

FACING CHALLENGES ON TWO FRONTS: EXPLORING THE PROCESS OF  
RESILIENCE FOR MILITARY FAMILIES RAISING A CHILD WITH AUTISM

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## ABSTRACT

ASHLEY C. FREULER: Facing Challenges on Two Fronts: Exploring the Process of Resilience for Military Families Raising a Child with Autism  
(Under the direction of Dr. Grace T. Baranek)

Managing daily life in the presence of their child's pervasive symptoms and coping with stressors unique to military culture characterize the battle on two fronts that face military families raising children with autism spectrum disorder (autism). Resilience models describe the process of adaptation to stressful circumstances and have been used to describe family stress and coping. However, little is known about the mechanisms that facilitate resilience for military families raising a child with autism or the impact that this process has on wellbeing for this particular population. Further, the concept of *occupation* is overlooked in the literature as a potential mechanism in the resilience process despite the identified link between participation in everyday routines and wellbeing. Family occupations consist of shared daily activities that provide structure and meaning within families.

A qualitative methodology was used consisting of a sequence of three in-depth semi-structured interviews and an iterative process of thematic analysis. The interviews included open-ended questions exploring resilience, parent experiences of raising a child with autism, and military lifestyle. Participants included 18 active duty military spouses who have a child with autism, ages 4 to 12 years old whose spouse was serving in an active duty capacity in the United States military. Families represented four branches of the Uniformed Services, including: Army (n=13), Marine (n=2), Navy (n=2), and Air Force (n=1). Families included both Officer (n=13) and Enlisted (n=5) personnel, and

were stationed at installations across the country, representing bases in nine different states and in the District of Columbia.

Six broad categories of themes emerged from the data, which I will refer to as ‘theme categories’. Six theme categories emerged, including *Barriers and Stressors*, *Supports and Resources*, *Strategies*, *Time and Place*, *Family Culture*, and *Moments of Resilience*. These theme categories describe both the components and the mechanisms that comprise the resilience process for these families. A model of resilience specific to military families with a child with autism is proposed to explain the transactional and complex nature of this process.

Dedication: To my grandmother, Jane, who thinks I hung the moon, although I know it was really her doing. To my grandfather, Charlie Douglas, whom I never had the opportunity to meet but in whose footsteps I have strived to follow.

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## **ABBREVIATIONS**

ABA	Applied Behavior Analysis
ADA	Americans with Disabilities Act
AMFAS	American Military Families Autism Support
CONUS	Continental United States
DD	Developmental Disability
DoD	Department of Defense
ECHO	Extended Care Health Option
EFM	Exceptional Family Member
EFMP	Exceptional Family Member Program
FRG	Family Readiness Group
FRS	Family Readiness System
IEP	Individual Educational Plan
NCD	National Council on Disability
NDAA	National Defense Authorization Act
OEF	Operation Enduring Freedom
OIF	Operation Iraqi Freedom
PCS	Permanent Change of Station
UNC	University of North Carolina
USMC	U.S. Marine Corps

## **CHAPTER 1**

### **Introduction**

#### **1.1 A Battle on Two Fronts**

Managing daily life in the presence of their child's pervasive symptoms and coping with stressors unique to military culture characterize the battle on two fronts that face military families raising a child with autism. Resilience models describe the process of adaptation to stressful circumstances and have been used to describe family stress and coping. However, little is known about the mechanisms that facilitate resilience for military families raising a child with autism or the role that participation in family routines plays as a mechanism in the resilience process despite the identified link between participation in occupation and wellbeing.

More than 13,000 United States military dependents, the majority of them children, have a diagnosed autism spectrum disorder (autism) (Department of Defense Report, 2007). In the presence of demands that stem from both a military lifestyle and raising a child with autism, these families face a unique set of challenges in everyday life that may impact individual family members as well as overall family wellbeing. This dual set of challenges makes these families of particular interest for the study of family stress and coping and of great significance to the Occupational Science literature through the consideration of these processes in the context of family routines.

In consideration of the nature of family life in the military, coupled with the diagnostic and associated features of autism, this study explored the experiences of

military families with a child with autism and the nuances surrounding adaptation processes in the presence of ongoing challenges while highlighting the role that occupation plays in this process. Striving to successfully overcome stressful circumstances is referred to in the literature as a process of *resilience* (McCubbin & McCubbin 1983). Patterson (2002) suggested that research focusing on families who are at 'high risk' for negative patterns of adaptation would seek to clarify current understandings of resilience. Therefore, studies that focus on military families with a child with autism who face ongoing stressors in the context of daily life will strengthen current conceptual and theoretical understanding of resilience as well as illuminating the role that human occupation, specifically characteristics of participation in everyday routines, plays in this process.

A plethora of research identifies the challenges that military families, as well as families with a child with autism, face. However, no research to date considers the unique set of challenges that military families who have a child with autism endure, and the nature of the ongoing process through which they strive to adapt to such challenges. Further, the concept of human occupation has been overlooked in the family stress literature, and subsequently omitted from theories and conceptual models surrounding resilience.

## **1.2 Aims and Significance**

The *purpose* of this study was two fold. First, this study aimed to explore experiences of active duty military families who are raising a child with autism that contribute to a conceptual understanding of *resilience*. Second, this study aimed to

illuminate the connection between occupation and wellbeing, which is one that is prevalent in the Occupational Science literature. This study has both theoretical and pragmatic significance. Theoretically, identification of caregivers' perceptions of mechanisms at play in the resilience process may clarify theoretical understandings surrounding this process. Further, consideration of resilience as embedded in everyday family life enables a shift in focus from psychological outcomes to the transactional processes that facilitate a family's active pursuit of wellbeing. Finally, consideration of the process of resilience in a broader context of everyday family life may contribute to an increased understanding of the relationship between family occupations and wellbeing.

Pragmatically, findings from this study may serve to inform programs and policies that aim to support military families who face barriers to participation in everyday routines that impact individual family members as well as overall family wellbeing. Exploring the experiences of military families who have a child with autism will reveal nuances within the contextualized resilience process distinctive to this population. Identification of 'what works' for some families who are positively adapting in the face of ongoing stressors will illuminate opportunities for intervention as well as policies to support these families.

The overarching *goal* of this study was to explore the experiences of military families who have a child with autism. More specifically, this study explored the processes that facilitate and/or inhibit resilience in military families with a child with autism maintaining a focus on family routines. The main research question guiding this study was: How do families characterize the resilience process and what role do family routines play in this process?

### **1.3 Why view this problem through a lens of Occupational Science?**

Although the Occupational Science literature has largely overlooked the concept of resilience, the relationship between participation in occupation and wellbeing is a foundational one in the discipline (Wilcock, 2006). Therefore, the nature of the connection between occupation, wellbeing, and resilience has yet to be fully explicated in the literature. If occupation and wellbeing are inextricably linked, and resilience describes the process leading to such positive outcomes as wellbeing, occupation is likely a key mechanism in such a process.

Occupation can be broadly understood as “a dynamic aspect of engagement in life and as an unfolding of interaction between a person and the world” (Royeen, p.112, 2002). Further, occupations consist of shared daily activities that provide structure and meaning within families (Humphry & Case-Smith 2005; Segal, 2004). Surfacing evidence suggests that occupations greatly impact wellbeing and family adjustment (e.g., Fiese, Tomcho, Douglas, Josephs, Poltrock et al., 2002). Despite a lack of clarity in the conceptualization of *wellbeing* in the Occupational Science and Therapy literatures (Aldrich, 2010), there are theoretical underpinnings in the Occupational Science discipline that support the notion that occupation and wellbeing are intertwined, and are closely linked to the phenomena of resilience. For example, Weisner, Matheson, Coots & Bernheimer (2005) suggested that that sustainability of meaningful family routines consists of a families’ “juggling ongoing demands and meeting long term goals, rather than coping with crisis and stress” (p. 9).



In order to clarify the connection between wellbeing and occupation, Christiansen (2007) revisited Adolf Meyer's (1943) philosophy. Meyer (as reviewed in Christiansen 2007) believed in a connection between the mind and body, and described wellbeing as a *balance* between demands and performance. He was also interested in how individuals with mental illness achieved 'adaptation' in the face of the stress of 'human existence' and Christiansen subsequently argued that Meyer was one of the first scientists interested in the concept of resilience. Meyer suggested that health and illness can best be understood in "the habits of everyday life" and that participation in occupation leads to positive adaptation.

Despite foundational beliefs presented in the Occupational Science literature suggesting an inherent connection between wellbeing and participation in occupation, there remains a gap in understanding the relationships between resilience and participation in occupation. Therefore, a consideration of families' participation in everyday occupations as a mechanism in the resilience process is needed. Locating family routines in the process of resilience will not only facilitate a shift from focusing on psychological outcomes to transactional processes, but will also highlight the active role that families play in managing their everyday lives within their cultural context. An exploration of experiences of military families who have a child with autism provides an opportunity to clarify these relationships and strengthen otherwise generalized terms and concepts, particularly that of resilience and wellbeing. Further, an Occupational Science perspective offers a consideration of the barriers that families face in participation in everyday routines in an ever-changing and mutually influencing context.

## **CHAPTER 2**

### **Current Missions, Policies, and Programs Impacting Military Families**

#### **2.1 Department of Defense Demographics and Current Missions**

Family life in the military can be optimally understood in consideration of the unique socio-, political, and historical time in which soldiers, marines, sailors, and airmen are serving. Military life has changed significantly over the past ten years, most notably following the events of September 11, 2001 (Martin & Sherman, 2012). Since that time, service members have maintained an active overseas presence facing combat operations in Iraq and Afghanistan. Since the beginning of these combat efforts in 2001, over 1.9 million US military personnel have been deployed as part of Operation Enduring Freedom (OEF) or Operation Iraqi Freedom (OIF), which together make up the longest sustained US military operation since the Vietnam War (Committee on the Initial Assessment of Readjustment Needs of Military Personnel, Veterans, and Their Families, Board on the Health of Selected Populations, 2010).

In consideration of the current demographics that make up military families, it is clear that an overwhelming number of family members have been impacted by the stressors that accompany long-term separations, particularly those whose loved ones are serving in combat zones. Military family demographics have evolved significantly since the era of World War I when the majority of service members were young, single males (Taylor, Wall, Liebow, Sabatino, Timberlake & Farber, 2005). Today, over half of active-duty service members are married, and over one third of service members have children, who are primarily under the age of five years (Martin & Sherman, 2012). In

addition, there are over 120,000 service members who have a documented dependent family member with special medical or healthcare needs (Military Onesource, 2012).

In order to access services to meet the needs of their child, families are required to enroll in the Exceptional Family Member Program (EFMP) (refer to section 2.2). Since the Department of Defense (DoD) does not maintain a registry specifically for family members with autism, neither the prevalence nor the geographic distribution for this population within the Military Health System is specifically documented (DoD Report, 2007). In addition, each service branch differs in how they maintain data and medical information on exceptional family members, and not all members are enrolled in EFMP (DoD Report, 2007).

One available Freedom of Information Act document, requested and obtained by a marine wife and mother of a child with autism, stated that there are approximately 22,027 military dependent children with autism, and of these, 13,243 are children of active duty members (FOI document, 2008). In consideration of the total number of active duty families with young children, these numbers suggest a 1:88 prevalence rate of children with autism in the current active duty military population, which is comparable to the 1:88 prevalence of autism in the general population (Baio, 2012).

## **2.2 Current Programs and Policies**

In addition to the stress of military life in a combat era, families with children with autism are also at the mercy of legislation and policies that greatly impact the educational and medical services for which they are eligible and to which they have

access. Therefore, it is necessary to consider the current state of policies impacting families as it sets the stage for understanding current family experiences.

*Family readiness* is a concept that underlies military family programming and policies. The concept of *readiness* has evolved to encompass the wellbeing of the family as impacting soldiers' job performance and retention. This shift in conceptualization occurred in response to both the changing demographics of the US military to include more families as well as the recognized needs of services for families following the Gulf War (Knox & Price, 1995). In addition, the transition to an all-volunteer force in the 1970's led policy makers to acknowledge military families and military lifestyle as impacting both National defense efforts as well as daily lives of its members and their families (Knox & Price, 1995). The concern of the whole family's *readiness* as impacting the soldier's (job performance as well as military retention) is one that is prevalent in current programming.

The Family Readiness System (FRS) consists of a constellation of support services and resources for military families with the intent of promoting quality of life of service members and their families (Military Onesource, 2012). These services range from financial consultation, recreational opportunities through Morale Welfare and Recreation (MWR) to Exceptional Family Member (EFM) services. Established by the DoD in 1987, the Exceptional Family Member Program is perhaps the most familiar to those military families with a child with autism, as it is a mandatory enrollment program that provides support to those families who have a family member with special needs (Military OneSource, 2012).

Soldiers on active duty are required to enroll in EFMP when they have a family member with a physical, emotional, developmental, or intellectual disorder requiring specialized services (Army Regulation 608-75, 2006). Exceptional family member services are designed to meet the needs of families in the realm of housing, educational, medical, and personnel services (Military OneSource, 2012). EFMP considers a family member's special needs and ensures assignment to a location with appropriate resources that address these needs, thus, EFMP families are assigned to duty stations where the medical and special education needs of their exceptional Family member can be met (Marine Corps Order (MCO), 1754.4B, 2010). Each branch of the military has specified regulations surrounding the EFMP screening, program enrollment, and related support and assignment considerations. For example, the mission of the Army's EFMP, first set forth in the 1980's, is described in the Army Regulation Rapid Action Revision (Army Regulation 608-75, 2006):

“The EFMP, working in concert with other military and civilian agencies, provides a comprehensive, coordinated, multiagency approach for community support, housing, medical, educational, and personnel services to Families with special needs. Delivery of reimbursable and non-reimbursable services is based on legislative and DoD authority and Army policy” (p. 22).

Marine Corps Order (MCO 1754.4B, 2010) similarly outlines the current mission of the MC EFMP:

“EFMP will improve the quality of life of families that support a member with a disability...EFMP will ensure that sponsors with Exceptional Family Members (EFM's) are assigned to duty stations where services exist to support the EFM with access, and availability, to medical and educational services. Families and service providers must work together in a climate of mutual respect and trust to be successful. Enrollment in the EFMP shall not prejudice advancement or promotion opportunities” (p.3).

Broadly, EFMP can be described as a program in which military families must enroll in order to utilize resources that support their family member's special needs on base as well as in having these needs considered upon relocation to various duty assignments.

In addition to services offered through EFMP, families with a child with autism have access to TRICARE health care benefits. TRICARE is the Department of Defense's health care program for active duty military members, retirees, eligible Reservists and National Guard members, and their families. TRICARE-eligible service members and their families have access to military-specific treatment facilities, as well as to civilian health care providers in the community through enrollment in one of five options through one of three Continental United States (CONUS) regions or through TRICARE Overseas (Tricare Management Activity, 2012).

The extended healthcare option (ECHO) is a TRICARE supplemental program for eligible active duty family members who are enrolled in EFMP and who have a qualifying mental or physical disability (Military Onesource, 2012). Qualifying conditions include moderate or severe mental retardation, a serious physical disability, or a physical or psychological condition that causes the beneficiary to be homebound (Tricare Management Activity, 2012). ECHO beneficiaries who have an autism diagnosis also have access to enroll in the Enhanced Access to Autism Services Demonstration, which expands the allocation of TRICARE-approved educational intervention related services, including Applied Behavior Analysis (ABA) to these family members. The TRICARE allotment of ABA services currently has a cap per year, and is only available to active duty military members and their eligible family members (Military Onesource, 2012). In other words, when service members retire or are medically discharged, their

family member's ECHO eligibility, and subsequent Applied Behavior Analysis (ABA) and other services (currently regarded as 'educational services') for their child, are discontinued.

Legislation is currently in progress to modify the existing parameters surrounding the allocation of services through TRICARE's ECHO program. Expanding the parameters that TRICARE has placed on service allocation, particularly surrounding ABA services, has been central to the efforts of military family grass roots advocacy, as well as civil lawsuits that have proven to be an ongoing feat for families in pursuit of continued or expanded coverage (e.g., *Berge vs United States*).

The 2013 National Defense Authorization Act (NDAA) was recently put before congress, which, among other initiatives, introduced an amendment expanding coverage of treatments for those military children with a diagnosis of autism. Although this bill passed in both the House and the Senate, a conference committee concluded that the DOD will instead conduct a one-year pilot program administered by the Pentagon (CRS Report, 2013). President Obama signed the NDAA, including the plan for a one-year pilot program delaying the proposed extension of coverage for military children, into effect in December of 2012. Jeremy Hilton (Navy veteran, Air Force spouse, and 2012 military spouse of the year) succinctly described his reaction to the overlooked extension of services to family members with special needs: "The question is no longer whether our leaders in government understand our needs. We feel confident they do. The question is: when will we matter enough?" (Hilton, 2012).

Clearly, the current and ever changing sphere of legislation and policies impacting military families of children with autism provide a timely backdrop for the family experiences that were examined in the current study.



## **CHAPTER 3**

### **Theoretical Perspectives Informing the Literature**

#### **3.1 Overview**

The current study drew from three theoretical perspectives that are pervasive in the literature and have shaped my world-view surrounding family stress and coping and human occupation. Family Stress Theory, Ecocultural theory, and transactional theories of occupation were considered. This study was guided by literature surrounding the concept of *resilience*, which informed my study questions, methodology and analysis. Family Stress Theory is one that is foundational to existing models of resilience. Ecocultural and transactional theories will supplement this foundational theory as they serve to contextualize resilience processes, as well as inform the discussion surrounding the inter-linked and reciprocally influencing and active mechanisms in this process.

#### **3.2 Family Stress Theory**

Resilience models have historically maintained a strong theoretical foundation, stemming mostly from literature surrounding family stress and coping. Family Stress Theory (Hill, 1949) was first developed after observing war-induced separation and reunion within families in WWII, and thus has particular relevance to the context of this study. Hill's model originally described how families experiencing the same stressor could react and respond differently.

Resilience models have developed over time to account for the differences in adaptive processes that Hill (1949) noted. The most prominent resilience models have

included: the ABC-X model of family stress (Hill, 1949), the Double ABC-X model (McCubbin & Patterson, 1983), the T- Double ABC-X model (McCubbin & McCubbin, 1987), and the Family Adaptation and Resilience model (Patterson, 2002). Generally, these models are comprised of three central components involved in the resilience process, to include: (A) stressful events, (B) resources or capacities (C) outcomes. Patterson's (2002) model added a more explicit 'meaning' component, as well as placed resilience in the context of family with an emphasis on how families actively try to balancing their demands and capabilities in the process of adapting to stressful life circumstances. Resilience models generally describe the adaptive process that families go through as they react to stressful life events, implement resources or capabilities, and the role that interpretations and meaning making play in this process (McCubbin & Patterson, 1983).

Specifically, Family Stress Theory will contributed to the current study as a language that describes the potential mechanisms at play in resilience processes as currently identified in the literature to include (1) *demands* (stressors, strains, daily hassles), (2) *supports* (coping, resources, supports), (3) *meanings* (constructed interpretations), (4) *resiliency outcomes* (balance of demands and capabilities).

### **3.3 Ecocultural Theory**

Ecocultural theory (Gallimore et al., 1993; Weisner, 1984; 1993; Whiting & Edwards, 1988) views family routines as central to family experience, and therefore facilitated a consideration of the act of managing everyday routines amidst the challenges

and affordances that accompany military life and raising a child with autism in the context of resilience processes.

Ecocultural theory suggests that families are proactive in the management of their everyday routines and highlights the ecological features that directly affect the daily routines of a family. Ecocultural theory maintains that families actively modify daily routines to accommodate to a broader cultural context, and that a family's culture can best be understood by gaining insight into their daily routines (Weisner, 2002).

According to this theory, broader societal and cultural influences place both affordances and limitations on families that are manifest in their everyday routines.

Ecocultural theory highlights the concept of *family ecology*, which includes parent's beliefs, values and personal experiences as they influence the creation of family routines. The sustainability of these routines is believed to be influenced by four dimensions: 1) Social Ecological Fit (balancing family ecology with available resources), 2) Congruence and Balance (ongoing assessment and accommodation to competing interests of family members), 3) Meaning (routines created in a culturally valued and meaningful way), 4) Stability (changing as needed, but maintaining predictability) (Weisner et al., 2005).

Overall, Ecocultural theory helps to contextualize the resilience process by considering the sustainability of routines within the family and broader social ecological parameters and the centrality of everyday routines in family life.

### **3.4 Theories of Transaction**

The concept of resilience, as an ongoing process aligns closely with a transactional perspective. The basis of resilience models is the underlying assumption that families are driven to actively ‘adapt’ within the constraints and affordances of everyday life circumstances. Therefore, transactional theories that consider the active, interdependent, and reciprocally influencing nature of individuals, families, and environments informed the current study.

A transactional view of occupation views the organism-in-environment-as-whole, thus overcoming the dualism of separation of person and environment (Dickie, Cutchin, & Humphry, 2006). These authors suggested that rather than viewing individuals as ‘adapting to’ their environments, they work in ‘functional coordination’ with the environment via action. Cutchin & Dickie (2013) described one particular transactional theory, Dewey’s pragmatism, as a ‘relational’ theory. Further, this theory describes the relationship among interconnected components, such as: action, actors, environment, thoughts, history and future orientation. Therefore, a transactional theory facilitates an embedded view of human action while considering the dynamic relationships between mechanisms driving the ongoing resilience process, as situated in context.

Overall, a transactional perspective served to embed the resilience process in an evolving context that is mutually influencing, as well as facilitated a more fluid view of the ‘components’ of such a process. A transactional perspective also strengthened the ‘action’ emphasis that has been implicit in past resilience models, in the form of family ‘supports’, as well as meaning making practices as a current throughout the resilience process.

## **CHAPTER 4**

### **Literature Review**

#### **4.1 Introduction**

This chapter will review the literature surrounding four primary areas of interest in the current study, to include (1) resilience, (2) occupations and family routines, (3) autism and family experiences, and (4) military families.

#### **4.2 Resilience**

Families are in a constant state of actively negotiating everyday demands and capabilities, within their ever-changing context (McCubbin & McCubbin, 1987). This process can be described as resilience. Doll and Lyon (1998) asserted, "while there is no universal definition of resilience, a central notion exists that resilience concerns successfully coping with or overcoming risk and adversity or the development of competence in the face of severe stress and hardship" (p. 348). Resilience can be broadly defined as the ongoing, daily process of positive adaptation in the face of stressors or adversity (Patterson, 2002). *Resilience* can be described as the process while *resiliency* is the outcome of such a process (Boss, 2002; Bowen & Martin, 2011). Resiliency outcomes serve as indicators of the extent to which families are successfully adapting in the context of everyday family life. Resiliency can range on a continuum, and may be measured by varying phenomena, depending on the study focus or theoretical orientation (e.g., depression, quality of life, wellbeing). Resilience models have been used to conceptualize resilience processes at both the level of the individual (e.g., Seligman &

Fowler, 2011), the community (e.g., Mancini & Marek, 2004) as well as at the family level (e.g., McCubbin & McCubbin, 1996).

Family resiliency has been defined as “the positive behavioral patterns and functional competence individuals and the family unit demonstrate under stressful or adverse circumstances, which determine the family’s ability to recover by maintaining its integrity as a unit...” (McCubbin & McCubbin, 1996, p. 5). Resilience models that focus on family-level outcomes offer utility in understanding the means by which some families effectively respond to adverse life circumstances or events that would otherwise impair family functioning (Doucette & Pinelli, 2004). Knowledge surrounding this process at the family level also offers implications for practice, as practitioners can use this knowledge to “facilitate family adjustment and adaptation by looking at family strengths and capacities for responding to stress” (Hanson, 2001, p.54).

Overall, the concept of resilience has been described as one of the most important in contemporary social sciences (Liebenberg & Ungar, 2009; von Eye & Schuster, 2000) as it facilitates an increased understanding of mechanisms of health and wellness.

### **4.3 Occupation and Family Routines**

Occupations are a prime context for consideration of the compounded challenges imposed by autism features and military life. Occupation can be defined as “a type of relational action through which habit, context, and creativity are coordinated toward a provisional yet particular meaningful outcome that is always in process...” (Cutchin, Aldrich, Bailliard & Coppola, 2008, p.164). Occupations have also been described as ‘living a balanced life’ via participation (Christiansen, 2007). In this regard, Matuska &

Christiansen (2008) put forth the Model of Lifestyle Balance, in which they suggest that a balanced life is one in which patterns of occupation are 'healthful, meaningful, and sustainable' in the context of circumstances of everyday life. These authors conducted a review of the literature, in order to identify the 'dimensions' of occupation that contribute to wellbeing, including 1) biological health and physical safety; 2) access to social supports; 3) feeling challenged and competent in life role; 4) meaning making and identity; 5) organizing time and energy for renewal and to meet goals. These authors suggested that wellbeing comes from a 'balance' of these dimensions in consideration of life circumstances, rather than any sole aspect of human experience.

Occupations have also been described from a family perspective. Family occupations are conceptualized as the shared daily activities that provide structure and meaning within families (Humphry & Case-Smith 2005; Segal, 2004). Family routines are a broad category of family occupations that contribute to the wellbeing, health, and adjustment of family members (Fiese et al. 2002). Family routines can be described as specific, repeated practices (Spangola & Fiese, 2007) that change over time, are impacted by culture, and contribute to health and wellbeing (Fiese et al., 2002). Participation in meaningful family routines or activities contributes to family satisfaction, interaction, and stability (Orthner & Mancini, 1990). Bernheimer and Weisner (2007) additionally suggested that families are driven by the task of creating and sustaining routines, which serve as 'windows' into family culture. Similarly, Segal (2004) described routines as a manifest family identity, or meaning system (particularly for families with a child with a disability). Further, Bowen & Martin (2011) suggested that managing the 'tasks of everyday life' (e.g., feeding the dog, paying bills, buying groceries) may serve as positive

outcomes of the resilience process. Therefore, Weisner (2002) suggested that in order to optimally understand the family ‘culture’, families should be asked about their daily routines.

Routines provide stability and predictability in family life, and can be described as ‘powerful organizers’ of family behavior (Wolin & Bennet, 1984). Family routines may serve as a protective factor for families who endure ongoing stressors such as single parent families, and those with limited resources (Fiese, 2006). Further, everyday family routines strengthen a family’s ability to positively adapt in stressful circumstances (Imber-Black, 2003). Specifically, stable routines have been identified as a key foundation for families during times of transition or family crisis, such as family geographic relocation, the death of a family member (Wolin & Bennet, 1984), or during normative transitions, such as starting kindergarten (Wildinger, 2008).

Evidence suggests that families with a child with a disability face barriers to participation in everyday routines (Law, 2002), therefore impacting their wellbeing. Law (2002) suggested that it is essential to identify such barriers in order for families to effectively create opportunities for participation in meaningful activities. The construction and maintenance of everyday routines may serve as both a barrier as well as an opportunity for engagement for caregivers with a child with a disability. Bernheimer & Weisner (2007) considered the nature of family routines in the context of family life and caring for a child with a disability, and suggested that caregivers make accommodations to everyday routines based on child needs. In exploring how caregivers orchestrate daily occupations for children with disabilities, Kellegrew (2000) similarly found that caregivers created opportunities for engagement in daily activities based on



their own perception of the child's current needs as well as in anticipation of the child's future skills and needs. Therefore, daily routines are particularly central to family life and carry unique meaning for those families who have a child with a disability.

Caregivers with a child with autism are confronted with the difficult task of creating and maintaining meaningful family routines that meet the needs of both the child and the family. There is evidence, however, that these routines often orbit around the needs of the child with autism, and subsequently become part of the family identity (DeGrace, 2004). In exploring the everyday occupations for families with a child with autism through interviews with caregivers, DeGrace identified such emergent themes as: feeling 'robbed' (of family time and 'normal' family life), occupy and pacify (focus of family activities becomes appeasing the child), and family identity as *being* autism. Overall, these findings highlight the 'pervasiveness' of autism in everyday family life.

Larson (2006) similarly set out to explore the impact of child features on family routines and examined how a child's propensity for routinization impacts family occupations. In this study, caregivers identified child characteristics that impact everyday routines, including a lack of social skills, lack of focus/attention, and increased dependency during free time as having the most impact on orchestrating daily routines. Through the mother's descriptions of daily routines, such themes emerged as: highly structured daily activities, strict adherence to consistent routines/need for predictability, and highly selective of family outings and events as well as visitors. Additionally, these mothers described feeling isolated, feeling that they had no one to 'turn to' (including professionals/interventions). Overall, Larson (2006) described the structure of such

routines as ‘circumscribed’ and revealed that daily routines are a source of stress for both the mother and the child.

#### **4.4 Autism and the Family**

Autism is a prevalent neurodevelopmental disorder that impacts 1:88 children in the United States (Baio, 2012). While there is increasing evidence of a genetic component, no clear markers have been identified, and subsequently the etiology remains elusive (Goldstein & Ozonoff, 2009). In the absence of a clear genetic marker, diagnostic criteria remain focused on overt behavioral features. The current diagnostic criteria for such features include a qualitative impairment in social interaction, a qualitative impairment in language, repetitive behaviors and circumscribed interests (APA, 2000). In addition, sensory features have been found to be prevalent, although not universal in children with autism (Baranek, David, Poe, Stone & Watson, 2006; Dawson & Watling, 2000) and have an impact on family life (Bagby, Dickie & Baranek, 2012; DeGrace, 2004; Dickie et al., 2009).

There is a wealth of evidence that identifies the difficulties that caregivers face when caring for a child with autism. The literature suggests that mothers of children with autism report higher rates of stress as compared to mothers with other developmental disabilities and those of typically developing children (Baker-Erikzen et al., 2005; Estees, 2009). Additionally, caregivers of children with autism report higher levels of marital discord (Dunn, Burbine, Bowers & Tantleff-Dunn, 2001), perceived stigma (Gray, 1993; 2002); as well as lack of social supports and increased isolation (Woodgate, Ateah & Secco, 2008).

Various aspects of an autism diagnosis have been considered in the literature as having an impact on caregiver experiences. Literature has generally identified such stressors as the elusive nature of the disorder, uncertainty surrounding the diagnostic process, and difficulty identifying effective treatments (as reviewed in Woodgate et al., 2008). Further, parents of children with autism have reported difficulties in navigating services and report low levels of positive perceptions of service providers, particularly pediatricians (Bishop, 2007). Additionally, caregiver stress has been considered in the context of child age and proximity to diagnosis, with findings suggesting that parents report higher levels of stress when the child is 3-6 years old (most proximal to child diagnosis), followed by age 16-18 (Davis & Carter, 2008).

The behavioral features of children with autism have a tremendous impact on caregiver wellbeing. Several studies have identified a strong association between autism symptomatology and parental stress (Konstantareas & Homatidis 1989; Kasari & Sigman 1997; Hastings & Johnson, 2001). For example, a child's lack of social reciprocity, challenging behaviors and difficulty with emotion regulation has been reported by caregivers as contributing to feelings of stress (Baker Erikzen et al. 2005; Davis & Carter, 2008). Externalizing behaviors, or hyperactive or aggressive behaviors, in particular are often reported by parents of children with autism (Lecavalier, 2006) and have been found to significantly impact caregiver strain (Baker Erikzen et al. 2005; Lecavalier, 2006). Studies have also found an association between parent stress and a child's physical aggression and self-injurious behavior (Konstantareas & Homatidis, 1989) as well as their self-isolation, rituals, and repetitive behaviors (Lecavalier, 2006). In addition to child behaviors, parents have identified prevalent concerns surrounding the disorder that

impact stress. Specifically, caregivers have identified concerns surrounding their child's future, identifying effective treatments, and difficulty understanding their child's needs as contributing to feelings of stress (Tehee, Honan & Hevey, 2009).

Research suggests that through the stressful and demanding experiences of raising a child with autism, caregivers exercise coping skills which have been identified as both positive and negative. Effective coping skills include cognitive reframing, perceived social supports, and emotion regulation skills, while 'negative' skills included social withdrawal and isolation (Dunn et al., 2001). Similarly, mediators to negative caregiver outcomes have been identified, such as perceived social supports and locus of control (internal locus of control significantly buffering the effects of stressors) (Dunn et al., 2001). In a recent qualitative study, Kuhaneck (2010) identified such themes in reported caregiver coping, to include: *taking 'me time'*, *lifting the restraints of labels*, and *sharing the load*. Similarly, the use of social support, family connectedness, spiritual beliefs/values and meaning making processes have been identified as coping mechanisms that contribute to positive outcomes for caregivers of young children with autism (Bayat, 2007).

*Meaning making* is another strategy that has been identified in the literature as an effective coping mechanism for parents of children with autism (Bayat, 2007; Larson, 2010). In a qualitative study, Bayat (2007) identified themes associated with meaning-making processes as a strategy for coping, including *seeing the child as a sense of pride*, *appreciating small gifts/accomplishments*, *changed world view* and *life purpose*, and *strengthened spiritual beliefs/values*. Larson (2010) similarly considered the relationship between meaning making processes and caregiver wellbeing for caregivers with a child

with autism. Without using the term *resilience*, but describing a similar notion, Larson sought to identify what makes some caregivers fare well (as measured by psychological wellbeing) in the face of stress, while others do not and identified that engaging in the process of meaning making served as a primary indicator for wellbeing.

While a great deal of literature has focused on the stressors, or negative experiences of caring for a child with autism, there are recent studies that identify positive experiences associated with caring for a child with autism. Bayat (2007) suggested use of the concept of *resilience* to explicate the experiences of families with a child with autism. Despite a lack of understanding surrounding the concept of resilience in the area of disability research, Bayat hypothesized that families with a child with autism have the capacity for resilience. Similarly, Kayfitz, Gragg & Orr (2010) identified an association between reported positive experiences for families with a child with autism and decreased reported caregiving stress.

#### **4.5 Military Families**

Military service has been described as more than an individual's career choice, rather a way of life that requires both personal and family sacrifice in support of the broader military mission (Bowen, 1990). For military families, then, everyday family life can only be understood in consideration of the unique culture of the military. Segal (1986) described both 'the military' and 'the family' as 'greedy institutions' in which nearly every aspect of families' lives are guided by particular rules, values, and expectations. Segal's description identified the 'intersection' of these two social

institutions (family and military), and the subsequent challenges individual service members face in meeting the demands set forth by each.

Military life is embedded in an overarching evolving military culture, including a well-defined hierarchical structure, implicit and explicit values and expectations, as well as social rules and norms. Military life is also characterized by the unique demands that are placed on individual service members and their families. Generally, active duty military families are thought to face such ongoing challenges as frequent geographic mobility, family separations, residence in foreign countries and risk of injury or death (Segal, 1986).

Post-combat service members are at high risk for mental and physical health issues. Literature suggests that common disorders and health issues associated with post combat service include post-traumatic stress disorder, traumatic brain injury, depression, and substance abuse (Lester, Mogil, Saltzman, Woodward, Nash, et al., 2011). While many service members who return from combat do not develop long-term mental health problems (Hoge, Austin & Pollack, 2007), shorter term difficulties are common, including difficulty sleeping, irritability, and difficulty concentrating (Shea, Vujanovic, Mansfield, Sevin, & Liu, 2010), as well as difficulty reconnecting with family members and reintegrating into everyday family life (Boss, 2002; Lester et al., 2011).

There is evidence that the prolonged deployments and/or combat exposure of service members have a tremendous impact on their families. There is a wealth of literature that identifies the impact of deployments on children, suggesting that children of deployed parents are at a higher risk for developing depression (Jensen, Martin, & Watanabe, 1996), anxiety (Jensen, Grogan, Xenakis, 1989), as well as academic and

disciplinary problems (Schwab, Ice, Stephenson, Raymer, Houser, Graziano et al., 1995). Recent research has also highlighted the tremendous impact of parental stress or psychopathology, rather than a direct impact of military lifestyle on child outcomes (Palmer, 2008). There is also clear evidence that spouses of service members face challenges during deployment, reporting such feelings as: numbness, shock, irritation, tension, disbelief, loneliness, somatic complaints, and increased emotional distance (Bey & Lange, 1974). In addition, spouses often experience emotional distress, anxiety or anticipatory grief (Wright, Burrell, Schroeder, & Thomas, 2006) and increased depression (Black, 1993). One recent study revealed the increasing mental health risk that spouses face during times of deployment and how this risk is compounded with deployment length. Mansfield, Kaufman, Marshall, Gaynes, Morrissey & Engel, 2010) identified that nearly one- third (31.3%) of spouses of soldiers deployed between 2003-2006 had at least one mental health diagnosis, with the percentage increasing to 60.7% of those whose husbands had been deployed for more than 11 months. Overall, these unique stressors are likely to greatly impact family life on the home front and compound parenting demands.

The service member's return home, and subsequent reintegration into family life, has also been identified as a significant stressor for families (Faber, Willerton, Clymer, MacDermid, Weiss, 2008). This reintegration of the service member may be characterized by a renegotiation of roles and boundaries within the family (Drummet, Coleman & Cable, 2003). The concept of *ambiguous loss* (Boss, 2004) has been used to describe events and experiences surrounding a loss or separation of a family member, and may be particularly useful for understanding family separations in the military. Family

members who experience ambiguous loss may suffer from feelings of uncertainty, hopelessness, and confusion (Boss, 2004). Similarly, *boundary ambiguity* is a concept that has been used to describe the situation whereby individuals must negotiate new roles during times of separation and reintegration (Boss, 2002). Boss described the ‘task’ that families face negotiating roles when a family member is either psychologically present, but physical absent, and/or the physical presence and psychological absence that might occur throughout the phases of deployment. Boss’ concept of boundary ambiguity, then, can be understood in more depth using the concepts of *ambiguous presence* and *ambiguous absence* (Boss, 2007). These phenomena likely play out in the context of daily routines and greatly impact family life as families struggle to maintain the psychological presence of separated service members, or to reintegrate them physically into everyday routines despite a perceived psychological distance.

Family life in the military comes with both normative and unique stressors that greatly impact the wellbeing of individuals within the family system, and subsequently everyday family life. These stressors include the ongoing anticipation of separation, constant interruptions in everyday routines and negotiation of roles, as well as frequent geographic relocations. There is clear evidence that family life is not only disrupted while the service member is geographically separated from the family, but also in the pre- and post- deployment phases, as well as during transitions such as geographic relocation.

These challenges are important not only in consideration of healthy adjustment of the child or spouse, but also in regard to the wellbeing service member themselves. In order for service members to fulfill their duties effectively, family life needs to be intact. Quality of adaptation at the level of the family system has been found to impact the



military's retention of soldiers (Bowen, Orthner & Zimmerman, 1993) as well as overall soldier effectiveness (Pincus et al., 2001). Despite the stressors that are imposed upon families in the military, there is evidence to suggest that most families do adapt to meet these demands (Knox & Price, 1995). Overall, the nature of life in the military may create ongoing stressful circumstances for families, which are likely compounded by the demands of caring for a child with a disability.

While very little is known about experiences of military families raising a child with autism, there is some research to date focusing on raising a child with a disability in the military. For example, Jensen, Watanabe, Richters, Cortes, Roper & Liu , 1995) found that military families with a child who is disabled showed significantly higher depressive symptoms, lower levels of effective coping, and low levels of self-perceptions surrounding their military skills and abilities. In addition, these authors found that service members with a child with a disability displayed more pessimistic attitudes surrounding their military career, including fewer perceived long-term options. Raising a child with special needs in the context of a military career not only impacts the service member's wellbeing and long term commitment to the military, but may also impact the wellbeing of the child, as these authors also found that children experience higher levels of stress when their parents did not identify positively with the military (Jensen et al., 1995). These authors identified that perceived social supports primarily served to buffer the effects of stress on the family with a child who is disabled. A more recent study was conducted by the National Council on Disability (2011) focusing on Marine Corps families and their access to healthcare, education and other support services. This study identified the challenges that caregivers face in navigating service systems and

establishing services for their family member with a disability (with a specific focus on EFMP, TRICARE, and school-related services). This study concluded “far reaching systemic changes are needed in our Nation’s health, education, and long-term service systems to address the significant barriers faced by exceptional family members” (p. 2).

#### **4.6 Conclusions and Gaps in the Literature**

Overall, evidence suggests that the nature of life in the military creates ongoing stressful circumstances for families, which are likely compounded by the demands of caring for a child with autism. The experiences of these families, therefore, may be best understood in consideration of their process of balancing ongoing challenges with their supports, within their given context. This process is played out in everyday family routines, which may contribute to (perhaps both positively and negatively) overall family wellbeing.

Research has individually characterized the ‘stressors’ among military families as well as those of families of children with autism. However, there is no research to date that considers the unique set of challenges that military families who have a child with autism endure, and the nature of the ongoing process through which they strive to adapt to such challenges. In addition, despite the evidence that family routines contribute to wellbeing, nuances surrounding these occupations have been overlooked in the literature, and omitted from theories and conceptual models surrounding resilience. This study aimed to address the following gaps in the literature: (1) factors contributing towards resiliency for these families, (2) the role that family routines plays in this process, (3)

consideration of the transactional nature of the resilience process, and (4) the relationship between occupation, wellbeing and resilience.

Overall, the experiences of these families may be best understood in consideration of their active participation in responding to ongoing challenges through enacting supports and resources within their given context. Nuances of this resilience process are played out in everyday family routines, which may contribute to (perhaps both positively and negatively) overall family wellbeing. This study sought to uncover the nuances of the process of resilience while highlighting families ongoing functional coordinating amidst ever changing contexts, which has tremendous implications for Occupational Science literature.

## **CHAPTER 5**

### **Methods**

#### **5.1 Introduction**

This study used a qualitative methodology consisting of a sequence of three in-depth semi-structured interviews and an iterative process of thematic analysis. The interviews included open-ended questions exploring resilience, parent experiences of raising a child with autism, and military lifestyle.

Methodological shortcomings in the area of resilience research have been identified, most notably surrounding the lack of qualitative research (Ungar, 2003). Ungar suggested that qualitative research with a focus on resilience will serve to contextualize this process, through integration of social and cultural factors that have historically been made implicit in resilience models. Further, qualitative methods have been identified as optimal for studies seeking to explore nuances of complex phenomena, generate rich descriptions about populations in context, shed light on populations about which little is known, and value the subjective experiences of individuals and groups (Marshall & Rossman, 2006). Given the lack of research that has used a qualitative approach to studying the unique nature of military and family life when raising a child with autism will serve, this study serves to fill a methodological and conceptual gap in the literature through consideration of the unique contexts in which families actively manage everyday life.

## **5.2 Design and Approach**

Since operationalizing family resilience in quantitative research has been problematic (De Haan, Hawley & Deal, 2002), it is has been suggested that further research use qualitative methodologies with a smaller sample of family members to support a strengthened conceptual understanding of resilience.

Semi-structured interviews were used to gain a rich description of the families' experiences and insight into the phenomena of interest in the current study. Marshall and Rossman (2006) suggested that semi-structured interviews have the ability to "capture the deep meaning of experience in the participants' own words" (p.55). The underlying assumption of this choice of methodology is that the participants' views are valuable and useful in gaining insight into a particular phenomenon (Marshall & Rossman, 2006). Therefore, semi-structured interviews facilitated the process of obtaining rich descriptions of participant experiences of raising a child with autism in the context of a military life-style.

Interview guides (see Appendix C) were used in order to support the interview process. Interview questions provided a guide for facilitating the participants telling of their story with open-ended questions surrounding their experiences as a parent with a child with autism in the context of military life. The nature of the semi-structured interview allowed for flexibility of question sequence as well as emergence of new questions or topics in the midst of the interview process (DiCicco-Bloom & Crabtree, 2006).

A sequence of three in-depth semi-structured interviews was conducted with each participant. The first consisted of a phone interview to gather basic demographic

information (see Appendix C.1) and to set up a second interview with the family. This phone interview allowed for an initial conversation with the caregiver in order to build rapport and establish a contextual foundation for the second interview. The second interview included open-ended questions exploring resilience, everyday experiences of raising a child with autism, and military life (see Appendix C.2). More specifically, the second interview was structured around the concept of resilience targeting such aspects this process as perceived stressors, family strengths and supports, as well as their interpretations surrounding resiliency. Further, questions targeted everyday family life experiences by focusing on construction, maintenance, and participation in family routines. Following the semi-structured interview, in-depth questions were generated that stemmed from a review of the first interview to facilitate a more in depth dialogue surrounding constructs of interest to be targeted in the third interview. The final interview served to expand further on points raised during the second interview (see Appendix C.3). Further, this final interview allowed an opportunity for closure in the research process and the caregiver to clarify and elaborate on any points in the prior interview.

The first and third interviews were all conducted over the phone, in some cases using SKYPE. Second interviews were conducted face-to-face when possible, and otherwise over the phone. Interviews generally lasted thirty minutes to two hours, depending on the course of the interview (DiCicco-Bloom & Crabtree, 2006).

### **5.3 Participant Inclusion and Sampling**

Families who reported having a school-age child with autism who have at least one parent currently activated in the Army, Marines, Navy or Air Force were included in

the study. Autism diagnosis as well as military status was based on parent report. A purposive sampling method, in which cases are selected based on specific criteria, was used (Miles & Huberman, 1984). From a review of the literature and consultation with committee members, the target number of families was between 15-18. To validate this sample size, 5 families were initially recruited and interviewed. Data generated from these initial interviews were reviewed for their amount and quality. Thirteen more families were recruited to establish saturation of data for a total of 18 families. Bloor & Wood (2006) defined theoretical saturation as “the sampling and data collection until no new conceptual insights are generated” (p.165). Following each interview, the amount and quality of each new set of data were reviewed throughout the recruitment process in consideration of the contribution of each interview towards saturation of data.

The first wave of recruitment targeted a three-state area (North Carolina, Virginia, Georgia). These states were selected based on proximity to UNC Chapel Hill, as well as the high percentage of active duty members per statewide population. Snowball sampling led to states outside of this three state area to include six additional states (Florida, Pennsylvania, Kentucky, California, Colorado, Hawaii) and the District of Colombia.

North Carolina served as the first ‘tier’ of catchment area based on geographic proximity to UNC as well as its high prevalence of military personnel in the state. As a percentage of its total population, North Carolina has the highest percentage of any state of the total active duty military, National Guard, and Reserve personnel (DoD report, 2010). The largest Army and Marine bases (Fort Bragg and Camp Lejeune) are located in the state of North Carolina, and were the initial target for participant recruitment.

## 5.4 Recruitment

Military-specific and civilian community resources were targeted for recruitment, primarily including base-specific Army and Marine Exceptional Family Member Programs. Information was simultaneously distributed (including information about recruitment, study purpose, and procedures) at the community level, including autism-specific organizations such as Autism Society county chapters surrounding bases in the initial three state catchment area as well as the University of North Carolina-TEACCH regional centers within a close proximity to bases in North Carolina. UNC TEACCH centers provide [clinical services](#) such as diagnostic evaluations and parent training for families as well as clinical training for practitioners with a focus on Autism Spectrum Disorders.

After initial recruitment strategies were implemented, snowball sampling was used to further identify potential participants. Snowball sampling utilized the social networks of participants and other informants with whom contact had already been made to find and recruit ‘hidden populations’, that is, groups not easily accessible to researchers through other sampling strategies (Marshall & Rossman, 2006). The process of snowball sampling included word of mouth recruitment amongst participants who were already enrolled as well as key gatekeepers in the community sharing information about the study via online resources and listservs.

While EFMP case managers were initially anticipated to be key resources for recruitment endeavors, it became apparent that families did not often utilize these on-base resources as a primary form of support and thus were not usually exposed to the study’s recruitment letters through this avenue. Only one of the participants reported hearing



about the study from their EFMP case manager. The majority of participants reported hearing about the study from an online support that is described as being “for military families, by military families.” One of the key gatekeepers was a military spouse who endorsed this study by posting my recruitment letter on this website. From there, another military spouse also included the recruitment letter in a listserv that extended to many EFMP families in a particular geographic area. Fourteen participants reported hearing about the study through either the military family support website or the family support listserv, both which are run by military spouses and are not affiliated directly with any governmental agency. Three of the participants heard about the study from ‘friends’ who were already enrolled as participants.

## **5.5 Procedures**

Institutional Review Board approval was obtained through UNC Chapel Hill (IRB Study #12-0225), to include study procedures and protection of human subjects. All participants consented to study procedures by signing an Institutional Review Board approved consent form prior to beginning in the interview process (see Appendix A). Study procedures in the form of a detailed consent form were reviewed over the phone and mailed to the participants with an envelope to be returned by mail. The interview sequence commenced following the return of the signed consent forms. Both electronic and printed records were stored in a locked office and on an encrypted computer, not to be shared with anyone not directly involved in the research. Participants will not be identified in any report or publication about this study.

All of the data gathered during this study were de-identified by the PI using a numerical identification system. Data were comprised of interview transcriptions as well as field notes collected surrounding context, general observations, and reflections following each interview. Interviews were recorded via audiotape and later transcribed in a word document for preparation for analysis. Field notes were maintained in the form of a running word document in preparation for analysis in ATLAS.ti. (Muhr, 2011). In addition to field notes, process notes in the form of an ongoing word document kept track of study timeline, procedures, methodological notes, personal reactions and reflections, and decision-making procedures (Marshall & Rossman, 2006). In addition, these process notes served as a reflective guide for the iterative process of data analysis.

## **5.6 Analysis**

A recursive process of thematic analysis identified codes and themes in the data. Braun and Clarke (2006) suggested that thematic analysis allows for “an accessible and theoretically-flexible approach to analyzing qualitative data...which can potentially provide a rich and detailed, yet complex account of data” (p.5). Thematic analysis is a qualitative analytic method in of itself that is similar to major analytic traditions such as grounded theory. While both methods seek to identify themes and patterns emerging from the data, these authors suggested that thematic analysis is not “theoretically bound” like grounded theory. The process of thematic analysis included six phases (see Table 5.1.). These steps provide a ‘loose’ guide to support a recursive analytic process, which occurred throughout the data collection, analysis, and writing phases of this study. Following the analysis process, data were then integrated into a comprehensive

descriptive model in order to generate conclusions, connect findings to the existing literature, as well as integrate multiple concepts and findings (Bazeley, 2009).

Table 5.1. Phases of Analysis

<b>Phase</b>	<b>Description of the Process</b>
1. Becoming familiar with the data	<ul style="list-style-type: none"> <li>• Transcribing, noting initial ideas</li> </ul>
2. Generating initial codes	<ul style="list-style-type: none"> <li>• Coding interesting features in a systematic fashion across entire data set</li> </ul>
3. Searching for themes	<ul style="list-style-type: none"> <li>• Collating codes into potential themes</li> </ul>
4. Reviewing and identifying themes	<ul style="list-style-type: none"> <li>• Reviewing and refining themes and associated coded data to support themes, generate thematic maps</li> </ul>
5. Grouping themes into categories	<ul style="list-style-type: none"> <li>• Identifying conceptually meaningful groups of themes</li> </ul>
6. Defining and naming theme categories	<ul style="list-style-type: none"> <li>• Identifying the “essence” of what each theme category is about, and determining what aspect of the data each theme captures</li> </ul>

*Modified from (Braun & Clarke, 2006)*

The first step of analysis involved becoming familiar with the data. This step occurred following each interview in the form of writing up field notes by reflecting back on the interview process itself. Transcription of the interviews began shortly following the first interview and was completed by the first author or the research assistant on this project (an undergraduate UNC psychology student). All first interview transcriptions were re-read prior to the second interviews and similarly the first author re-read through the second interviews to construct the final interview. In cases where transcriptions were not yet complete at the time of the third interview, the first author reviewed the audio recordings in order to generate follow-up questions for the third interview.

The second step involved generating initial codes. *Codes* served to initially break down the large amount of data collected in this study into manageable segments (Schwandt, 2007). These codes emerged directly from the data rather than being generated prior to analysis. Codes identify common ideas at the most basic and descriptive level, in preparation for identifying broader themes that served to represent the data in total. The process of coding was informed by a grounded method strategy called constant comparison in which an a posteriori inductive process was used to “constantly comparing and contrasting various successive segments of data and subsequently categorizing them” (Schwandt, 2007, p. 32). A line-by-line coding process of all interviews was used for this first round of analysis in order to identify emergent codes in the data in addition to those generated through the process of field notes. Recurring ideas were identified in the process of recording field notes and reviewing interviews to generate a list of ‘initial codes and ideas’ list that served as the starting point for the ATLAS.ti coding scheme for the process of coding the interview transcripts. Eighty-six codes were identified in the first ‘round’ of coding. Throughout the process, the ‘notes’ feature was used in ATLAS.ti in order to reflect on the codes themselves and to identify possible points of convergence through the constant comparison process. A second round of coding involved a review of previously coded segments of data and a combining of codes that represented comparable ideas as well as noting the beginning emergence of groups of codes that would later serve to support the themes. The final coding list after codes were combined resulted in a total of 56 codes.

Themes were then identified (Step 3) by conceptually grouping coded data. Marshall & Rossman (2006) described this process as “noting patterns evident in the

setting and expressed by the participants” (p. 159). These themes were differentiated using an evolving process of hand drawn concept maps in order to visually identify relationships between various codes and broader descriptive themes. A review of these themes served to recognize the emergence of meaningful categories that were both internally consistent as well as distinct from other themes (Guba, 1978). This process generated 26 themes, which were then grouped into meaningful categories. Six theme categories were identified, two of which described concepts related to ‘context’ and the other four relating to embedded ‘components’. All six categories of themes revealed characteristics of both descriptive *content* as well as relational *processes*.

Following identification of theme categories, they were then named (Step 5). ATLAS.ti was used to filter quotes that had been coded under each theme category in order to generate examples of supporting evidence directly from the data to further review and consider the meaning and properties of each category. Theme categories were named such that they could communicate to the reader a meaningful summary of the data that the theme represents (Bazeley, 2009). Theme categories evolved throughout the process of reviewing theme properties, and even through the process of writing up findings as details of the properties themes were further refined. Category names resulted in brief and straightforward names to ensure that neither the content or process characteristics were given weight in the theme name alone.

The final step involved tying the themes back to the initial research questions as well as to place the themes in the existing literature. Following the guide of Bazeley (2007), the term *concept* is used to identify broader and more abstract findings that move beyond the identification of themes in order to place these themes in the literature and to

think of broader, more abstract ideas that are generated from an interpretation of the identified themes to generate study findings. Findings were integrated back into the existing literature by identifying previous literature that was supported by the finding as well as the contributions that the current study findings made to existing literature.

## **5.7 Trustworthiness and Researcher Identity**

The concept of *trustworthiness* in qualitative research serves to describe what is traditionally recognized in quantitative research as internal and external validity and reliability (Lincoln & Guba, 1985). These authors suggest that trustworthiness of data can be evaluated through consideration of the *credibility*, *transferability*, *dependability* and *confirmability* of the data.

*Credibility* can be assessed by the extent to which a qualitative study clarifies and describes its goals, boundaries, and limitations. This consists of the qualitative researcher explicating the parameters and limitations of the study in the context of a particular time and place with a focus on a specific subject matter, to include recognition of study limitations (Marshall & Rossman, 2006). Broadly, the current study addressed the issue of credibility by 1) clarifying the goals and parameters of the study; 2) outlining the limitations of study findings; and 3) providing an ongoing description of the “complexities of process and interactions” with study participants that aims to be “so embedded with data derived from the setting that it is convincing to readers” (p. 201).

*Transferability* is similar to the quantitative concept of *external validity* in that it describes the extent to which a study design can be replicated or findings can be generalized (Lincoln & Guba, 1985). Like those qualitative studies that have come before

this one, the inherent concern surrounding generalizability of the current study is recognized as a limitation due in part to the fact that I am focusing on a particular population in a unique historical time and place. However, an explicit description of the theoretical orientation of the current study does allow for a starting point for future studies to consider the as well as demonstrating how study findings may be tied back to the literature (Marshall & Rossman, 2006).

Dependability is similar to the traditionally quantitative concept of reliability (Lincoln & Guba, 1985). Dependability is a problematic concept in the realm of qualitative inquiry, in that the basic assumptions underlying ‘replicability’ assume an unchanging context under investigation based on a positivistic view of reality (Marshall & Rossman, 2006). Therefore, in order to address the concept of dependability, a review of the epistemological considerations of the current study is necessary.

Quantitative research can be described as maintaining an underlying positivist paradigm, which can be described generally as *objectivist*. This epistemological assumption holds that there exists an external reality, and ‘Truth’, about which hypotheses can be proved or disproved through a deductive and objective process of measurement and analysis (Daly, 2007). Such an assumption also holds that there is one Truth that applies to all individuals and groups, and therefore clear conclusions can be made surrounding the relationships of variables, including identification of independent and dependent variables, can be made (Daily, 2007). Conversely, qualitative methodology most often maintains a social-constructivist paradigm, which can be generally described as ‘subjective’ (Daily, 2007). Within this paradigm, there is an underlying assumption that reality is a socially constructed phenomenon, about which

nuances are revealed through the subjective interpretation of individuals or groups. Hammersly (1991) suggested that there are many social realities, not just a single one. The concept of *dependability*, therefore, is addressed in the current study with an identified underlying epistemology that supports the use of qualitative methods as an optimal mode of inquiry for the identified research questions targeting a specific population.

Finally, the concept of *confirmability* can be related to that of ‘objectivity’ and addresses the question of whether the interpretations of the qualitative researcher are clear to other researchers or to the reader (Lincoln & Guba 1985). To address the issue of confirmability, my advisor and other available committee members participated in ongoing review of data through transcript reviews as well discussions surrounding research experiences and interpretation of data. In addition, I periodically checked in with an identified ‘critical friend’ who was a fellow doctoral student familiar with the target population in order to de-brief following interviews as well as to discuss ongoing interpretations surrounding interview content and experiences.

In addition to the above criteria for assessing trustworthiness of data, an ongoing awareness of my role as researcher and interpretations surrounding data based on my own world-view are necessary for strengthening the trustworthiness of my study. Dean, Eichorn and Dean (1967) highlighted that all qualitative research is left to the subjective interpretation of researchers, who are not without their own opinions, biases, and limited world-views. Lincoln and Guba (2000) suggest that an ongoing process of *self-reflexivity* is necessary throughout the research process as it forces the researcher “to come to terms with” not only our research question and population whom we study, but also “with



ourselves and with multiple identities that represent the fluid self in the research setting” (p. 183). The process of reflexivity called on me to reflect on my past experiences, my personal biases, strengths and weaknesses of my own character, and on-going awareness of aspects of my own world view that would potentially to arise or cloud my perception or interpretation of data or my interactions with my participants.

As a trained counselor, I found myself having to remain acutely aware of my role as researcher, particularly in speaking with participants whose experiences were laden with emotion. Additionally, as the wife of a service member myself, I often times found myself in an interesting position of interfacing with a population with whom I can somewhat relate based on my own personal experiences. For example, my experiences as a military spouse over the past eleven years have taken us to multiple duty stations where my husband has been deployed several times into combat zones. Many of the families talked about their experiences at the beginning of combat operations in Iraq in 2002, during which time I was also experiencing separation from my spouse and navigating military culture for the first time. Throughout the interview process, although I did recall my own experiences in my mind, I was able to maintain awareness of these experiences as being potentially related to, but also separate from those of my participants and therefore used opportunities to clarify participant stories by not interjecting specific information about my own experiences. Generally, I found that my experiences as a military spouse facilitated my entrée into the culture and context of this particular population. I chose to disclose this information about my own life at various points in the process of interacting with my participants, depending on their questioning or my recognition of appropriate timing of information sharing. Most of the participants asked

me directly whether I am affiliated with the military, and this often times came up in the first interview in terms of whether or not they needed to clarify the acronyms that they used in talking about military related or autism related concepts. I was also asked on some occasions which branch of service my husband was in, but was not ever questioned about his job or rank. In addition, I was asked on several occasions whether or not I had a child with a disability. Although I do not, I found that simply offering the fact that I was also a mother facilitated my ability to further connect with the participants.

Overall, my experiences as a counselor facilitated my ability to quickly build rapport through providing empathetic and attentive responses to the participant's stories. Similarly, I found that my journey as a military spouse, having lived on various bases and having been through deployments, allowed me to connect with my participants as an 'insider'. I had to maintain a consistent awareness of the role that I played as a researcher, maintaining a boundary between understanding the broader aspects military culture, while at the same time creating a space free of preconceived notions in which the participant will feel free to tell his/her story.

I maintained this awareness through the use of process notes (in addition to my field notes) that consisted of my personal reactions to the interviews themselves as well as my general feelings surrounding the research process itself (Marshall & Rossman, 2006). I also used the strategy of peer-debriefing through ongoing consultation with my advisor and other committee members, as well as other doctoral students who were familiar with my study procedures and population of interest, as previously described.

## **CHAPTER 6**

### **Findings**

#### **6.1 Overview**

This study aimed to explore resilience processes for military families raising a child with autism and the role that family routines play in this process. The overarching research question was: “How do families characterize the resilience process and what role do family routines play in this process?”. Concepts stemming from previous resilience models (McCubbin & McCubbin, 1997; Patterson, 2002) guided the interviews, with questions addressing caregivers’ (a) stressors; (b) coping and resources; (c) resiliency outcomes; and (d) meanings. In addition, questions also focused on the structure and nature of family routines.

This chapter will review the participant demographics as well as a review of the findings that emerged from the process of analysis. Six theme categories were identified in the process of analysis, which represented meaningful groups of themes. Moving a step beyond a simple descriptive analysis, an integration of themes will be presented in a visual model in order to optimally demonstrate the complex relational aspects and transactional nature of the resilience process.

#### **6.2 Participants**

Participants included 18 active duty military spouses who have a child with an autism diagnosis, ages four to twelve years. While all participants happened to be female,

this was not a specific inclusion criterion. In three instances, the service members themselves also participated in the second face-to-face interview, with the understanding that the focus of the current project is to gain the perspective of the primary caregiver.

Families represented four branches of the Uniformed Services, including Army (n=13), Marine (n=2), Navy (n=2), and Air Force (n=1). Families included both Officer (n=13) and Enlisted (n=5) personnel. At the time of interviews, families were stationed at various installations across the country, representing bases in nine different states (North Carolina, Virginia, Florida, Georgia, Kentucky, Colorado, Pennsylvania, California, Hawaii) and in the District of Columbia. Mothers worked primarily in the home, with some holding both part-time and full time paid positions outside of the home (n=4) and several additionally serving in volunteer positions. Four participants were enrolled as part-time or full time students at the time of interview. Additionally, two of the mothers were homeschooling one or more of their children. Three of the spouses were prior service military personnel (Army, Navy and Air Force). Fourteen of the families had multiple children, with four of those having more than one child with autism.

### **6.3 Identified Themes and Categories**

Analysis consisted of an iterative process of coding and identifying themes in the data. Twenty-six themes were identified across the data that were subsequently grouped into six broader categories of themes, as seen in Table 6.1, including 1) *Barriers and stressors*; 2) *Support*; 3) *Strategies*; 4) *Time and place*; 5) *Family culture*; and 6) *Moments of resiliency*. The categories are presented in an order that facilitates an evolving understanding of the resilience process. It is necessary to first understand the

barriers and stressors that families face to then set the stage for a description of the resources and strategies that are enacted. An understanding of these resilience components provides an optimal starting point for understanding the more complex contexts in which these components and their processes are embedded. The *content* of each theme is described in this chapter, ending with a description of the relational *processes* within and between resilience components as depicted in the visual model.

Table 6.1 Identified Categories and Themes

Category	Themes
<i>Barriers and stressors</i>	<ul style="list-style-type: none"> <li>a. Navigating complex systems and obtaining services</li> <li>b. Meeting safety needs and opportunities for participation on base</li> <li>c. Geographic relocation,</li> <li>d. Challenging behaviors and community-based occupations</li> <li>e. Isolation and stigma</li> <li>f. Deployments and separations</li> <li>g. Meeting the needs of other children</li> </ul>
<i>Supports</i>	<ul style="list-style-type: none"> <li>a. Social supports</li> <li>b. Therapeutic programs/services targeting autism needs</li> <li>c. Other military, healthcare, and community programs</li> <li>d. Online resources and supports</li> <li>e. Other key personnel</li> </ul>
<i>Strategies</i>	<ul style="list-style-type: none"> <li>a. Advocacy and education</li> <li>b. Taking “me time”</li> <li>c. Structuring and managing family routines</li> <li>d. Sense of community &amp; building a “team” of support</li> <li>e. Prayer, cognitive re-framing/mantras, self-talk</li> <li>f. Maintaining organizational tools</li> </ul>
<i>Time and Place</i>	<ul style="list-style-type: none"> <li>a. Time</li> <li>b. Place</li> </ul>
<i>Family Culture</i>	<ul style="list-style-type: none"> <li>a. Situation</li> <li>b. Routines and roles</li> <li>c. Beliefs and expectations surrounding autism</li> <li>d. Career decisions</li> <li>e. Ascribing meaning to experience</li> </ul>
<i>Resiliency</i>	<ul style="list-style-type: none"> <li>a. Moments of resiliency</li> </ul>

## 6.4 Theme Category 1: Barriers and Stressors

Throughout the interviews, caregivers identified the *barriers and stressors* they encountered while raising a child with autism in the context of a military lifestyle. These *barriers and stressors* most often fell into one of the following themes: (a) navigating complex systems and obtaining services; (b) meeting safety needs and opportunities for participation on base; (c) geographic relocation; (d) challenging behaviors and community-based occupations; (e) isolation and stigma; (f) deployments and separations; and (g) meeting the needs of other children.

(a) Caregivers engaged in an ongoing process of navigating complex systems in order to obtain services to meet the needs of their child with autism. These systems were described as disjointed, creating barriers to continuity of services or care across duty stations. Following their child's diagnosis, caregivers found themselves lost in a complex system in which they had to find their way. This navigation served the purpose of identifying resources and establishing services for their child with autism. This system is one that is complex, at the mercy of current policies, and lacking consistency from one duty station to the next. Families not only had to navigate the broader TRICARE and EFMP systems, but also the on-base Community Service (CS) systems, local school districts, and state Medicaid programs, to name a few. One mother described her frustrations following an attempt to initially establish services at a new duty station for her son saying, "there's just really not that much help. I've kind of stopped seeking because I don't have the time or the energy to fight the system and there's no system, it's just a mess."

Families often felt “lost” as well as a lack of support or guidance immediately following an autism diagnosis. One mother described her experience:

I think that’s the worst part about when you get diagnosed, nobody really tells you anything and being a military family if you’re not familiar with the area, you don’t know what you’re looking at. If they could have some sort of guidebook or something that they can give, I feel like the EFMP on post, they’re helpful in setting things up but that’s it, after that they kind of leave you. And you’re kind of like floating around trying to figure out what to do, and for new families that can be very intimidating.

This act of navigation essentially puts the caregivers in a position of being a case manager for their child, which one mother described succinctly as “it’s my job.” While fulfilling this role appeared to be a strategy to effectively obtain services for their child, it was also described as an all-consuming position. One mother said:

... it’s very, very overwhelming. You basically have to just focus on your mission of getting the services for your child. Then, what happens is, you kind of just put aside all the emotional things that are going on with yourself or your spouse, your other children... You’re frantically trying to cobble together the therapies that you think you need; even when you don’t really know what you need.

Similar to the process that other mothers described, this mother had to piece together information from a disjointed pool of sources to subsequently set up services, and to do so while feeling emotionally overwhelmed.

In addition to the challenge of navigating systems, caregivers identified the challenges in obtaining sufficient autism-related services in the healthcare system, on base or in the surrounding community, as well as in schools. These challenges were most often discussed in terms of identifying available and effective healthcare practitioners and service providers, anticipation of loss of services covered by TRICARE, as well as having the needs of their child met in school as legally mandated by their child’s IEPs.

Parents consistently revealed the challenges they faced in obtaining effective, consistent, and knowledgeable care from pediatricians on base or in military hospitals. Many caregivers shared the ongoing difficulties they had with “military doctors” and a lack of knowledge surrounding an autism diagnosis and associated medical concerns. One mother said bluntly, “I’m always surprised when they have a good military doctor, because there don’t seem to be very many of them.” While parents did often describe positive experiences with developmental pediatricians, they also identified lengthy waitlists in certain areas, as well as having limited scheduling options (e.g., the developmental pediatrician is only on base six days out of the month).

Many of the families made the decision to seek health care treatment for their child in the surrounding community in order to have a continuity of care as well as to have a doctor that they felt understood the needs of their child with autism. Two mothers shared their experiences of feeling like they were not afforded any options in treatment other than medication for their child. Both decided to find community-based doctors and to pay out of pocket for therapies that they described as not otherwise considered by the TRICARE-approved doctors. Further, caregivers expressed the challenges in obtaining referrals and approvals for therapy such as Occupational, Physical and Speech Therapies as well as ABA therapy from the doctors on base, and as one mother said, “Essentially, you have to get a referral before you can start them with ANY types of therapy.” Many mothers encountered challenges in obtaining these initial referrals.

While respite care and ABA therapy were two of the most consistent sources of support and perceived effective intervention for children and families, these two services were also often the most challenging in terms of getting services established and



identifying available and effective providers. Those mothers whose husbands were deployed at the time of interview stressed the “vital” nature of TRICARE’s coverage of respite care. However, these mothers also depicted the challenges in setting up services due to a difficult process of eligibility and subsequently finding respite providers who had availability or met the requirements for certification. One mother said that she did not begin receiving respite for 4 months into her husband’s deployment due to a lack of certified respite providers in her area. Another mother expressed difficulties in getting approved for respite care under new Army restrictions on respite care eligibility. After describing the lack of programs available to families with a child with a disability, this mother said “(the Army’s) answer is the respite program; but they’ve made the eligibility so difficult by now, and my favorite one is they said Respite can only now be used to service the top 5% category of EFMP.” Another mother similarly expressed concerns surrounding eligibility for respite care hours for her son whom she described as “severely autistic” due to the fact that they choose not to medicate him, and that the psychiatrists who review the “severity” of the diagnosis for purposes of respite eligibility might see this choice as a reflection of her family “not being stressed out enough.”

One of the primary stressors for caregivers in terms of access to programs and services for their child with autism was the concern surrounding the loss of eligibility of ABA services upon retirement. At the time of interviews, TRICARE policies considered ABA to fall under “behavioral health” services and therefore were not covered upon retirement from active duty service. This policy impacted many families’ decision to extend their military commitment in order for their child to maintain eligibility for ABA.

Anticipating the loss of these services was a consistent source of stress for many mothers, and for a few in particular had become an avenue for tireless advocacy efforts.

Finally, caregivers portrayed the challenges they faced in assuring that the schools were meeting the needs of their child and adhering to the goals and standards as outlined in their child's Individualized Education Plan (IEP). As identified previously, geographic relocations served to compound this issue, as IEPs were often not considered valid from state to state, DoD to civilian schools, or even across within-state school districts. Four of the families revealed ultimately having to pursue legal action to ensure that their child's IEP was being followed, which created a significant source of stress and in some cases financial burden on the family. Some mothers observed a 'regression' in their child's behaviors as a result of their needs not being met at school, which usually occurred after relocation to a new school following a PCS. One mother portrayed her experience upon relocating and enrolling her child in a new school:

Basically the (new) school reviewed the IEP he had in (state) and simplified it.... they did not add any new goals, and they are only offering him one hour of speech therapy a week! Within a few months, he was no longer showing any words, when he had at least made some progress before. He does not qualify for three times a month like some of the other kids in his class, which I don't understand because (child) is non-verbal.

This mother went on to express that the school district assumed that since the family was military they were receiving services outside of the school day as covered by TRICARE. The mother then had to explain to them this was not yet the case due to a lack of service providers willing to travel on-base to provide therapy.

(b) Parents revealed the barriers they faced in meeting the safety needs of their child and identifying opportunities for participation in on-base resources and military related services. These challenges were specifically depicted both in terms of a lack of

availability of on-base support and family programs as well as barriers to obtaining appropriate housing that met the medical and safety needs of their child with autism.

Many mothers mentioned feeling that they had limited options and resources available on base to support their child with autism. They expressed having a number of options available in terms of ‘family support’ that have opportunities for typical families and their children, but that these programs are often not appropriate for their child or family. One mother illustrated the culture of the military as a backdrop for challenges she faced in accessing family support resources and programs and the assumption that local community programs are a viable solution to meet the needs of children with special needs. She said:

I will tell you our number one problem in the army is sometimes I feel like I’m in 1950’s. You go on post at (base) and let’s pretend you’ve got a seven year old and you go to the MWR (Morale Welfare and Recreation) Program. You’re going to have lists and lists of stuff. You’re going to have karate, you’re going to have swim programs; you’re going to have lacrosse. We go and say, “What can my severe autistic kid do?” They’ll hand you a pamphlet for Special Olympics for North Carolina and that’s it. Military community assumes the local and state will support us, but we are not ever anywhere long enough for local and state support.

Another mother similarly identified having been directed to the local community to find programs to meet the needs of her child. She explained that while one local YMCA turned out to be an “incredible match” for her child, she was disheartened when there was no YMCA close to the next duty station to which they were assigned.

In addition to identifying a lack of recreational programs for their child, mothers identified challenges in participating in family-centered events that were not conducive to the needs of their child with autism. For example, families mentioned bowling activities and family movie nights that, because of the needs of their child with autism, families felt were not an option. These activities were often portrayed as occurring during times of

deployment when families in the unit would come together for support during times of separation from their soldiers, leaving these families to feel isolated.

Mothers spoke of the challenges they faced in obtaining adequate housing on base that would meet the safety needs of their child with autism. While families often chose to live in the community rather than on base, all had at one time or another had an experience of living on base. One of the primary challenges identified was the “bureaucracy” (as one mother described it) through which they had to go in order to make accommodations to the home to meet the safety and accessibility needs of their child with autism. One mother expressed the family’s experience trying to obtain an accessible home following a major surgery that her child underwent. She explained that she had to move the family (they had to move themselves) into an accessible house that she, in fact, saw as not being accessible at all (for example no grab bars in the shower). Another mother similarly illustrated her experience of trying to meet the safety requirements of her child by making modifications to their home:

I had to fight for everything. I had to get special approval for the fence, which means going up to the command Sgt. Major, and they didn't want any fences to extend- only generals get the privacy fence. I mean, (child) was a runner and he would run! We needed a fence.

She went on to expand on the safety concerns driving the families’ need for specific type of housing and the impact that it had on their ability to connect with their peers:

...another thing (child) started doing was, he thought it was fun to open windows and climb out. So we needed a 1-story house. So as punishment, they put me in a 1-story house, but on the farthest side of base than anyone close to my husbands rank, not that it is about rank, but it is about shared experience. Here my husband had just come out of command and they put me with lieutenants and captains...So people thought, “if you live over there you must not be one of us.”

After facing barriers in trying to make accommodations to their home on base, one family ended up moving off base in order to pick a home that met the needs of their family. In describing their experience living on base, this mother said, “they were supposed to put in door chimes and they never did. We were there like 9 months and they were on order the whole time.”

Overall, families were faced with significant barriers to feeling like they ‘fit in,’ particularly when it came to military programs and services afforded to their child with autism. Further, families had to fight for accommodations that they needed to meet the accessibility requirements accompanying their child’s disability.

(c) Families also described feelings of stress, ambiguity, and an increased need for parent-led coordination of services when facing geographic relocations or a PCS. During times of anticipating a PCS, caregivers reported having to navigate from afar in order to establish and coordinate services with little to no support. In all instances, there was a reported lag in services for their child, ranging anywhere from a few months to 9 months time. This lag in service was often identified as a function of the non-portability of any previously established services, ranging from community and on base supports to DoD or civilian school systems to healthcare and medical needs. One parent stated:

So everywhere we have gone, once you get there, you have to go all the way back to the primary care provider. So you have to go to her pediatrician and show the diagnosis and say, “at our last installation we had these services and this was done by referral, this one we found on our own, this one was ABA, etc.”. You just have to go through that entire process of setting it up, it’s absolutely non-portable.

In addition to the non-portability of services, parents also identified challenges in trying to identify points of contact in order to set up services at a new duty station. One

mother described this ongoing challenge that she encountered from one duty station to the next:

EFMP didn't know much about ABA. The school liaison was the most responsive, but then you change posts and it was the EFMP coordinator. Then we headed to (state) for a year, and the school liaison knows nothing, BUT the brigade commander's wife has an autistic child! ... and in (state) if your child has a disability, they qualify for Medical Access and they pay for everything! So, there is NO consistency from location to location, and I don't think that has changed.

Another mother similarly identified a gap in services during relocations when she attributed a 9-month lag in ABA services for her daughter due to incorrectly written referrals and miscommunications between the mother and the ECHO program manager as well as with the base community hospital. This mother further identified a two-month period of time that it took to find an ABA provider that had availability on their caseload to provide services.

The non-portability of services was often described in terms of a lack of recognition of IEPs from previous school districts, be they public schools or DoD schools. One mother portrayed such an instance when her family moved cross-country for her husband's new duty assignment:

And so I leave (West Coast) with this comprehensive treatment plan in place and go to (East Coast) and my son's services went from 25 to 0. The school wouldn't honor my son's IEP and said "We don't do that here" and there's a 12 year waitlist for Medicare assistant from the (state) and that's when TRICARE slashed or "terminated" my son's treatment plan. So nothing happened to my son's diagnosis or autism but the services that were available in (state) were not available to me here.

This mother went on to ask rhetorically, "My husband had just returned from war and this is what you're doing to me?"

Many caregivers talked about the stress of the logistics of moving with a child with autism. In addition to the actual travel and staying in unfamiliar environments,

caregivers often revealed the difficulty in making decisions about what to hold onto and what to let go. Parents depicted their child's need for maintaining favorite toys in the presence of their circumscribed interests, and the associated challenges in making frequent moves. One mother explained how children with autism often get attached to certain items and the difficulty that parents have in knowing exactly which items are meaningful to them because "they don't play with toys in the same way that other kids do." This mother went on to describe her challenges in constantly trying to identify her child's "special toys" when she said, "you think that they have absolutely no interest in them, but you find when you put them in storage, in a matter of a few weeks your child seems kind of confused and you're wondering what's going on." This mother went on to place this challenge in the context of her child's current interests and their basement that is in storage in preparation for an upcoming move:

Like, he's now asking me for books that I stored two years ago, like *Wheels on the Bus*, and all that kind of thing downstairs where I absolutely can't get to it because it's in the storage room in the very farthest corner on the bottom. There's no way. He knows where it is and he'll sometimes try to lead me downstairs to get it.

This mother said that getting rid of any toys is "a real challenge." Another mother similarly described her experience in having to move "basically all of the toys he's had his whole life" with each relocation.

Geographic relocations often left mothers feeling isolated, as some depicted the challenges moving farther from extended family members as a stressor. One mother said "...its not like they live around the corner where I know I have access to a reliable babysitter – and particularly with (child), that can be a big challenge." Another mother counted solely on her spouse to watch the children so that she could run errands or have a

break, particularly since having moved from the West coast where both of their extended family was located. Describing her life since her husband's deployment a few weeks prior, mom stated, "I can barely manage" and reported feeling like "I have no backup."

(d) Mothers identified the barriers they faced in managing challenging behaviors and engaging in occupations in the community. Caregivers described what their family could or could not do because of the needs or behaviors of their child with autism. Families most often expressed an inability or challenges associated with eating out in restaurants, going to movies, or running everyday errands such as going to the grocery. One mother said, "We would love to be that kind of family that says 'let's go see a movie this weekend,' but unless it's a movie that he has been obsessing on, no chance." Another mother illustrated the challenge of going into the community and managing her son's symptoms, saying "I have to take him out before he has a vocal stim; he makes very loud noises so we don't do a lot of that. Birthday parties at Chuck-e-cheese, forget it...sensory overload." When asked about the frequency of outings into the community when dad is deployed, one mother said:

I would love to, but I can't drag him just anywhere. (Child) doesn't like to have shoes on. I go to do something with (sibling), and he is already without shoes and socks. If I open the car door, he is trying to get out, and he will even jump the fence.

This mother went on to express her desire to be able to go out into the community to meet other families at their new duty station, but based on her son's behaviors, she had to mostly stay home.

The occupation of grocery shopping was consistently identified as challenging, particularly during times of separation or deployment. One mother explained that her son with autism experienced the grocery as "traumatic," which posed a tremendous challenge



for her in buying groceries for her family. Mothers mostly talked about the difficulty of grocery shopping in the context of challenging behaviors from the child with autism. Some mothers reported additional stressors in having to find grocery stores that carry products that meet the dietary needs of their child. One mother went to a local farm in order to get fresh and organic produce to meet the dietary needs of her child. Another mother additionally explained her increased frequency of grocery visits due to having limited time in the store based on her child's behavior:

I've been leaving the two younger ones and doing a really big grocery shop. And then I'll just go for one or two things up to Food Lion and come back. And they're like "we go to the grocery store every other day!" and I'm like "well, I cannot be in there for more than 5 minutes!" It's crazy.

She went on to identify increased challenges that she faced while her husband was deployed in having to either have child care for her young children in order to grocery shop, or taking all of the children with her. She said, "I feel bad if we have to leave somewhere because he throws a tantrum or whatever- I mean, I say- sometimes I wish I could clone myself!"

Often times, mothers explained the need for their family to "split up" rather than engage as a whole family in community activities due to the needs of the child with autism. For example, mothers often said that the father (when he's home) took the other child/ren out to run errands or see a movie while mom stayed at home or took the child with autism to therapy. One mother said:

Before (child) got older, family time was always together, right? Especially in (state), it's more family based if you like the beach, right? Nobody cares if you've got wild kids at the beach. Now that the youngest is getting older...He doesn't like his brother because he's loud and he's weird. I'm starting to feel a lot more division in family time. My husband is going in Saturday mornings to fish at 6 AM and he's taking the youngest with him. It makes me really sad, honestly.

Other mothers similarly described an increasing division in family time, particularly in the presence of the evolving needs of their other children.

(e) Caregivers expressed feelings of isolation and the encountered stigma, both in civilian and military settings, associated with having a child with autism. Mothers explained that feelings of isolation stemmed from limited options to socialize with other military families or families of their child's peers due to the needs of their child with autism. One mother said, "...as a parent of a child with autism, its hard, I mean, it's not like people are banging down our door for play dates and things like that." Another mother depicted feelings of isolation when her family was not able to access the same types of supports as other military families during a time of deployment:

...Talk about isolating. It was depressing for me because all of my friends who were going up to the North Shore to this really cool YMCA camp on the ocean for bonding with other families of deployment. I couldn't go because I couldn't afford an additional \$200 for both therapists to go with us, and leaving them home wasn't an option either. It is very, very isolating.

Another mother stationed at this same base similarly identified "tons of cool family programs" that the base offered, but said that she and her family rarely got to participate due to the needs of her boys.

Caregivers further illustrated their experience with encountered stigma in the community or by fellow parents or other military spouses. Mothers explained the stress associated with feeling stigmatized as well as the ongoing 'explanations' that they have to give to those who appear to judge their child's behavior unknowingly. One mother said:

...yeah there are some people there where we've had issues where people just don't know and they assume that he's just a really bad kid. Until they found out who we are and learn who we are, then they change their attitude or perspective of

(child). So we've had to deal with that a couple times but that's to be expected I think.

Similarly, another mother expressed her encountered challenge in connecting with other spouses in the unit due to a lack of understanding of autism. She said,

The hardest thing was that people didn't understand autism. At one point during deployment number 3 - this was right before ECHO and Respite- we were at (base)... and I was complaining we had no services, and a friend of mine said to me "you know, people are really tired of people complaining about this". When so and so was in the field, her son had a heart defect and she handled it! And she did it alone- and he even went through surgery!

This mother went on to describe the significant challenges that she faced in trying to balance meeting the needs of her child with autism and fulfilling the role "commander's wife" during a time when her husband's brigade was deployed. She expressed the difficulties that she encountered in meeting the expectations of this role amidst an "officers' wives" culture in which the other wives more easily upheld such roles. For example, she illuminated the expectation of attending late-night cocktail parties, and being able to throw a "welcome party" at the drop of the hat. For this mother with two children, one with "severe" autism, fulfilling both the role of 'mother' and 'officer's wife,' in this particular context, posed as a tremendous challenge. This mother reported feeling that she was ultimately ostracized and generally misunderstood.

Another mother similarly described this clash in roles and the challenges that her faced in meeting the needs of both their child and filling the role of commander's wife:

I can't tell you the thousands of dollars I had to spend out of pocket to attend FRG meetings, brigade steering committees in memorial because I can't use childcare for that. Yeah, the financial cost for me took a toll at my husband. When you're in command on a post like (base) or something, as one of the battalion commander's wife, you need time for chief star, one star, three star wife comes in you've got to get a farewell coffee, the welcome coffee, you've got to get a divisional organization day brigade, I mean the list goes on and on.

The challenge of balancing the needs of their families and ‘fitting in’ to the military culture was an ongoing struggle for many of these caregivers.

(f) Mothers depicted the compounded challenges that they faced during times of separation or deployment. Specifically, mothers expressed the challenges of being “the only one” available to care for their child with autism and other children, as well as serving as the primary support to their soldiers during this time of separation.

Caregivers illustrated their experiences during times of deployment as challenging in terms of feeling like “a single mom,” as one mother put it. Some mothers explained the challenges that they faced in taking on household duties that their spouses typically take care of, such as, mowing the lawn, taking out the trash, and even cooking dinner. In addition, mothers encountered difficulty in trying to meet the needs of all of their children, whereas when their spouse is home they have more support in meeting the needs of the whole family.

Mothers also expressed their emotional experiences in anticipation of and during deployments. Some mothers reported feeling accustomed to deployments and labeled these times of separation as part of the job, or as one mother put it, “it comes with the territory.” For example, one mother who was herself prior enlisted said, “I think that I’ve mentally prepared myself, like, okay, this is what I have to do and I don’t have a choice.” Other mothers depicted the intense emotional toll that deployment took on them. One mother said:

Something just snaps after a certain period of time when you feel unsupported and you feel beaten down; I felt like I was breaking. I couldn’t handle it. And I kind of put myself in the category of “the strong of the strong”, I feel like I am extremely resilient and if I can’t get through a year.... I was still broken after 7 or 8 months. It was hard, 12 months is too long on a family.

This mother went on to describe her decision to go on medication in order to “get to the level of functioning” that she felt she needed in order to meet the demands of her family during the time of deployment. Another mother portrayed her feelings in anticipation of an upcoming deployment and the toll that it would take on her children who both have a diagnosis of autism: “we haven’t told them yet and I’m completely stressed out. I don’t want to think the glass is half empty but I’m just thinking the worst; Like regression with school and pooping in the pants again and transition issues and anger issues.” Another mother similarly identified her concern regarding her husband’s return and its impact on their child (with autism). She said, “he looks at the calendar, and we talk about how daddy is coming home soon, but I am honestly nervous about how they will react to each other. A lot changes in a year.” This mother also highlighted the challenges that the family faced over time amidst cycles of deployment and the challenges is re-integrating into family life. She said:

..you know I’ve said to my husband at least 20 times since he’s been home, “we’re great married apart!” it’s perfect, it’s nobody’s business. You know all of that separation, you get used to it! You’re either getting ready for deployment, coming home from deployment but you know that there’s another one looming. That even changes your year together because you know that you only have this set amount of time.

This mother went on to describe the challenges that her family is facing with retirement looming, knowing that her husband’s new career will not involve deployment and separations and that for twenty plus years they have lived, and gotten used to, deployment as a consistent force in their family.

Finally, many of the mothers alluded to their concerns about the service member themselves during times of deployment, particularly in the context of the challenges in maintaining communication with their child with autism. As one mother said, “I hate to

say it, but (child) is sort of ‘out of sight out of mind’ when it comes to missing his dad.”

Depending on both the age and severity of the child’s symptoms, mothers explained varying degrees of interest or ability on their child’s part in participating in communicating with their deployed father via as Skype or phone calls. This lack of consistency and contact with their child made caregivers concerned both about the service member’s wellbeing during the deployment, but also their reintegration into family life following their time away.

Overall, mothers identified feeling isolated from opportunities for social interaction with other families as a product of a lack of accessible resources. In addition, families were often stationed far away from extended family members who were described as otherwise having the capacity to serve as a consistent source of support, particularly during times of deployment.

(g) Caregivers faced challenges in meeting the needs of their other children, or those without an autism diagnosis. Mothers often expressed concern surrounding their ability to provide their other children with opportunities to engage in activities like “typical” kids, rather than always being at the mercy of the needs of their sibling with autism. One mom expressed her concern about her oldest daughter saying:

I always worry about her, she’s very well adjusted, she’s a great little girl, she’s very social, she’s very smart and I always worry about her because I feel like she gets the short end of the stick because (child with autism) does require a lot more attention and it’s hard for me because to split my attention among the both of them and I always try to make sure that she gets her attention too. But sometimes that can be difficult especially with (husband) being gone.

Similarly, another mother illustrated the challenge of being a ‘typical’ family and the way in which she had to overlook the vision she had in terms of raising her older daughter:

We can't do things with her that other families can do with their kids. I wanted to teach her Russian, we would go to the museums, and I would show her art, music... but we can't really give her that because of (child with autism). Having basic things like a like a normal dinner; we just cannot have that...he climbs on the table- he swings...we cannot do elementary things.

Daily routines were often described as governed by the therapy schedules and needs of the child with autism, which had an impact on the options available to the typical child, particularly in terms of extra-curricular activities. Several of the mothers said that their 'typical' child/children could not play on sports teams due to the lack of feasibility in picking them up after school, or taking them to games on the weekends – particularly when dad is deployed. One mother said succinctly “my other son is 10 and he's never played soccer in his life and he's never been part of a baseball team because we have therapy every day after school.” Some mothers also expressed a lack of involvement in family-centered activities on base that they felt their 'other' children would enjoy or benefit from.

Overall, caregivers expressed concerns surrounding meeting the needs of all of their children. Families faced the challenge of needing to allocate significant amounts of time and resources to meet the needs of their child with autism, which often left in question whether their other children's needs were being met. Siblings of children with autism often had to miss out on opportunities to participate in extracurricular activities or outings in the community due to family routines and outings being focused on meeting the needs of the child with autism. Caregivers expressed guilt and concern surrounding whether or not their other child's needs were being overlooked or sufficiently met.

Broadly, *barriers and stressors* were those situations or experiences that families perceived as distressful, as having a negative impact on one or more family members, or

which served to impede families attempts to implement strategies or solutions. These situations arose when families recognized a need to manage or change an aspect of their current situation either to meet the needs of an externally placed expectation or when the family recognized a decreased ability to effectively meet needs they deemed important or essential for one or more family members. *Barriers and stressors* were dynamic in nature and constantly being recognized and interpreted by families through their ongoing reflections of evolving experiences and anticipated future. Over time, *barriers and stressors* were also impacted by families' strengthened, or weakened, ability to effectively prevent and respond to previously encountered distressful situations depending on their current situation and access to necessary resources and strategies.

## **6.5 Theme Category 2: Resources and Supports**

When describing the stressors or barriers they faced, caregivers often referred to the resources that they had available, or that they utilized in response to experienced stressors. Family *resources* and *supports* were most often described in terms of available (a) social supports; (b) therapeutic programs/services targeting autism needs; (c) other military, healthcare and community programs that support the family; (d) online resources and support; (e) key personnel.

(a) Social supports were a primary resource that mothers regularly utilized in the presence of everyday life and in times of encountered stressors. Caregivers highlighted the importance of establishing a sense of community through forming social connections both in close geographic proximity as well as via online web resources. A sense of community was established first and foremost by making social connections, most often



consisting of other ‘autism moms’, other military families and neighbors, church communities, and extended family members. The common benefits across these types of social supports included that of a shared understanding, a sense of acceptance, a feeling of universality, and an opportunity to feel ‘normal’.

Most of the mothers described relating to and relying on support from ‘other autism moms’ (or other autism parents). Caregivers portrayed a sense of community and support from these parents who had similar circumstances and life experiences to their own. One mother said “they just get it...they know what the day in and day out is because they are living it too.” Another mother said, “It seems like a family almost that you get adopted into and parents of kids who have been there, they are very, very helpful in helping you.” Another mother joked about the way that she always seemed to “find” the other families with a child with autism and that “autism moms” must have “an invisible tattoo on our foreheads” as a form of identification that only other autism parents can see and relate to.

Other military families, particularly those who lived in close proximity, were identified as sources of friendship and support. One mother said, “the neighborhood has been such a big support...It seems like everywhere you go, whether they come in before you or after you, there’s another military family that you can relate to.” Other families made connections with neighbors who most often had children in a similar age range to their own and who most often were other military families themselves. Neighbors sometimes provided childcare or other forms of support when the caregiver was ‘in a pinch’, especially for those families who were living on base. Even for those families who were not well connected, mothers often made the effort to introduce themselves (and

their child with autism) to their neighbors in order to ensure their child's safety in the case that he wandered away from their home.

Caregivers identified church communities as a place where they felt accepted and in some cases 'normal'. One mother said, "Our church even has a coffee bar, which helps; I can actually feel like an adult for an hour." Another family said "... and then everywhere we've been we've had the support from church. So every Sunday is very much the same for us so we always find families there who are very similar to us in circumstance." Another mother similarly described church as a place of support:

It just makes me feel normal, just like everybody else, even though we have (child). Sometimes we bring him to church in the auditorium where everyone else is and sometimes he's loud and sometimes he just doesn't want to be there. But most of the time well- everybody knows (child), so it's ok.

Mothers also found support in their extended family members, most often their own and/or their spouse's parents. Many of the mothers identified the frequent visits that family members made in order to help the family with the kids, particularly during times of deployment. One mother explained her husband's last deployment and the support that they got from the grandparents who lived in other states, but made scheduled visits:

When he was deployed, I worked it out with my mom and his mom- I knew I could do it on my own but I also knew I would burn out if I didn't have time to myself. So my mom and stepdad came out for the first few weeks...I was on my own for a few weeks...his mom came out for two weeks and then we had about a month on our own ..his mom came out again for another two weeks and then towards the end of the deployment, my mom came out for another 2 weeks.

Other families similarly described grandparents as making the effort to be present on a consistent basis, particularly during times of deployment. For one family, the grandmother had recently sold her home in another state and was moving into a new home close to her daughter and her family in order to provide support during a

deployment cycle and thereafter. This mother said that her own mother had made this decision “because I need help. I need respite, I need sanity.”

(b) Therapeutic programs and services targeting the needs of the child with autism were also resources that served to meet the needs of both the child and the family. The primary resources that caregivers identified were ABA therapies. Applied Behavior Analysis (ABA) was endorsed by all but two families as their primary form of therapy, and the therapy ‘of choice’ for their child with autism. While it was often a challenge to identify effective service providers, or those that met the standards of coverage by TRICARE, ABA programs were seen as an integral aspect of daily life for many of the families. Mothers went into great detail about the effectiveness of ABA therapy in helping their child meet developmental goals, as well as helping the family effectively integrate the child into everyday family routines to include community outings. ABA therapy was described by one mother as a “lifeline,” wherein she felt that she had tools with which to respond to her child’s challenging behaviors. Another mother said that she felt “desperate” for help prior to beginning ABA therapy and had subsequently observed tremendous progress in her son’s behaviors.

Caregivers expressed the way in which they aimed to incorporate strategies from ABA therapy into their everyday lives, as well as the way in which these strategies facilitated integrating the child into the family. One mother described her ABA program in the following way:

If you get your child into an ABA program, but you don’t know the fundamental of what ABA is and live ABA, you’re not going to make as great strides as you could possibly if you really understand it. You don’t have to become an expert and you certainly don’t have to become your child’s therapist, but you need to integrate it into your home life. It’s not something that you just drop your child off with the therapist for a couple of hours and then you get your child back and

then that's the end of it. We live it and breath it. All of the insight and everything we've learned from speech to ABA, we integrate it as a team.

Some mothers similarly spoke of a 'team' approach to their ABA program in which not only the providers played a role, but also the other children. In several cases, siblings were seen as being routine 'helpers' in the process of ABA sessions who often times served to model targeted behaviors. One mother explained that having ABA therapy take place in their home eased the incorporation of strategies into their everyday lives and that by their other children being familiar with the goals and strategies, they were able to participate in this integration. Another mother joked that basic behavior modification strategies "also works on typical kids" and described her parenting style with all of her children being impacted by her growing knowledge of ABA.

Finally, having a therapist in the home allowed the mother a brief opportunity to not feel like 'the only one' caring for their child. Some mothers utilized therapy hours to catch up on case management tasks such as making phone calls, scheduling doctor's appointments and working on weekly schedules. Other mothers utilized this time to help their other children with homework or to catch up on such household chores as dishes and laundry, as well as to take a shower. One mother joked that the therapists coming into the home were one of the only consistent opportunities that she had for adult interaction and explained how much she appreciated someone else 'taking over' with her kids at the end of the day when she was often at the point of, as she put it, "about to go crazy."

Overall, ABA was strongly endorsed by most of the families in the study as a vital aspect of their child's development, as well as supporting the wellbeing of the whole family by facilitating integration of the child into everyday family routines and

community outings. Further, parents described feeling that by utilizing ABA strategies, they had tools to manage their child's challenging behaviors.

(c) Other military, healthcare, and community programs that aim to support the family also served as family supports and resources. The most prominent programs that families described effective resources included respite care programs, autism related community organizations (e.g., county Autism Societies), and special recreation programs that could accommodate children and families with special needs (e.g., YMCA's and Special Olympics).

The respite care programs proved to be vital for caregivers in order to catch up on household chores, go to the grocery store, to have time for self-care time or going on social outings with friends. The mothers who relied most heavily on respite hours were those whose husbands were deployed at the time of interview. For example, one mother described her goal of training for a marathon as an "outlet" in preparation for her husband's upcoming deployment, and found it helpful to have respite care for her son while she did "long runs" on the weekends in particular. Other mothers relied on respite care as their only opportunity to get chores done around the house or to run errands such as going to the grocery store, which otherwise proved to be an incredible challenge as described previously. Respite care also afforded mothers time "just to have a bit of a break," as one mother said. She said that without respite care, she would likely not be able to maintain relationships, especially with her "non-autism mom" friends. Finally, respite care hours were often utilized by caregivers to take time with their 'typical' child/children to participate in outings that otherwise prove to be a challenge with their child with autism.

Some mothers also identified that they were active in their local Autism Society groups, either through seeking out support from other families or by actively participating through volunteer work. One of the mothers who identified her son as “high functioning” expressed her positive experiences in participating in the Special Olympics as well as the Boy Scouts of America. She praised her son’s experience in Special Olympics based on the coaches being able to work well with the kids, and for a feeling of acceptance and encouragement of her son’s “unique” personality and abilities. This mother also said that the Special Olympics provided an opportunity for her husband to participate in an event in which he had a common interest (i.e., sports) with their son.

(d) Online resources served as valuable and consistent avenues for support and information gathering for caregivers. Mothers participated in autism-related Facebook groups and were members of geographic-specific or subject-specific listservs. The American Military Families with Autism (AMFAS) Facebook group in particular was identified as an avenue for parents to both contribute information about their own experiences as well as to find encouragement and support. In addition, there were a number of national and local web resources that were consistently endorsed by parents that served as information resources targeting autism or military families, such as Autism Speaks ([www.autismspeaks.org](http://www.autismspeaks.org)), Military OneSource ([www.militaryonesource.mil](http://www.militaryonesource.mil)), and specific Autism Society organizations (e.g., [www.autismcc.org/](http://www.autismcc.org/)).

Mothers utilized these resources in order to seek out information specific to the unique needs of their child, or their unique family situation. One mother gave an example of asking the AMFAS Facebook group for information about her families’ upcoming PCS to a particular base, and said that she received a wealth of information and opinions

from other parents who had already experienced this particular base and school system. Another mother said that she found a tremendous amount of support for the specific treatment paradigm that she had chosen for her son (which consisted of treatment for vaccine injury) from an online forum that consisted of dialogue between families who similarly endorsed or had interest in this particular treatment. She said, “It is encouraging to know that there are other parents out there who are also trying to cure their child”. Other mothers described navigating school district websites, with one mother indicating, “I know by now what I need to look for – the numbers, the test scores, the demographics.”

(e) Mothers identified key people along their journey who educated, guided, or supported them in a significant way. These key people ranged from a friend who first told a mother about ABA to a “crotchety old preschool teacher” who took time to educate the mother about the public school systems. Other significant individuals included a commander’s wife who was also an ‘autism mom’, a new EFMP case manager, a university professor who ran a community intervention program, and teachers and aides who were highly motivated and effective in working with their child. In addition, many of the mothers mentioned specific advocates in the autism (military) community whom they felt were leading the efforts in bringing about policy changes. One name in particular was recurrent through many of the mother’s stories. This individual was described as retired military personnel, parent, and autism advocate who provided information through a listserv about events and resources in a particular geographic region. This specific individual made himself available to several of the families, providing his personal phone number and time to educate families about services in a

particular area, as well as sharing his own family's experiences. One mother said "if we could just have a (name) at every base, we would be in good shape."

In summary, access to *resources and supports* was a key component in the process of caregivers meeting the needs of their family. Caregivers identified having access to particular resources as being at the forefront of their ability to meet basic needs of their child with autism, including their healthcare, educational and safety needs. Qualitative assessment of experiences with available *resources and supports* were consistently present in families' stories. These consisted broadly of sources of assistance or support that families viewed as accessible and/or helpful. They encompassed both tangible forms of support or services (e.g., respite care, ABA therapy, social supports) as well as perceived internal supports (e.g., perception of personal strength, "I see myself as the strong of the strong," and accumulated knowledge about autism therapies/treatments).

### **6.6 Theme Category 3: Strategies**

Caregivers implemented ongoing strategies throughout their everyday lives that they felt were positively contributing to their own and/or their family's wellbeing or in direct response to specific barriers they confronted. Mothers revealed tenacity in implementing strategies and engaged in an ongoing process of coping, both in preparation for and in response to the challenges that they faced. Ongoing strategies included (a) advocacy and education; (b) taking "me time"; (c) structuring and managing family routines; (d) establishing a sense of community & building a "team" of support; (e) prayer, cognitive re-framing/mantras, self-talk; and (f) maintaining organizational



tools. Examples of specific strategies used in direct response to specific barriers are identified in Table 6.2

(a) The first theme describes the way in which mothers went above and beyond to meet the needs of their children with autism and often found personal meaning in their advocacy efforts. Advocacy ranged from providing for their children's individual needs to contributing to broader awareness or system changes in the military or autism communities. In addition, engaging in advocacy efforts also appeared to fulfill a need for the mother herself, as advocacy was often described as a form of coping and a source from which mothers found meaning in their lives.

All participants in this study described filling a role of 'advocate' when talking about the journey of obtaining diagnosis, services, and treatment for their child. Advocating came in the form of navigating resources, relaying the needs of their child to their healthcare providers and therapists, as well as ensuring proper placement and intervention in the school setting. Some mothers specifically described themselves as 'advocates', while others simply described advocacy efforts in which they consistently engaged in order to meet the needs of their child.

One common foundation of advocacy included mothers' endorsements of developing knowledge about autism, treatment options, 'rights' in obtaining optimal education and other services, and the nuances of broader systems and politics. One mother described her ongoing effort to keep up with current policies and education rights for her child in order to obtain optimal services. She said, "knowledge is so powerful." Many of the mothers were well aware of their child's education rights through the IDEA act and some subsequently participated in filing suit in order to maintain these rights. One

mother did a wealth of research on vaccine injury and recovery in particular and developed a platform in her community from which she could educate other families about her son's experience. Another made it her mission to educate other families about establishing effective ABA programs by opening her home to families in order to observe what she had developed into an "optimal" example of an ABA program. The research and education efforts of each mothers appeared to be specifically tailored to support their individual efforts in meeting the unique needs of their child.

Many of the mothers additionally took on volunteer, and in one case paid, positions directly targeting advocacy efforts to meet the needs of children and families with a disability such as autism. Mothers served in volunteer positions to include Special Olympics event volunteer, Autism Society chapter leader, active member of a local military hospital boards, board member of military-specific strategic planning committee, board member of the state board of education, consultant to national Autism organizations, as well as guest speaker for local church and military community groups, to name a few. Mothers also took on more informal advocacy roles, mostly in the form of reaching out to other families (both civilian and military) who they saw as needing guidance in identifying resources or setting up therapeutic programs. Further, mothers expressed the importance of participating in online support and advocacy communities with the goal of not only finding support for themselves, but also to reach out and provide information to other families who may not be as far along on the journey of diagnosis. As one mother described, "So many families are spinning their wheels and it's the least I can do to help them out by sharing my own experience."

While navigating and case managing services for their child was identified as a stressor, many of the mothers described this occupation an effective way of coping or contributing to their own wellbeing. Mothers alluded to finding a sense of purpose through their advocacy efforts as well as positive feelings associated with feeling like they were doing *something* to contribute to their child's wellbeing. One mother in particular identified the time that she spent researching autism and treatment options as an activity in which she found "comfort" and the primary means by which she enjoyed engaging her own time. She said:

I know this might sound kind of weird but to me, I get comfort in doing those things that might help (child) get better. Like spending time on the computer looking for things that help him or just communicating with other people, just talking to them about what has helped my son or what could help him. I get more stress relief from that than I do anything else like going out or quiet time by myself. I would rather do that than.... To me, it makes me feel a lot better just doing something like that and knowing that I'm trying to help him because I really want to help him get better.

Further, some mothers expressed the dual benefit of simultaneously participating in awareness or advocacy efforts while also having a positive impact on their own wellbeing. One mother illustrated the role that running played in her life following her child's diagnosis, as well as the connection that she formed between running and her desire to contribute to the broader mission of autism awareness:

...after (child) was diagnosed, I was so depressed that I didn't want to do anything...So I went back to the gym and I started taking classes and I ran a 5K race for autism awareness. And after, I actually ran a marathon last year. And all of it was for autism awareness and to raise money for autism research. So I've kind of taken my hobby and turned it into something good. And honestly, that makes me feel good to be able to do something. Because a lot of time with autism, your hands are tied and you're kind of at the mercy of whatever's going to happen that day. So to be able to do something feels good.

Overall, mothers often went beyond advocating for their own child by supporting other families that needed guidance or participating in larger awareness and advocacy efforts. In addition, many caregivers found comfort in their advocacy efforts and identified these efforts as positively contributing to their own wellbeing.

(b) A second strategy that caregivers endorsed was that of taking “me time” or taking time for themselves away from their children. This “me time” ranged from hanging out with friends or attending bible studies to engaging in personal interests or hobbies. Sometimes “me time” was as simple as being able to take a shower or to grocery shop, as one mother put it, “in peace and quiet.”

Mothers described the importance of having time with friends – either meeting for coffee, going to a movie or dinner, or even during play-dates. They often utilized respite care hours in order to take time away to pursue these social activities, particularly when dad was deployed. Mothers varied in their desire to engage in social activities as an outlet, with some indicating that social outings were non-existent and others saying that meeting with friends was very important and a consistent part of their weekly routine.

Some mothers took time to pursue individual interests and occupations, which they often called hobbies. These hobbies consisted of participating in recreational athletic activities (e.g., softball team, yoga, running, etc.) to craft related occupations (e.g., crocheting, painting, refurbishing furniture and interior design). Some mothers identified writing as an activity that they did on their own time, to include blogging or keeping a journal. One mother stressed the importance of taking time for herself and expanded upon her own experiences of engaging in various recreational activities:

I’ve always told people, any of the moms, the most important thing to do is you’ve got to find something that you’re passionate about outside the autism.

You have to make time for yourself. That's really hard...I think you have to have a healthy balance for your family. For me it is always finding a hobby. To give you an example, when I was in (state) I became really, really involved in a tennis group. It was great. They just knew me as (name), not the autism mom, right? In Hawaii I became really, really interested in the surfing community. I surfed seven days a week. Then I got into open ocean rides. For me it's physical activity. Here in (state) because obviously there's no ocean, I've become part of--I call it the cult, because they were kind of a cult, I giggle at them. I joined a croquet community. I do croquet five days a week.

Similarly, some of the mothers that worked outside of the home described their job as rewarding and in some cases a relief from the day-to-day challenges of being at home with their child. One mother said "When I'm at work I feel like that's the easier job, rather than being at home with my son and taking him to the therapy and trying to fit everything in...that's harder than my day job."

For some mothers, time was spent focusing on their own education. Four of the mothers were part-time or full time students at the time of interviews. While three of the mothers were enrolled as students in degree programs, one of the mothers was taking community language courses and had taken art courses in the past, as she said, "I like to do things to improve myself."

Overall, mothers took time for themselves, but also described the challenges in finding this time. Some talked about hobbies or activities that they used to enjoy, but said they did not have time for anymore. Some mothers planned to get back into particular activities or hobbies in the future (e.g., after kids start school, following PCS, or upon dad's redeployment).

(c) For many families, establishing consistent and strategic family routines facilitated an ease of transition during times of deployment or relocation. Consistent family routines provided ground on which to stand during otherwise unpredictable times

of transition. Specifically, structuring family routines were also used as a strategy in preparing children for deployments as well as creating a consistent means for integrating their soldier into everyday family life. One father who participated in an interview described establishing a routine to prepare his daughters for upcoming separations. He said:

In my current job, probably every other month I go over to Japan for about a week. They're at the point now where that bothers them. Most of my trips are leave on a Saturday, cross the international dateline to be arriving there Sunday afternoon for work starting on Monday morning, local time- So most of my flights are midday out of (airport). And our little tradition is we don't tell them until it's the day of. So Saturday we wake up and "We're going to I-HOP!" And they're all sniffly because they know what that means but they're excited because it's I-HOP!

The mother went on to describe the way in which they would the routinely Skype throughout his time away, at a specific time of day. She would encourage the kids to tell dad three things that they did that day, and although mom said that it was often the same three things each day, mom said that "the girls came to expect and enjoy that."

Besides regular Skype sessions, other means of incorporating the soldier into everyday family life were described. Mothers reported sending pictures frequently from their iPhones via email, or posting pictures to their Facebook pages for their spouses to see. Families engaged in craft projects or letter writing activities to send to their dad in care packages. One mother said that she intentionally took several family pictures before her husband deployed so that she could have them printed and visible throughout the house for both herself and her children to see. Two families mentioned participating in a program through the USO in which their soldier reads books on video that the children can then watch/listen to while following along in their own copy of the book.

Other mothers similarly described the way in which routines provided a predictable environment in which the family functioned while the father was deployed. One mother described her desire to maintain structured routines as a way to “keep things normal” while dad was gone. Maintaining a structured routine appeared to be a protective mechanism by which mothers created a stable environment that was filled with activities (including school, therapy, and family time). These structured routines appeared to be a proactive strategy that the caregivers used in easing their own burden of managing everyday life by providing organization and consistency in which family life could operate as smoothly as possible. On the contrary, one mother described family routines as being “more laid back” when the father was deployed. She described more flexible house rules, such as letting the kids sleep in “the big bed” and having special treats such as movie/popcorn nights.

Mothers also described modifying routines as a strategy for circumventing facing challenges in participating in community outings. For example, in order to circumvent the challenge of having to go to the grocery store or running errands with their children, mothers utilized online shopping. However, these services were described as being only available in the community, rather than at the PX on base. Mothers also shopped for clothes and shoes online both for themselves and their children. One mother said, “Zappos is a lifesaver, because I don't have to drag him into a store to try on shoes, and they have free returns.” Another was also able to find specialty foods online from Amazon.com (e.g., gluten free) that she would have otherwise had to buy in a grocery store that was across town.

Overall, family routines served to structure family's days in a consistent way and provided stability during times of transition. Consistent routines served to meet the needs not only of the child with autism, but also other family members, and were used by mothers as a tool for organizing family life.

(d) Mothers engaged in prayer and cognitive-reframing, or utilized mantras or positive self-talk in moments of needing encouragement or as an ongoing strategy that they used throughout their everyday lives. These strategies assisted mothers in tolerating distressful situations, as well as to provide ongoing means of viewing and interpreting their situation such that their situation felt hopeful.

Many of the caregivers mentioned their faith as being an important aspect of their life. Faith often took shape in form of going to church on a regular basis, having a defined set of values by which they lived their everyday lives, as well as engaging in prayer. When asked about the way in which she copes with everyday challenges presented by her child's difficult behaviors, one mother responded, "we are trying to be good Christians. God delivers. We have to hold onto hope."

Mantras, or repeated words or phrases for the purpose of self-encouragement, were also described to as an ongoing strategy that caregivers used. For example, more than one mother described repeating to herself her belief that "God doesn't give you more than you can handle," particularly when enduring difficult times. Another mother said that she took time to "stop" in the midst of challenging moments and said "breathe" over and over until she could return to the situation. Another kept a journal in which she liked to write positive quotes or phrases that she found uplifting and could read through when feeling overwhelmed.



Similarly, caregivers also described a process of cognitive reframing, or finding the ‘positive’ in situations that might otherwise appear daunting. For example, during times of transition or geographic relocations, one mother realized that there was actually a benefit to having environment changes when working on new goals with her children. She gave the following example:

I said to myself, Oh wow! This is an opportunity for me to make some changes that I needed to make anyway. Changes in routine, maybe for a child - not that (child) ever slept in his bed, but if he did - with that move, now he’s going to sleep in his own bed. Or, with that move, now he needs to move into being fully potty-trained, or whatever.

Another mother similarly demonstrated her recognition of the ‘positive’ following her explanation of the challenges that her son’s autism-related behaviors cause for her and the family. She said, “...but we cannot complain, he is precious when he does not have his behaviors.”

This act of reframing also took form in the mother’s recognition or focus on their role in meeting the needs of their family and supporting other families on a similar journey. One mother said:

So for me, especially being a military spouse and a stay home mom- your husband gets promoted, he gets pay raises, he gets awards. So for me personally, when someone comes to me for advice it makes me feel like ‘ok wait a minute, I am valued’. I mean my family appreciates me but it’s not the same. For me, it just makes me feel like ok I really am doing something good here. And you get caught up in the everyday of your life and laundry and all of that and there’s days where you’re just like ‘no one appreciates me!’

This mother depicted a common sentiment among some of the mothers who described feeling that they needed something ‘outside of the autism,’ as one mother put it. Similarly, another mother described her belief about the purpose surrounding their ‘journey’:

The beauty in it, that I see, is that we are very open about our situation. We're not ashamed of the situation. We see it as a blessing. There's a reason why we're on this journey. We want to help other people. We truly, we want to share the information. Know that people aren't alone.

Overall, prayer, cognitive-reframing and positive self-talk served as an immediate and effective strategy in caregivers in times of distress as well as ongoing practice that brought them comfort. Additionally, many families described re-framing or seeing the positive aspects of raising a child with autism as an effective strategy when facing challenges or as an ongoing practice.

(e) Families strived to build a team of support around their child with autism.

Teams of support often included therapists, teachers, and other adults whom the caregiver identified as trustworthy and having a stake in the child's wellbeing and development.

One father who participated in one of the interviews described the efforts their family put forth in creating a "team of support" (as he called it) around their son. He said:

The investment in money, in effort, in tears, is all to get it to where you have an acceptable program to help your child develop to his fully potential. ..."Principal, an OT, Speech Pathologist and a separated Phys Ed, Adaptive PE, the Aid or parapro, the Special Ed Teacher, Developmental pediatrician, a psychologist, a normal pediatrician at (base) dentist that knows him and understand his case. A lot of other kids have these same things- but these are people that you need to know, know (child) and know what his needs are.

Such an established village of support did make the idea of moving problematic. In anticipation of an upcoming PCS, one mother explained that "everything we have built up, we will have to recreate...we have maintained a system here that we have built around (child)."

Overall, families strived to establish a network of families, both in person and online, with whom they could identify and feel a part of a broader community.

Additionally, families created stable teams of support around their child that consisted of multi-disciplinary and even informal forms of support.

(f) Organizational tools were ongoing strategies that caregivers used throughout the process of navigation, resource identification and establishing services for their child with an autism diagnosis. These strategies most often included maintaining organization tools in order to prepare for PCSs, setting up IEPs in new school districts, and maintenance of medical records as well as online research and networking with other families who had previously experienced life at a particular duty station.

Organization tools that mothers used to maintain records ranged from “the white notebook” to electronic files stored on their computer or email that could always be accessed. One mother described her “white notebook” that she brings to every new Dr.’s appointment, school enrollment, IEP meeting, etc. This white notebook contained health records, IEP records, letters from former teachers and therapists, etc. Other mother similarly described systems of organization that they maintained since they identified that there is no centralized system of recordkeeping. Another mother similarly said that she had all of her research surrounding potential school systems and neighborhoods in Excel files, and also maintained boxes of notecards with important contact information. These record-keeping systems facilitated the transitions from one place to another and setting up services both in the school and healthcare settings that ultimately prevented families from having to start at ground zero due to the non-portability of services and lack of centralized record keeping systems.

Table 6.2. Supports and Strategies in Response to Perceived Barriers/Stressors

Barrier/Stressor	Resources and Supports	Specific Strategies
Navigating	<ul style="list-style-type: none"> <li>• Social supports</li> <li>• Online resources</li> <li>• Key Personnel</li> </ul>	<ul style="list-style-type: none"> <li>• Networking, online research, learning the ropes, asking for help</li> <li>• Organization tools (e.g., spreadsheets)</li> <li>• Sharing knowledge</li> </ul>
PCS/Relocation	<ul style="list-style-type: none"> <li>• Social Supports</li> <li>• Online resources</li> <li>• Military programs</li> </ul>	<ul style="list-style-type: none"> <li>• Organization tools (e.g., ‘the notebook’) to maintain medical records, IEP, etc.</li> <li>• Social stories, re-creating environment, special toys</li> <li>• Strategic move based on school system</li> </ul>
Healthcare/Community Resources and Services	<ul style="list-style-type: none"> <li>• Autism Services</li> <li>• Online resources</li> </ul>	<ul style="list-style-type: none"> <li>• Interviewing providers/finding a good fit</li> <li>• Identifying non-military providers in the community</li> <li>• Paying out of pocket for non-covered therapies</li> </ul>
Participating in Community Outings	<ul style="list-style-type: none"> <li>• Autism services</li> </ul>	<ul style="list-style-type: none"> <li>• Incorporating ABA Strategies/Therapy goals</li> <li>• Splitting the family</li> <li>• Selectively choosing outing locations (e.g., familiar environments, fenced parks, of interest to child with autism)</li> </ul>
Isolation/Stigma	<ul style="list-style-type: none"> <li>• Social Supports</li> <li>• Online resources</li> </ul>	<ul style="list-style-type: none"> <li>• Educating community/other families about autism/ Advocacy</li> <li>• Support from ‘other autism moms’</li> </ul>
Safety and Options for Participation	<ul style="list-style-type: none"> <li>• Social Supports</li> <li>• Military programs</li> <li>• Key Personnel</li> </ul>	<ul style="list-style-type: none"> <li>• Moving into community to meet safety needs</li> <li>• Advocating/diligence in having needs approved and met on base</li> </ul>
Deployment	<ul style="list-style-type: none"> <li>• Social Supports</li> <li>• ASD Services</li> <li>• Other programs</li> <li>• Online resources</li> </ul>	<ul style="list-style-type: none"> <li>• Consistent routines</li> <li>• Having resources in place (ABA therapy, respite care, etc.)</li> <li>• Skype, iPhone, picture sharing, Facebook</li> </ul>
Meeting the Needs of Other Children	<ul style="list-style-type: none"> <li>• Social Supports</li> <li>• Other military/ civilian programs</li> </ul>	<ul style="list-style-type: none"> <li>• Splitting the family</li> <li>• Special events and outings with sibling during respite</li> </ul>

Overall, in the face of significant stressors, caregivers revealed the ways in which they managed to cope and maintain strength in their everyday lives. *Strategies* ranged from spending time doing research about autism to participating in recreation activities. The implementation of strategies was ongoing and unique to each individual caregiver. Through various strategies, many caregivers appeared to enact a form of ‘self-care’ in order to meet the demands of everyday life. Caregivers revealed their use of *strategies* through actively engaging in particular approaches to managing experienced, or anticipated, *barriers and stressors*. These mechanisms highlight the active role that family members played in the process of resilience.

#### **6.7 Theme Category 4: Time and Place**

*Time* played an integral role in the everyday life and broader context of family experiences. Experiences were recalled and relayed through the use of various indicators of points of time in the family’s history and were often delineated by deployment cycles, specific duty stations, and autism diagnosis or child-related medical issues and care. In addition, the concept of *time* itself was a prominent part of the nature of military lifestyle. Time was often described in terms of “waiting.” As one mother said,

So... you have lots of time waiting. You wait for them to come home at night, you wait for them to come home from the field... you wait for the next 4-day weekend and then you wait. And then the deployments start and you wait for a year, or you wait for the next phone call...

Caregivers often referred to cycles of deployment as a backdrop to the family timeline. Family experiences were obviously greatly impacted by the actual time during which their service members were deployed, as well as anticipation of both the actual

deployment and re-deployments (or the point during which the service member is anticipated to return). A tremendous amount of ambiguity surrounded these cycles of deployment, with ever-changing timelines, delays, and even unexpected deployments requiring a tremendous amount of flexibility and patience on the part of the families. Further, everyday family life was directly impacted by the cycle of time in which the family found itself, with family routines adjusting to varying phases of the aspects of deployment cycles. Whether or not the service member was deployed was generally the overriding aspect of family life, with many descriptions of everyday family life beginning with “when (husband) is deployed...” versus “but when dad’s home, we....”. The phase of deployment cycle in which any other family experiences were occurring appeared extremely salient to understanding the wellbeing and resilience of caregivers.

Talking about experiences over a period of time also revealed a diagnosis story in the case of all participants. The process of their child being diagnosed with autism appeared to be a key marker in time, as caregivers all spoke of the diagnosis experience as being a pivotal moment in their family’s experience. The diagnosis story often consisted of details of the context surrounding the circumstances of diagnosis, despite the amount of time that had passed. This description of context often included where the family was stationed, the hospital/pediatrician who was involved in diagnosis, as well as the status of their military member (who in a few instances was either deployed or on the verge of deployment at the time of diagnosis).

In addition to the details surrounding their child’s diagnosis, some of the caregivers relayed their emotional reactions and ‘state’ surrounding and immediately following their child’s diagnosis. One mother described her realization about the

magnitude of her son's diagnosis months after he was diagnosed. While standing at the kitchen sink doing dishes, this mother recalled:

I remember watching this beautiful scene, the surfers, the sunset, the ocean. But the waves. As far out to the horizon. The waves kept coming, some would hit the shore, but they kept coming.....I realized, this is a marathon...I couldn't see the end of it in that moment...And it is, it's always something. I remember thinking: this is it for the long haul. It's not going to be easy.

The emotions that caregivers described immediately following a diagnosis appeared to be a starting point for a progression of developing strategies for mothers. One mother compared the emotional state that she was in immediately following her son's diagnosis with her current position as chapter leader of her county's Autism Society, when she said, "back then I couldn't even think beyond the walls of our own home." As time went on, mothers learned from particular experiences that served to build their knowledge and ability to meet the needs of their child based on the evolving process of evaluating their experiences.

In addition to specific points of time as salient points of demarcation in family stories, geographic location, more specifically duty stations, served as a primary descriptor when caregivers talked about family experiences. Setting the stage for a description of family experiences was often preceded with "when we were stationed at (place)." All of the caregivers were easily able to rattle off the list of duty stations to which they had been assigned, some over a 20-year period. When asked about previous duty stations, one mother replied with "you want me to start from the beginning?" and then proceeded to easily list a total of 12 duty stations from memory spanning across the globe and an almost thirty year military career.

The concept of “home” for these families, as far as geographic location, was one that was ever changing. One mother described feeling like she no longer felt like she was “from” any one place in particular after having moved so often over the years since being married to her service member. She explained:

I’m from California, but I have not lived in California for many years now and I’ve been gallivanting with my husband everywhere. I don’t even feel like I’m from anywhere anymore. Like people ask me that all the time like “where are you from?” and I’m like “I don’t know” and they think I’m joking and I’m like “I really don’t know where I’m from anymore, it’s just wherever I am at the time, that’s my home”. But you kind of have to have that attitude to survive.

Caregivers generalized their experiences as being either positive or negative at specific duty stations. For example, one mother said, “pretty much everything about our time at (duty station) was a nightmare.” Conversely, many parents expressed positive experiences at specific duty stations. Caregiver assessments of these experiences were predominately determined by their assessment of their child’s school, healthcare, and therapy experiences as well as resources available to support the family (e.g., services through EFMP). Often times, friendships were cultivated at particular duty stations that were maintained following relocation, and the quality of these supports also appeared to greatly impact the caregivers experiences at particular duty stations.

Perceived experiences in particular geographic locations were also greatly impacted by the resources available in the surrounding communities. For example, families often talked about the benefit of being near a major medical hub during the time of diagnosis (e.g., John’s Hopkins University Hospital). Similarly, for those families whose children additionally faced major medical issues, being in close proximity to major hospitals facilitated their receipt of care for serious pediatric medical issues.



Finally, caregivers stressed the importance of having access to safe recreation spaces to meet the needs of their child with autism. As described earlier, some parents identified challenges in meeting the safety needs of their child particularly on base, and subsequently chose to live in the surrounding communities. Parents illuminated importance of having fenced in yards and play spaces accessible to their home. Many families had chosen their homes based on proximity to a particular recreation area that they felt met the needs of their child. Some of the families could walk to a local playground or swimming pool. One family had chosen a house with a swimming pool since this was a primary source of joy and reward for her son and was “something that they (both children) can do and enjoy together.”

Overall, time and place were significant markers and served to ground family stories. Perception of time was often at the mercy of the father’s career with deployments serving as salient points in a family’s story. The trajectory of time following an autism diagnosis also revealed a progression of caregiver’s coping and resource building. Geographic location similarly served to impact family experiences, with access to available resources that met the needs of their child being a primary influence on the quality of family experiences.

## **6.8 Theme Category 5: Family Culture**

While themes emerged across the participant’s stories, each family relayed a unique set of life circumstances, beliefs about autism, patterns of organization of everyday life and family roles, decision-making processes, and attributing meaning to their experiences that culminated in the form of a particular *family culture*. Families in

this study shared the common experiences of living amidst both a military lifestyle as well as well as that of raising a child with autism, but situated themselves between these two broader cultures they had in common. Thus, all families had the tasks of negotiating the expectations of a military family as well as meeting the needs of their child with autism. Family experience diverged from these common cultures, however, as each family revealed nuances of a *family culture* specifically surrounding the following sub-themes: (a) situation; (b) routines and roles; (c) beliefs and expectations surrounding autism; (d) career decisions; and (e) ascribing meaning to experience.

(a) Caregivers revealed the nuances of their family situation throughout the interviews. These situations were presented as a snapshot of their accumulated life experiences in that moment in time. While families in this study shared common experiences such as being in the military and raising a child with an autism diagnosis, each family revealed other life circumstances that cumulatively served to impact their overall wellbeing. Specifically, the family situation provided a lens through which multiple stressors were evaluated and prioritized in order to understand what was most salient at any given time. Such circumstances included having multiple children with an autism diagnosis, having aging parents who required care, speaking English as a second language, having other children with serious medical conditions, and having spouses (service members) struggling with various health or combat-related trauma issues, to name a few. Family situation also consisted of those experiences that were interpreted as positive, such as dad returning from a deployment, anticipation of an upcoming family vacation, having additional support from visiting family members, positive experiences with a new school, dad getting a new assignment to a desired location, etc. Overall,

situations included both normalizing as well as stressful ‘other’ circumstances that contributed to the unique story of each family.

A holistic view of the family’s situation served as a primary context in which resilience components and processes came to the forefront or were enacted at any given time. Overall, those families whose situations were laden with other challenges placed some families at higher risk for negative patterns of resilience than those families whose situation consisted of stressors that were interpreted by the family as less threatening.

(b) The structure of family routines and distribution of family roles yielded insight into the ins and outs of daily life as well as the role that family members played in everyday tasks and within the broader family system. These routines were similarly structured across families, but the nuances and meaning surrounding these routines served to reflect a unique family culture. Mothers illuminated descriptions about the typical sequence of events in their family’s day, from waking up to going to bed. The details of routines varied across families, but often included a description of morning routines, followed by transporting kids to school or beginning homeschool lessons, and then therapy in the afternoons/evenings followed by family or free play time, or in some cases homework, following dinner.

For most families, everyday routines varied between weekday or weekend routines as well as those that were typical when the father is home versus when he is deployed. Routines were often described as being more structured during the week with varying routines on the weekends, sometimes including outings into the community. This was in part due to the fact that, when the service member is not deployed, he was often home and available on the weekends and able to participate in family activities and

outings. Family routines also depended on such factors as the age and number of children, the father's commute time and deployment status, the mother's responsibilities or activities during the day, and the structure and amount of therapy that the child received, to name a few.

Family routines were often described as a way in which families maintained an expected and pattern of activities that structured the days in a consistent way. One mother described the way in which consistent routines were important to her and served to support her role. She said:

...my husband is not the clock-doctor like I am... You know the routine is as much for me as it is for the boys because when they're calm, my job is easier. I'm not putting out fires all day. So that routine is so important to me.

This mother went on to describe how her husband would take his sons out fishing on his time off and how they would often not come home until very late. The mother felt conflicted about these outings, knowing that it was enjoyable shared experience for her husband and his sons, but that she would be the one to have to manage getting them back on track the next day, particularly on weekdays.

In addition to the structure of family routines, delineation of family roles also provided insight into a family's daily life. The mother and father each played a role, as they did together as parents. Mothers' descriptions of their partnerships with their spouses varied from being described as equal partners to mothers saying that they feel "like a single mom." Family roles were often described by particular jobs of individual family members – ranging from everyday household chores to more formal roles such as 'the breadwinner' or 'the stay at home mom'. These roles broadly appeared stable over time but did appear to shift along with deployments, most notably in the mother having to

take over the responsibility of everyday household chores for which some fathers were otherwise responsible. Caregivers described the role they play in managing household chores including grocery shopping, laundry and cooking. Two of the mothers described dad's typical occupations, or chores, when he is home and highlighted the added burden of having to take over these chores (in multiple cases, taking out the trash and mowing the lawn were specifically mentioned). Other families described systems of doing chores when dad is home versus when he is away. For example, in one family, the father was responsible for cooking the main dishes ("the meats," as the mother put it) when he is home on the weekends, while the mother prepped the veggies to prepare for the week ahead while dad is gone.

Participants in this study humbly depicted the multifaceted roles that they played as caregiver of child with autism and their siblings, a wife of a service member, as well as a volunteer/advocate or in some cases a student, working professional or homeschooler. Caregivers were responsible for the organization and scheduling of everyday family life (e.g., coordinating therapists, doctors appointment, driving kids to school, etc.). Mothers were often in the position of being the sole consistent source of care for their children due to the father's job responsibilities, sometimes including frequent deployments.

Similar to mothers wearing multiple hats, fathers were often depicted as having to balance fulfilling the role of 'soldier' as well as those of 'spouse' or 'father'. At the forefront of family life was the recognition that the father's role was to fulfill his duties as a service member which varied depending on his specific job, rank, time in service and assignment at the time. Mothers often spoke in great detail about their spouse's positions and work experiences, which indicated a common knowledge and understanding of the

circumstances surrounding their soldier's careers and the cultural expectations under which they fulfilled their duty. Further, mothers revealed their expectation, which was often mutually agreed upon, that their spouse participate in family life as much as possible, which often led to father's having to set boundaries for themselves (when possible) at work. For example, some of the mothers said that their husbands would prioritize being home in time for dinner whenever possible. Two of the fathers who did participate in interviews expressed the ongoing challenge that they faced in trying to balance the expectations of their jobs with their desire to play a more consistent role in family life.

(c) Families varied in their hopes and expectations surrounding autism. These came to light when mothers described both the treatments that their family pursued for their child, as well as the expectations that their family had of their child now or for the future. For many families, their hopes for treatment efficacy were so strong that they served as a guiding beacon for many important family decisions (e.g., where to live, how many years to remain active past retirement, etc.) and became the primary focus of many mothers' endeavors. The variations in the paths that families take in making choices surrounding the wellbeing of their child elucidates both the ambiguities surrounding optimal treatment and intervention as well as the overwhelming hope and optimism that families put forth in attempt to foster their child's potential and to facilitate their integration into family life and future situations.

One mother described the process families go through in making decisions about what types of therapy to pursue following her child's autism diagnosis. This mother

described the line of thinking that led her family to choose one particular therapy following her son's initial diagnosis:

I remember I saw an article in Newsweek...by a physician whose child was autistic. And she wrote about how you never want to look back and say I didn't try everything- but at some point you have to pick a plan and go with it... what if in 20 years we look back and see what the road we picked was wrong??? But you have to look at what works for your family, and the other person in your marriage...

She went on to say, “at some point you kind of pick the battle you are going to fight and you go for it, and we picked ABA.” This illustrates the way in which families make decisions early on in the journey of an autism diagnosis in hopes of choosing the ‘right’ interventions for their child, despite a lack of a clear guide on what is optimal for their child.

Most of the families in this study similarly chose to pursue ABA therapy, as it was often perceived as the gold standard of treatment. Additionally, families described ABA as being a good fit for their family based on their personal expectations for their child's trajectory of development, or the way in which an ABA program could incorporate sibling participation and strategies into their daily lives. Other families had hopes of mitigating their child's symptoms, and in one case, facilitating recovery from autism, through such CAM (complementary and alternative medicine) therapies such as special diets vitamin based recovery programs, and hyperbaric chamber therapy to support their primary forms of therapy. Whatever the course of treatment they so chose, families passionately described the significant role that specific therapies played in both their child's and their family's life and subsequently became determined to maintain these services at any cost.

Following her experiences in a parent support group, one mother described her observation of the different approaches that families take and their beliefs about autism:

...what I saw in the few that I attended, was people who were either: (a) new in the diagnosis so they were still in the mourning process or (b) “why me?” and “fix my child!” And a lot of people who would do some therapies that I... you know I think to each his own and every parent has to do their own thing but its like they’re looking for Lorenzo’s Oil... I think we can help our kids better by just accepting who they are and working from there. Not if someday they didn’t say “hey we have a magic pill!” not that I wouldn’t be willing to investigate that!

In addition to beliefs and expectations about treatments and therapies, parents also expressed expectations of their child’s behavior and ability to follow family rules. One mother described their expectations of their son in the context of mealtime. She said:

We eat with utensils at a table. We sit in our chair at the table. We don’t run around. We sit and we wait until everybody’s finished. We say our prayer. We take our dishes to the sink. There’s no less expectation placed on him than his sisters do. That’s how it plays out.

Another mother described she and her husband’s expectations for their son as well as his therapeutic program goals, which stemmed from their desire for him to live independently one day. She said:

We’re very realistic people...We’re looking for skills that he can be successful in a private home one day. I get a lot of push for social engagement for (child). He’s severe autism. We can work on it, work on it but I don’t think it will ever be achievable. What’s achievable for me is for (child) to be able to walk up to somebody and communicate what he needs, to perform whatever job he wants to have and makes him happy. For me it’s more of self-help than social engagement skills that will let him live in a private home and have a job if that makes any sense.

Other mothers similarly spoke about what they saw as attainable for their child and how their expectations of their child’s future impacted their current strategies in meeting his needs. For example, one family described their decreasing concern over time as their daughter continuously progressed in school to the point where they began to see a



brighter potential future – one that potentially included attending college and achieving a level of independence that was heretofore uncertain.

Some participants additionally expressed the differing processes by which they came to terms with their child's 'abilities' as well as their current and future expectations. These processes appeared to contribute to the mother's wellbeing, and were often confounded by concerns surrounding whether and how the fathers fully embraced the realities surrounding their child's diagnosis. One mother expressed concerns about her husband's wellbeing in having to face legally declaring their son as 'disabled' as part of the retirement paperwork process. Another caregiver similarly described her ongoing struggle with wondering whether her spouse understood the "magnitude" (as she saw it) of their son's possible needs in the future.

Overall, families varied in their beliefs and hopes surrounding optimal treatments. Further, families diverged in their expectations of their child. For many families, convictions about the optimal course of intervention for their child was so strong that it became a driving force in the lives of families and guided ongoing goals and decisions.

(d) Families faced career decisions that were impacted by both the culture of the military as well as the needs of the family. Additionally, decisions were overwhelmingly impacted by the goal of meeting the needs of their child with autism. Families had to make decisions surrounding retirement, which for some was a looming concern both in terms of losing services for their child, as well as ambiguity surrounding civilian family life following a 20 plus year military career. The process of continually assessing, prioritizing, and strategizing to meet these goals was unique to each family, and embedded in their family culture.

The father's career goals and decisions often took into consideration the sacrifices that the family had to make (or not make) in order to meet the demands of and opportunities for promotion (e.g., moving more frequently and experiencing more deployments). When possible, caregivers described engaging in a decision making process that included positioning themselves for particular promotions, duty stations or deployments. While family decisions were often overridden by the needs of the military, at certain points in the service member's career, there were opportunities that allowed families to participate in deciding their family's path based on their own goals.

Families also described decisions surrounding un-accompanied tours or deployments. Two families described their spouses as having been assigned to overseas duty stations and the families' decision not to accompany them due to the lack of resources available for their child with autism, which resulted in a year long separation. Other families explained their decision to volunteer for deployments in order to have their orders extended either to prolong their retirement or to extend their stay at a particular duty station. One father who participated in the interviews portrayed deployments as a "double edge sword," because for his family, he and his spouse had made the decision to volunteer for a deployment in order to ensure that the family would stay in the community in which they had set up optimal school-based and community services for their child with autism. Another family similarly identified the "benefit" of having been given deployment orders late in his career which "took away the option" at a time when a decision about retirement needed to be made. This mother said "if he hadn't have been deployed twice since the time that (child) was diagnosed, then she may not have been able to receive the ABA services that have been such a life saver for her."

Career decisions often revolved around meeting the immediate education and healthcare needs of their child with autism. For example, families considered available resources to meet their child's needs and subsequent decisions to live on or off base. Caregivers described the phenomena of "homesteading" as a choice that some families made that greatly impacted their soldier's career options yet served to meet the needs of their child with autism. Homesteading involved making career choices that would provide the opportunity to stay at one duty station for a prolonged period of time. One family described their desire to keep their child in the same school, with the same therapists, and so that the family could maintain their social support system that they had built up over the years. This particular family had opted for consecutive deployments in order to maintain their soldier's assigned duty station, and had just made the decision to live separately from their soldier during the week (5 hours away) so that they could maintain their home and "team of support" in order to optimally support their son's needs. This family described the benefit of making the choice to stay in on place as long as possible, saying:

Our goal was to maximize the stability for (child), to minimize transitions and maximize stability. If you are in a good place, not that this has been perfect, it has been A LOT of work to get it as good as it is, but it has lent itself to the progress that (child) has made.

Other families made similar decisions in order to stay in one place for longer periods of time to establish consistent school and therapy experiences for their child with autism as well as to maintain the established supports that served to meet the needs of the whole family.

One mother succinctly depicted decisions that her family faced in the context of her son's needs. She said that following her son's diagnosis, she and her husband decided

that they would make decisions in order “make the most money we could knowing we will be caring for our son for his entire life; I mean, we only have 20 something years so we better make the most of it for his sake.” When asked about the impact that an autism diagnosis had on her family, another mother expressed that it had the most impact on her husband and his career. After describing her husband as very proud of his job and as incredibly career-driven, and that the point of his hard work was to one day take command of a ship, she explained that having a child with autism changed this focus.

She said:

...when we got the diagnosis, you know he still had two more chances, but we kind of started re-thinking and we were like well, maybe it's for the best and maybe we don't want him to qualify for that because he would be second in command to a ship or first in command to a ship and he would be gone all the time.

Other families similarly expressed feeling a lack of support (in terms of not having their spouse as a consistent presence as well as a lack of services) as having an impact on their soldier's career decisions based on the intensity of the needs of their child's needs.

(e) Finally, ascribed meanings surrounding retirement were rooted in family culture, as families grappled with or anticipated what their civilian lives would look like and the ambiguity surrounding the services that their child with autism may or may not receive under the health benefits of a civilian career. For those families who had been ‘in’ for many years, the idea of retirement was often one that was intimidating and uncertain. One mother described a recent experience of going to a civilian pharmacy and realizing the way in which some of her typical occupations would have to change as they planned to move further away from a military installation. This experience also prompted the

mother to relay her expectations surrounding health coverage in regards to her husband's potential civilian career she said:

... like just here recently I had to go to the pharmacy and I had to go to the civilian's pharmacy and I had to pay a co-pay. So that is starting to hit me. All of the things that because we're not going to be near a military facility, we're not going to have the commissary to shop at, we're not going to have the PX to shop at, we're not going to have the (Army hospital) to go to, we're going to have to pay co-pays and we're going to have to pay a monthly premium for medical insurance. All of that really has me looking at my husband thinking "oh my gosh, like you better go work for a big corporation with a great medical plan!" I'm not saying it out loud right now, but I'm thinking it!

Later in this interview, the mother stepped out of the room and the father began to describe his own anticipation of retirement and his hopes that he would be able to find a position with another government agency, perhaps in a civilian contract position. He relayed his anticipation of the uncertainties that retirement would bring and his ongoing question of whether "getting out" was the right decision. This father alluded to the pressures that he felt of meeting the needs of his family as compounding an already uncertain next step for his career.

Another mother similarly described her looming anxiety about retirement and reintegration into civilian life following her husband's 28-year career, all during which time she was with him. She thought ahead to the way in which she would manage this transition:

So now, I'm going to have to reinvent the wheel, and I don't know how to do that. So I need to start reaching out to my friends who have already retired and are navigating that world. So in 3 months when school gets out and when things close down a little bit, that's one of my things on my list to do-to talk to some of my friends, especially the ones who have children with special needs.

This mother also described her concerns about entering into a new world that she and her husband had never navigated before together.

Conversely, some families described looking forward to retirement and relayed minimal concerns about what family life would look like as civilians. One mother described:

...so I look to that (retirement) and in a dream state- we will move close to family, my husband will get a boring 9-5 job (laughs), and we'll focus more energy on family. He'll be able to make more commitments for coaching soccer or cub scouts or whatever. He'll be a more active role in the family because his job will just be a job and not a lifestyle.

Another mother mentioned that she expected that retirement would not impact their life very much because of the way that they had chosen to maintain as close to a civilian life as possible, especially following their son's diagnosis. This mother said specifically said:

I don't think it would change my lifestyle that much except for a feeling of security or peace of mind...I would have some of the same challenges but I wouldn't be worried that (husband) was unavailable and that I would have to be doing it all on my own for any extended period of time. I'm sure he would still have to travel with another job but I would guess that he would have a lot more control over it. It's more a psychological thing than anything else. Our life wouldn't change that much except for that security that we can stay here and I can have him home more often to relieve me.

Overall, families had to consistently negotiate meeting the needs of their child with autism within the scope of a military career. These decisions were rooted in an evolving family culture, took into consideration the needs of the family and were driven by evolving goals. These goals often led families to prioritize the child's needs as driving decisions that impacted the whole family. When afforded the opportunity, families were driven to strategize in order to place the family in particular locations, or to maintain their assignments for longer periods of time. For other families, prioritizing the advancement of the soldier's career was seen as most beneficial in order to plan for care for their child with autism throughout their lifetime.

The process of ascribing meaning, or a family's ongoing evaluation and appraisal of their experiences, was central to this theme and occurred throughout the process of resilience. At the crux of family culture was the ongoing process of ascribing meaning to their experiences. In other words, families consistently defined the significance of life events as they impacted their family. Specifically, family meanings served to define which situations or experiences families perceived as challenging, as well as the means by which families felt they could optimally prioritize and manage such challenges given their current circumstances. Further, families identified positive experiences that contributed to overall family wellbeing. In addition, family meanings changed over time and contributed to their holistic view of their life situation. For example, one father who participated in the interviews described the meanings he had ascribed to his experience in raising his daughter. He said:

...you spend enough time around (child) and she's really endearing. You can't spend time around her without falling in love with her. So that part of it too, that's been really neat. She's very different from other kids. She's sometimes hard to be around and does things that bother you, but once you know her and understand her and can respond appropriately, she's a great kid to be around. And that is very, very rewarding.

Ascribed meanings were dependent on a unique life story, including a family's history, their current situation and their anticipation of the future. The process of ascribing meaning varied across families, with their characteristics being deeply embedded in family culture.

Overall, *family culture* was comprised of a families' perceived situation, the structure and purpose of their everyday routines, delineation of family roles, beliefs surrounding autism, family decision-making processes and finally meanings surrounding experiences. While all families in the study had circumstances that were situated within

two broader cultures (that of the military and autism), situations varied across participants, with each situation being comprised of unique circumstances or experiences that were interpreted as salient to families' lives at any given time. Family culture was also comprised of roles and patterns that emerged in the family system requiring ongoing negotiation and management as families encountered new circumstances that impacted the system structure, way of thinking, or usual way of life. Families also managed the ongoing task of making decisions in line with family goals, consideration of their unique position as situated between two broader cultures (that of the military and autism).

Family culture is complex and dynamic in nature and is central to the resilience process for military families with a child with autism. A family's circumstances were in constant interplay with daily routines and roles, goals, beliefs, and interpretations of experience that all merged to form a unique family culture. Family culture evolved in unison with the changing needs and available resources of the family from both within the family system as well as the interaction with broader systems with which the family culture is situated. Families negotiated this experience of 'straddling' two broader cultures by consistently drawing from or making changes to their own family culture. Further, from the vantage point of awareness of their own unique situation, families could prioritize their needs, and the extent to which particular stressors were more or less threatening at any given time. Similarly, families made strategic decisions in the face of challenges in order to meet the needs of their family in life with family and career goals. Family culture changed from within, in response to the needs of the family, as well as was impacted by broader contexts of time and place. Overall, the malleable nature of



family culture facilitated a family's ability to meaningfully participate in the resilience process.

## **6.9 Theme Category 6: Moments of resiliency**

Through the process of ascribing meanings to their experiences, families provided glimpses into what they perceived to be *moments of resiliency*. Rather than describing states of resiliency, families identified moments in which they recognized having successfully overcome a challenge, or when life generally appeared to be going well or even felt 'normal'.

Families described *moments of resilience* as those times when they felt 'normal' or 'like a typical family' and often occurred when the whole family was able to engage in a meaningful activity together. 'Good days', for example, were often described as those that included minimal problematic autism-related behaviors that facilitated positive family experiences. One mother described her idea of a 'good day', saying "A good day is when (child) doesn't throw (husband's) boots in the bathroom- if he doesn't wake up at night- a full nights sleep!" Caregivers also identified 'good days' as times when their family was able to go about their day in a typical way, as well as those times when the family is able to participate in meaningful activities together as a whole. One mother described a good day in their household:

That's a good day, when just everybody's in a good mood from start to finish and everybody's happy and our routine is on and in the evening we take the dogs for a walk and we're all happy, everybody's well and we go to bed with a smile on our face.

In this way, typical family routines served as an indicator of 'normal' as families described being able to participate in daily activities as a family. Similarly, another

mother described having a recent positive experience as being able to participate in outings like ‘a typical family’. She said:

A great day is when everybody is just getting along with each other. And we can just, be out as a family. For example, (husband) was here about 2 weeks ago and we went on a little vacation together and it was the best vacation. He was home for five days so we decided to go to Virginia. It’s a different transition but (child) was great! We went to an amusement park, we did things that typical families do. That’s the thing, to be able to get up and go do what you want, and not have to worry about ‘is he going to have a tantrum?’ or ‘is this going to affect him?’ or ‘is he being able to do this?’.

Other mothers described looking forward to a ‘normal’ life when they spoke of their families’ future following retirement. One mother said:

Normal life for us means a job where it’s reasonable to expect that you will be able to stay in the same location. You know that even if they were to change what it is that you’re doing, you can have the same home base or home office and a job that will allow you to work the 50 hours and then stop. Not have to stay late or do duty... a job where he could work from home and have some flexibility.

Feeling like a ‘typical’ family was most often associated with increased opportunities for family time, and occurring during times when the father was not deployed. Further, although fleeting, caregivers were incredibly encouraged by, and celebrated, these moments of resiliency.

Caregivers indicated that ‘survival’ is one way in which they experienced resiliency. One mother described how her primary social supports did not understand the grim struggle that her family faces day to day:

I call my cousins and my aunt, but they don't understand...They try to comfort- but they are thousands of miles away- and they don't see the day to day- they tell me to go on being a good Christian.... they don't understand... you are just trying to survive.

Another mother similarly referred to the idea of ‘survival’ when she said, “I thought that this (deployment) was going to kill me. I thought, how am I going to do this?...So it’s

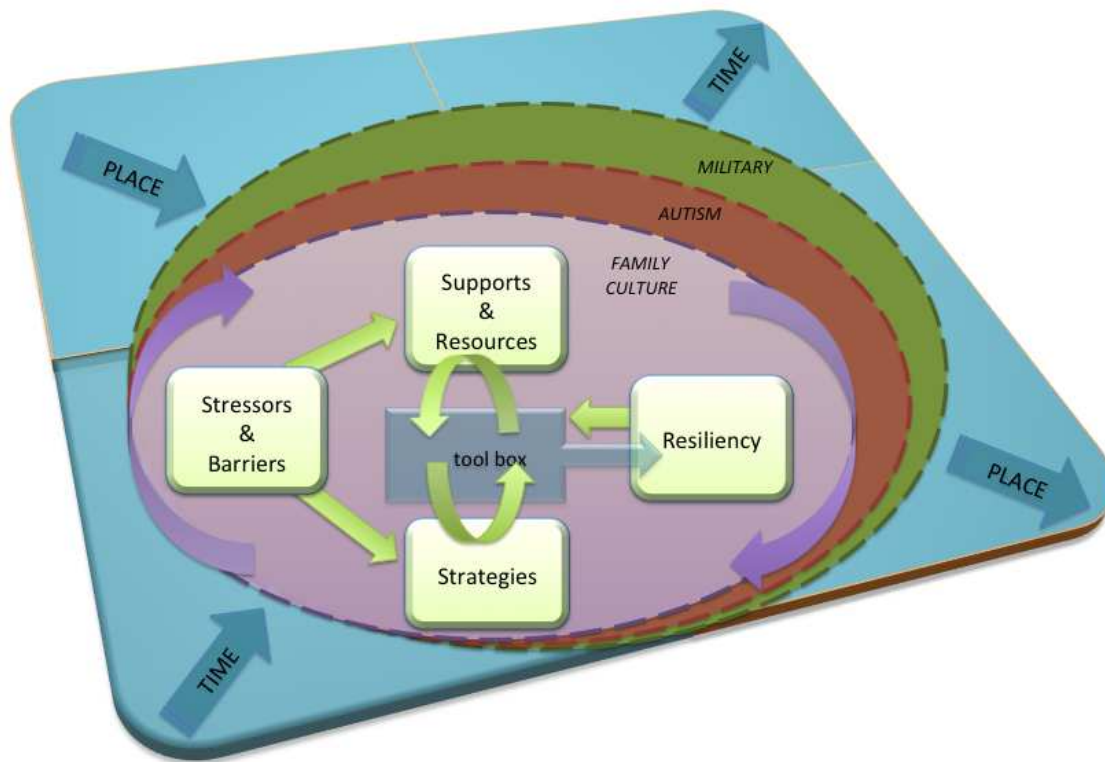
kind of like running a marathon I think. You feel like you're going to fall apart but you don't."

Overall, caregivers recognized *moments of resiliency* when their family was able to go about their way in a typical way, as well as those times when the family is able to participate in meaningful activities together as a whole.

## **6.10 Summary and FAM-TRM Conceptual Model**

This chapter revealed six broad theme categories that were identified in the analysis process and that represented the data. Each theme category was comprised of themes that mutually supported the essence, or content, of each category. The content of these identified theme categories described the constructs in this model, while the process descriptions serve to represent the dynamic interplay and relational qualities that make up the broader system of resilience. Collectively, these themes and processes serve to address the primary research question guiding this dissertation, How do families characterize the resilience process and what role do family routines play in this process? In order to clarify the dynamic resilience process that these families described, the Families Impacted by Autism in the Military Transactional Resilience Model (FAM-TRM) model (Figure 6.1.) is presented. This model demonstrates the inter-relationships between the constructs presented in the themes as well as the dynamic nature of the resilience process as explicated in these findings.

Figure 6.1. Families Impacted by Autism in the Military Transactional Resilience Model (FAM-TRM model).



The process of resilience is transactional, dynamic, and complex. To begin to understand the nature of these complexities, the inter-play of various components will be described, with the caveat that this sequence in no way implies a linear model. Description of the inter-relationships among resilience components will be grounded with additional case examples.

*Barriers and stressors* surfaced acutely at varying points in time and some were additionally recognized as chronic in nature. The impact of these stressors varied based on a family's ascribed meanings at any given time, place, or situation. For example,

families often identified specific duty stations as being particularly challenging in terms of a lack of family supports. For those families whose husband was deployed, this lack of resource was particularly salient in their family's situation. Barriers and stressors propelled caregivers to enact strategies and utilize resources when confronting or anticipating those stressors. For those families who were anticipating an upcoming deployment, for example, mothers often took steps to identify and set up respite care in advance. Some barriers and stressors were ameliorated over time by the practice of effective resource allocation and strategic actions. For example, for those mothers who had been through deployments previously, they were able to face subsequent times of separation with an evolved interpretation of the significance of stressors accompanying deployment as it specifically impacted their family and the strategies and resources that served to be effective previously. This process of ascribing meanings and taking action formed a sort of 'tool box' from which caregivers could draw over time, with accumulated experience of what works for them in any given situation in consideration.

Identifying, accumulating, and gaining access to *resources and supports* was a continuous process for families that occurred over time and across geographic locations. An ongoing process of generating meanings contributed towards recognition of what was feasible for responding to challenging situations at any given point in time. For example, one mother described utilizing trusted neighbors as a source of support and even respite care while living on base, however, upon relocation, the family opted to live off base and the mother described not knowing or finding support in any of her neighbors. Over time, families created pools of resources and supports from which they could draw, including not only resource information but also knowledge the nuances of the systems in which

they navigated these resources. In addition, families similarly created teams of support and strived towards establishing a sense of community. For example, families described investing efforts in establishing networks of support that were both geographically present, or which transcended a specific place. Further, access to particular resources varied across duty stations creating a need for families to navigate new systems in which they lived amidst relocations and to possibly modify or replace the resources that they once found helpful.

Resources and supports served as the means by which caregivers put some *strategies* into action. These strategies appeared transferable across geographic location, but were dependent on the family's situation, particularly whether or not dad was deployed. With every challenge that arose, over time, caregivers had the opportunity to implement and put into practice particular strategies in order to determine what works. Again, this practice and recognition of effective actions contributed to the 'tool box' from which families could increasingly draw. Those strategies that were interpreted as feasible or effective became consistent 'go to' strategies that served to prevent or ameliorate subsequent stressors. For example, those families who moved most frequently became savvy in navigating resources when relocating to a new duty station.

Over *time* families could reflect upon their accumulated experiences as they confronted new barriers and stressors. Time facilitated a families' practice of identifying and enacting effective resources and strategies. Anticipation of the future impacted families' evolving meanings of barriers and stressors, as well as the nature of selected strategies. For example, as families neared retirement, the stress of the uncertainty surrounding a civilian life increasingly prevailed. This rising concern motivated mothers

to enact strategies such as networking with families who had already made this transition out of military life. Time facilitated an ongoing opportunity for reflection, anticipation and practice upon which experiences were built and interpretations of other components and processes evolved.

*Family culture* served as a primary context through which barriers and stressors arose, strategies and resources were enacted, and moments of resilience were recognized. Meanings surrounding the ongoing resilience process appeared to be embedded in family culture, and simultaneously evolved alongside mutually influencing family experiences. While family culture appeared ‘transferable’ across place, there was an ongoing need for synchronization of family culture with changing environments. Similarly, family culture evolved as accumulated family experiences and developing future orientation resulted in an ongoing process of reflection, anticipation, and planning.

Family culture served to influence the strategies that families chose or perceived as most feasible and salient to their own family. These strategies became practices that were incorporated into their everyday lives and were strengthened over time. For example, strategies often took form as family routines. The function of family routines was often aimed at ameliorating or preventing stressors. The nature of family routines and the means by which they served to meet family’s needs were individualized. Families came to describe ‘what works’ for them, but continued to have to renegotiate those situations in which these strategies were not feasible or were recognized as ineffective.

Through accumulated experiences, families *ascribed meanings* surrounding each of the other resilience components including what qualified as a barrier/stressor, which supports/resources were accessible and potentially useful, what strategies might work in

any given situation and which of those were feasible at the time, and finally what constitutes moments of resiliency. Families additionally attributed meanings surrounding of broader contextual variables such as time and place and attributed the significance these variables had to their particular situation. In addition, the process of ascribing meaning was ongoing, and changed over time as a result of accumulated experiences. This evolving process often took form in the accumulation of awareness and 'know how' of the nuances of navigating military supports and services that specifically met the needs of families with a child with autism.



## **CHAPTER 7**

### **Discussion and Conclusions**

#### **7.1 Overview**

Military families raising a child with autism face challenges on two fronts, with one being that of a military lifestyle and the other being raising a child with autism. While the literature addresses family experiences associated with each of these ‘fronts’ separately, there is limited evidence to date that integrates the two to explore the circumstances of these families. This study was informed by theories surrounding family stress and coping as well as human occupation and subsequently aimed to identify the way in which families characterize the resilience process as well as the role that family routines played in this process.

This chapter will integrate the findings into the existing literature by addressing the primary research gaps that informed the original study question. A discussion of findings offers implications for both Occupational Science as well as Family Stress and Coping literatures. Finally, this chapter will conclude with implications for program development and practice as well as other future directions.

#### **7.2 Addressing the Research Gaps**

Findings revealed six categories of themes that represent components and mechanisms in the resilience process for this particular population. Categories included *Stressors and barriers*, *Resources and supports*, *Strategies*, *Time and place*, *Family culture*, and *Moments of resiliency*. These components were represented visually in the

FAM-TRM model to demonstrate their relationships as well as the contextualized and dynamic process in which families actively engage in order to experience moments of resiliency in the face of ongoing stressors.

Four primary research gaps were identified in a review of the literature that motivated the original research question. These gaps included a lack of understanding surrounding (1) risk and protective factors; (2) family routines; (3) transactional nature of the resilience process; and (4) occupation, wellbeing and resilience.

### **7.3 Risk and Protective Factors**

First, there is lack of literature surrounding the specific challenges and ongoing means of striving towards resiliency that military families face while simultaneously striving to meet the needs of their child with autism. Findings from my study address this gap by explicating potential factors that may serve to inhibit or strengthen opportunities for positively responding to or preparing for the challenges that these families encounter. Previous literature has identified the concepts of ‘risk’ and ‘protective’ (or ‘resiliency’) factors that might serve to support or inhibit the resilience process for military families (Burrell, Adams, Durand, & Castro, 2006; Lester et al., 2011; MacDermid, 2010; Luthar, Cicchetti & Becker, 2000). The primary risk and protective factors that emerged from my study findings are outlined in Table 7.1. Literature suggests that the more ‘protective’ factors a family has in place or recognizes as accessible, the more potential they have for resiliency (Luthar, Cicchetti & Becker, 2000). In this regard, identification of specific risk and protective factors for these families has translational implications.

Table 7.1. Risk and Protective Factors Identified in this Study

<i>Risk Factors (Barriers and Stressors)</i>	<i>Protective Factors (Supports/Resources &amp; Strategies)</i>
<ul style="list-style-type: none"> <li>• Lack of access/availability of resources</li> <li>• Time spent navigating and establishing services</li> <li>• Safety concerns and lack of base programs to accommodate to child's needs</li> <li>• Isolation (geographic, or interpreted)</li> <li>• Challenging behaviors and lack of opportunities for participation</li> <li>• Lack of social supports</li> <li>• Deployments</li> <li>• Geographic relocations</li> <li>• Perceived stigma</li> <li>• Newly diagnosed/new to military lifestyle and lack of guidance/unfamiliarity with system</li> <li>• Ambiguity surrounding retirement</li> <li>• Concern re: meeting the needs of other children/the whole family</li> <li>• Family-system stressors and unmanaged challenges</li> </ul>	<ul style="list-style-type: none"> <li>• Access to resources family sees as feasible and accessible</li> <li>• Sense of community and Network of social supports</li> <li>• Knowledge of system and resources</li> <li>• Opportunities for meaningful family outings and experiences</li> <li>• Consistent family routines that meet the needs of multiple family members</li> <li>• Opportunities for advocacy</li> <li>• Respite care</li> <li>• Finding meaning in role</li> <li>• Planning for future/ family decisions</li> <li>• Key supports along the way</li> <li>• Cognitive strategies/emotion regulation skills</li> <li>• Hobbies outside of 'autism'</li> <li>• Support from spouse</li> <li>• Acceptance and understanding from other unit spouses</li> <li>• Guidance from more seasoned families/mothers</li> <li>• 'Tool Box' of resources and strategies</li> </ul>

Families in this study described the challenges associated with having a child with autism and the ways in which these challenges were compounded by a military lifestyle. Findings are consistent with previous literature that suggests that families of children with autism face obstacles such as identifying where and how to obtain services, paying for services, and negotiating with disconnected service systems (Coonrod & Stone, 2004). In addition to navigating complex systems of care, findings revealed the choices that parents face in making decisions about a lack of clear treatment options, which has also been identified in the literature as contributing towards parent's wellbeing (Levy et al. 2003; Mandell & Novak, 2005). Further, these findings align with those that identify

caregiver experiences of encountering stigma from members of their community surrounding their child with autism (Gray, 2002). Literature has also previously identified caregivers experiencing feelings of isolation (Larson, 2006; Woodgate et al., 2008) and an inability to participate in community outings or activities due to the needs of their child (Bagby et al., 2012; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011).

These findings also identified the role of advocate as being central to mothers' experiences. Mothers' advocacy efforts played out in various ways, but appeared to serve as a protective factor both through mothers' finding personal meaning in their role as advocate, as well as advocacy serving as a means through which mothers contributed to their child's wellbeing. These findings align with recent literature that identified advocacy as a central aspect of the caregiving experience for mothers of children with autism, and that advocacy may serve as a means through which mothers develop a sense of self as well as collectivism in the broader autism community (Ryan & Cole, 2009).

Findings revealed the ways in which mothers described typical stressors of military lifestyle compounded the unique challenges that they faced. Mothers predominantly spoke about challenges surrounding cycles of deployment and geographic relocations. During times of deployment, these mothers were particularly susceptible to feelings of isolation and a lack of support in meeting the incredible complex needs of their family. Previous literature suggests that spouses of military personnel are at significant risk for mental health concerns during times of deployment (Mansfield et al., 2010) and lack sufficient resources for obtaining effective services to alleviate their symptoms (Eaton, Hoge, Messer, Whitt, Cabrera, McGurk, et al., 2008). Further, these

findings support the wealth of research that identifies a military lifestyle as a challenging one, particularly for families (Bowen, 1990; Martin & Sherman, 2012).

The autism and Family Stress and Coping literatures overlap and are supported in regards to the social nature of effective support systems. Both literatures identify social supports as being incredibly salient to the wellbeing of spouses and caregivers. For example, establishing a network of social supports has been identified as especially salient for the wellbeing of both military spouses (Verdeli, Baily, Voursoura, Belser, Singla & Manos, 2011) as well as mothers of children with autism (Bromley, Hare, Davison & Emerson, 2004; Ekas, Lickenbrock & Whitman, 2010; Luther, Canham, & Cureton, 2005). Similarly, developing a sense of community through their social networks was identified as both meaningful and effective to the families in this study. Developing a *sense of community* has been identified as contributing to positive experiences and wellbeing in military families (Bowen, Mancini, Martin, Ware & Nelson, (2003). Similarly, research has found that caregivers of children with disabilities benefit from the support of other parents through formal support groups (Kerr & McIntosh, 2000; Solomon, Pistrang & Barker, 2001). Aligned with previous findings, families in this study identified maintaining a network of strong social supports as well as establishing a sense of community as positively impacting their wellbeing. Mothers found support from ‘other autism moms’ and described feeling a sense of community through their shared experiences with other mothers who understood their journey. Similarly, mothers identified other communities of support through which they felt connected and a sense of belonging, including homeschooling groups, church and other military families. Caregivers often connected with those military spouses who similarly had a child with

autism, which was often by chance meeting on base or through the social network of AMFAS. For these families especially, a sense of community spanned geographic location as families developed networks that would remain intact as well as serving as sources of support through relocations.

Overall, findings from this study align with previous literature that suggests both risk and protective factors for families with a child with autism as well as military families. These findings extend this knowledge by highlighting an overlap in the social nature of supports that these families recognize as effective as well as the importance of families having opportunities to participate in programs that can accommodate to their child with autism to foster a sense of community and belonging. Further, this study contributes to the literature by suggesting potential protective factors that have been previously overlooked in the literature including both advocacy efforts and the role that family routines serve in meeting the needs of both caregivers and families. These findings also highlight the concept of an evolving ‘tool box’ that represents the interplay between resources and strategies that caregivers accumulate over time through continued exposure to opportunities to participate in the resilience process and their developing sense of ‘what works’ in the face of chronic stressors.

#### **7.4 Family Routines**

The current findings shed light onto the role that family routines play in the process of resilience. Family routines were (1) recognized as a strategy by which mothers organized everyday family life and provided stability during times of transition; (2)

impacted by the needs child with autism and contributed to family culture; and (3) served as an indicator of resiliency.

(1) Establishing consistent routines was described as a means for mothers to organize everyday life and provided an expected and consistent sequence of events for the family, particularly during times of transition. Many mothers used organizational tools to structure and manage family routines and also utilized family routines as an opportunity for working towards goals or facilitating their child's development. These findings are consistent with the literature that suggests that mothers primarily construct and manage everyday routines, particularly for families who have a child with a disability (DeGrace, 2004; Larson, 2006). These findings also support previous literature that describes family routines as a context for providing opportunities for learning (Spangola & Fiese, 2007) and suggest that a mother's future hopes or expectations for her child determine which behaviors are reinforced in the context of everyday routines (Kellegrew, 2000). The current findings diverge from previous research that suggests the circumscribed nature of routines that meet the needs of their child with autism places stress on mothers (DeGrace, 2004). This study revealed that the maintenance of consistent routines offer a strategy for mothers to manage everyday life.

(2) Routines served as a means for re-gaining stability when life felt in flux. While nuances of routines changed to meet the new demands brought about by transitions (e.g., mother taking on additional household responsibilities when her spouse was deployed, changing to a new school schedule), families aimed to generally maintain their patterns of activity, particularly those that they described as meaningful. These findings are supported by previous literature that identifies family routines as a 'protective' factor

during times of stress or transition. For example, Luthar et al. (2000) suggested that stable and meaningful family routines enable military families to manage the stressors of deployment of their family member. Imber & Black (2003) also found that family routines serve to strengthen family identity, which serves as a means by which families withstand challenges.

Broader family roles and the delineation of tasks of everyday life were played out in the context of daily routines. The shifting of roles during times of transition was especially problematic for families and required flexibility of aspects of family routines. In this way, family routines served as the context for negotiating family roles. While maintenance of consistent family routines served to buffer the challenges of transitions, the reintegration of the father after returning home from a prolonged deployment proved to be problematic. These findings are similar Boss' (2002; 2004) concept of *boundary ambiguity* that describes the challenges surrounding an ongoing negotiation of roles during times of separation and reintegration. These findings are also consistent with evidence suggesting that reintegration of the service member may be characterized by a renegotiation of roles and boundaries within the family (Drummet, Coleman & Cable, 2003).

The findings related to shifting and ongoing negotiation of roles within military families of children with autism expand the current literature by highlighting the transactional nature of resilience. In particular, this transactional nature of resilience was found to consist of an ongoing negotiation of family culture within ever-changing cultures of the military and autism over time and place. The dynamic nature of family



roles and routines serves as the active means by which families strive to situate themselves within the complex systems of mutually influencing environments.

(3) Broadly, family routines often revolved around the needs of their child with autism and were embedded in family culture. Descriptions of family routines specifically revealed characteristics of overall family, sibling, and mothers' occupations.

Most of the families in the study described an inability to do things as a family in the community due to the negative consequences of having to manage the behaviors or challenges that their child exhibited in particular settings (e.g., restaurants, movie theatres, etc.). Siblings also missed opportunities to participate in extracurricular activities after school or on the weekends due to the therapy schedule of the child with autism or the mother's inability to be in two places at once (particularly during times of deployment). These findings are supported by previous research which suggests that daily routines among families of children with autism are often highly structured, conform to a need for predictability, and are selective in regards to family outings or other changes in routine (Larson, 2006). Overall, these findings are consistent with those that suggest that the lives of parents of children with autism revolve around the needs of their child, leaving parents with little time for themselves (DeGrace, 2004; Montes & Halterman, 2007; Olsson & Hwang, 2003). Further, this focus on the needs of the child has been found to impact a family's opportunities and choices surrounding their participation in outings and activities that are meaningful to the family (Altieri & von Kluge, 2009; Gray, 2002; Olsson & Hwang, 2003).

Mothers' occupations in particular were impacted by the needs of their child with autism. For example, mothers often lacked opportunities for time spent in activities that

might otherwise contribute to her wellbeing beyond that of meeting the needs of her family. Organizing therapy schedules, school schedules, and doctor appointments often took up much of the mother's time. In addition, mothers often utilized childcare, school, or respite hours to go grocery shopping in order to avoid having to take her child with the potential for meltdowns. These findings are congruent with recent literature that suggests that mothers of children with autism have to restructure daily occupations based on the needs of their child with autism (Bagby et al. 2012, Larson, 2006, Schaaf et al., 2011). Bagby and colleagues further described the way in which families choose those activities in which to participate versus those that they want to avoid as well as the extent to which they were willing to try exposing their children to potentially challenging situations or environments. While there is evidence that mother's experience stress surrounding family routines with their child with autism (DeGrace, 2004), these findings more specifically highlight the way in which the mother's occupations are impacted.

Family routines were both a product and primary characteristic of family culture. The means by which families negotiated the circumstances of their everyday lives was played out in the context of family routines. Further, family routines served to meet the individual needs of family members, while also providing opportunities for participation in activities as a family, fostering a sense of connection and even normality. A description of families' routines provided insight into the activities that families enjoyed doing together as a family. Further, the purpose and structure of family routines were served to meet the broader goals of the family. Participation in activities as a family fostered a sense of normality for family members, thus contributing to family wellbeing.

These findings are consistent with the literature suggesting that family routines contribute to family health (Fiese, 2002) and fosters a sense of family identity (Imber-Black, 2002). In this way, and as Bernheimer & Weisner suggested (2007), family routines provide a window into family culture.

(4) Moments of resiliency were characterized as those when families were able to do what they typically do or desired to do. These moments served as a mean by which families recognized instances of ‘normality’ in their everyday lives. Mothers provided examples of ‘good days’ for their family as being those when things ‘run smoothly,’ when the needs of family members are being met, and when the family was able to participate in everyday activities together. These moments often occurred when there was a lack of behaviors related to autism and when the father was able to be home with the family. Further, these experiences were described as brief instances or occasions rather than prolonged periods of time. This finding parallels that of Gray (2002), who suggested that caregivers of children with autism longed for “having a normal family life”. Similarly, these findings support those of DeGrace (2004) who described moments of families feeling like a family were “fleeting” and often were identified in the absence of autism behaviors. In addition, these findings align with Weisner’s (2005) suggestion that “a family’s ability to sustain a daily routine of life that is viable the rest of the time, surely deserves serious study and increased recognition as a complementary family strength” (p. 6). Overall, consistent routines served to structure everyday lives for families and varied to meet the changing needs and dynamics of families, particularly during times of deployments. Further, family routines were recognized as valuable to

families and played an important role in the process of resilience as both an aspect of caregivers enacted strategies, as well as serving as an indicator of moments of resiliency.

These findings are also consistent with previous literature that identifies family routines as revolving around the child with autism (DeGrace 2004; Larson, 2000), providing opportunities for learning and participation in transmission of family culture (Fiese et al., 2002; Fiese, 2006; Spangola & Fiese, 2007; Wolin & Bennett, 1984), and fostering a sense of family identity and group membership (Eaker & Walters, 2002; Leon & Jacobvitz, 2003). Further, these findings support previous literature suggesting that mothers with children with autism have a minimal amount of free time (Altiere & von Kluge, 2009; Hutton & Caron, 2005) or time to engage in personal activities (Luong, Yoder & Canham, 2009). Further, engagement in meaningful activities is often impacted by the barriers associated with caring for a child with autism (Altiere & von Kluge, 2009; Gray, 2002; Olsson & Hwang, 2003). Finally, families strived to maintain the basic integrity of their routines, but showed flexibility in their change of routines in order to optimally meet the evolving needs of the family over time (Denham, 2003).

These findings extend this literature by suggesting that for families enduring chronic stressors, structured family routines not only serve the needs of the child with autism, but also that of the mother. While mothers may engage in the organization of routines to meet the needs of their child, this strategy may also serve to contribute to their feeling of having successfully filled their role in organizing family life. Further, participation in family routines that are viewed as meaningful contributes to an evolving family culture and thus plays a significant role in process of resilience. Finally, these findings contribute to the gap in the literature by elucidating a connection between family

wellbeing and participation in occupation by revealing that families recognize participation in meaningful routines as contributing to their wellbeing. In this regard, it is suggested that a consideration of the structure and meaning of family routines provides a prime opportunity for understanding of resiliency outcomes at the family level.

## **7.5 Transactional Nature of Resilience**

Findings from this study serve to strengthen understandings surrounding the transactional nature of resilience processes that are overlooked in current models. Findings revealed that families are active agents in the resilience process through an ongoing process of evaluating and interpreting their experiences and circumstances as well as enacting subsequent solutions. In addition, families engage in the identification and appraisal of available resources, while simultaneously putting into action strategies or coping mechanisms in attempt to optimally manage their circumstances. Families actively strive to resolve challenges they face; through practice and appraisal over time, they become savvy and proactive navigators of complex systems. Families who endure chronic stressors are continuously prioritizing their needs, within the affordances of their environment, and enacting strategies that contribute toward overall wellbeing. This process occurs simultaneous with families' ongoing negotiation of living amidst broader contexts in an evolving family culture of their own.

This characterization of resilience provides insight into the embedded nature of resilience processes, in addition to the dynamic and mutually influencing relationship between families and their environments (time, place, cultures). The current findings support the notion that resilience is more than simply a process of families 'adapting to'

their environments, which suggests a false dichotomy between person and environment. Instead, these findings suggest that this separation of person and environment is disputable, as resilience process were deeply embedded in an evolving context, and therefore cannot be extracted as a sequential and uniform process, void of context.

This study's findings are consistent with a transactional view of occupation, which suggests the concept of person and environment as whole (Cutchin & Dickie, 2012). More specifically, findings move beyond the concept of "adaptation" to support the transactional concept of *place integration* (Cutchin, 2004) which provides an explanation of the means by which families actively negotiate their ever-changing environments. *Place integration* explicates the role of families actively participating in the process of resilience in consideration of time and place, as demonstrated in this study. This phenomena, as it relates to resilience, might best be understood with the following explanation: "as change in the person–place whole occurs and place (the situation) becomes problematic, the challenge is to reintegrate person and place through activity" (Cutchin, 2004, p.309).

In addition to the consideration of resilience as embedded in *place*, these findings also suggest that resilience processes are evolving over a trajectory of *time*. As families encountered new experiences over time, the meanings they attributed to these experiences evolved with an ongoing reflection of past experiences and anticipation of their future. The transactional concept introduced by John Dewey of 'ends-in-view' is particularly consistent with these findings as it offers a means for describing the way in which family goals and future expectations were constantly changing and served to impact their actions in the present moment, and overall resilience process.

Finally, these findings highlight resilience as an ongoing *practice* and *process* that is not just reactive, rather a continuous means by which dynamic family systems negotiate their experiences as mutually influencing their ever-changing environments. A transactional theory of occupation further supports this finding through Dewey's concept of *functional coordination*, which Cutchin & Dickie (2012) describe as "a 'transaction' via the dynamic, coordinated restructuring of relationships of person and situation" (p.9).

Overall, the complex nature of resilience processes may best be understood from a transactional perspective. From this view, families strive towards resiliency by strategically and functionally coordinating their occupations within the broader contexts of time and place. These findings serve to contribute to a transactional view of occupation by highlighting family culture as a significant aspect of the situated nature of occupation and resilience.

## **7.6 Occupation, Wellbeing and Resilience**

A final significant gap in the literature is that of a lack of clear connection between occupation, wellbeing and resilience. Consideration of the findings in the context of current models surrounding both resilience and occupation may serve to elucidate the relationship between these phenomena. Of the models that were reviewed in the literature, two demonstrated congruence with the presented model, including the FAAR (Patterson, 2002) as well as the Model of Lifestyle Balance (Matuska & Christiansen 2008). The FAM-TRM model, however, serves to fill the gap by moving beyond the concept of 'balance' to emphasize the transactional nature of the resilience

process and by highlighting the complex and situated nature of family culture in this process.

The FAM-TRM model demonstrates not only the relationship between components of the resilience process, but also the transactional nature of the relationships between the components and their processes as situated in context. Both the FAAR model and the Model of Lifestyle Balance offer an opportunity for consideration of the connection of occupation and resilience by suggesting that wellbeing is attained by an active ‘balance’ of either demands and stressors (resiliency) or a balance of participation in multiple dimensions of occupation (occupation). However, in consideration of resilience as a sequential (FAAR) or ongoing means (Model of Lifestyle Balance) of balance, the nuances of the embedded nature of this process are overlooked. The current study subsequently ignites the question: Is family wellbeing achieved through individual members successfully maintaining a balance of various dimensions of occupation? These findings suggest that this assumption would be especially problematic for those families who are enduring chronic stressors and whose family members have varying roles in the process of family culture.

The FAM-TRM model suggests that family culture serves as an ongoing mediator of these processes by which meanings are generated across time and place. The centrality of family in the current model is similar to Patterson’s concept of ‘family meanings,’ which is central to the resilience process. The FAAR model offers insights into various dimensions of family culture and the role that family meanings play in the process of resilience, however, this model falls short in making a connection between the active means by which families negotiate their situated experiences (occupation) while



simultaneously participating in the process of resilience. While the content of the current study findings are particularly aligned with the dimensions of the Model of Lifestyle Balance, family culture is overlooked by the individualized nature of the dimensions of occupations in the Model of Lifestyle Balance. Although this study primarily focused on the experiences of caregivers, it additionally sought to understand the broader experience of the family and did so in one way by gathering information about family routines and a broader inquiry surrounding family experiences.

The FAM-TRM model bridges a gap in understanding surrounding the relationships between occupation, wellbeing and resilience. Although this model aligns with aspects of the two models reviewed in the literature, it moves beyond to offer an understanding of a transactional view of resilience, and the active means by which families attain moments of resiliency and subsequent wellbeing. From a transactional perspective, the process of engaging in occupation is so aligned with that of resilience that the two may not necessitate differentiation. These findings suggests that resilience models could strengthen the Occupational Science literature to understand how families negotiate experiences and strive towards wellbeing through strategic action.

Overall, these findings align with existing literature and offer new insights into the process of resilience for this particular population. Specifically, these findings identify specific risk and protective factors, offer a transactional perspective, bridge a gap between occupation and resilience, and contribute to the literature an increased understanding of the role of family routines in this process.

## **7.7 Limitations**

Questions surrounding the generalizability to broader populations are inherent in the current study, as it included a small sample of a very specific population. However, I suggest that a focus on this ‘at risk’ population will serve to contribute to conceptual understanding surrounding the resilience process, and therefore may yield findings that apply to broader populations. Future studies could be strengthened by recruiting a more diverse sample to include more Enlisted families, fathers, and increasing the number of families from various military branches. Further, this study utilizes the mother as a spokesperson for the family. This avenue for research could be strengthened by gathering a more robust understanding of the family experience by including voices from all of the members of the family.

## **7.8 Future Directions**

There are several possible avenues for future research, and this study has potential for direct translation to program, practice, and policy development. First, future studies could look at how resilience is or is not related to severity of the child’s autism symptoms using a mixed methods approach. Next, based on the transactional nature of the resilience process, the voices of other family members and stakeholders in the community could strengthen understandings of these processes. While this study focused on the caregivers as a spokesperson for the family, future studies could strengthen this area of research by additionally including the voice of the service members themselves as well as other family members. In addition, research would be strengthened from participation of other stakeholders in the community to include personnel who work directly with these

families (EFMP case managers, teachers, therapists, etc.), as well as policy makers, unit personnel and other military families. Next, future research may be strengthened by utilizing mixed methods approaches to include longitudinal measures of wellbeing as well as incorporating measures of autism severity that may or may not contribute to differences in family experience and participation in the resilience process. Expanding the inclusion criteria of participants could also benefit this area of research and reveal nuances surrounding resilience processes that were not addressed in the current study. Other populations of interest may include dual service members, fathers as primary caregivers, single soldiers, retired/National Guard/Reserve families, families with children over the age of 12, as well as families with children with disabilities other than autism. Additionally, research that explores the concept of family culture through a lens of resilience in more depth would contribute to this literature. Qualitative methods would be well suited for gaining new insights into family culture with an increased focus on nuances of the negotiation within family systems through an increased understanding of family occupations.

Increased understanding of resilience processes for this population also has significant translational implications. Luthar et al. (2000) supports this claim by pointing out that resilience models focus on positive outcomes and the mechanisms that support them, thus offering solutions to be addressed by modifications in programs and policies. Further, these authors highlight that from the perspective of intervention and policy, there is a need for a shift in focus from “attempting to ameliorate serious maladjustment after it has already crystallized” to an emphasis on primary supports and prevention (Luthar et al., p.5). These findings may contribute to strengthening existing programs by focusing

on those resilience components that families identified as being effective and feasible tools with which they have had success in managing chronic stressors. Existing programs should recognize not only the resources and strategies that families described as accessible and effective, but also recognize the situated nature of their experiences and the ongoing process of negotiating place amidst two broader cultures. Further, the family system is an opportune avenue for intervention and practice, as families may need support in establishing effective routines and re-integrating family roles following periods of transition.

Programs and policies that may serve to support families in the process of resilience would focus on the importance of social networks and establishing a sense of community, the need for consistency in points of contact across duty stations, the vital role that therapies such as ABA plays in the lives of families, the essential need for respite for caregivers particularly during times of deployment, increased opportunities for siblings to participate in support and extra-curricular programs, more formal systems of parent-to-parent mentorship and support, education of other military families and unit leaders, increased opportunities for participation in family outings and meaningful routines, as well as recognition of the safety and accessibility needs for these families to integrate into their on-base communities. While programs and policies that serve to meet the needs of these families do currently exist, they could be strengthened by establishing uniformity across geographic locations, across branches of service, as well as upon transition to retirement. Supporting families in this way would have the potential to increase family readiness and wellbeing, but also service member performance, retention and wellbeing. These steps may prove vital to wellbeing of military families that will

subsequently strengthen the readiness, durability, and quality of the United States Armed Forces.

## **7.9 Conclusions**

Broadly, this study contributes an occupational science perspective to existing models of resilience. Findings from this study provide insights into the resilience process for military families raising a child with autism and support much of the existing literature surrounding Family Stress and Coping. These findings suggest that resilience processes consist of dynamic components and processes that are in constant transaction with one another amidst an ever-changing and mutually influencing environment. Therefore, the process of resilience for these families cannot be described as sequential or linear, but rather an ongoing transaction of multiple mechanisms. The process by which families participate in resilience evolves with accumulated experiences and across geographic location through an ongoing process of appraisal. In this way, families enduring ongoing stressors are provided with a means of ‘practicing’ resilience through accumulation of resources and strategies that work together to form a “tool box” from which they can draw. Resiliency is not a state of mind or being, it consists of moments and experiences that the family appraises as ‘good’ or ‘normal’. Finally, processes that occur amidst family culture, specifically everyday routines, play a dynamic role in the resilience process.

This study reveals that resilience models may serve as a useful framework for understanding specific populations and their evolving strategies for negotiating affordances and barriers in their environments. Further, resilience models lend

themselves to translational implications for research and practice. This study serves to fill a number of gaps in the literature, particularly surrounding nuances of the resilience process for this population, as well as parallels between occupation and resilience. In addition, this study highlights the significant role of family culture as an evolving context within the resilience process. Finally, this study contributes to an understanding of occupations at the level of the family and offers a transactional perspective of resilience.

## **APPENDIX A: Informed Consent**

**University of North Carolina-Chapel Hill  
Consent to Participate in a Research Study  
Adult Participants  
Social Behavioral Form**

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**IRB Study #\_12-0225**

**Consent Form Version Date:** \_\_February 28, 2012\_\_

**Title of Study:** Facing Challenges on Two Fronts: Exploring the Process of Resilience for Military Families Raising a Child with Autism

**Principal Investigator:** Ashley Freuler, MS  
**UNC-Chapel Hill Department:** Allied Health Sciences  
**UNC-Chapel Hill Phone number:** (919) 370-0858  
**Faculty Advisor:** Grace Baranek PhD

**Study Contact telephone number:** (919) 370-0858

**Study Contact email:** afreuler@med.unc.edu

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**What are some general things you should know about research studies?**

You are being asked to take part in a research study. To join the study is voluntary. You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study. You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

**What is the purpose of this study?**

The purpose of this study is to learn about the everyday experiences of military families who are raising a child with autism. This research study will contribute to building a better understanding of the daily lives and everyday routines of families of active duty military personnel who are raising a child with autism, and challenges they face in coping with a unique set of challenges surrounding symptoms associated with autism within the context of military life.

**How many people will take part in this study?**



If you decide to be in this study, you will be one of approximately 15 people enrolled.

**How long will your part in this study last?**

Each interview will last approximately 1-2 hours. The total time commitment will be approximately 3-5 hours.

**What will happen if you take part in the study?**

1. *Your participation in the study will begin with an initial screening interview, which will be conducted by the PI over the phone at your convenience. This interview contains general questions addressing basic information about your family, like, who is part of the family, whether or not you live on base and how long your spouse has been serving in the military. This interview will only last about 30 minutes.*
2. *Following that interview, the PI will arrange a second interview to be conducted in your home, or a location of your choosing. You also have the option to be interviewed over the phone. This interview will consist of open-ended questions about your families' experience in the military, raising a child with Autism, and your everyday family activities. This interview will last approximately 1-2 hours.*
3. *A closing interview will allow both you and the researcher to reflect on any topics that were addressed in the second interview, or any other experiences of topics that came up in between interviews. Finally, this will serve as a wrap-up to your participation in the study, which may include your reflections on the research process. This interview will last approximately 1 hour.*

**What are the possible benefits from being in this study?**

Research is designed to benefit society by gaining new knowledge. You may not benefit personally from being in this research study.

**What are the possible risks or discomforts involved from being in this study?**

There are no anticipated risks to being in this research study. You may feel some discomfort sharing personal experiences; care will be taken to listen to your concerns and to ensure that you are not pressured to answer questions that may cause discomfort. You are encouraged to report any problems to the researcher.

**How will your privacy be protected?**

Your privacy is very important. The data in this study will be confidential. All materials will be coded with an identification number and will not contain any names. All of the data gathered during this study will be de-identified by the PI, and she alone will have access to a master list of information such as names and telephone numbers of participants. Both electronic and printed records will be stored in a locked office or on a password protected computer, and will not be shared with anyone not directly involved in the research.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal

information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies for purposes such as quality control or safety.

During interviews, the researcher may wish to make a digital audio recording. Recordings will help the researcher more accurately recall and transcribe the interview, and will not be shared with anyone not directly involved with this research. Recordings will be stored on a computer that is password protected, and will be destroyed at the end of the study. If you consent to audio recording, you may still request that the recording be turned off at any point in time.

Check the line that best matches your choice:

- ☐ OK to record me during the study  
☐ Not OK to record me during the study

**What if you want to stop before your part in the study is complete?**

You can withdraw from this study at any time, without penalty. The investigators also have the right to stop your participation at any time.

**Will you receive anything for being in this study?**

You will not receive anything for taking part in this study.

**Will it cost you anything to be in this study?**

There will be no costs for being in the study.

**What if you have questions about this study?**

You have the right to ask, and have answered, any questions you may have about this research. If you have questions, complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

**What if you have questions about your rights as a research participant?**

All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to [IRB\\_subjects@unc.edu](mailto:IRB_subjects@unc.edu).

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**Title of Study:** Facing Challenges on Two Fronts: Exploring the Process of Resilience for Military Families Raising a Child with Autism

**Principal Investigator:** Ashley Freuler

**Participant's Agreement:**

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

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Signature of Research Participant

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Date

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Printed Name of Research Participant

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Signature of Research Team Member Obtaining Consent

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Date

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Printed Name of Research Team Member Obtaining Consent

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In addition, please indicate whether or not you wish to allow audio tape recordings to be used for educational purposes, such as in presentation at professional conferences or for classroom teaching purposes.

\_\_\_\_\_ I grant permission for audio recordings during my interviews to be used for educational purposes.

\_\_\_\_\_ I do not grant permission for audio recordings obtained during my interviews to be used for educational purposes.

## **APPENDIX B: Institutional Review Board Approved Recruitment Letter**

## UNC Research Study Focusing on Military Families with a Child with autism

March 14, 2012

Dear Families:

I am a doctoral student conducting dissertation research in the School of Allied Health at The University of North Carolina at Chapel Hill. I am working under the supervision of my faculty advisor, Dr. Grace Baranek, who is a Professor and Associate Chair for Research in the School of Allied Health at UNC. **I invite you to participate in a research study entitled “Facing Challenges on Two Fronts: Exploring the Process of Resilience for Military Families Raising a Child with Autism.”** The purpose of this study is to learn about the everyday experiences and daily routines of military families who are raising a child with an Autism Spectrum Disorder. This research study will contribute to building a better understanding of the daily lives of families of active duty military personnel who are raising a child with autism, and challenges they face in coping with a unique set of challenges surrounding symptoms associated with autism within the context of military life.

Participants will consist of active duty Air Force, Army, Marine, or Navy spouses who have a child with an autism. Participation will involve a series of three interviews over the course of a few weeks, and should only take about 1 to 2 hours for each interview. The total time commitment will be approximately 3-5 hours. Interviews will take place either over the phone or in the participant's home, whatever they feel most comfortable with.

Involvement in the study is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled. All data obtained in this study will be confidential. The results of the research study may be published, but your name will not be used. In fact, the published results will be presented in summary form only. Your identity will not be associated with your responses in any published format.

The findings from this project may inform practices, programs, and interventions that support military families with a child with Autism. Building knowledge surrounding this particular population will allow for a strengthening of current policies and programs that have the potential for a positive impact on individual and family wellbeing, and overall family readiness.

If you have any questions about this research project, **please feel free to call me, Ashley Freuler, at (919) 370-0858** or send an e-mail to [afreuler@med.unc.edu](mailto:afreuler@med.unc.edu). My faculty advisor can be reached at (919) 843-4467 or by email at [gbaranek@med.unc.edu](mailto:gbaranek@med.unc.edu).

Thank you for your consideration! I look forward to hearing from you.

Sincerely,  
Ashley Freuler  
[afreuler@med.unc.edu](mailto:afreuler@med.unc.edu)  
UNC Chapel Hill

## **APPENDIX C: Interview Guides**

## Facing Challenges on Two Fronts

### **1. Initial Phone Interview: Family Demographics and Background**

#### **Questions:**

1. Service member history in the military:
  - a. Time in service
  - b. Rank
  - c. MOS
  - d. Current Duty Station
2. How long have you been married to service member?
3. Does your family live on or off base?
4. Do you work outside of the home on a paid or volunteer basis?
5. Number of children, child's name/age/diagnosis
6. Children attend school on/off base?
7. Current autism-related services received (general)
  - a. School-based? In home?
  - b. Tricare Reimbursed? Or Self-Pay?
8. Current Family Support Services Received:
  - a. Military Related
  - b. Community-based

## **2. Interview Guide II. Family Experiences and Resilience**

**Script:** Today's interview will consist of a series of open-ended questions that will guide our discussion surrounding your families' experiences. I will use these as a guide, but I expect that we will stray a little bit from the order of the questions as I have them written. This is meant to be more of a dialogue than a question answer format. The time frame will be about an hour and a half (or longer) and we will have an opportunity for follow-up and clarification of any details that we do not cover today during our third interview.

### **I. The CHILD and autism**

1. I am interested in learning more about (child's name) and would like to start out by your telling me a little bit about him/her?
  - a. what are some of the things that (child) likes to do?
  - b. what types of things are you working on with (child) now?
  - c. what do you see as his/her biggest challenges?
  - d. what are his strengths?
2. You described some of the services that (child) is receiving in our first interview, can you tell me a little bit about how that is going for him and what your experiences have been with his current placements/services?
  - a. Current school placement:
    - i. Experiences with school placement:
    - ii Experience with home therapies:
  - c. Other:
3. How would you describe 'good days' for (child)?
  - a. How do (child's) 'good days' impact the family as a whole?
  - b. How would you describe a 'good day' for the family?
  - b. How about you as a caregiver?
4. What do you feel are your biggest hurdles in experiencing these 'good days'?
5. What biggest difficulties/challenges that you face raising (child)?
  - a. How do think these challenges impact the whole family?
  - b. What supports do you tend to utilize when facing these challenges?
6. What are the most rewarding aspects of raising (child )?
7. How do you see the overall family as being impacted by (child's) needs and challenges? (or How is the family impacted by Autism?)



## II. THE FAMILY:

1. Can you tell me a little bit more about your family as a whole? What types of things do you all like to do, etc?
2. Can you walk me through a typical weekday in the \_\_\_\_ household??
  - a. What are your typical routines, etc.
  - b. What role do family members play in these routines- who organizes/facilitates?
  - c. Are these routines fairly consistent/what experiences have impacted or required a change in routines? (e.g., school lets out for summer)
3. Do you ever face barriers to getting through a day smoothly?
  - a. if so, how do you usually respond to these challenges?
4. What do weekends typically look like in your house?
5. Do your routines change significantly when your husband is deployed?
6. What types of activities do you all enjoy doing together?
  - a. How often do you get to engage in these activities?
7. Can you describe a time when your family faced significant challenges?
  - a. Who/what keeps the family going during challenging times?
  - b. How do challenging times impact the whole family?
  - c. How do challenging times impact you as a caregiver?
8. How would you describe times when your family is 'doing well'?
  - a. How often do these days come about?
  - b. How does 'having a good day' impact the family as a whole?
  - c. How do 'good days' impact you as a caregiver?

## III. MILITARY LIFE

1. Can you tell me about the role that 'the military' plays in your family life?
2. Describe the most rewarding aspects of military life for your family.
3. What are the biggest challenges that your family faced in terms of military service/obligations?
  - a. What supports do you tend to utilize when facing these challenges?
  - b. Have these supports changed over time?
4. Are there certain times when you feel your family life is more or less impacted by the military?

5. Can you describe your role as a military spouse?
6. Do you feel like you have the supports and resources that meet the unique needs of your family?
  - a. Can you describe the military resources that you have utilized?
    - i. What barriers did you face in utilizing these resources?
    - ii. Are there any services that you plan to use in the future but have not yet had the opportunity?
7. What supports would be helpful for you in order to more easily fulfill these roles?
8. In general, how does raising a child with autism 'fit'/'not fit' with military service?
  - a. What do you do in order to make it work?
  - b. (if no) What would it look like if these two obligations did 'fit' together?
9. How do you manage the role of supporting your service member and raising a child with autism?
  - a. What are the biggest challenges you face in this role?
  - b. What supports do you utilize when you feel challenged?
10. What does it mean to you to fulfill the role of military spouse and caregiver for a child with autism?

### **3. Interview III: Follow-up from Second Interview**

**Script:** “Today I would like to ask you a few more questions following our last interview, as well as give you a chance to elaborate on any points that we already discussed or to bring up any other thoughts or topics that have come to you since our last meeting.”

#### **Example Third Interview: (final interviews tailored to participant)**

1. Update on family life since husband has deployed (3 weeks ago):
  - a. Is dad still stateside, or is he now overseas?
  - b. How is he doing?
2. Can you tell me how everyday life has changed since he has been gone?
  - a. How is (\*child\*) doing with the transition?
  - b. How are YOU doing with dad being deployed?
  - c. What aspects of daily life have changed?
  - d. What has remained the same?
2. You described everyday routines and (child) knowing ‘what to expect’ as being very important in your house. Have you found it difficult to maintain this consistency with your husband being gone?
3. You mentioned not knowing what communication would look like once your husband was boots on the ground. Have you found a consistent way to stay in touch with your husband? and are the kids involved in this communication?
4. Since the kids are out of school now for the summer- you mentioned summer camps and trying to keeping kids busy... can you tell me a little bit more about what this summer schedule looks like? Are (\*child\*)’s services impacted in any way?
5. You mentioned ‘respite’ as a hope that you have while your husband is gone. Have you been able to complete the paperwork- what is the status?
  - a. (if not approved- what barriers has she faced?)
  - b. More about what this time means to mom and how it contributes to her (as she put it “sanity”).
6. What have the biggest challenges been since the deployment?
  - a. How have you ‘met’ these challenges?
  - b. Any new resources that mom has put in place/identified as helpful?
7. How have your supports changed or remained the same since he has deployed?

- 7.What are you most looking forward to upon his return? What will life look like when he gets back?
- 8.You mentioned that your husband had made career decisions based on the needs of your family. I am wondering if you can tell me more about how you feel your child's needs have impacted these decisions and opportunities?
- 9.You mentioned training for a marathon while your husband was gone if you can get the respite care that you need. Are you still working towards this goal? Can you tell me more about what it means to you to have something that you are working towards?
- 10.Do you all have any plans coming up over the summer? You mentioned in our last interview that you hoped to get to the beach with your family?
- a. Other plans while dad is away?

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