al., 2013). Parents who are stressed and distressed are more likely to utilize negative parenting practices than positive parenting practices (Bader et al., 2014). Consequently, parents who utilize a harsh and rigid parenting style, known as authoritarianism, typically have increased levels of stress as well as increased child behavior problems (Hutchinson, Feder, Abar, & Winsler, 2016). Conti (2015)

explained that cultural background, religiosity, and socioeconomic circumstances also have an influence on parenting styles. Parental religiosity and effective parent-child communication, investment, and satisfaction are all directly linked (Weyand, O’Laughlin, & Bennett, 2013). Families of high socioeconomic status exhibit significantly negative associations, internalizing and externalizing behaviors, but positive associations with measures of intelligence and academic achievement (Xu et al., 2016). Parenting styles impact the self-esteem, anxiety, academic achievement and narcissism of typically developing children as well as the children with ASD (Uji, Sakamoto, Adachi, & Kitamura, 2014). Family functions (responsiveness, roles, problems solving, and behavior control) impact the prosocial behavior and behavior problems of the typically developing sibling (Mohammadi & Zarafshan, 2014).

Authoritative parenting is noted for being high on warmth and firm control (Mohammadi & Zarafshan, 2014). This parenting style is associated with the parents attempting to rationally direct the child’s activities through use of verbal reasoning (Baumrind, 1971). The authoritative parent will set clear, reasonable guidelines while exercising reliable control (Berzonsky, 2004). These parents in the study expressed affection, approval, and acceptance towards their child while setting reasonable rules that are adapted to the needs and wishes of their child (van Steijn et al., 2013). Behavior regulation is an aspect of authoritative parenting that involves setting limits, utilizing reasoning, applying consequences and establishing structure for the child’s behavior (Dyches, Smith, Korth, Roper, & Mandleco, 2012). These authoritative or positive parenting components are found to lower levels of maladaptive social skills and when this parenting style is missing, children have increased levels of childhood depression, anxiety, and antisocial behavior (Dyches et al., 2012). Mohammadi and Zarafshan (2014) also indicated that children with authoritarian and authoritative parenting are more likely to present an increase

in prosocial behavior and a decrease in behavior problems. Children of authoritative parents tend to be more individuated, self-reliant, mature, and motivated (Baumrind, 1971; Berzonsky, 2004).

Mohammadi and Zarafshan (2014) describe authoritarian parents as low in warmth, yet high in restrictiveness and firm control. Characteristics include large amounts of control, and little responsiveness of the parents towards the child's behavior (van Steijn et al., 2013). The authoritarian parent is one who attempts to shape and control the child to meet their own standards of conduct, placing obedience as a virtue and willing to use forceful measures to alter the child's self-will to fit this mold (Baumrind, 1971). The authoritarian parent has definite limits and rules that are not open for discussion (Berzonsky, 2004). Parents dominate the child and the child's behavior, displaying hostile or negative attitudes toward the child (van Steijn et al., 2013). Feinberg et al. (2013) stated that authoritarian parenting is associated with an increased amount of sibling conflict.

Permissive parents are high on warmth and low on both restrictiveness and firm control, giving the child much positive attention (Mohammadi & Zarafshan, 2014; van Steijn et al., 2013). The permissive parent is acceptant and non-punitive, allowing the child to regulate his or her own activities while encouraging the child to obey externally defined standards (Baumrind, 1971). Permissive parents are associated with making few demands and exercising low control (Berzonsky, 2004). Permissiveness was determined to intensify the child's narcissistic tendencies as the parent's behavior is adjusted to the wishes of their children (Barzonsky, 2004; van Steijn et al., 2013; Uji et al., 2014). Permissive parenting was found to result in an increase of behavioral problems and a decrease of prosocial behaviors in the children (Mohammadi & Zarafshan, 2014). Children who have permissive parents are found to demonstrate higher levels of impulsivity and may have higher levels of aggression (Mohammadi & Zarafshan, 2014).

Parenting styles that are great for TD children may not be as effective for children with ASD (Uji et al., 2014). The differences were identified in a study by Mohammadi and Zarafshan (2014) which recognized the positive impact authoritative parenting styles had on TD children in the household and a negative impact on the behavioral problems of children with ASD. However, although the authoritative parenting style had a negative impact on behavior problems in the TD child the style had a positive effect on the child with ASD, essentially lowering the symptoms exhibited by the child with ASD. In contrast, the authoritarian parenting is associated with higher levels of behavioral control, lower levels of antisocial behavior, and positive socialization processes for TD children; yet that same parenting style has been found to increase the frequency of symptoms of ASD (Mohammadi & Zarafshan, 2014; Uji et al., 2014). A large amount of control can be positive for the child with ASD, as the rules are clearly laid out and strict. However, the benefit is lost when paired with insensitivity for the needs of the child and hostile reactions to the child's behavior (van Steijn et al., 2013). Authoritarian parenting has been described as more harmful to children's self-esteem and resulting in poorer behavioral outcomes than the other two parenting styles (Mohammadi & Zarafshan, 2014; Uji et al., 2014). Although this parenting style may exhibit a negative impact on prosocial behavior, Mohammadi and Zarafshan (2014) explain that this parenting style can have a positive effect on the child with autism.

Research suggests that some parents of children with ASD utilize permissive parenting which is evoked by the child's pathology (van Steijn et al., 2013). It has also been found that parents of children with ASD utilized less control and punishments towards their child with ASD (van Steijn et al., 2013). This is possibly due to a need to avoid confrontation or because they feel they are not able to influence their child's development. Regardless of the why, this creates a

less authoritative style for the TD siblings and ultimately puts a negative influence on their parenting style as a whole (van Steijn et al., 2013).

Compassionate parenting goals have been reported to predict positive outcomes in family and parenting satisfaction (Conti, 2015). By setting compassionate goals, parents of children with ASD can effectively buffer stress and boost their own well-being (Conti, 2015). Family environments associated with fewer behavioral problems involve a presence of positivity and lack the element of criticism (Mohammadi & Zarafshan, 2014; Woodman et al., 2015). Positive parenting can be described as accepting, warm, involved, caring, empathetic, directive, and fostering social, emotional, and cognitive growth (Dyches et al., 2012). Dyches et al. (2012) describe positive parenting as authoritative in nature with elements of acceptance, warmth, sensitivity, empathy, and directive. Positive parenting is associated with behavioral regulation, respect for the individual, and parental support or connection (Dyches et al., 2012).

Families that have children with autism, parents tend to take on a dual role of parent and coach (Hoogsteen & Woodgate, 2013; Zhou & Yi, 2014). Many parents feel compelled to coach their children through their speech, motor and social skill deficits (Hoogsteen & Woodgate, 2013; Zhou & Yi, 2014). Zhou and Yi (2014) presented four categories for parenting styles of parents with children with ASD: training priority, relationship precedence, alternating, and letting alone (Zhou & Yi, 2014). Zhou and Yi (2014) presented these parenting styles as fluid and changing over time, based on the needs of the children.

In the training priority style, the parents place priority on skills training for the child with great expectations for progress (Zhou & Yi, 2014). In the relationship precedence, the focus of the parent is on the importance of the parent-child relationship and expectations are actively adjusted (Zhou & Yi, 2014). Parents in the training priority style acted more like coaches than

caregivers while in the relationship precedence phase parents put the role of caregiver over that of coach (Zhou & Yi, 2014). Although these styles are fluid and typically are based on the needs of the family and the child, the relationship precedence style typically follows the intense training priority style in an effort to repair the relationship (Zhou & Yi, 2014). Although training is evident in the relationship precedence parenting style, it is milder and subtler (Zhou & Yi, 2014). In the alternating parenting style, parents switch between the role of caretaker and the role of coach, struggling find balance in these roles (Zhou & Yi, 2014). Finding a balance between coach and caretaker is important as too much stress on the parent as a coach may cause the parents to become strict and less warm, which impacts the relationship between the parent and the children in the family system (Hoogsteen & Woodgate, 2013; Zhou & Yi, 2014). This parenting style typically occurs in the early stages after initial ASD diagnosis (Zhou & Yi, 2014).

The final type of parenting is labeled as letting alone, as these parent's lack hope for their child's improvements and have minimal motivation in seeking treatment (Zhou & Yi, 2014). The letting alone phase is usually a secondary response, following frustrations caused by the child's problems and the parents' inability to change the child (Zhou & Yi, 2014). However, maternal responsiveness has been directly related to social interaction in children with ASD (Dyches et al., 2012). The sibling relationship is impacted not only by the parent child relationship in the home, but also the parenting style in any given family system (Feinberg et al., 2013; Hesse et al., 2013). Positive family relationships and interactions are associated with positive outcomes in the children with ASD (Woodman et al., 2014).

### **Sibling Relationship**

Sibling relationships, both in general and of siblings with ASD, can act as a buffer against family stress; or they can cultivate negative experiences, rivalry, competition for parental

attention, and aggression or behavioral issues (Brewton et al., 2012). Diener et al. (2015) reported that some mothers expressed some degree of disappointment for the typically developing sibling for having endured the trials of having a sibling with autism. As these parents focused more on the challenges between the siblings, their views were somewhat less positive about the relationship between the TD sibling and child with ASD (Karst & Vaughan Van Hecke, 2012; Diener et al., 2015). These mothers described the interaction between siblings as difficult and described their interactions and play time as more of parallel play rather than integrated play (Diener et al., 2015). Siblings of children with autism may find the social interactions difficult to relate to which could lead to unsuccessful play (Walton & Ingersoll, 2015).

In early childhood, it is the sibling interactions that facilitate development and relationship skills needed throughout the life course (Diener et al., 2015; Feinberg et al., 2013; Martins et al., 2015; Saxena & Adamsons, 2013). These relationships are shaped by “individual, family, and extra familial forces” (McHale et al., 2012, p 923). As children spend more free time with their siblings than just about anyone else, the TD sibling has ample opportunity to impact the social, cognitive, and behavioral development of the child with ASD (Feinberg et al., 2013; Lam et al., 2012; Martins et al., 2015; McHale et al., 2012; Petalas, Hastings, Nash & Duff, 2015; Tomeny, Barry, & Bader, 2012; Tsao et al., 2012). In relation to other close relationships, sibling relationships can “involve more frequent and intense conflict” (Feinberg et al., 2013, p. 98) which is a factor that can shape emotional responses and social behaviors. This conflict can also shape an understanding of emotion, persuasion and problem solving (McHale et al., 2012). In addition, these intense exchanges can give children the opportunity to learn about other individuals’ perspectives and develop empathy (Lam et al., 2012). TD siblings may find

themselves 'giving in' to appease the sibling with ASD to which socially reinforce aggressive behavior (McHale, Updegraff, & Feinberg, 2016). However, it is also mentioned that in circumstances where the sibling is older than the child with autism spectrum there are lower levels of conflict than if the TD sibling is younger (Petalas et al., 2012).

The acquisition, instigation, and maintenance of behavior are regulated through interactions with one's environment (Cullen & Wilcox, 2010). Humans are social learners and children shape their environments, as identified by Bandura (2001b). In a household, siblings act as the first models, helping to influence the development of the behaviors and attitudes of other children in that environment; when one child has poor communication skills, limited social interactions, and embarrassing or difficult behavior the likelihood of impact is great (McHale et al., 2012; Karst & Vaughan Van Hecke, 2012). These behavior problems present in the child with ASD have been found to predict the psychological well-being in siblings (Hastings et al., 2014). Typically developing siblings may even present with ASD characteristic traits themselves (Petalas et al., 2015; Tudor & Lerner, 2015). The motivation behind the TD sibling expressing themselves with ASD characteristics may be an effort to gain attention from the parent. Because of these complex needs of the child with ASD, the parents' attention is spent more with the sibling with ASD than with that of the other TD siblings (Chan & Goh, 2014; Hoogsteen & Woodgate, 2013; Martins et al., 2015). However, parents involved in studies have stated that though they strive for equality between their children it is not always possible (Chan & Goh, 2014; Diener et al., 2015; Nealy et al., 2012). By attending to the child with ASD behaviors, the parent is reinforcing the behavior and the TD sibling may be motivated by the attention to act accordingly, as explained in the self-determination theory (Ryan & Deci, 2000). Walton and Ingersoll (2015) reported that siblings of children with ASD were less involved and

more avoidant of their siblings, when compared with siblings of TD children. Siblings have the potential to be powerful peer interventionists, given the proper training and attention (Banda, 2015). Pollard and co-researchers (2013) determined that siblings of children with autism had less social support in the sibling relationship and more negative interactions which led to lower overall quality of relationship. The impact of having a sibling with ASD is an area that has been less explored than that of having a child with autism. In many cases, it is difficult to determine whether sibling adjustment is directly related to parental mental health, parental satisfaction, demographic variables, or the presence of a sibling with ASD (Green, 2013; Hesse et al., 2013; Shivers et al., 2013; Tudor & Lerner, 2015). Evidence suggests that having a sibling with ASD may prove insignificant as a factor regarding adjustment and may serve to exacerbate adjustment problems when other problems are evident, such as parent stress or lower socioeconomics (Hesse et al., 2013; Tudor & Lerner, 2015). In research conducted by Hesse et al. (2013), income was indicated as one factor in the adjustment of siblings. They found that families with higher income and female siblings were better well-adjusted than those with lower income and male siblings (Hesse et al., 2013). Shivers et al. (2013) also found that male siblings of children with ASD had higher anxiety scores than their female counterparts. Although it is difficult to link the sibling adjustment directly to living with a sibling with ASD with so many other factors present in a given family system, the potential for these TD siblings to require some clinical services is evident (Tudor & Lerner, 2015). However, when asked, many typically developing siblings valued the duality of both the positive and negative aspects of their relationship with their sibling with ASD (Diener et al., 2015; Chan & Goh, 2014).

Between 80-90% of children grow up with a sibling (Brewton et al., 2012; McHale et al., 2012). The sibling relationship is not only a fixture in the family life, but it also is special in that

it has the potential to be the longest lasting relationship in a person's life, extending from the birth of the youngest sibling through the death of a sibling (Arnold et al., 2012; Green, 2013; Martins et al., 2015; McHale et al., 2012). Sharing biological and affective ties with the parents, this bond between siblings can be a special source of companionship, help, and emotional support (Martins et al., 2015; Tsao et al., 2012). Siblings are a child's first playmates and friends; their role and influence in social development has great potential. What is learned from the sibling relationship can influence and enhance skills in cognitive, affective, and social interactions (Martins et al., 2015). Sibling relationships are influenced by various factors ranging from the individual child's characteristics to cultural norms and values (McHale et al., 2012). As the numbers of ASD diagnoses increase, so do the number of siblings growing up with a brother or sister with ASD (Diener et al., 2015; Shivers et al., 2013). ASD is almost five times more common among boys such that typically developing siblings are more likely to have a male sibling with ASD (CDC, 2014; Diener et al., 2015).

### **Sibling Impact**

Growing up in a family with a sibling with ASD can encompass both positive and negative outcomes for the typically developing sibling (Brewton et al., 2012; Chan & Goh, 2014; Cridland et al., 2013; Diener et al., 2015; Gold & McCabe, 2012; Green, 2013; Hesse et al., 2013; Tsao et al., 2012; Walton & Ingersoll, 2015). Given the genetic and environmental influences of having a child with ASD in the house, maladaptation may be stronger but then again, it may mirror that of any other sibling relationship (Tomeny et al., 2012). Maladaptation can occur regardless of the presence of a disability in the family. Pollard et al. (2013) found that siblings of children with ASD had fewer social support qualities, more negative interchanges and a lower overall quality of the relationship because of anxiety which may or may not correlate

with the ASD diagnosis in the household. Research is fairly inconclusive, depending on the population being studied. The mixed findings from previous studies indicate neither a clear positive nor negative impact of the presence of an ASD child on sibling development (Hastings & Petalas, 2013). The characteristics of the siblings themselves, such as gender or age, can impact the likelihood of them exhibiting anxiety problems (Shivers et al., 2013). Green (2013) determined that siblings of children with autism may have vulnerability for behavioral and emotional dysfunction. Chan and Goh (2014) discussed how some typically developing siblings whose brother or sister has ASD can become more mature and experience greater empathy with their given situation. The TD siblings may show few disadvantages towards social relationships or cognitive impairments, but some experience mental health problems in the area of depression (Howlin, Moss, Savage, Bolton, & Rutter, 2015). When Green (2013) looked at multiple studies on the impact on siblings in the general population, it was determined that many quantitative studies have the siblings of children with ASD rate their emotional and behavioral experiences in a clinical and non-clinical manner. The results often report that typically developing siblings appear to be well adjusted.

When Green (2013), reviewed research from multiple other sources it was noted that qualitative data reveals some disturbing emotional challenges that impact the well-being of TD individuals who have a sibling with ASD. Other research reported that siblings of children with ASD exhibit higher levels of internalizing and externalizing problems (Brewton et al., 2012; Diener et al., 2015; Green, 2013; Hesse et al., 2013). Other areas of concern included the TD siblings exhibiting higher levels of social and behavioral problems, along with increased distressing emotions such as guilt (Green, 2013). Other research showed that TD siblings of children with ASD exhibit lower level of social communication and social-emotional functions,

and significantly lower expressive language (Brewton et al., 2012). Siblings of children with ASD report the lowest levels of intimacy, nurturance, and prosocial behavior when compared to individuals with TD or Down syndrome siblings (Gold & McCabe, 2012).

In contrast, other researchers found no differences in the adjustment of siblings with ASD (Green, 2013; Hesse et al., 2013). They found siblings of children with ASD tend to have less conflict in their sibling relationship, a sense of family resilience, and increased self-perceived competence (Diener et al., 2015; Green, 2013). In addition, the research revealed these siblings often exhibit higher levels of maturity, well-rounded character, and an increased ability to show empathy (Brewton et al., 2012; Diener et al., 2015). These TD siblings were also more likely to view their own behavior and intelligence in a positive light (Brewton et al., 2012; Gold & McCabe, 2012). Diener et al. (2015) found that TD siblings of children with ASD viewed their relationship as typical.

The siblings of children with disabilities often are providing significant caregiving responsibilities with typically less parental support (Cridland et al., 2015). The siblings may or may not have a disposition for possible mental health problems, but the appropriate support from childhood could be beneficial (Howlin et al., 2015). There is ample research on siblings of children with autism, reporting mixed results and emphasizing large gaps in the literature in relation to the outcome of said siblings (Green, 2013; Hastings & Petalas, 2013). Many parents, specialists, and researchers recognize the importance of looking at this population of typically developing siblings (Tsao et al., 2012). Tsao et al. (2012) also discussed the underexplored role of the TD sibling, as well as their potential to enhance the family life. Little research is found in regards to the unique perspectives and experiences of family life of a child with a sibling diagnosed with ASD and even less in regards to military affiliation. There is very little

information about military children and less about military children with disabilities (Davis et al., 2016). Military families with ASD are underrepresented in research, despite the number of military dependents with a diagnosis of ASD reaching 23,500 (Davis & Finke, 2015). By gaining a better understanding of the lives of the TD siblings of children with ASD in a military family living on a military base, perhaps research can lead to methods that will help foster positive relationships and positive outcomes for the individuals involved.

### **Summary**

With the prevalence of ASD on the rise, it is imperative for society to gain an understanding of the impact that a child with ASD has on the family system, in particular the TD siblings in a military family. To help shape and provide a theoretical framework for research the social cognitive theory (Bandura 1999), the self-determination theory (Ryan et al., 2008), and the family systems theory (Bowen, 1966) were utilized as a lens through which to examine the phenomenon. Bandura (1962) studied how the environment shaped the individual, and this research examined how the military family is shaped through the eyes of a TD sibling when one sibling has ASD. Ryan and Deci (2000) focused on the necessary components for optimal psychological developmental and the process which leads to motivation and well-being. This research expanded on this theory by examining influences the well-being of the TD sibling in a military family with a sibling with ASD. Bowen (1966) looked at the whole family system as a set of subsystems all related and impacting the others in the family and this research examined the working of the family system, presenting roles that the TD sibling has within the military family setting when one sibling has a diagnosis of ASD. Through a narrow and unique application of these theories, research focused on a specific environmental situation and the sibling relationship through the perspective of the TD sibling and parent.

The history of autism was presented in this chapter as it discussed how ASD was first thought to be an early form of childhood schizophrenia (Wing, 1981). When this idea was abandoned, it became recognized as a cerebral dysfunction (Thompson, 2013). As perceptions about ASD changed over time, changes in diagnostic criteria for a diagnosis of ASD also changed. ASD is not a easily categorized condition, but rather a family of overlapping conditions which can vary greatly in severity (Thompson, 2013; Wolff, 2004). As students with ASD attend school and may require special services, prevalence within the school setting and IDEA were also discussed.

Although the direct focus of the research relies on the inclusion of a sibling with ASD, other noted influences on the family include socioeconomics of the family, maternal depression, and family size. There is limited information about the TD sibling's perspective of his/her life with a sibling with ASD (Davis et al., 2016). There is even less information when these siblings are in military families (Davis et al., 2016). Davis and Finke (2015) confirm there are no other peer reviewed studies relating to ASD and the military population except for their qualitative investigation on children with ASD during relocation and separation in a military family. This research helped bridge the gap in the literature while giving professionals and parents valuable information about the well-being and roles of the TD sibling of a child with ASD in a military household.

## CHAPTER THREE: METHODS

### Overview

The purpose of this qualitative study was to understand the typically developing (TD) sibling's well-being and role in a military family with a child with autism spectrum disorder (ASD). Case study research was an appropriate method as it allowed for an intensive description of analysis of this phenomenon of having a sibling with ASD within the social unit of the military family (Merriam, 2002; Stake, 1995). Baxter and Jack (2008), stated that a multiple or collective case study will allow analysis within each setting as well as across settings. By examining several cases, both the similarities and the differences between cases can be explored (Baxter & Jack, 2008). Collective or multiple case study are utilized to examine the phenomenon through different perspectives and to explore of the phenomenon through a variety of data sources (Creswell, 2013). Data was collected from multiple military families and information provided insight from the perspectives of one parent and one typically developing sibling within each of these families through interviews. By doing so, the research explored the issue through a variety of lenses and allowed for multiple facets of this phenomenon to be revealed and ultimately understood (Baxter & Jack, 2008). There is a plethora of quantitative statistics and some qualitative research about the well-being of TD siblings with ASD. However, there is an empirical gap concerning the impact on the TD sibling of a child with ASD in the military family (Green, 2013; Hastings & Petalas, 2013).

Within this chapter, the description and rationale for the chosen research design of collective case study are more fully developed. The participants and the setting are described, as are the data collection methods of interviews, photographs, timelines, and journaling. The data

analysis procedures utilized are explained, followed by a discussion of the trustworthiness and ethical considerations of the study.

### **Design**

This qualitative research study employed a collective case study design. A qualitative study design was selected to utilize multiple design methods to focus on the subject matter in an interpretive and naturalistic approach (Denzin & Lincoln, 2008b). This study was qualitative, as the purpose was to seek out the perspective of the TD siblings within the military family. Qualitative research allowed the participants to speak using their own voices and from their own perspectives of their lived experiences (O'Day & Killeen, 2002). As the focus of this research was on how having a sibling with ASD impacts the TD sibling, by way of well-being and roles in the family, a case study design was an effective way to allow participants to tell their stories (Baxter & Jack, 2008). Collective case study was an appropriate design for this study as the intent was to discover and portray multiple views within this perimeter (Stake, 1995). A collective case study provided a better understanding of and reflection on the complex, situated, problematic relationships and well-being of typically developing siblings of children with ASD who live on one military post (Stake, 1995; Stake, 2006). As explained by Denzin and Lincoln (2008a), the purpose of this research was to seek answers and stress the socially constructed nature of said reality.

Collective case study, or multiple case studies, can effectively examine one issue or concern and utilize multiple cases to show different perspectives of the issue (Creswell, 2013). By utilizing a collective case study design, differences within and between cases was explored with a goal of identifying commonalities across cases (Baxter & Jack, 2008). Each case included a military family that has multiple siblings, with a minimum of one sibling with a diagnosis of

ASD. Collective case study will be utilized to examine a number of cases to “investigate the phenomenon, or general condition” (Stake, 2005, p. 445). This collective case study strived to seek out information from within each setting and across settings (Baxter & Jack, 2008). As suggested by Patton (2002), to better understand and gain insight about the phenomenon that occurs, utilizing case study research will not only allow for greater understanding but also moved away from empirical generalizations. This qualitative method allowed the participants to speak in their own voices, rather than conforming to the words and categories chosen by others for them, allowing for greater understanding of their perspectives (O’Day & Killeen, 2002). The principal use of a collective case study is to obtain the descriptions and interpretations of others (Stake, 1995). Through thick descriptions and experiential understandings, multiple realities were revealed (Stake, 1995). The goal was to understand the experiences of the participants from an insider’s point of view and develop a firm grasp of the issues beyond conventional wisdom and preconceived notions (O’Day & Killeen, 2002).

### **Research Questions**

- RQ1:** How is the well-being of a typically developing child in a military family living on a military post impacted by having a sibling with autism in the home?
- RQ2:** How does having a sibling with ASD impact the roles of the typically developing siblings in a military family who lives on a military post?
- RQ3:** How do parent perspectives on the experiences of TD siblings compare and contrast to the TD sibling’s actual experiences and perceptions when one sibling has ASD on a military post?

## Setting

In this collective case study, all participants were connected to the same large United States military post. This setting was chosen, in part, due to convenience, as I work at a school on the post. It was an excellent location in which to conduct this research as it is one of the top three largest in the United States. According to the United States Census Bureau (2017) at the time of the most recent census, this post had a population of 13,685 individuals who lived within the gates. Of this population, 37.3% were under the age of 18 (U.S. Census Bureau, 2017). There were 2,708 households reported between 2011-2015 (U.S. Census Bureau, 2017). With the prevalence of ASD on the rise, the number of military families affected by ASD is substantial (Davis & Finke, 2015; Kline et al., 2015). Interviews took place at the family's home, on post, or a convenient place of each family's choosing.

On this army base, there are over 20 different neighborhoods and over 80 neighborhood parks. On any given school day, the post looks like small town America with countless helmeted children riding their bikes to one of the five neighborhood elementary schools. Moms follow in droves, pushing babies in prams. Many of the neighborhoods center around a park and a community center that can be reserved for parties and meetings. To add to the small town, feel on post, there are small shops located around the base. The base has its own hospital, police station, fire station, post office, restaurants, golf course, horse stables, multiple gyms, indoor swimming pool, splash park, and multiple outdoor swimming pools.

The military member's rank determines their basic housing allowance (BAH) is, which ultimately determines in which neighborhood a family resides. There are enlisted rates (ranging from an E1 to an E9), warrant officer rates (ranging from W1 to W5), and officer rates (ranging from O1E to O7). BAH rates change annually and are utilized to cover rent and some utility cost.

Because the BAH drives the amount a family has to spend on rent and the way the neighborhoods are set up, there are divisions based on rank within this military installment. When a family member moves up in rank, they can move into a different house if they so desire. This move can relocate the family to one of the other neighborhoods that will fit their BAH. This move may be less than a mile away and result in a change of neighbors and the school which their children will attend.

The military post provides a sense of community for the individuals that live there. Communities can provide important support for individuals while promoting psychological and physical well-being (La Flair et al., 2015). These families have access to the support and resources associated with a military community. The families who participated in this study live on this military installment and have multiple siblings in the household at least one of which has the diagnosis of ASD. The Army alone has at least 8,500 known cases of Autism (Klin et al., 2015).

### **Participants**

For this collective case study, all participants were members of families living on the same large southeastern United States military post. Participants included both a parent and TD child from each participating family. The families were selected based on the criterion that the family had multiple children, at least one with a diagnosis of ASD and at least one who was considered typically developing. The TD sibling may have been older or younger than the child with ASD, however that TD sibling had to be at least 11 years of age. Snowball sampling took place. The snowball procedure is described by identifying cases of interest from people who know people that fit the study (Creswell, 2013). An Applied Behavioral Analysis (ABA) therapist on post assisted in the location of participants (Appendix A). As she worked directly in

support of families that have children with ASD on the post and understood the individual family dynamics, she initiated this snowball procedure. This ABA therapist associated with the military post was provided with the parameters of the research. She knew which families with multiple siblings fit the parameters of the study, with at least one of siblings having a diagnosis of ASD. She also knew which TD siblings were old enough, at least 11 years old, to be considered as a participant in the study.

Creswell (2013) suggested no more than four or five cases in a single study to provide different perspectives and provide an in depth understanding of the situation. The desirable amount was four families for this study. From each case, or family, one parent and the TD sibling participated in the study. Within this sample, ideally the siblings with ASD would have varied in birth order. However, the cooperating sample found limited oldest and limited female siblings with ASD. This sampling sought out to find both male and female siblings with ASD. For this study six families were originally interviewed, but two were eliminated because they were outliers in the data. One family had a child with ASD as the oldest sibling; this sibling with ASD was also female. The second family was the only family to have a female sibling with ASD in the study, so they were also removed from the data.

The chart below describes the demographics of the TD siblings who participated in this study. The pseudonyms utilized were chosen by participants.

<i>Demographics of TD Sibling Participants</i>					
<u>TD Sibling</u>	<u>Age during Interview</u>	<u>Ethnicities</u>	<u>Gender</u>	<u>Sibling Order</u>	<u>Number of siblings in Family</u>
Bruce	17	Caucasian	M	oldest	5
Isabella	14	Hispanic	F	oldest	4
Elaine	19	Caucasian	F	oldest	4
Jennifer	18	Caucasian	F	oldest	3

Maximum variation was involved in predetermining that some criteria differentiated between participants (Creswell, 2013). The sought-after differentiation included gender of sibling with ASD, gender of TD sibling, number of siblings within the household, ethnic variation, and rank of service member. The rank of the service members was specified on the initial demographics form. However, only one of the interviewees was an actual service member herself and the rest were wives of service members. The data was provided, but seemed irrelevant to the variation. By maximizing the differences at the beginning, the likelihood of finding different perspectives and reflections was increased (Creswell, 2013).

### **Procedures**

Following approval from the Liberty University Institutional Review Board (IRB), and approval of the dissertation committee, I began the recruitment of participants, distribution of informed consent, and collection of data. I provided an email to the ABA therapist to send to the families she had identified as meeting the criteria for the study. This email included an explanation of the study, contact information, and the demographics questionnaire (Appendix C) for participants to complete and return. By returning the questionnaire, families showed their willingness to participate. From there I contacted the families to set up an initial meeting to discuss the parameters of the study. These informal first meetings took place at a coffee shop near the participants' neighborhoods. At this meeting the research was discussed, as well as the methods used (i.e., interviews, recordings, coding, etc....). Families were selected based on the returned demographic data forms and specific criteria. This data was then utilized to ensure maximum variation of participants in the study. Any incomplete information for selected families was collected through interview format during the initial meeting. At this initial meeting, the participants were provided with the Informed Consent (Appendix B) and were given

a description of the study both in writing and verbally. Participants were also given a copy of the interview questions to prepare for the actual interview. Informed Consent (Appendix B) was completed appropriately and we (parents, siblings, and I) verbally discussed the study's purpose and description. The typically developing sibling was asked to provide his/her assent to participate in the study. As some of the TD siblings were under the age of 18, parental consent was also obtained. The participants' rights to discontinue participation in the study at any time were reviewed and the participants were informed of the availability of counselor on call, if needed. Two families withdrew from the study before the interviews took place. One sibling didn't want to participate and the other family removed themselves from the study because of family issues that were going on at the time. As part of the data, each sibling was asked to provide 10 pictures of the roles they have within the family and common emotions they experience. The sibling participants were offered a digital camera, but all participants chose to utilize their smartphones to gather photographs. The parents were asked to create a timeline of events that had impacted their family. Interviews were scheduled at this time with the expectation that photographs and timelines would be completed by that date. At this initial interview, families were informed of their rights to privacy and the means by which their identities would be protected throughout the study. Families were asked to choose the pseudonym name by which all information was recorded and referenced.

At the scheduled interview time, the parent interview happened first. The first three questions began the interview process (Appendix D). From there the interviewer asked about the timeline and the parent explained and answered questions (Appendix F). At this point, the interviewer went back and addressed the remaining parent interview questions (Appendix D). The TD sibling interview took place following the parent interview. The sibling was first asked

the sibling interview questions (Appendix E). The photographs they selected were discussed following the selected prompts (Appendix G). The final discussion with the TD sibling was in regards to the timeline the parents provided, with prompts specifically for the sibling (Appendix F). Interviews were recorded on a voice recorder application on a smartphone that is password locked. On the day following the interview, each participant was sent a follow up predetermined prompt and encouraged to dictate a journal. If there was information gathered from the interviews that needed clarification, it was asked in this format. These were through text or through a digital voice message response application.

This collective case study utilized several data collection techniques to gain data. The primary sources for this study included recorded semi-structured interviews, timelines and discussions thereof, photographs and explanations thereof, and dictated journals. Merriam (2009) promoted the use of interviews and observations to support qualitative research. Informal observations were utilized, both at the initial meeting and during interviews. Following these encounters, I recorded my own personal thoughts and considerations.

To build a complex, holistic picture of the lived experiences of military siblings of children with ASD, the primary source of data collection was through recorded interviews with parents and siblings. Both interview transcriptions were entered into Atlas.ti7 for Windows software for coding and data organization. In addition, I completed journal observations from interactions with participants. Thick narratives that provided abundant details to interconnect themes were created from the data (Schwandt, Lincoln & Guba, 2007; Stake, 2010; Creswell, 2013). The messages resulting from the follow-up communication were also transcribed into Atlas.ti7 for Windows software for data organization and analysis. By pattern matching the data and cross-case synthesis (Yin, 2009), a better understanding of the roles and well-being of TD

military siblings who have a sibling with ASD were presented. To ensure that the finished product was a quality case study report, Stake (1995) provides a 20-question critique checklist (Appendix H) that was utilized.

After all interviews and communication were transcribed, follow up meetings were arranged with the participating families to review transcripts, discuss themes and similarities between families that participated in this study. The participants were provided the opportunity to review and respond to the preliminary synthesis of data (Kjell, Rudestam & Newton, 2001). Once participants had reviewed the transcript, further questions were asked to confirm the results (Schwandt et al., 2007). Families chose to meet and discuss these findings or receive them through electronic mail. The purpose of this meeting was to be transparent about what was found in the study and discuss how the families felt about the findings.

### **The Researcher's Role**

As the researcher and human instrument in this study, my role was to observe, interview, collect and analyze data (Yin, 2009). My goal, as a qualitative researcher, was to “collect, present, and analyze data fairly” (Yin, 2009, p. 3). As the human instrument, I used myself as the primary tool to gather information and as such I was flexible to adapt to indeterminate situations that I encountered (Lincoln & Guba, 1985; Merriam, 2002). The advantages of being the researcher and human instrument included the ability to utilize nonverbal and verbal communication in the data collecting phase as well as the ability to process the information immediately (Merriam, 2002). Data presented was clarified, summarized, and checked for accuracy on the spot (Merriam, 2002). Experiences relevant to my role as the human instrument include teaching at middle school level on this particular U.S. Army post school since 2009 as well as teaching special education at other military installments since 2003. I have personally

watched the numbers of students with ASD increase annually in school settings and will continue to be an advocate for these students and their families. As I served as the primary instrument in this qualitative study, familiarity with the families, setting, and nature of ASD helped to validate my research.

My education includes a BS in Special Education K-12, a MA in Curriculum and Instruction, an EdS in Educational Leadership, and I am currently pursuing an EdD in Educational Leadership. I understood that individuals being interviewed were the experts and they were treated with respect. They were encouraged to share their lived experiences and my personal assumptions from former experiences were kept at a distance. Through my experiences, I felt that the TD children of a sibling with ASD often live in the shadow of that sibling, as the parent is often overwhelmed. However, within this research, I took in information presented and looked for commonalities within only the presented information and I did not bring previous experiences into said research. This research focused on understanding the well-being and roles of military siblings of children with an ASD diagnosis.

### **Data Collection**

This collective case study utilized several rigorous and varied data collection techniques. The three most common sources of data collection for qualitative research include interviews, observations, and documents (Merriam, 2002). Merriam (2009) indicated that interviews and observations are valuable ways to support qualitative research. As suggested by O'Day and Killeen (2002), in-depth interviews and carefully selected participants helped to gain significant appreciation for the complexity of the situation, relationships, and interactions. However, observations, timelines, photographic artifacts, and dictated journals

were also useful methods to promote understanding of the well-being and roles of the TD siblings of children with ASD (Creswell, 2013).

### **Document Analysis: Timeline**

At the initial introduction meeting, parents were asked to create and provide a timeline of family events. An example of a timeline was provided to the family and online resources for timeline creation was discussed with the family. The timeline depicted life events that impacted their military family. Events relevant to this timeline included, but were not limited to, deployments of a family member, family moves, separation of family members, and any other relevant occurrences that have shaped their family. At the interview with the parent, the participant explained and reviewed said timeline utilizing the prepared prompts (Appendix F) in regards to how these transitional periods impacted the family dynamics and the role of the siblings.

These timelines were also reviewed in the sibling interview to explore and understand the impact of these family events from the perspective of the sibling utilizing a series of prompts (Appendix F). These family events were the primary factors that set military families apart from other families who cope with ASD. By reviewing the timeline with the parents and the siblings, the same situations were evaluated from the multiple realities that existed within the same family system. Responses were recorded for transcription.

### **Artifact Analysis: Photographs**

At the initial introduction meeting, TD siblings were offered a digital camera to collect photographs. Each sibling offered refused and utilized their camera application on their smartphone instead. Photographs served as important documentary evidence to which the subjects reacted (Slavin, 2007). The expectation was that they were to take 10 pictures that

captured not only their emotions, but also their roles within the family. If they were responsible for helping their sibling off of the bus after school, parents could assist by photographing that activity. The purpose of this camera being digital was to allow the TD siblings to review their images and select the 10 that best represented their emotions and their roles within the military family system. At the beginning of the interview, the photos were shared with the interviewer for later discussion. The selected photographs provided insight into the phenomenon and revealed much about the individuals who are taking part in this research (Slavin, 2007). These photos were saved in a folder that is labeled with their family pseudonym. Siblings were asked to justify how each picture related to their well-being or a role that they play in the family. The TD sibling then discussed their selected photos and they were given an opportunity to explain why each was relevant using a series of prompts (Appendix G). The purpose of this data was to allow the sibling to think about their roles within the family and create evidence of said role. Responses to these prompts and descriptions were recorded and transcribed.

### **Interviews**

Interviews were utilized as interviews generate useful information about lived experiences and the meaning of these experiences (Denzin & Lincoln, 2008a). Semi structured individual interviews took place with a parent and a TD sibling. These interviews were mostly separate. Bruce was the exception and he was also the only male interviewed. All interviews were recorded with two electronic devices, to ensure no data was lost. Interview questions were created by the researcher and were checked for validity with a qualified qualitative educational researcher prior to being utilized in this study. Interviews took place at the location chosen by the family. Both parent and sibling interviews were in a private setting.

**Interview.** The interview stage began with the parent. It began with a brief introduction to the study and review of informed consent. All interviews were recorded on multiple devices to ensure quality of sound for transcription. After the parent interviewee answered questions, the timeline they created was reviewed. Descriptions of how these noted events impacted the sibling and family life over time were reviewed as the parent was asked to explain the timeline they provided.

*Parent Interview Questions: Appendix D*

1. Please introduce yourself, as if we just met one another.
2. Please describe your family.
3. Please describe your schedule for weekly activities (therapies, extracurricular, support groups).
4. Are there any other routines that take place on a daily or weekly basis (eating, bedtime)?  
If so, would you describe them to me?
5. Does (TD sibling) have specific responsibilities in the house?
6. Does (TD sibling) have specific responsibilities with the (Sibling with ASD) ?
7. How would you describe the willingness for (TD sibling) to participate in these responsibilities?
8. How would you describe your children's relationship?
9. How would you describe (TD sibling) performance at school?
10. What expectations do you have for (TD sibling)'s future (continuing education, relationships, career, family)?
11. What expectations for you have for (child with ASD)'s future (continuing education, relationships, career, family)?

12. Has anyone in your family ever been diagnosed with anxiety, depression, or other emotional concerns?

Question one was demographic in nature and provided particular demographics, but it also was experience in that the response showed what information was relevant to the interviewee (Merriam & Tisdall, 2015). Questions two through six were experience or behavior questions. The experience and behavior questions asked about behaviors, actions, and activities in which the person, or family in this situation, participated (Merriam & Tisdall, 2015). Cridland et al. (2015) found that the parent's perspectives of the sibling relationships and sibling responsibilities varied from that of the TD sibling. For this reason, both the parent and the TD sibling were asked these questions and responses were compared. Questions seven and eight were opinions or values questions. Opinion and value questions asked what the individual thought about something, in this case the relationship between siblings and the TD sibling's performance in school (Merriam & Tisdall, 2015). Questions seven and eight also bordered on sensory questions, as the intention was to elicit specific data about what has been seen, heard, and witnessed (Merriam & Tisdall, 2015). Question ten and 11 asked the parent to provide expectations for the future. This qualified as a cross between an opinion or value and knowledge questions. The parents were asked what they thought about something, their beliefs for what they thought the future holds, but it was expected that their beliefs were grounded in factual knowledge about the situation (Merriam & Tisdall, 2015). The final question was demographic in nature as it provided relevant information to compare to other data sources about the mental health of family members of children with ASD in the family (Merriam & Tisdall, 2015).

Sibling interview. The TD sibling interview followed and once the sibling responded to the provided questions, he/she was asked to look over the timeline and explain how these events impacted his/her life and roles. He/she was provided his/her pictures for review and discussion. The siblings were asked to take 10 pictures. The TD siblings were asked about his/her pictures and he/she was given the opportunity to explain the images' relevance.

*Sibling Interview Questions: Appendix E*

1. Please introduce yourself, as if we have just met.
2. What activities are you involved in (sports, work, extracurricular)?
3. How would you describe yourself as a student?
4. Tell me about growing up with your sibling.
5. Describe your relationship with your sibling.
6. About what age did you understand that your sibling had ASD?
7. What are your responsibilities regarding your sibling?
8. How are you involved in your sibling's treatments and caretaking?
9. How do you think your sibling's presence has affected your family?
10. How do you think your sibling's presence has affected you (personally, socially)?
11. How do you think your sibling will affect your plans for the future (continuing education, relationships, career, family)?
12. Have you ever been diagnosed with anxiety, depression, or other emotional concerns?

Question one was demographic in nature as it provided particular demographics, but it also was experience in that the response showed what was relevant to the interviewee (Merriam & Tisdall, 2015). Question two was an experience or behavior style question, in that the interviewee explained his/her activities (Merriam & Tisdall, 2015). Current research suggests

that siblings of children with ASD may be less involved in extracurricular activities than children with TD siblings (Tint & Weiss, 2015; Walton & Ingersoll, 2015). Questions three, four, and five were opinions or values questions, as the TD sibling had to express his/her own personal beliefs and opinions (Merriam & Tisdall, 2015). Questions six, seven, and eight were experience or behavior style questions, in which the interviewee explained his/her behaviors, actions, and knowledge of his/her sibling with ASD (Merriam & Tisdall, 2015). In question seven, the interviewee discussed his/her responsibilities or roles in regard to his/her sibling with ASD. In question eight the TD sibling discussed his/her role in the caregiving or treatment process of his/her sibling with ASD. Research shows that little information is present about how much time siblings spend together and in what capacity, whether it be caregiving, play, or assisting in therapy sessions (McHale et al., 2016). Questions four, nine, and 10 inquired into the relationship between the TD sibling and the family. Few studies have looked into sibling relationships in siblings of children with ASD (McHale et al., 2012; Tint & Weiss, 2015; Walton & Ingersoll, 2015). The influence of a child with ASD may extend to all members of the family (Tint & Weiss, 2015). As the sibling relationship was one that is important to development, questions nine, 10 and 11 explored how this relationship affected the family dynamics from the TD sibling's point of view (Lam et al., 2012; McHale et al., 2012; McHale et al., 2016; Petalas et al., 2015). Questions nine, ten and 11 were knowledge questions with some relevance in experience and behavior, as the knowledge presented from these questions was grounded on experiences, behaviors, and factual knowledge (Merriam & Tisdall, 2015). The final question, number 12, was demographic in nature as it provided relevant information to compare to other data sources about the mental health of family members of children with ASD in the family

(Merriam & Tisdall, 2015). In a review of literature, Green (2013) found siblings of children with ASD tend to have higher levels of behavioral adjustment problems.

These interview questions sought to assist in finding an understanding of the well-being and roles of the typically developing siblings in a military family with one sibling who has ASD. The focus of this study was on the TD sibling's well-being and roles in the military family and as the children could have been as young as 11, the parent interviews were woven into the sibling's perspectives and experiences to generate themes. The goal of the interviews was to explore the perceptions of the parent and sibling. Merriam (2009) emphasized that a semi-structured interview helps to obtain a rich base of information concerning the perceptions of the participants.

### **Document Analysis: Dictated Journals**

Following the interviews, parents and siblings were encouraged to send auditory journals via Whatsapp. This program allows for participants to send verbal messages and can be added to any smartphone device. Following this research, the program was removed. The day after the interview a prompt was sent via Whatsapp for the participants to reply and continue communications on an as needed basis. The intention of the prompts was to initiate dialog that assisted in answering further questions that came up through the transcription process. Each family used a standardized initial prompt and from that response, Whatsapp was utilized to clarify questions that arose during transcription.

*Parent Prompt 1:* After the interview was there anything else that you considered that we did not discuss your child's role in the family?

*Sibling Prompt 1:* After the interview was there anything else that you thought about your role in your family?

## Data Analysis

All interviews were recorded, uploaded, and transcribed into the Atlas.ti7 program for coding. This software was utilized to assist with locating and analyzing patterns and themes within the raw data. Techniques for analysis included pattern matching within the transcriptions, explanation building, and cross-case synthesis (Baxter & Jack, 2008). Baxter and Jack (2008) referenced the utilization of an online data source as a means to effectively organize data. Baxter and Jack (2008) also described how the use of a database can not only improve the reliability of the case study, but allows data to be tracked and organized for easy retrieval. By using this program, I was able to save and archive my remarks, thoughts, and comments. I was able to highlight and color code themes for easy retrieval. A drawback from using such a database is that it put distance between myself and the data (Baxter & Jack, 2008). However, this program only assisted with the analysis; the interpretation and codes created were my responsibility.

As this was an exploratory collective case study; data was collected from recorded interviews, transcribed, and uploaded into the Atlas.ti7 program. Pattern matching between the empirical based pattern and the findings from the presented data took place (Yin, 2013). Codes were affixed to sets of notes, observations, and interview transcriptions, along with reflections. From here, I began sorting and sifting through material to identify similar phrases, relationships between variables, patterns, and themes (Miles & Huberman, 1994). Thick narratives were created to provide abundant details which interconnected the cases (Creswell, 2013; Schwandt, Lincoln, & Guba, 2007; Stake, 2010). The narratives were created and categorized, coded and tabulated (Yin, 1981).

This collective case study, for validity purposes, utilized open coding. I utilized open coding to divide the data into manageable sections; this assisted in the determination of themes

within the data (Corbin & Strauss, 2008). As part of this data analysis, I gradually began to elaborate small sets of generalizations and with these generalizations formulate a body of knowledge and the essence about the presented phenomenon of TD siblings in a military family with a sibling with ASD (Miles & Huberman, 1994). Data was then pattern matched, built on through explanation, and cross-case synthesized (Yin, 2009). While shifting through this copious amount of data, I worked towards data reduction, which refers to the process of “selecting, focusing, simplifying, abstracting, and transforming the data” (Miles & Huberman, 1994, p. 10). This data reduction acted as a way to sharpen the focus of the research while organizing data for final conclusions (Miles & Huberman, 1994).

### **Trustworthiness**

To increase the trustworthiness of the findings, steps were taken to address credibility, dependability, transferability, and confirmability for this study.

### **Credibility**

In qualitative research, credibility was used rather than the term validation (Baxter & Jack, 2008; Creswell, 2013). By ensuring the interpretations of participants were accurate and authentic, credibility was established (Creswell, 2013). By allowing the members to validate their solicited opinions, member check ensured that the transcriptions were accurate and complete (Merriam, 2009). By combining differed inquiry strategies to include multiple perspectives, it was possible to achieve triangulation and ensure credibility (Patton, 1999). Any discrepancies were addressed and reconciled after this process. Merriam (2009) emphasizes how important member checks are to ensure the interview transcripts are an accurate reflection of the responses they provided. Participants were given the opportunity to review the transcript, and further questions were asked to confirm the results (Schwandt et al., 2007).

Because I utilized multiple sources to acquire data (interviews, observations, timelines, photographs, and dictated journals), I gained in-depth understanding of the roles and well-being of military siblings of children with autism. Utilizing several sources of data increased the reliability and enhanced validity, strengthening the conclusions found in this study (Merriam, 2009). In chapter four, direct quotations from the data and the interviews are provided which allows for personal interpretations and conclusions to be made on said data.

### **Dependability**

Dependability is the qualitative researcher's parallel to reliability and focuses on the stability of data over time (Guba & Lincoln 1989). Dependability was established with an audit trail and by the utilization of an external auditor to carry out an audit (Schwandt et al., 2007). The auditor held a PhD in education and had experience with military children as well as a background in special education. In qualitative research, the auditor should have no connections to the study and should be able to examine the findings, interpretations, and conclusions supported by the present data (Creswell, 2013). According to Creswell (2013), the auditor will examine both the process and the end product of the study.

### **Confirmability**

Confirmability is looked at as a parallel to objectivity and is concerned with assuring the data, interpretations, and outcomes are rooted in context with the participants rather than in the imagination of the evaluator (Guba & Lincoln, 1989). In the process of reflexivity, as evidenced in journaling throughout the research procedures, I was conscious of the values, motives, biases, and experiences that I brought to the research study (Creswell, 2013; Guba & Lincoln, 1989). Participants were aware of my affiliation with the school on the post. My role in this research was explained in this chapter and also in chapter one.

## **Transferability**

Transferability can be viewed as the parallel to external validity or generalizability in the qualitative research world and is achieved when the data is as complete as humanly possible (Guba & Lincoln, 1989). Sufficient descriptive data must be provided to make transferability possible (Merriam & Tisdell, 2015). By having lengthy and intensive contact with respondents in pursuit of in-depth case elements, and utilizing different sources to obtain information, credibility was established (Schwandt et al., 2007). Thick, rich descriptions enhanced the possibility of the results transferring from one setting to another (Merriam & Tisdell, 2015). Thick, descriptive narratives were developed to assist in the analysis of cross-case perspectives (Schwandt et al., 2007). This case study was large enough to warrant cross-case tabulations (Yin, 1981). Maximum variation was utilized to enhance transferability (Merriam & Tisdell, 2015). Maximum variation in race, gender, military rank, and family make up were sought out in this multiple case study. Maximum variation was utilized to maximize differences and different perspectives on the phenomenon (Creswell, 2013).

## **Ethical Considerations**

The specifics of this study were reviewed by the Institutional Review Board at Liberty University. Once the study was approved through IRB, the study was reviewed through the Department of Defense Educational Activities (DODEA), then the data collection began. The study was not meant to reflect badly on the families or the post, but rather to gain understanding of these military siblings lived experiences. All participants were informed of the purpose of the study in the informed consent form (Creswell, 2013). The consent forms were reviewed by the committee members to ensure completeness. Parental consent was provided by the parents of the TD siblings. Each sibling gave his/her assent to participate in the study. Pseudonyms for the

individuals, as well as the military post were utilized to ensure confidentiality and protections of all stakeholders. Participants were informed and held the right to discontinue the voluntary participation in the study at any time without repercussion.

In the data collection phase, ethical considerations were included to respect the site of interviews and to ensure as little disruption to family life as possible (Creswell, 2013). I set clear boundaries throughout the data collection. Participating in these interviews allowed participants to become more reflective of their own personal well-being and the roles within the household. This reflection provided a residual benefit to the family members or resulted in a need for a counselor. A counselor was on call for the families, if they required services. Due to the conditions of the study, privacy of the participants and the post was a priority. All identities were closely protected and remain unidentified. Although there were no physical risks involved in this study, emotional upheavals could have arisen. Having a counselor available helped families cope with emotions on an as needed basis. Although the counselor was available, it was never required. On the contrary, the mothers and siblings were all very happy to discuss their memories of their children/siblings growing up. Privacy and confidentiality of participants was respected at all times (Yin, 2009). All transcripts and data were kept under lock and key, information on computer was always password protected. All information was collected, presented, and analyzed fairly and honestly (Yin, 2009). When completed, all data was shared with participants, stakeholders, and peer researchers for review.

Personal considerations included my personal employment at a school on this post. This study was in no way associated with the school, and when I worked with participants, I presented myself as a researcher and not a teacher. To ensure this division, no families of the students in my personal caseload or classroom were utilized for this study. Through demonstrating research

reflexivity through journaling, preconceived assumptions and biases were minimized (Yin, 2009).

### **Summary**

Chapter three has covered the methodology and research process for this multiple case study. This qualitative study utilized face-to-face semi structured interviews, timelines, photographs, and journals to understand the lived experiences of typically developing siblings of children with ASD in a military household. These families completed a demographic questionnaire and the parents and one sibling participated in a semi-structured, open-ended interview. Parents were asked to create timelines and explain the relevance of the events indicated. Siblings were also be asked to reflect on these events and how they impacted their well-being and roles in the family setting. Siblings were asked to provide 10 pictures and they were asked to explain the relevance of the images selected in the semi structured interview setting. The data collected was analyzed and coded for themes, and cross-case analysis determined thematic similarities and provided a better understanding of the roles and well-being of typically developing siblings of children with autism in a military family.

## **CHAPTER FOUR: FINDINGS**

### **Overview**

The purpose of this collective case study was to understand the typically developing (TD) siblings' well-being and role in a military family with a child with autism spectrum disorder (ASD) on a military post through the parent and TD sibling perspective. The research questions that were answered by this study were, how is the well-being of the TD child impact; what are the roles the TD sibling in this family setting; and how parent perspective differs from that of the TD sibling in a military family, when one sibling has a diagnosis of ASD. In this chapter, the participants are introduced and discussed extensively. This chapter includes a chart that details their family size, birth order, sibling with ASD birth order and sex, current living situation, and number of separations they have experienced within their lives. This is followed by a detailed description of each family situation to paint a picture of who each participant was based on information provided by the participants. Next, the parent and sibling interviews are presented and commonalities discussed. Timelines and answers to timeline questions are reviewed, followed by the photographic data and questions. Based on all provided information, responses to the research questions are also provided in this chapter.

### **Participants**

Participants included both a TD sibling and a parent from a military family that included one sibling who had a diagnosis of ASD. The TD sibling was required to be at least 11 years old to participate in the study. Each family was giving a pseudonym to ensure confidentiality. The chart below gives these chosen names and the ages of the TD siblings. The number of children in the household and birth order are provided next as well as the sex and birth order of the sibling with ASD. Because one of the participants was just starting college, and this being her first

semester out of the house, the current living situation was also added to this chart. The final information provided is the number of moves, deployments, and educational separations that have occurred during the TD siblings' lifetime.

Table 2				
<i>Participant Information</i>				
<u>Pseudonyms</u> <u>Parent and</u> <u>TD sibling</u>	<u>Birth Order</u> <u>of TD Sibling</u>	<u>Sibling with ASD</u> <u>Birth Order</u>	<u>Living Situation</u> <u>at time of Interview</u>	<u>Family Separations</u>
Martha Bruce	Oldest	2 <sup>nd</sup> oldest of 5	lives at home	3 PCS moves 5 deployments 1 educational Divorce, remarriage
Ruth Jennifer	Middle	Youngest of 3	lives at home	7 PCS moves 5 deployments 3 educational
Mary Elaine	Oldest	Youngest of 2	Elaine is away at college	4 deployments 6 educational Divorce, remarriage
Felicity Isabella	Oldest	2 <sup>nd</sup> oldest of 4	lives at home	5 PCS moves 4 deployments 3 educational Divorce, remarriage

### **Martha and Bruce**

Martha is a stay at home mother of five children including a senior in high school. Her children include a 17-year-old, an 8th grader, 3rd grader, 2-year-old, and 2-week-old baby. The 8th grader is the child with a diagnosis of ASD. Evan was diagnosed with ASD at age two and received many services in and outside of the home (SLP, OT, ABA). Martha divorced three years prior to this interview and remarried within months. This was followed by the growth of their family by two siblings.

Bruce is the oldest of five siblings and was four years old when Evan was born. At the time of the interview, he was 17 years old and a senior in high school. His extracurricular activities include the archery team, the school band, and participates in JROTC. Two years ago, Martha divorced Bruce's father and remarried in a matter of three months. She was already pregnant with his little sister and it all happened very quickly. Bruce was resentful of the change in family life and his stepfather changed the way family business was conducted. Bruce spent his junior year at a military school, as his grades were not great and he was struggling with the new life at home.

### **Ruth and Jennifer**

Ruth is a stay at home mother of three. Her two daughters have already graduated and her son is currently in the 9th grade. Her youngest, Mark, has a diagnosis of ASD. He was born in the 21st week of pregnancy and required hospitalization until week 36. During this hospital time the girls went to visit a grandmother until Mark and Ruth came home. Five weeks after coming home from the hospital, Mark was introduced to his first deployment as his father was gone for three months. With multiple family separations, Ruth called on the girls to help with Mark.

Jennifer, who is 18 at the time of the interview, was five when Mark was born. She is the middle child of Ruth; her sister is two years older. Jennifer is still in the household, while the oldest sibling has moved to another state. She attended college for a semester, but now works in the restaurant business, after not returning to college. Growing up, Jennifer was always very patient with Mark and would step in and help him with his homework. This has transpired into her now feeling maternal towards him.

### **Mary and Elaine**

Mary is a school psychologist with two children; Elaine, who is currently away at college, and Tobias, who is a junior in high school. Tobias was originally diagnosed with ASD when he was two and a half years old. Mary immediately sought out in home treatment. Tobias received about 35 hours a week of therapy (SLP, OT, sensory) for six days every week, both in the home and some at school. Mary called Tobias a “classic child with autism.” Unfortunately, Tobias’s and Elaine’s father didn’t believe in ASD and this caused complications in their family life. They divorced and the father did remarry.

Elaine is 19 years old and currently living in a dorm as it’s her first year in college. Elaine and Tobias are 18 months apart in age. Psychology is her current major, but she is unsure of what career path she will follow. Growing up she played the piano and violin; participated in basketball and soccer; and was on the cheer team. In high school, she worked at a local grocery store and she is currently cleaning buildings on her college campus. Elaine was able to participate in the study while home visiting her family for Thanksgiving holiday.

### **Felicity and Isabella**

Felicity joined the military at 18 and was initially stationed in Japan. She had Isabella when she was 19. Her son Anthony was born two years later. She divorced their father and remarried in 2009. Her husband had two children. She describes her blended family as a “mini UN” as her husband is African American, his children are biracial, she is Hispanic, and although Isabella and Anthony are Hispanic, they both look very Arian with blond hair and blue eyes. Anthony has a diagnosis of ASD, but the family doesn’t call it Autism to Anthony or other siblings. However, Anthony had in home therapy three times a week (to address behavior concerns in the school setting) when he was in the fourth or fifth grade.

Isabella is 14 years old and in the 9th grade at the time of the interview. She was two years old when Anthony. She enjoys being part of the stage crew for plays at her school, but she didn't participate in the last play. She doesn't feel she is the best student, but she shines in the areas of biology and health, and math is her hardest subject. She feels that having so much diversity in her family "brings everyone together closer, especially different mixed family, and it's just better." She plans on a future in law enforcement or as a crime scene investigator. However, she might also like to be an actress or an author as well.

### **Results**

The goal of this particular inquiry was to gain a better understanding of the TD sibling's well-being and role in a military family with a child with ASD on a military post through the parent and TD sibling perspective. Through interviews, timelines, and photographs insight was gained regarding the roles within the family of the TD sibling as well as their well-being. Analyzing that data revealed common themes that helped in the understanding of the TD sibling's well-being and role in a military family with a child with ASD on a military post. This section explores those findings.

### **Theme Development**

Information was collected through timelines provided by the parents, pictures provided by the TD siblings, and interviews with both parent and TD sibling. Since family separation is such a huge part of being in a military family, the timelines were provided to note any Permanent Change of Station (PCS) moves, educational separations, and deployments. Each of these require family members to be separated from friends, family, and/or familiarity. Military personnel are also expected to spend time in the field. When military members are in the field, the duration can last anywhere from three days to three weeks and these happen multiple times in a given year.

None of the families interviewed added this to the timelines, as they were so frequent to not be noteworthy to the family. Felicity stated, “It’s hard enough just to remember the moves and deployments that we have been through.” Other life events, just as births of siblings, deaths of family members, marriage, divorce, and remarriages were added to the timelines. Timeline results were taken, categorized and counted based on frequency. This data can be found on the chart found at the beginning of this chapter. The most common separations included PSC moves, extended school separations, deployments, divorce and remarriage.

Each sibling was offered a digital camera to document their well-being and roles they play within the family. Each sibling declined the offer, as they all had smartphones with camera technology to take and share images. Each sibling was asked to provide 10 photographs. Jennifer, Elaine, and Isabella provided ten photographs and Bruce provided six photographs. Once the 36 photographs were collected, they were categorized into different subgroups based on subject matter. The first categories that the subject matter broke down to included selfies, pictures with friends, and pictures with siblings. Photographs over five years old then presented as a subcategory. From that subcategory came a final grouping of photographs taken during therapy sessions as children. Of the 36 photographs submitted and discussed, 19 (52%) were photos with their sibling with ASD or other siblings. Seventeen (47%) were photographs from over five years ago, when the siblings were younger. These were typically taken by the parents. Of those 17 (22%) photos, eight of them were taken while the TD sibling was helping the at home service provider work with the sibling with Autism. Of the ten (27%) selfies provided, six were serious and four were with smiles. Of the seven (19%) photographs provided with friends, all were smiling and appeared to be having fun. These photographs

directly address the first research question about well-being and also showed reactions to home therapy.

Interviews were conducted with both the parent and the TD sibling. These interviews were transcribed into Atlas.ti8 to code electronically. Transcripts were coded and then compared for commonalities. Appendix J displays a table that shows the frequency of themes based on data collection points. As part of the coding process, common themes became evident between the interviews as common themes emerged in regards to the well-being of the TD sibling as well as the roles they took on with in the military family where one sibling held a diagnosis of ASD, directly relating to the research questions. The themes revealed from the TD sibling interviews, timelines and photographs included; the protective nature of these siblings over their siblings with ASD, the annoying little brother, reactions to home therapy at an early age, and improvement of sibling relationships as they matured.

The parent interviews were also coded for themes. These interviews typically lasted longer than the sibling interviews, as they shared stories of their children growing up, how far their child with ASD had progressed, and what life was like for them as a parent. The themes that emerged from their interviews included the striving for fairness among their children, anticipation for the future for their children, and self-reflection of their parenting choices.

After all the information was collected it was then all coded to determine what themes would emerge from the data. See Appendix J to see how frequently the determined themes presented themselves in the research. The photographs directly responded to the first research questions in regards to well-being, but even these were utilized to support themes after the themes were determined. The themes revealed from the TD sibling interviews, timelines and photographs included; the protective nature of these siblings over their siblings with ASD,

changes in lifestyle created by separations, the annoying little brother, reactions to home therapy at an early age, and improvement of sibling relationships as they matured. The themes that emerged from their parental interviews included the striving for fairness among their children, anticipation for the future for their children, and self-reflection of their parenting choices.

**Protective nature of these siblings over their siblings with ASD.** The first commonality between the sibling interviews was their feelings of protection in regards to their sibling with ASD. This theme was presented in both parent and sibling interview, in the timeline discussions, and in the photographic evidence in all participating families. Bruce mentioned that his friends knew that Evan was different and “they all either accepted it or we probably weren’t friends for very long.” As soon as Evan learned to walk, he was able to open the door. This meant that Bruce was on watch from the age of five to ensure that if his brother did run out of the house, his mother was informed. Isabella stated that when her mother deployed and she was young, she “felt more of a responsibility to Anthony. I still remember him crying, he was so upset. My grandparents didn’t understand him, so I was there for him.” She could also recall early recesses in elementary school where she would find him playing alone, rather than going to her friends she would sit with her brother so he wouldn’t be alone. Elaine stated that after her parents divorced, she was “always a bit overprotective of Tobias when they went to dad’s house. Neither of us had a great relationship with our father and he didn’t agree with the ASD diagnosis, so I always felt like Tobias needed me more there.” Jennifer just said that Mark “is the baby of the family and so he always needed protection and comforting, especially in new situations with new people.”

Reviewing the older photographs was interesting because many of the siblings didn’t always remember the photograph being taken, so their explanation of what was happening in the

photograph was more than likely the same explanation their mother told them when she provided them with the photograph. When asked what the most important role they provided in their house three of the sibling stated in some way the most important role was just to support their brother with ASD and help their moms with the household. Isabella is the youngest interviewed TD siblings, and also the only one that doesn't know her brother holds the diagnosis. Isabella stated that her role was to be there for all her siblings and to help them when they need her, be it supervising them on a trip to the shoppette, helping with their homework, or drawing with them when they were upset. Isabella was also a support for her family.

Elaine included a photograph of her and Tobias swinging in their backyard as children. This photograph was touching as Mary explained that Tobias was always terrified of swings. He screamed "piercing screams of death" every single time he was put on a swing. Mary recalled looking in the backyard as Elaine had set Tobias in a swing and he allowed her to swing him. Mary shared, "I watched from the window and held my breath, waiting on his screams that never came. Then I grabbed the camera with tears in my eyes. She was always doing things like this and he just loved her so much he would do anything for her." From that day on, Tobias would swing without any issues. Mary also provided a photograph of Elaine playing beauty parlor with Tobias. She shared that Tobias was sensitive to haircuts and would require being pinned down to have his head shaved. These beauty parlor games at her childhood vanity helped him to learn to tolerate haircuts. Neither of these acts were parent solicited. Elaine just wanted to help Tobias.

**Separations caused a change in lifestyle.** This theme was presented in both parent and sibling interview and in the timeline discussions in all participating families. Davis and Finke (2015) presented the statistic that 60% of all military families have relocated once in the last

three years and 47% have relocated three or more times in the past five years. The results of this study support this previous research. Mary reported six educational separations. Elaine is currently away at college, which would be seven total educational separations in her 19 years of life. “Although the divorce was hard for everyone, the hardest deployment was when he got sent to Iraq in his 20th year in the military.” Elaine said that he came back from that specific deployment ‘more hostile and a very different person.’ Bruce had experienced five deployments and three PCS moves in his life, between his father and step-father. The hardest event in Bruce’s life, however, was the divorce from Evan’s father and his mother’s remarriage. Bruce had known Evan’s father to be his father, even though he was adopted at age two. When the adults separated, Evan’s father’s family completely cut Bruce off. They “dropped me like a hot coal and it hurt, so I sort of stopped caring about school or respect or anything really. It was a very difficult time for me and I felt very lost.”

Ruth and Jennifer reported the most moves of the interviewed families, with seven PCS moves in her 18 years of life. They will move again in a year. In addition, the father has gone on five different deployments and the shortest of those was nine months. This deployment happened only five weeks after Mark was born, leaving Ruth alone with two young girls and a baby. “Deployments meant that the girls had to step up. We were all in it together. Dad was gone, so we pulled it off.” The hardest deployment for Jennifer was leaving Hawaii because she had a friend and they were inseparable. “Jennifer cried for months after leaving that base, she couldn’t handle not seeing her friend.” At the time of the interview, the family planned to move again at the end of the school year and Mark was already struggling with the next deployment, as he struggles to make friends and he finally found himself with a solid group of friends at their current location. Jennifer said, “Even being able to talk on the phone or email, leaving friends is

hard. I feel like pieces of me are scattered all over the states.” Ruth and Jennifer are the only pair that haven’t been through a divorce and remarriage.

Felicity is the only mother interviewed who was also active duty. She moved to Japan with Isabella’s father and both were deployable parents. Isabella’s first deployment occurred when she was four months old and this one was the hardest on Felicity. She was breastfeeding and she was forced to wean her quickly so that she could leave for Iraq for eight months. She was given some vaccinations the day before departure which made it so she wasn’t allowed to hold her the night before she left. Felicity said, “I literally was in a combat zone with leaking nipples.” Because Felicity was special operations, she was frequently deployed. While in Japan, Felicity and Isabella’s father divorced. He still lives in Japan. Because of the frequent deployments of both mother and father, Felicity had a nanny who lived with them as a family and stayed with her after they separated. Felicity recalled another deployment that was four weeks long when Isabella and Anthony stayed with their father. He had dogs at the time and the children were fearful of the dogs. This fear, in conjunction with a different diet and the stress from their mother being gone, caused some stomach issues for Isabella. Felicity shared that even to this day when she gets stressed out, she has immediate stomach issues. Thankfully Isabella doesn’t recall either of these deployments. The deployment that Isabella remembers happened when she was seven years old. Felicity went to Iraq again, but this time the children went to stay with her parents in Oregon for six months. At the time, Felicity was married to Isabella’s stepfather and he was also deployed. Isabella said she remembered “that I felt responsible for Anthony and I can still remember him crying.” Anthony was “so upset and I felt like I needed to be there for him, so I would hang out with him and we would draw.” Felicity also discussed this deployment and how when they came back together, she and Isabella just clicked back into their

relationship. She also shared that Anthony took longer to become the warm, loving child that she had known when she left. Anthony and Felicity had to regrow and relearn their relationship. This particular deployment left him with anxiety and even daycare drop offs would upset him greatly. Isabella also mentioned another deployment that happened more recently with her stepfather. Her step father has been in her life for almost ten years now and he recently went somewhere to a combat zone. Isabella stated that when she was little and her parents deployed, she felt bad about missing them and she felt responsible for Anthony, but as she got older, she realized the possibilities of what could happen and that they might not return. She said, “I love moving around and experiencing new things, but I don’t like my family going into dangerous situations.”

**The annoying little brother.** This theme was presented in both parent and sibling interview in all participating families. Bruce mentioned that Evan “was irritating, always talking about things in a loop. Even if we discussed it just a minute ago, Evan would tell me again. Also Transformers, I hate Transformers because of Evan. It was all he wanted to watch and if he didn’t get to watch he would get mad. To keep him happy mom would make me let him watch and we saw it every day for months.” Elaine mentioned that Tobias would “get stuck on or claim my toys and he would just take it. I would put up a fight to get it back and then get in trouble for making him meltdown. It was irritating because he always got what he wanted.” Jennifer shared that “Mark always got his way; he was always the one in the right. Mom always worked to keep him happy, so if we pushed the limit we were in the wrong because we were older. We were supposed to help with homework when she needed it, but then we were supposed to let him do as he pleased. Thankfully Mark really just wanted to play, so most of the time I just played with him. But when you played with him it was his way or no way. I learned early on to give him

what he wanted or I would end up in my room.” Isabella had a little different take on the irritations of having a sibling, she stated that “they annoy you because they are your brothers. They get on your nerves and mock you or draw on your artwork, just to be annoying.”

**Reactions to home therapy at an early age.** Home therapy was evident within three of these military houses. Two of these families had therapy when the TD sibling was at a young age, one family had the therapy when the TD sibling was older. The reaction theme revealed itself in parent and TD sibling interviews in two of the three families that experienced home therapy. Of the 36 photographs submitted, eight photographs (22%) showed the siblings participating in home therapy. The siblings’ reaction to the various therapy providers was split. Both Bruce and Elaine mentioned the in-home providers and how they felt left out, whereas Jennifer and Isabella didn’t. When Isabella’s sibling received in home therapy, she was in middle school and she had friends of her own and Jennifer never experienced at home therapy. Elaine said, “Tobias always had fun people coming over to the house to play with him and I wasn’t able to play with them. I was really jealous because they would bring fun stuff. Some would let me play, but most of them wanted me just to let them alone.” Bruce also shared that he had “an extreme case of ‘I’m older and I don’t get paid attention to’ because Evan was always getting to do stuff and go fun places and mom was always spending time with him.”

Mary fought hard to stay in one location, to ensure consistent care for Tobias and because her job as a school psychologist demanded this consistency. Mary and Elaine’s father separated when Tobias was only five years old. They are the only family that hasn’t endured any PSC moves, however the father did go on multiple (four) long deployments in that time they were a family unit and “I’m not really sure how many after we separated.” After that Mary and Elaine’s

father had split custody, but when he got remarried his wife didn't want the home therapy to make home visits to their house.

**Improvement of sibling relationships as they matured.** This theme presented itself in the parent and TD sibling interviews in all four families. Growing up with a sibling who has a diagnosis of ASD may come with irritations and difficulties, but as these siblings grow up they gain a better understanding and acceptance of their sibling with ASD. Jennifer, Elaine, and Bruce all shared that they didn't have the best relationship with their sibling growing up, but now it was better. Bruce stated that he would visit friends' houses and their siblings were just like him and "I would get home and I was almost nothing like Evan. We use to bicker so much, and he just talked so much about the same stuff. But now I can tolerate him and we can actually have a conversation." Elaine said that she and Tobias had a good relationship growing up and they still have one, "We just don't talk on the phone every day or anything. We were close as kids, but then when I went to middle school, we sort of drifted apart a bit. I think we could say we have sort of reconnected in the last couple of years." Jennifer said, "We have always been close and I will always look out for him, he's my little brother."

In response to stress from family separation, Bruce was lashing out and doing poorly in school. The family decided to enroll Bruce in a residential "quasi military school." Bruce spent from January to June away from the family and this acted as their educational separation. During this time away, Bruce made a friend and enjoyed himself. "I liked the routine and structure and even ended up making honor platoon." When he got back to the home Bruce was much more tolerant with Evan and more respectful to everyone else as well. Martha even stated that, "the boys almost have conversations now. Since Bruce went to military school, he is able to talk and listen Evan without the frustration in his voice that I use to hear."

**Fairness among siblings.** This theme emerged in the parent and TD sibling interviews and timeline discussions. The first common things that all four parents discussed was fairness. Each parent interviewed discussed how their child with ASD required more of their attention and support. Maria said it best, “As a parent you try to be there for what the kid needs, but what the kids need isn’t always equal and equal is not always fair.” All four parents talked about how they worked hard to show all their children that they loved them equally, but their child with ASD just required more individualized time with parents. Marie stated that she was “sure that Elaine feels like her brother has been the preferred child, but as parents unfortunately some children need more attention. I always worked hard to make her feel special.” Martha shared that it was family members who stoked these emotions of inequality in Bruce. She shared that these individuals would tell Bruce that, “I love Evan more because I spent more time with him and always took him places (various therapies).” Although Bruce doesn’t remember this, Martha shared that it caused a family divide when the boys were younger. Ruth mentioned she worked hard to keep relationships even, but Mark just required extra time and care. She felt like her girls understood this and “wanted Mark to have the support because he was the baby and they knew he needed it.” Felicity discussed a level of fairness to all her children. Because Anthony and Isabella were not informed of the diagnosis there was no discussion of the idea that Anthony was considered preferred child. Felicity looked to Isabella as a sort of translator or go between person when Anthony was hard to reach. She shared that “it was always harder for me to bond and connect with him, but she was connected with him.”

**Anticipation for what the future holds for their children.** This theme emerged from all parent interviews. Parents were asked about what they anticipate the future to hold for their children, both with ASD and TD. Three of the four parents were certain their TD child would be

completely fine. Ruth did have some worries about Jennifer because she has recently dropped out of college after her first semester to work in the restaurant business. However, she also expressed that at the moment Jennifer was happy with the work, no matter how long the hours were, and that was really all that mattered. All four parents voiced concerns about their ASD child's efforts. Martha was considering homeschooling Evan. Ruth homeschooled Mark last school year. Felicity described Anthony's school setting as a behavior classroom with a smaller number of students. Maria described Tobias as a, "his words, not mine...lazy student." However, each discussed the child's brilliance. Maria said, "His IQ is through the roof and he out debates me all the time. I have to tell him, 'I am not as smart as you, but I am your mother'." He is junior in high school and has been fixing computers for his school district for four years. He builds and restores damaged laptops, computers, and phones for resale as a way to make some extra money. Martha said, "Evan is full of facts, but they are facts that he wants to know like animals or space. It all depends on what he is obsessing over at the time. He is interested in a career with electronics, I just don't know how we will ever get him through school now." Felicity stated that Anthony was "reading at a senior level when he was in 3rd grade and his math was that of a freshman in high school. He couldn't explain the reasoning, but he could always find the answer. He just always had trouble not cussing or having angry outbursts." Ruth expressed that Mark "enjoys building and electronics, but struggles with the social aspects of school. He also has anxiety about testing and the teachers just can't always get what he knows out of him." Ruth joked about how she would "have to just go to college with him."

**Self-reflection of their parenting choices.** This theme emerged from all parent interviews and timeline discussions. All four mothers questioned their parenting and analyzed their struggles at some point in the interview. Each one said at some time during the interview,

“Is this a typical boy challenge or is it the Autism?” Although each of these mothers are trying to maintain a household, multiple children, and survive the day to day, all strive to be loving parents. Mary shared that she “wanted Elaine to have a support system and I wanted her to understand of what was going on even when she was a young girl. I sent her to sibling camps every summer and she would go to sibling workshops once a month. This gave her friends who also had siblings with ASD or other disabilities. Then when she was gone, I would worry that she would think that I had sent her away. I wanted her to know that she was not the only kid going through this and I never wanted her to feel like I loved him more. Just to understand that he needed more of my time.” Mary questioned what Elaine would recall and was worried what she would share during the interview. Martha was very disheartened by a comment made to her son by a family member, when he was just four or five years old. She still holds onto that one comment for fear that he sees truth within it. Felicia questioned her career field and having to leave her children at such a high frequency, mentioning a specific time where her daughter had some digestive issues when she was gone. Ruth talked about how Jennifer wanted to mother Mark, asking herself, “Does she think I am not doing it correctly or that I can’t parent my own son?” All of these mothers wanted the absolute best for all their children. They had sacrificed and struggled with parenting and the choices their lives have made for them. Not one of the parents noted these struggles as resulting from having a child with ASD. Although they obviously had many struggles, having their child with ASD had shaped their family unit.

With the self-reflection, there was also an element of self-sacrifice. At the time of the interview, Bruce’s step father had already moved (two months prior) and the family was to join him in four months at the end of the school year. Martha didn’t want to uproot all the children in

Bruce's senior year and she just had a baby two weeks ago. Ending the school year where they started was what Martha decided was best, both for Bruce and also for Evan.

### **Research Question Response**

**RQ1:** How is the well-being of a typically developing child in a military family living on a military post impacted by having a sibling with autism in the home?

Military families have so many factors to consider, having a sibling with ASD doesn't even seem to take a precedence. The two related themes to this specific research question included the annoying little brother which then transformed into the improved relationship with maturity. Each of the interviewed siblings could tell of a time when they were annoyed or irritated with their sibling with ASD, yet all of them also felt like their relationship had improved as they grew up. Although each of these four families had a history of mental illness and each of the four siblings had taken antidepressants and anti-anxiety medication at some time in their short lives, all four siblings interviewed were positive about their current well-being.

Photographic evidence also supported this research question. When asked about which photograph best described their well-being, described as state of happiness, most of the time, the three girls showed a selfie with a great smile. Bruce showed a selfie photograph of him looking serious. When asked to explain Jennifer said, "I try to be happy." Elaine said, "What can I say, I am a positive person who likes to smile." Isabella stated, "I am happy and it's a cute pic." Bruce stated, "I know it looks serious, but that's a smile for me. I am happy just not a teeth showing kind of guy."

**RQ2:** How does having a sibling with ASD impact the roles of the typically developing siblings in a military family who lives on a military post?

Having a sibling with ASD on a military post impacted every child differently. In regards to the roles of a TD sibling, it depended mostly on the individual parenting styles and family dynamics. It was expected that the TD siblings would be utilized as social role models and to some degree this was true. Each of the siblings played a role in home therapies and all had feelings about these experiences. However, the TD siblings looked more at their physical roles, either their day to day responsibilities or chores within the family unit. Mary was the only parent that didn't reinforce household chores with her children. She "worked really hard to let Elaine be a child." The only real expectation she had for Elaine was that "she wasn't allowed to call him (her sibling with ASD) stupid or retarded. Her only responsibility was to be kind." When they rode the bus there were a few times that she was left to walk with him there, but most of the time Mary walked with them. The other interviewees utilized age appropriate chore charts to help teach responsibility. The chore chart was inclusive of all children in the household.

Ruth stated that the older the children got, the more chores they had. They were all expected to help out because much of the time she was on her own. Mark was the only boy and significantly younger than his two sisters. "When he was a baby the girls wanted to help because he was like a real live baby doll." But there were no set responsibilities in regards to Mark's care that fell on their shoulders. Jennifer was the more patient of Mark's two sisters, so she typically stepped up to help with homework. As Jennifer got older, she was more inclined to offer motherly advice to Mark and often felt it was her responsibility to give punishments, which caused some resentment with Mark.

Martha utilized a chore chart with all of her children, Evan was assisted by the ABA to complete his chores. Bruce was responsible for taking out the trash and he also was on the same school schedule as Evan, so his daily responsibility was to ensure Evan was up, had his teeth

brushed, and got on the bus. Growing up, Martha also relied on Bruce to help watch the door when Evan was a toddler. He was a runner and if he left the house, Bruce would let his mother know and follow Evan.

Felicity also said she utilized a chore chart with all her children from an early age with age specific chores. Isabella felt like her only responsibility was to help the younger siblings with their homework and they had a rule in their house that no one goes anywhere alone. If a sibling wanted to go play outside or go to the shoppette, as the oldest it was her responsibility was to go with them.

**RQ3:** How do parent perspectives on the experiences of TD siblings compare and contrast to the TD sibling's actual experiences and perceptions when one sibling has ASD on a military post?

True to form, with any story, there are multiple perspectives to any story. Mary shared with me that Tobias would become obsessed with Elaine's toys. Mary shared, "He loved her Barbies and her little pets. We would always two sets of everything and wrote a T on his copy of the toy. We had two of everything Polly pockets, Barbies, Barbie cars. He was so obsessed with her Barbie car that he got it and she got a new one." Elaine recalled, "He would get stuck or claim the toys. He would take it and put up a fight to get it back." Elaine specifically remembered him taking it and putting up a fight to getting it back, but not that there were two sets. Both Mary and Elaine marked the hardest deployment was the father's return from Iraq and both stated, separately, that he came back "different." However, this was after the divorce, so chances are Mary received this information from Elaine directly.

Similarly, Felicity and Isabella both discussed the hardest deployment for their family as a time when Felicity went to Iraq for nine months and they went to stay with grandparents. Both

mother and daughter recalled how traumatic that was for Anthony. Isabella shared, “I remember that I felt responsible for Andrew. I still remember him crying. He was so upset and I hung out with him and drew with him. I felt like I needed to be there for him. I felt more responsible then, than I would now.” Whereas Felicity remembers how difficult it was to reconnect with him after returning home. “We had to regrow and relearn this relationship. For my daughter it just clicked back into place, mom was home. But for him, it took a while. He had so much anxiety about me leaving that even day care was difficult.”

Martha and Bruce discussed an afternoon when he was three or four years old. Martha swears Ethan was in the house, Bruce thinks it was before Ethan was born. They talked about a time when three friends from the base were running in and around the back yard, jumping fences. Bruce said, “We were all just running in and out of the back door and handing out in the backyard, like a miniature party. Mom made no bake cookies and I remember my friends saying how good they were, but I didn’t eat them. It was before I understood what summer meant, but it was hot out. That was a good day.” Martha argued that it could have been any day, “living on post means there are always random children at your house.” But Bruce argued that this was “a really special day.”

Jennifer and Ruth discussed homework routines with varying perspectives. Jennifer shared that, “Mom struggles to look at Mark objectively. She gets emotional and he works it so that he can put off the homework that has to be done. He knows she will make excuses for him or even just do the work for him. I won’t. How is he going to learn if I do it for him? This is why I am, or I was when I was home more, usually to go to homework person. I don’t give him a chance to pull my heart strings. We just do the work.” Ruth agreed to disagree, “Jennifer likes to play mom, so she often seems rough and rigid with Mark. She enjoys giving out punishments

and threats. He becomes anxious. It's hard for me to watch sometimes. She always got the work done though in less time than I could, but at what cost? So, we could have dinner, usually. He is different with me; he is my baby. Jennifer loves her brother, but she is no nonsense and sometimes he needs some love and a few breaks to get it all done.”

### **Summary**

In this chapter the participants were introduced and discussed extensively. The themes revealed from the TD sibling interviews, timelines, and photographs included the protective nature of these siblings over their siblings with ASD, separations create a change in lifestyle, the annoying little brother theme, reactions to home therapy at an early age, and the siblings' relationships improved as they matured. Other themes that emerged from this research in relation to the parents included the striving for family fairness among their children, anticipation for the future for their children, and self-reflection of their parenting choices. Of the four families interviewed three have worked through a divorce and remarriage. Timelines also showed that these four families have endured family separations that lasted between three to twelve months an average of 11.5 times during the TD sibling's life. One family worked hard to stay in the same location, while one has moved seven times, with the eighth move planned the year after the interview. The photos showed the TD sibling, throughout their lives, with family and friends. After discussion with the four siblings the underlying message that the most important role they played within their family was just to support their brother with ASD and help their parents with day to day life. Be it through assisting with home therapies or completing their part of the chore chart, these siblings understood that families work together for a common goal of making their household run a little bit smoother.

## **CHAPTER FIVE: CONCLUSION**

### **Overview**

The purpose of this qualitative study was to understand the typically developing (TD) sibling's well-being and role in a military family with a child with autism spectrum disorder (ASD). The themes revealed from the TD sibling interviews included the protective nature of these siblings over their siblings with ASD, the annoying little brother theme, reactions to home therapy at an early age, and the siblings' relationships improved as they matured. The themes that emerged from the parent interviews included the striving for fairness among their children, anticipation for the future for their children, and self-reflection of their parenting choices. In this chapter, the findings of the research are discussed, along with the theoretical, empirical, and practical implications of the study. Contributions and recommendations for various stakeholders, such as parents and at home therapy providers, are presented in this chapter, as well as delimitations, limitations, and recommendations for future research are also discussed in this chapter.

### **Summary of Findings**

This collective case study was designed to answer three research questions. The first question examined the well-being of the TD sibling in a military family, living on a military post, when one sibling in the home has a diagnosis of ASD. The second research question investigated the specific roles the TD sibling has within the military family. The final research question reviewed, compared and contrasted the TD siblings' actual experiences and perceptions to that of the parents. The families interviewed were all military families living on a military post, and all had multiple siblings in the family, one of which had a diagnosis of ASD.

The first research question addressed the well-being of TD sibling in a military family and the impact of having a sibling with ASD in the home. This study found that all participants had been through rough patches in their lives, but all felt content with their level of happiness at the time of the interview. All four families had a history of mental illness and all four TD siblings had taken medication for anxiety or depression at some point in their lives. At the time of the interviews, all four siblings were managing without medication. Three of the four interviewed had gone through a divorce and remarriage. Jennifer and Ruth were the only pair that had not experienced divorce and remarriage. The TD siblings had all endured countless separations, isolation from family and friends, and sibling irritations. At the end of the day, their relationships with their siblings improved as they got older with a loving family to provide them with the needed support to maintain a healthy well-being.

The second research question this study addressed the roles within the family unit for the TD sibling of a military family where one sibling has ASD. The roles varied based on family dynamics and expectations. Most of the families interviewed had an established chore system put in place and the children were all expected to contribute. One family felt strongly that the children needed to be children, and therefore the specific TD sibling was not expected to really do anything but be kind. However, that sibling gave herself roles. She was very protective of her brother and she helped him break through on various activities that bothered his personal sensory barriers. The other three families had weekly expected chores and the TD siblings were expected to step in and watch after their sibling with ASD in social situations and also help out in the home, either with homework or just to ensure that their sibling didn't leave the house when their mother was otherwise occupied.

The third research question this study addressed was the actual experiences and perceptions of the parent versus the TD sibling. The parents strived for fairness and worked hard to provide love and care for all of their children. The siblings all recognized this, to some degree, but this recognition came later in life. The parents interviewed shared their worries of the time and how they reacted to their children. However, the TD siblings were often very unaware of the worries or parental struggles. Whether this meant buying another set of Barbies for the son to claim or recognizing how difficult it was to leave your children at Grandmother's house while you go to Iraq for nine months, the parents worked hard to heal wounds that childhood may have brought. One parent shared that a family member mentioned that the child with ASD was the preferred child to the TD sibling when the TD sibling was very young. Even 15 years after this, the parent was still very angry and hurt by the accusation. The TD sibling didn't even recall being told such a thing. He even stated that he thought "it was utter nonsense." This one conversation has bothered that parent for all these years. Even when it was discussed and he denied ever hearing it, the mother's face still portrayed the pain that it caused her at the time.

## **Discussions**

The purpose of this section is to discuss the study findings in relationship to the empirical and theoretical literature reviewed in Chapter Two. This is the section that will show how presented research confirms and extends previous research.

### **Theoretical Discussion**

Multiple psychological theories were utilized to frame this study, including the social cognitive theory (previously known as the social learning theory) (Bandura, 2001a), the self-determination theory (SDT) (Ryan & Deci, 2000), and the family system theory (Bowen, 1966).

According to the social cognitive theory, older siblings often act as socialization agents for the development of their younger sibling (Lam et al., 2012). This was evident in all four of the interviewed families. Three of the four siblings were utilized in therapies to help with social skills and the fourth was an active participant in the social development of her brother. The parents all looked to the older sibling to not only accept their sibling with ASD, but also to nurture a kind and caring relationship to help build their socialization abilities out in the ‘real world.’ Elaine and Tobias practiced social situations in the home, and Mary talked about how this success is due to Elaine’s time with him. This was exemplified when Tobias was sensitive to haircuts as a child and would require being pinned down to have his head shaved. Elaine would play beauty parlor games at her childhood vanity and this role playing helped him to learn to tolerate haircuts.

According to the SDT, an individual must have three psychological needs (competency, autonomy, and relatedness) met for optimal social development and personal well-being (Deci and Ryan, 2000). All four TD siblings demonstrated a high level of psychological health and well-being at the time of the interview, and felt part of a warm, supportive environment (Deci, 2012). It could be concluded that at the time of the interview all of their psychological needs were met to satisfaction. They all were performing well academically, and finding success in their own personal undertakings. However, all four TD siblings had a history of requiring medical supports to stabilize their moods and anxiety levels at some time in their lives. Meeting these psychological needs is not something that is checked off and stays completed. It is an ongoing process that requires attention and fluctuates with the personal and family unit needs. Three of the four families had been through a divorce and remarriage. This was exceptionally difficult for Bruce, as during this time his father’s family completely disconnected with him.

Martha talked about how he struggled within the family unit during that time. He was tense with Evan and he only saw their differences. This inability to relate to Evan caused irritations and frustrations for Bruce. As a result, he was not willing to foster certain behaviors and give appropriate social exchanges. He spent a few months of his junior year in a military school which helped him to appreciate the family system that he had. When he returned to the family for his senior year he had matured and Martha expressed joy in the changes she had observed. He thrived in the military school and came back to feel more comfortable in himself and in the supports of his new family circumstances. Both Martha and Bruce admitted that he became more accepting of Evan and their relationship was becoming more friendly and traditional. Evan required less coaching from Bruce and they are now able to converse without hostilities. Isabella and Jennifer, like Bruce expressed a time when they lacked personal motivation to help with their sibling. Both connected these feelings to deployments and separations from a parent, leaving them feeling controlled in the environment with low self-esteem and anxiety (Deci, 2012; Ryan et al., 2008). All four siblings had reported taking medication for anxiety and/or depression medication before in their lifetime. Mary and Elaine both noted that middle school was a difficult time for Elaine to support Tobias, noting this time being when their relationship suffered the most. Mary is a school psychologist and she stated that “middle school is a time of great selfishness, and Elaine was more worried about fitting in than her brother.” She also said she never worried, that it was completely developmental and since then the relationship had been repaired.

The family systems theory discusses how a set of subsystems impact family members and ultimately influence the family unit (Bowen, 1966). Bowen (1966) looked at the relationships within the family system and how they function efficiently. The four TD siblings that

participated in this study presented multiple relationship bonds in their family subsystem. There were times when parents were away that they acted with parental intent, they were siblings, friends, mentors, and children. They had relationships with their parent and also with their sibling with ASD, but they also all had times when they were stepping into a parental role with the sibling with ASD. Elaine mentioned becoming overprotective when they visited their father after the separation. She stated that they didn't have the best relationship with their father and he didn't believe Tobias had a diagnosis, so she stepped in because her brother needed the support. Isabella talks about supporting Anthony when her mother had to send them to their grandmother's house to live for nine months. She talked about how she knew what he needed and she was the mediator between Anthony and the grandparents. Ruth talked about how Jennifer often forgot that she was only Mark's sister and still to this day feels the need to correct him and even often imposes restrictions, if she sees fit. Bruce kept a protective eye over Evan both in the home and in the neighborhood to ensure that he would stay close to the house and not flee. These siblings all felt a compulsion, as part of their roles within the family or subsystem, to protect, care for, and supervise their sibling with ASD.

### **Empirical Discussion**

The four families that participated in this study exemplified current research. All four mothers indicated a concern about the socialization and the peer relationships of their sibling with ASD. This is consistent with findings that indicate social impairments for individuals with ASD are common in the area of social and emotional reciprocity (Arya & Sindhwani, 2016; Bernier & Gerdts, 2010; Gold & McCabe, 2012; Green, 2013). Of the four families interviewed, all four of the siblings with ASD had a history of speech difficulties. Two of the four indicated that speech was delayed while the other two spoke in echolalic speech for the first few years of

life. This is consistent with Arya and Sindhvani's (2016) research which stated that communication impairments can range from slightly delayed to robotic repetitive to completely nonverbal for individuals with ASD. Restricted interest was another commonality between the empirical research and the interviewees. All four TD siblings talked about how their sibling with ASD would become fixated on a certain video game, television show, movie, or cartoon which would hold their full interest and limit all conversations while it was the focus. Repetitive and restrictive behaviors in children with ASD are common according to Arya and Sindhvani (2016). In addition, McHale, Updegraff, and Feinberg (2016) mention that older siblings of children with ASD found themselves "giving in" just to appease their sibling. Three of the four siblings discussed this being a part of their childhood.

While this study aligned with much of the research related to ASD, there were some conflicting findings. One of the differences is regarding the statistic that 68% of individuals with ASD can have an increased rate of aggression at some point (Hodgetts et al., 2013). However, only one family in the study discussed aggression and this was in the form of self-harm when the sibling with ASD was younger and would reach frustration. The family that spoke of this, talked about it as being brief and they recovered. The other three families (75%) had no mention of physical aggression. Other contradictions were related to the TD siblings' involvement in the family and school settings. Walton and Ingersoll (2015) reported that siblings of children with ASD were less involved and more avoidant of their siblings, when compared with siblings of TD children. However, each TD sibling interviewed was active within their family unit and in their schools, participating in multiple extracurricular activities, and within their family unit.

Because there is limited research on the siblings of children with ASD in the military, this study sheds light on how these individuals respond to the challenges that life presents. The

sibling interviewees presented as a collective group of protectors, both for their families and for their siblings with ASD. This study shed light on the parents' struggles with fairness and desire to treat all their children with some degree of sameness, even though the individual children required different supports growing up. The parents interviewed felt remorse for different situations that occurred in their children's lives, and felt inadequate in some measure. In all cases, their children didn't recall the situation begrudgingly or even with a hint of bitterness. One positive effect of parental deployments can be fostering resilience, and increasing responsibilities can foster growth and maturity (Brendel et al., 2013; Richardson et al., 2016). This resilience and increased responsibility presented as identifiable in all four families. The TD siblings all presented themselves in a manner of growth and maturity beyond their years.

### **Implications**

The purpose of this section is to address the theoretical, empirical, and practical implications as they directly relate to this collective case study. The roles within the military family and well-being of the TD sibling with one sibling who has a diagnosis of ASD could provide connections for in-home service providers, teachers, therapists, and other military families who have a child with ASD.

#### **Theoretical implications**

Within the theoretical frameworks of this study, the social cognitive theory (Bandura, 2001a), self-determination theory (Ryan and Deci, 2000), and family systems theory (Bowen, 1966) were examined. Through the lenses of these theories, motivations and characteristics were explored to help find a better understanding in the connections with social development, roles and well-being for the TD sibling in a military family where one sibling has a diagnosis of ASD. Bandura (1962) explored how individuals learn behaviors from their surroundings through

modeling within the family system. This was confirmed by all four families; the TD sibling was looked at as a social model. Elaine especially helped Tobias to overcome fears of swings and haircuts by practicing in a play situation. She did this without prompting or suggestion, but she stepped up because she genuinely wanted to help him overcome these fears. This ties in directly to the self-determination theory, which examines how an individual's needs fuel his or her motivation (Ryan and Deci, 2000). She observed multiple therapist in the home, coming to help her brother and this presented itself as a motivator for her to also want to help. The same was found in Isabella who found her brother playing alone on the playground and she was motivated to be with him. The family systems theory discussed various family subsystems that help families counterbalance and compensate for situations (Bowen, 1966). This was evident in Jennifer's situation as she took on a more parental role within her family unit, wanting to discipline Mark and helping with homework, whereas Bruce was the parental assistant that helped to watch over Evan from a very young age. Elaine acted as a sibling, but placed herself in a role of therapy provider in play. Isabella was the protective older sibling, but she was also the comforter when mom wasn't there because of deployment. Each of these roles shifted with the demands that the military placed on their individual family needs.

### **Empirical implications**

Literary research presents a plethora of information about having a family member with autism, stating that these families will cope with speech concerns, social impairments, and fixations from the sibling or child with ASD. This was true with the participants of this study, but within each family unit these situations present themselves all together differently. The families that participated in the study were all very strong, supportive family units. The TD siblings that were interviewed all took responsibility for helping out in their family and with their

sibling with ASD. Each one discussed a time of stress and a time when they weren't as willing to assist, but with age and maturity they changed their perspective. The same was true of their relationships with their siblings with ASD. Similarly, each family interviewed discussed some form of depression or anxiety within their family and each of the siblings interviewed had been on medication of some kind at one time or another. However, at the time of the interview all were managing without medication.

This study provides information about the life of a military family on a military post and how this aspect of life could impact the well-being of the TD sibling and the roles they take on within the family unit that has one sibling with ASD. These families have friends and know people all around the country, because of the military affiliation. Each family mentioned the need to foster these relationships. Parents were pushing for their kids to visit, call, or message past friends from previous bases to maintain and strengthen these bonds. The military life offered an enrichment that these families may not have had without the military to bring them together with these people. These families withstood multiple separations within their family unit, either military directed or for personal reasons. These separations brought them closer to their military friends and neighbors. These separations were to directly support the advancements of careers and also to benefit the children within the family, to improve the life of the family members. The mothers interviewed work hard to provide a 'normal' family life for themselves and their children, whatever normal means. But to these families it means saying goodbye and relearning each other more frequently than most. They strive for sameness, but find a way to thrive in change.

## **Practical implications**

The practical implications of this study include benefits for both parents and in-home service providers. This study has shown that TD siblings, especially if the child is younger in age, feel left out of in-home sessions while the providers come to work with their sibling with ASD. As the TD siblings felt that their sibling had special friends who came to visit only him/her, in home therapists might strive to include the TD sibling to a higher degree. Obviously, there are times when this wouldn't be appropriate, but typically children with ASD struggle with social skills and often require a visual model or social story. These TD siblings could be utilized in these sessions to benefit the sibling with ASD and include the TD sibling.

The parents could also take from this study to not sweat the little things, even when they don't feel so little at the time. These interviews provided insight into the parents' thinking on the job they did raising their children. The parents were all very critical of decisions they made to benefit their family even though all were done with thought and others in mind. However, their children were never keeping score. Their children were just children, who were growing up and learning where they fit into the world. They weren't analyzing behaviors or comparing their lives to others.

## **Delimitations and Limitations**

This study was purposefully limited, in the beginning, to only include TD siblings over the age of eleven. Later in the study, the limitations spread to only that of male siblings with ASD. This decision was made intentionally, as there was an interview conducted with female siblings with ASD. However, this interview was conducted with the second born sibling as the first-born sibling was the female with ASD. The decision to made to remove that interview from the study as it was not in alignment with the other participating families who had male TD

siblings older than the sibling with ASD. Had more individuals participated that had a younger sibling with ASD, this would have been a good addition to the study. But as this family was the only one with a female sibling with ASD and the TD sibling was the second born, they were excluded.

A second limitation was the restricted setting. The study took place on one army post which limited the number of individuals who could participate. Finding female siblings with ASD proved more difficult than originally expected. The same is true of finding siblings of varying birth orders. Because the TD siblings ranged in age from 14 to 19, this is a limitation for the study. The older the sibling, the more they shared about their life. Another limitation of this study is that only mothers were interviewed. The father's perspective is, no doubt, somewhat different, and equally valuable.

### **Recommendations for Future Research**

In consideration of the study findings and limitations, there are several recommendations for future research. Firstly, although variation was sought by participants who came forth all fit within a similar type. There was a family interviewed who had female siblings with ASD and the responses and themes didn't fit with those presented by the other cases in this research. Future research should take place in families with only female siblings with autism. This could be done as a multiple case study, utilizing similar techniques to this research.

Secondly, an interview was conducted with a TD sibling who was younger than their sibling with ASD. The sibling interviewed idealized their sibling with ASD and they also presented an element of strain that the older siblings interviewed didn't possess. The responses varied so much from the selected participants, they were also removed from the study. Future research could evaluate only families that have TD siblings younger than their sibling with ASD.

This could be done in a multiple case study, utilizing similar techniques to this research for comparison utilizing focus groups and interview formats.

All parents that agreed to participate were mothers. Future research should involve interviewing only fathers. Utilizing phenomenological research techniques, interviews and focus groups, would be beneficial to better understanding the fathers' perceptions of having multiple children, one with a diagnosis of ASD.

The military aspect of this study did play a huge part in this research. This exact study could be done with civilian families to see how their views change. This could be done in a multiple case study or phenomenological research, utilizing interviews and focus groups.

The final recommendation for future research is to look into the impact of home therapy on the family unit or the TD siblings. This could be done in focus groups or through interviews, multiple case studies or phenomenological research techniques.

### **Summary**

The purpose of this collective case study was to understand the typically developing (TD) siblings' well-being and role in a military family with a child with autism spectrum disorder (ASD) on a military post through the parent and TD sibling perspective. Participating families were interviewed. They shared time lines to include moves and other life events, and photographs to depict these roles and the TD siblings' well-being. Within these interviews, the parents and TD siblings shared stories of their childhood, struggles, and victories. From these data collections, the themes revealed from the TD sibling interviews included the protective nature of these siblings over their siblings with ASD, separations create a change in lifestyle, the annoying little brother theme, reactions to home therapy at an early age, and the siblings' relationships improved as they matured. Other themes that emerged from this research included

the striving for fairness among their children, anticipation for the future for their children, and self-reflection of their parenting choices. The participants shared details about their frequent deployments, PSC moves, educational separations, and marital separations that impacted their lives. The TD siblings shared images, both current and of their youth, to best describe their roles within the family and their well-being. Although each of these siblings had taken medication for anxiety or depression at one time or another, all presented themselves in a place of happiness and all expressed great contentment in no longer requiring medication to maintain this state of happiness. Throughout the years, these siblings had taken on many roles, but the one that started the earliest and was more prevalent than other was that of protector. This role reflected the parents within the household, as these siblings modeled behaviors they had witnessed. Although each parent was critical of their role as a parent, the siblings were all happy and healthy. Each parent had a circumstance that worried them, something that they expected their TD sibling to share, and in the end these incidents were forgotten by the child and replaced with other memories of childhood. These parents all strived for a level of fairness among their children, and the children felt these efforts. Even if they did feel left out during home therapies, they still felt loved and cared for in their family situations. As children, they wanted to be included with the visitors that entered the home, and as young adults they understood that those visitors had a purpose that was greater than just bringing toys to the house to play with their sibling with ASD.

As soon as Evan learned to walk, he was able to open the door. This meant that Bruce was on watch from the age of five to ensure that if his brother did run out of the house, his mother was informed. Jennifer sat up at the table, helping Mark with his homework, while their mother prepared dinner and helped the oldest daughter. Elaine helped Tobias to overcome his

fears of the swings, when she was only three. She then moved on to help him conquer his fear of haircuts, by offering play situations where she would cut his hair. Her efforts and his love for her made these situations tolerable for him to overcome. Isabella sat helping Anthony with homework or walked with him to the shop if he needed company. These siblings were active participants in the social development of their sibling with ASD. They may have lost patience when it came to the thousandth viewing of the Transformer movie, because it's the only thing he wanted to watch, but they were there for the important things. Their love and support helped to shape the success of their family and their sibling.

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## **APPENDICES**

### **APPENDIX A: EMAIL FOR RECRUITMENT**

Hello. My name is Jennifer Henderson-Rudling and I am doctoral student at Liberty University. I am in the process of recruiting research subjects for my doctoral dissertation which will examine well-being and roles of the typically developing siblings of children with Autism Spectrum Disorder (ASD) in a military family. I am looking for families with multiple siblings, one of which has a diagnosis of ASD.

The actual research process will require the completion of a family timeline by a parent which will indicate deployments, moves, and other life events as well as an interview with the participating parent which will take approximately an hour. I would like to hear the sibling's perspectives on his/her life experiences first hand, therefore he/she will be provided with a digital camera to document his/her roles within the family and will participate in an interview that will take approximately an hour. For this study, I would like the sibling to be at least 11 years of age. Follow up interviews may be conducted to confirm themes and similarities with the experiences of individuals from different families.

If your family meets these requirements and you are interested in participating in this research, please complete the attached demographic questionnaire and contact me at [jmhendersonrudling@liberty.edu](mailto:jmhendersonrudling@liberty.edu) or by phone 931-436-0244.

Jennifer Henderson-Rudling

Doctoral Candidate, Educational Leadership at Liberty University

## APPENDIX B: INFORMED CONSENT

### Collective Case Study on Life with a Sibling with Autism

Principal Investigator:

Jennifer Henderson-Rudling  
Doctoral Candidate  
Educational Leadership  
Liberty University  
[Jmhendersonrudling@liberty.edu](mailto:Jmhendersonrudling@liberty.edu)  
931-436-0244

You are being invited to participate in a collective case study which will examine the parental and sibling perspectives on the roles a sibling of a child with ASD within a military family has within the family as well as his/her well-being. I am interested in understanding your thoughts, feelings, experiences, and history of growing up with a sibling with a diagnosis of Autism Spectrum Disorder. You were selected as a possible participant in this study because of the unique make-up of your family. At any time, you may withdraw your consent to participate in this study without any adverse consequences as all participation is voluntary. If at any time you would like to withdraw from the study you may do so by informing me in writing. At that time, all transcriptions and data collected from you will be deleted immediately.

There are no foreseen physical, psychological, emotional, social, or spiritual risks associated with your decision to participate in this research study. There are no costs to you for participating in the study and there is no financial reward for participation. The information collected may or may not benefit you directly, but the information gained in this study will help to inform parents and professionals and aid in the understanding of the roles these siblings play within the family and information gained can be utilized to support similar families.

You will be asked to provide a timeline and the typically developing sibling will be asked to photograph evidence of their roles within the family as well as their well-being. Both a parent and the typically developing sibling will individually participate in a face-to-face interview, which should take approximately an hour. A follow up interview may be necessary to necessary to confirm themes and findings of the study. These interviews will be recorded through audio format and this recording will be maintained locked cabinet and the only key belongs to the researcher for a minimum of three years before they will be destroyed. These recordings will be transcribed into a software program and these transcriptions will be maintained in a secure location that will be password protected computer. Transcriptions will be destroyed after 3 years.

All data obtained will be kept confidential. Pseudonyms will be utilized for all participants to ensure confidentiality. The researcher, advisor, and dissertation committee will be the only

persons who will have access to the data collected during this study. The Liberty University Institutional Review Board may also inspect these records. The results of this study will be available through Liberty University Library and could be used in degree seeking research doctoral thesis, reports, publications, and presentations; your identity will be included in none of these.

If you have any questions about the study, please contact Jennifer Henderson-Rudling via email at [jmhendersonrudling@liberty.edu](mailto:jmhendersonrudling@liberty.edu). If you have concerns about your rights in this study, please contact [irb@liberty.edu](mailto:irb@liberty.edu) or call 434-592-5530.

Your signature on this consent form indicates that you fully understand the above research study, what is being asked of you in this study, and that you have read and understand all information presented in this document. Your signature on this consent form indicates that you understand and agree to participating in personal interviews. In addition, you agree that your minor child will also participate in personal interviews.

I hereby agree willingly to participate.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

(Parent)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

(Sibling)

A copy of this consent form is available for you to keep with your records.

**APPENDIX C: DEMOGRAPHIC QUESTIONNAIRE**

Age of parents: Mom \_\_\_\_\_ Dad \_\_\_\_\_

Which parent is active duty military?

Years in military:

Rank in military:

Years living on military post:

Distance to nearest relative:

Culture that best describes your family (Ethnicity):

Sibling with ASD age and gender:

All other siblings' age and gender:

Is there anything you would like to share about your children prior to the face-to-face interview?

## APPENDIX D

### PARENT INTERVIEW QUESTIONS

1. Please introduce yourself, as if we just met one another.
2. Please describe your family.
3. Please describe your schedule for weekly activities (therapies, extracurricular, support groups).
4. Are there any other routines that take place on a daily or weekly basis (eating, bedtime)?  
If so, would you describe them to me?
5. Does (TD sibling) have specific responsibilities in the house?
6. Does (TD sibling) have specific responsibilities with the (Sibling with ASD)?
7. How would you describe the willingness for (TD sibling) to participate in these responsibilities?
8. How would you describe your children's relationship?
9. How would you describe (TD sibling) performance at school?
10. What expectations do you have for (TD sibling)'s future (continuing education, relationships, career, family)?
11. What expectations for you have for (child with ASD)'s future (continuing education, relationships, career, family)?
12. Has anyone in your family ever been diagnosed with anxiety, depression, or other emotional concerns?

## APPENDIX E

### SIBLING INTERVIEW QUESTIONS

1. Please introduce yourself, as if we have just met.
2. What activities are you involved in (sports, work, extracurricular)?
3. Can you describe yourself as a student?
4. Tell me about growing up with your sibling.
5. Describe your relationship with your sibling.
6. About what age did you understand that your sibling had ASD?
7. What are your responsibilities regarding your sibling?
8. How are you involved in your sibling's treatments and caretaking?
9. How do you think your sibling's presence has affected your family?
10. How do you think your sibling's presence has affected you (personally, socially)?
11. How do you think your sibling will affect your plans for the future (continuing education, relationships, career, family)?
12. Have you ever been diagnosed with anxiety, depression, or other emotional concerns?

## APPENDIX F: TIMELINE PROMPTS

Parent:

1. Please explain how each of the identified events is important to your family?
2. How did each impact your child with ASD?
3. How did each even impact your TD child?
4. Was there an event that was more difficult? Please explain why it was more difficult.

Sibling:

1. Your parent provided this timeline, what do you remember about these events?
2. Which of these was the most difficult for you?
3. Why was this event most difficult for you?
4. How did your roles change because of this event?
5. Which of these events was the easiest for you?
6. Why was this event the easiest for you?
7. How did your roles change because of this event?

**APPENDIX G: PHOTO PROMPTS**

1. Please explain which of these photographs indicate a role you play within the family.
2. Of these roles, which of these do you see as most important?
3. Why is that role more important, in your opinion, than the others?
4. Of these roles, which is your favorite?
5. Why is it your favorite?
6. Of these roles is there one that is your least favorite?
7. Why is it your least favorite?
8. How have the roles changed over time?
9. In the area of well-being or state of happiness, explain why you have selected these pictures to share.
10. Which picture of your well-being do you feel is most accurate for you the majority of the time?
11. Why did you select that photo?

**APPENDIX H: Stake (1995) Critique Checklist**

1. Is the report easy to read?
2. Does it fit together, each sentence contributing to the whole?
3. Does the report have a conceptual structure (i.e., themes or issues)?
4. Are its issues developed in a serious and scholarly way?
5. Is the case adequately defined?
6. Is there a sense of story to the presentation?
7. Is the reader provided some vicarious experience?
8. Have quotations been used effectively?
9. Are headings, figures, artifacts, appendixes, and indexes used effectively?
10. Was it edited well, then again with a last-minute polish?
11. Has the writer made sound assertions, neither over- nor under interpreting?
12. Has adequate attention been paid to various contexts?
13. Were sufficient raw data presented?
14. Were data sources well-chosen and in sufficient number?
15. Do observations and interpretations appear to have been triangulated?
16. Is the role and point of view of the researcher nicely apparent?
17. Is the nature of the intended audience apparent?
18. Is empathy shown for all sides?
19. Are personal intentions examined?
20. Does it appear that individuals were put at risk? (Stake, 1995, p. 131).

## **APPENDIX I**

### **THEMES THAT EMERGED FROM RESEARCH**

Protective nature of siblings over their sibling with ASD

Separations create a change in lifestyle

The annoying little brother

Reactions to home therapy

Improvements of sibling relationships as they mature

Fairness among siblings

Anticipation for what the future holds for their children

Self-reflection of parent choices

## APPENDIX J

TABLE OF CODE FREQUENCY BASED ON DATA COLLECTION SOURCES

Table 3							
<i>Codes by Themes and Data Collection Sources</i>							
<u>Major Themes</u>	<u>Parent Interview</u>	<u>TD Sibling Interview</u>	<u>Parent Timeline</u>	<u>TD Sibling Timeline</u>	<u>Photo Image</u>	<u>Photo Discussion</u>	<u>Totals</u>
Protective nature of siblings over their sibling with ASD	✓✓✓✓	✓✓✓✓	✓✓✓✓	✓✓✓✓	✓✓✓✓	✓✓✓✓	21
Separations create a change in lifestyle	✓✓✓✓	✓✓✓✓	✓✓✓✓	✓✓✓✓		✓✓✓	19
The annoying little brother	✓✓✓✓	✓✓✓✓	✓✓	✓✓✓			13
Reactions to home therapy	✓ ✓✓	✓ ✓	✓ ✓	✓ ✓	✓ ✓	✓ ✓	13
Improvements of sibling relationships as they mature	✓✓✓✓	✓✓✓✓	✓ ✓				10
Fairness among siblings	✓✓✓✓	✓✓✓✓	✓				9
Anticipation for what the future holds for their children	✓✓✓✓		✓		✓	✓	7
Self-reflection of parent choices	✓✓✓✓		✓✓ ✓				7
KEY: ✓ indicates multiple (2 or more) references to the theme within data sources ✓ Martha and Bruce ✓ Ruth and Jennifer ✓ Mary and Elaine ✓ Felicity and Isabella							