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Caregiving in Military Families

2020 Military Family Lifestyle Survey Special Report

In partnership with:

ROSALYNN **FOR**
CARTER **CAREGIVERS**
INSTITUTE

In collaboration with:

S Syracuse University
Institute for Veterans
& Military Families
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ROSALYNN CARTER INSTITUTE FOR CAREGIVERS (RCI)

The Rosalynn Carter Institute for Caregivers promotes the health, strength, and resilience of caregivers throughout the United States. Established in 1987 by former First Lady Rosalynn Carter, the Institute's priority is the family caregiver: those individuals who care for a relative, friend, or loved one. In 2011, RCI launched Operation Family Caregiver, which coaches the families and friends of returning service members and veterans to manage difficult transitions.

BLUE STAR FAMILIES (BSF)

Blue Star Families builds communities that support military families by connecting research and data to programs and solutions, including career development tools, local community events for families, and caregiver support. Since its inception in 2009, Blue Star Families has engaged tens of thousands of volunteers and served more than 1.5 million military family members. With Blue Star Families, military families can find answers to their challenges anywhere they are.

THE INSTITUTE FOR VETERANS AND MILITARY FAMILIES (IVMF)

Syracuse University's Institute for Veterans and Military Families (IVMF) is the first national institute in higher education singularly focused on advancing the lives of the nation's military, veterans, and their families. Through its professional staff and experts, the IVMF delivers leading programs in career and entrepreneurship education and training, while also conducting actionable research, policy analysis, and program evaluations. The IVMF also supports veterans and their families once they transition back into civilian life, as they navigate the maze of social services in their communities, enhancing access to this care working side-by-side with local providers across the country. The Institute is committed to advancing the post-service lives of those who have served in America's armed forces and their families.

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AUTHORS

From the Department of Applied Research at Blue Star Families in partnership with the Rosalynn Carter Institute for Caregivers, supported by the Institute of Veterans and Military Families at Syracuse University.

BLUE STAR FAMILIES

Jessica D. Strong, Ph.D., Co-Director of Applied Research

Jennifer L. Akin, M.P.A., Co-Director of Applied Research

Kim D. Hunt, Ph.D., Senior Research Manager

Charo Bates, Policy & Social Impact DEPLOY Fellow

Drew S. Brazer, Manager of Government Relations

CONSULTANTS

Karly Howell, M.A., Applied Research Analyst Consultant

ROSALYNN CARTER INSTITUTE FOR CAREGIVERS

Jennifer Olsen, DrPH, Chief Executive Officer

Lauren S. Tobias, Advisor

INSTITUTE FOR VETERANS AND MILITARY FAMILIES, SYRACUSE UNIVERSITY

Rosalinda V. Maury, M.S., Director of Applied Research and Analytics

Rachel K. Linsner, M.S., Doctoral Research Fellow

Jeanette Yih Harvie, Ph.D., Research Associate

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INTRODUCTION

While the challenges unique to caregivers and to military-affiliated families have been examined independently, the interaction of these two sets of circumstances have not been studied in conjunction. Military families face unique challenges associated with military life, and caregivers shoulder the additional burdens of caring for loved ones. However, to date it has remained unclear what caregiving looks like in military families and how the military lifestyle impacts caregivers. Blue Star Families has tracked caregivers in military families for years through the annual Military Family Lifestyle Survey (MFLS), and other research endeavors, but heretofore has not reported in depth on this unique group.

This report presents a unique, focused profile of caregivers in military families, examining:

- How caregivers identify themselves
- The prevalence of caregiving in military families
- Demographic characteristics of caregivers and care recipients
- How military life impacts caregiving
- How caregiving in military families affects caregiver health and mental health
- Financial stressors of caregivers in military families
- Supports available and needed for caregivers in military families
- Recommendations for improving supports for caregivers in military families



DEFINING CAREGIVERS IN MILITARY FAMILIES

“Military caregivers” typically are defined as those caring for an active-duty or veteran service member who has serious injuries or illnesses¹ which are often caused by military service. This definition, however, does not fully capture the many different types of caregiving taking place in military families. “Military caregivers” are most frequently wives caring for a spouse or partner with a military-connected injury, or sometimes adult children or battle buddies.² Flipping the term and referring to “caregivers in military families” allows inclusion of caregivers of all kinds. A caregiver in a military family may care for children with special needs, other family members with chronic conditions, aging parents and grandparents, battle buddies, and many others.

Military service introduces unique challenges to the work of caregiving. These caregivers are asked to manage the workload of caregiving while dealing with relocations, deployments and family separations, financial insecurity and additional barriers to employment, and their own health and mental health concerns. Therefore, in this report “caregivers in military families” are defined as a spouse or a service member in a currently-serving family (active-duty, National Guard, and Reserve) who is providing care to an adult or child with special needs.

“Caregivers in military families” are defined as a spouse or a service member in a currently-serving family (active-duty, National Guard, and Reserve) who is providing care to an adult or child with special needs.

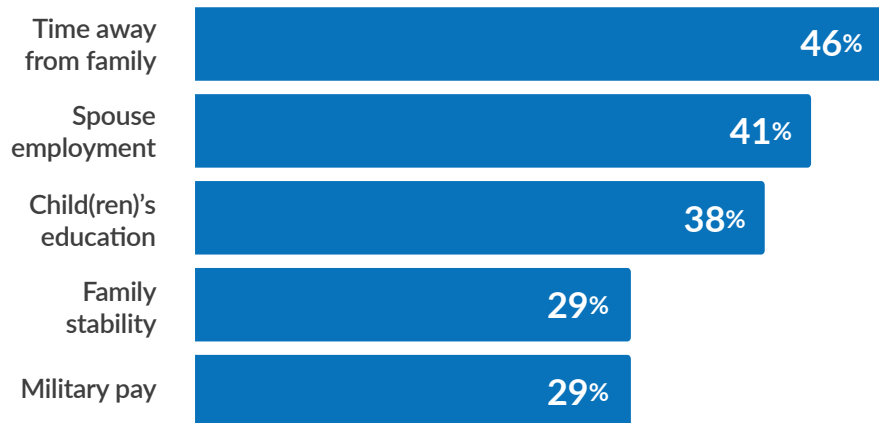
Blue Star Families' annual **Military Family Lifestyle Survey (aMFLS)** has been providing a comprehensive understanding of the experiences and challenges encountered by military families since 2009. The 11th annual survey, fielded from September to October of 2020, captured the experiences of nearly 11,000 respondents worldwide, including those of **3,777 caregivers in military families and their non-caregiving military peers**. This special report is the first of its kind, providing a deep dive into caregiving among military families.

Caregiving in military families is common, but these caregivers differ from their counterparts in the general population in many ways. Caregiving in military families does not fit conveniently into a single paradigm. It takes many forms and encompasses a variety of caregivers and care recipients. Caregivers in military families may not recognize the tasks they are doing as “caregiving” or define themselves as an “unpaid caregiver.” Caregivers in this sample were younger than caregivers in the general population, and a greater proportion were female and married. They are often caring for more than one care recipient, such as a child with special needs, a typically-developing child, and a parent or grandparent, all at once. Their care recipients most commonly have “invisible” conditions, such as emotional or mental health concerns, in comparison to general population care recipients, who are older and more often have physical health concerns.

These caregivers do have commonalities with their peers in the general population in that both groups report mental and physical health challenges and financial concerns. Caregivers in military families, however, often have to balance caregiving responsibilities with the military lifestyle. The military lifestyle brings a unique set of challenges, often prioritizing military service obligations and day-to-day military job demands over family and caregiving needs. It can include separations from the service member, isolation from family and friends, and frequent relocations for active-duty families that require re-establishing

TOP MILITARY LIFE ISSUES

Caregivers in Military Families



Please select up to 5 military life issues that most concern you.



local support, which may be challenging for families who have additional caregiving needs. Caregivers in military families experience the same military lifestyle challenges as their military non-caregiver peers and their top issues reflect those of military families at large, but some “typical” stressors may be intensified or carry a different meaning for caregivers.

TOP FINDINGS

1. More than a quarter (26%) of caregivers in the sample report feeling “excessively burdened” by the tasks of caregiving, but do not consider themselves “caregivers.”
2. Caregiving may be more prevalent in military-connected families than in the general U.S. population.
3. Compared to caregivers in the general U.S. population, caregivers in this military subsample are younger and a greater proportion are female and married.
4. Caregivers in military families may be “sandwiched,”; 44% of caregivers in military families are caring for more than one care recipient at the same time, often kids with special needs, typically-developing kids, and a parent or grandparent.
5. Caregivers in military families are caring for recipients with “invisible” conditions. Most commonly they are caring for someone with “emotional or mental health concerns” rather than or in addition to physical health concerns.
6. Similar to caregivers in the general U.S. population, a greater proportion of caregivers in military families experience mental health challenges and sleep issues than non-caregivers.
7. Caregivers in military families report more financial stress than non-caregiver peers.
8. To adequately balance military life and caregiving responsibilities, caregivers in military families need flexible commands and supportive community programming.

RECOMMENDATIONS

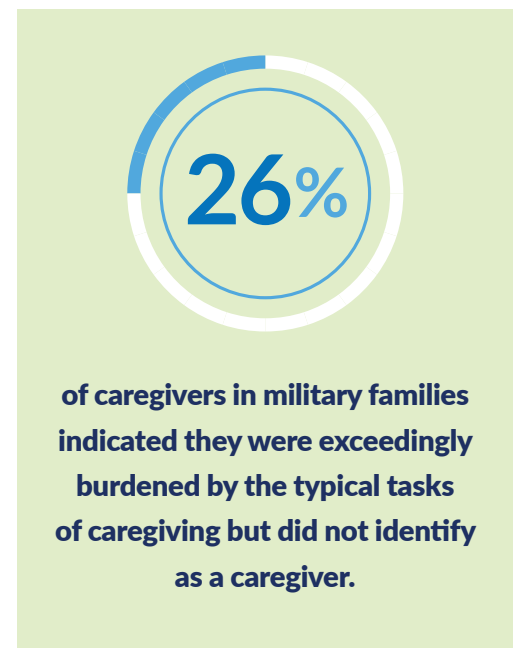
1. Recognize the diversity in caregiver experiences within military families, develop more inclusive approaches to identify caregivers through active screening, and incorporate these inclusive approaches into daily operations.
2. Focus on upstream solutions to financial difficulties among caregiving military families.
3. Increase awareness of and expand access to caregiver respite and support programs, including local community support.

Finding 1: More than a quarter (26%) of caregivers in the sample report feeling “excessively burdened” by the tasks of caregiving, but do not consider themselves “caregivers.”

Caring for loved ones who have special needs is imbued with moral and cultural meaning. For many cultures, caring for those with additional needs is deeply ingrained in familial roles; it is not “caregiving,” but simply part of being a son or daughter, parent, grandchild, relative, or friend. Individuals who hold these values may not identify themselves as a caregiver but still are doing the work of caregiving, and may be overwhelmed by the needs of their care recipient(s) or the care that they provide. Perhaps especially among parents of children who have special needs, the line between being a “parent” and being a “caregiver” blurs. Identifying as a “caregiver” may rely on the needs of the care recipient and whether those needs exceed those of typically developing children, the proximity or age of the care recipient, or a number of other factors. Due to these varying factors, it becomes challenging to identify respondents who are “caregivers” and are providing care that goes beyond the typical familial and friend relationships.

SELF-IDENTIFIED CAREGIVERS VERSUS TASK-IDENTIFIED CAREGIVERS

The 2020 Military Family Lifestyle Survey explored caregiver identity by asking not only about a respondent’s self-identification as a caregiver,^a but also about tasks for which caregivers are typically responsible and that may feel exceedingly burdensome in the past 12 months.^b The series of questions intended to identify those respondents who were performing the work of caregiving even if they did not consider themselves “unpaid caregivers.” The majority of caregivers in military families respondents (62%) indicated that they identified as a caregiver and that they were exceedingly burdened by typical caregiving tasks (both self-identified and task-identified), while over a quarter (26%) of caregivers in military families indicated they were exceedingly burdened by the typical tasks of caregiving (task-identified) but did not



^a Self-identification was determined by an adaptation of the National Alliance for Caregiving definition of caregiver.

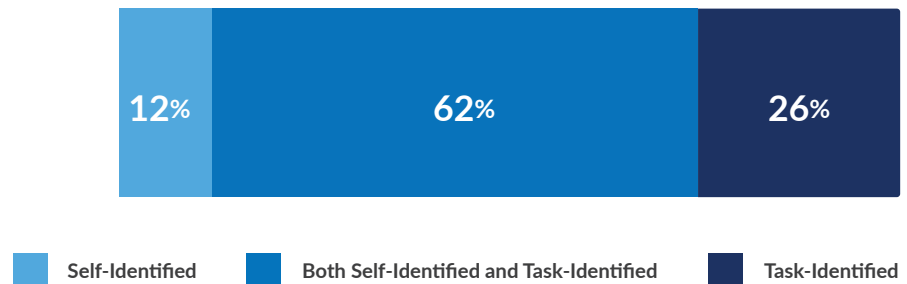
^b Caregiving tasks were identified in collaboration with the Rosalynn Carter Institute for Caregivers.



identify as a caregiver (“self-identified”). A smaller proportion identified themselves as a caregiver (12%), but did not report feeling exceedingly burdened by any of the typical caregiving tasks (“self-identified”).

CAREGIVER IDENTITY

Caregivers in Military Families



Self-Identified Caregivers

Responded “yes” to the following question:

For the purposes of this survey, unpaid caregiving is defined as care for ongoing medical conditions, or serious short-term ones, including emotional, behavioral, or developmental challenges. The care you provide may include help with personal needs or household chores. It might be managing a person’s finances, arranging for outside services, or visiting regularly to see how they are doing. You do not need to live with this person to meet the definition of being their caregiver. Routine care for children only meets this survey’s definition of unpaid caregiving if your child(/children) meet(s) the terms above. In the last 12 months, have you provided unpaid care to a spouse, child, relative, or friend to help them take care of themselves?

Task-Identified Caregivers

Responded “yes” to *any* of the following questions:

During the past 12 months, have you experienced any of the following as exceedingly burdensome in relation to a friend or relative you care for? Please select all that apply.

- Assisted with normal activities of daily life such as eating, dressing, toileting, shaving, etc.
- Helped through emotional “storms” or outbursts
- Often miss work to care for someone else
- Advocated for new and/or better treatment
- Sometimes felt overwhelmed for care I have provided
- Took on legal and/or financial responsibilities
- Assisted in health care (such as giving shots, changing dressings) or medication management
- Identified and coordinated professional care and services (making arrangements for occupational health, physical therapy, etc.) for them
- Other

Finding 2: Caregiving may be more prevalent in military-connected families than in the general U.S. population.

To compare caregivers in military families with non-caregiving military-connected peers, a subsample of 3,777 respondents from the 2020 Military Family Lifestyle Survey (MFLS) was selected for analysis.^c Two groups of respondents were identified — 43% of respondents in the sample were identified as caregivers, either through self-identification (“self-identified”) or by indicating they were burdened by caregiving tasks (“task-identified”), and 57% were identified as non-caregiver peers.^d

The National Alliance on Caregiving (NAC) defines caregivers as those providing care to an adult or child.³ For those caring for adults, it includes those who indicate they have or anyone in their household has, in the last 12 months:

Provided unpaid care to a relative or friend 18 years or older to help them take care of themselves. This may include helping with personal needs or household chores. It might be managing a person’s finances, arranging for outside services, or visiting regularly to see how they are doing. This adult need not live with you.

For those caring for children, it includes those who indicate they have, in the last 12 months:

Provided unpaid care to any child under the age of 18 because of a medical, behavioral, or other condition or disability. This kind of unpaid care is more than the normal care required for a child of that age. This could include care for an ongoing medical condition, a serious short-term condition, emotional or behavioral problems, or developmental problems.

Using these definitions, 21% of NAC survey respondents are identifying as caregivers (6% were caregivers for children, and 19% were caregivers for adults).^e In contrast, 32% of the military subsample for this report self-identified as caregivers, indicating that caregiving may be more prevalent in the



^c See Methodology section for full description of sample inclusion and exclusion criteria; definition differs from previous Military Family Lifestyle Survey reports.

^d “Non-caregiver peers” includes respondents to the 2020 Military Family Lifestyle Survey who saw the caregiving section, and indicated that they were not a self-identified caregiver and that none of the caregiver tasks were exceedingly burdensome.

^e 3.6% of respondents in the NAC 2020 sample were caregivers for both children and adults.



military population than in the general U.S. population, even without including the additional caregivers who reported being burdened by caregiving tasks without self-identifying as caregivers.

Military culture includes the values of self-sacrifice⁴ and caring for “brothers and sisters.” These values may extend into the military family, creating a culture in which caring for others, whether members of their immediate family or other service members and their families — the figurative “military family” — are simply expected as part of the culture. For example, 15% of caregivers in military families reported that their care recipient was not a family member (child, parent, or grandparent), but the spouse or child of another active-duty service member. Across the service branches, military family fitness⁵ initiatives focus on the acquisition of resources by military families to help them to adapt to competing demands and the ever-changing stressors associated with military life. The development of these protective factors encourages resilience in the face of adversity. Taking on the role of caregiver may not be thought of as a unique portion of a military-connected individual’s identity but merely as another responsibility that they are capable and prepared to navigate.



Finding 3: Compared to caregivers in the general U.S. population, caregivers in this military subsample are younger and a greater proportion are female and married.

The majority of caregivers in military families in this sample are the spouses of active-duty service members (68%) or active-duty service members themselves (16%). The mean age of caregivers in military families is 37 years old,^f considerably younger than the average age of caregivers of an adult in the general U.S. population (49.4).⁶ The difference between this sample of caregivers in military families and their counterparts in the general population can likely be attributed to the overall younger age of military-connected families, among whom 85% are under 40 years old.⁷

| % OF CAREGIVERS BY GENERATION Caregivers in Military Families | |
|---|-----|
| Gen Z: Born 1997 or after, ^A 23 years or younger in 2020 ^B | 2% |
| Millennial: Born 1981 to 1996, ^A 24-39 years old in 2020 ^B | 62% |
| Gen X: Born 1965 to 1980, ^A 40-55 years old in 2020 ^B | 34% |
| Baby Boomers, Greatest Generation, Silent Generation: Born 1964 or earlier, ^A 55 years or older in 2020 ^B | 2% |
| ^A Generation definition used in NAC "Caregiving in the U.S. 2020 Report" ^B Generation definition used in 2020 Military Family Lifestyle Survey | |



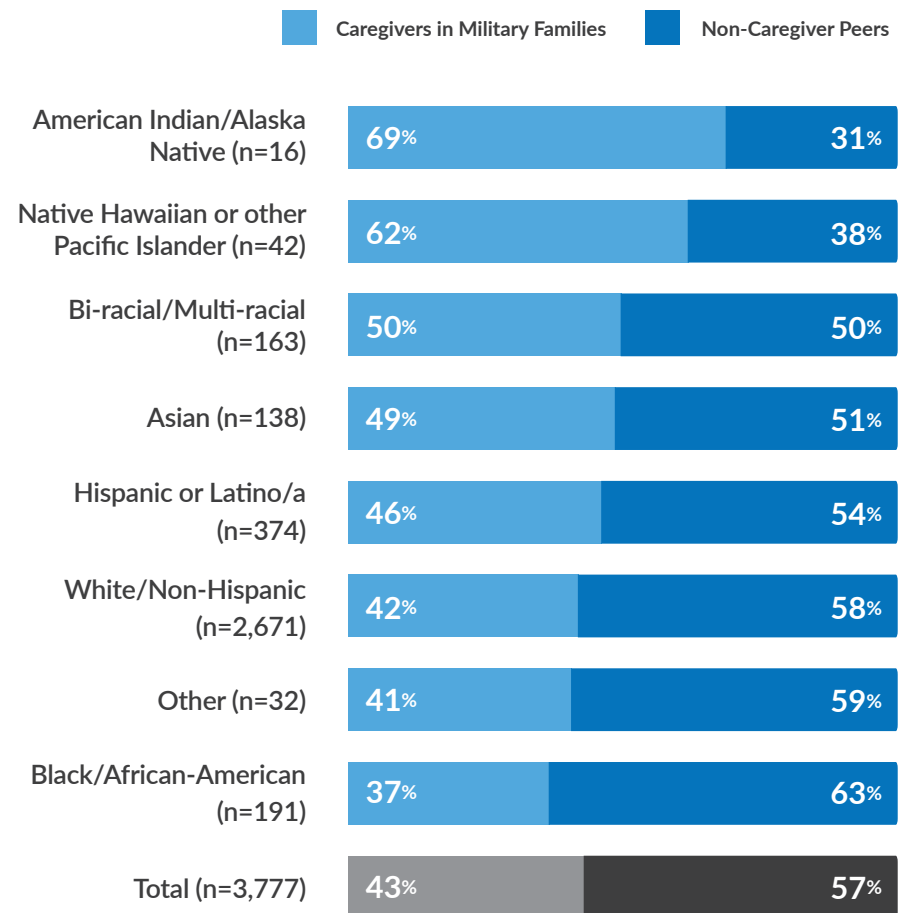
^f Respondents over the age of 65 (n=3) were grouped in an “65 or older” age category and were excluded from the average age calculation.



The large majority of caregivers in military families are married (93%), female (88%), and white, non-Hispanic (72%). The breakdown of race/ethnicity among military caregiver respondents reflects the proportion of the race/ethnicity of all military-connected respondents in the 2020 Military Family Lifestyle Survey. However, there is a slightly greater proportion of military respondents of color who were caregivers (46%) compared to their non-Hispanic white peers (42%).

% OF CAREGIVERS IN MILITARY FAMILIES BY RACE/ETHNICITY

Active-duty, National Guard, and Reserve family respondents in the report sample



Of this sample, caregiving is slightly more prevalent among National Guard (48%) and Reserve (50%) families than among active-duty families (42%). This may be due to the older age of National Guard or Reserve families in comparison with active-duty peers,⁸ or because National Guard and Reserve families are not as mobile as active-duty families and may be more likely to live in proximity to a care recipient and therefore provide more tangible care.

Finding 4: Caregivers in military families may be “sandwiched;” 44% of caregivers in military families are caring for more than one care recipient at the same time, often kids with special needs, typically-developing kids, and a parent or grandparent.

As reflected in the military family population as a whole, most caregiving military families (86%) have children in the home. The largest proportion of

| % PROVIDING CARE FOR 3 MOST COMMON CARE RECIPIENTS Caregivers in Military Families (Active-duty, National Guard, and Reserve Families) | | | | |
|---|-------------|----------------|---------|-------------------------|
| | Active-duty | National Guard | Reserve | ALL military caregivers |
| Child under 18 years of age with special needs | 36% | 29% | 23% | 35% |
| Child under 18 years of age without special needs | 29% | 29% | 23% | 29% |
| Parent or grandparent | 26% | 38% | 44% | 28% |
| Respondents who reported they provided caregiving only for a child without special needs were excluded from the caregiver sample; however, respondents often were caring for an adult or a child with special needs in addition to a child without special needs. | | | | |

care recipients of caregivers in military families are children, both with and without special needs. Over a third of caregivers in military families (35%) are providing care for a child with special needs,⁸ another 29% are also providing care for a child without special needs, and over a quarter (28%) are providing care for a parent or grandparent. Many are caring for multiple recipients.



National Guard and Reserve family caregivers, however, may be caring for different care recipients. The largest groups of care recipients that active-duty caregivers are caring for are children with and without special needs, parents, and grandparents. Comparatively, the largest group of National Guard and Reserve caregivers are those caring for parents or grandparents (38% and 44%, respectively). Additionally, about a quarter (29% of National Guard and 23% of Reserve caregivers) are caring for children (both with or without special needs). These differences may reflect a difference in age and

⁸ Respondents who reported they provided caregiving **only** for a child without special needs were excluded from the caregiver sample; however, respondents often were caring for an adult or a child with special needs **in addition to** a child without special needs.



stage of life, or that Guard and Reserve families are less mobile than their active-duty peers. National Guard and Reserve families are, on average, older than their active-duty peers.⁹

MULTIPLE CARE RECIPIENTS

As noted, in the general U.S. caregiver population, a growing proportion of caregivers are providing care for more than one care recipient simultaneously.¹⁰ This is especially true for military family caregivers, among whom many caregiving families are providing care for two or more care recipients simultaneously (44% of caregivers in military families). A smaller proportion (13% of caregivers in military families) are even providing care for three or more care recipients. Most commonly, caregivers in military families who were caring for more than one person were caring for a child with special needs and a child without special needs, or caring for children with and without special needs and a parent or grandparent.

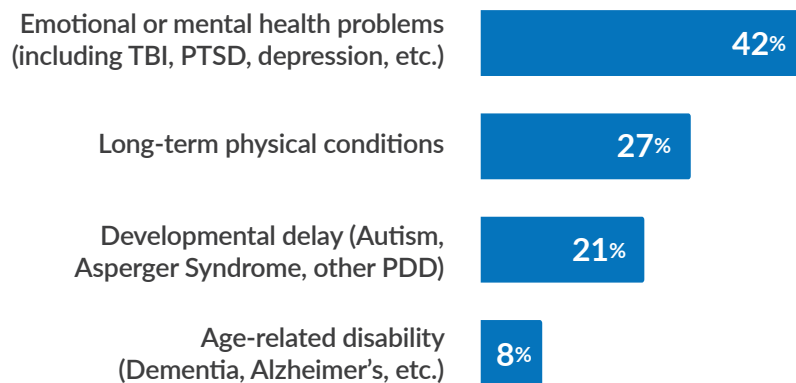
Finding 5: Caregivers in military families are caring for recipients with “invisible” conditions. Most commonly they are caring for someone with “emotional or mental health concerns” rather than or in addition to physical health concerns.

Given the younger age of most care recipients (children with and without special needs) in military caregiving families, the reasons for needing care differ from that of their general U.S. population caregiver peers, who are most commonly caring for adults. Caregivers in military families most commonly report the reasons their care recipient needs care are emotional or mental health problems (42%), long-

term physical conditions (27%), and developmental delay (21%). This contrasts with care recipients in the general population, for whom caregivers most commonly reported long-term physical health

MOST COMMON REASONS FOR NEEDING CARE

Caregivers in Military Families



conditions (63%); 27% reported emotional or mental health problems; and just 9% reported a developmental delay or intellectual disorder.

Given the preponderance of emotional or mental health issues as military families' care recipients' reasons for needing care, it is understandable that more caregivers identified the emotional tolls of caregiving as burdensome. Emotional and mental health concerns are often called “invisible illnesses” because they are not always readily apparent.¹¹ Helping the care recipient through emotional storms, feeling overwhelmed, and coordinating and advocating for better care may all be more common when



caring for care recipients whose care needs are ill-defined or difficult to observe. It is important to note that a stigma associated with needing mental health support or care still exists in military populations,¹² and may contribute to emotional burden or feelings of shame and overwhelm for caregivers in military families who are managing mental and emotional health conditions of their care recipients.

| % REPORTING TASKS IDENTIFIED AS “EXCEEDINGLY BURDENSOME” Caregivers in Military Families | |
|---|-----|
| Helped through emotional "storms" or outbursts | 61% |
| Sometimes felt overwhelmed for care I have provided | 41% |
| Identified and coordinated professional care and services (making arrangements for occupational health, physical therapy, etc.) for them | 38% |
| Advocated for new and/or better treatment | 38% |
| Assisted with normal activities of daily life such as eating, dressing, toileting, shaving, etc. | 23% |
| Took on legal and/or financial responsibilities | 23% |
| Assisted in health care (such as giving shots, changing dressings) or medication management | 21% |
| Often miss work to care for someone else | 13% |
| Other | 5% |
| <i>During the past 12 months, have you experienced any of the following as exceedingly burdensome in relation to a friend or relative you care for? Please select all that apply.</i> | |

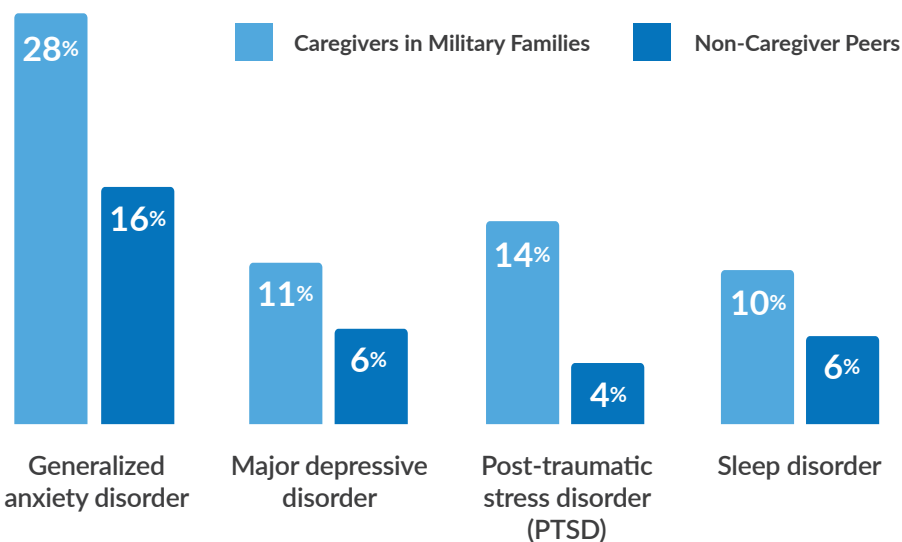
Caregivers providing care for recipients with behavioral symptoms may be at greater risk for mental health concerns themselves, or for caregiver burnout.¹³ The military lifestyle of frequent relocation may also make supportive resources and opportunities for respite care more scarce, so it is critical to examine the impacts of caregiving in military families on caregivers' physical, mental, and financial health.

Finding 6: Similar to caregivers in the general U.S. population, a greater proportion of caregivers in military families experience mental health challenges and sleep issues than their non-caregiver peers.

Caregiving can be simultaneously rewarding for the individual providing care¹⁴ and a source of stress.¹⁵ Long-term stress has been shown to have deleterious effects to an individual's mental and physical wellbeing.¹⁶

Similar to caregivers in the general population,¹⁷ a greater proportion of caregivers in military families reported a variety of current mental health diagnoses than their non-caregiver peers. A quarter (28%) of caregivers in military families reported a current diagnosis of anxiety

MENTAL HEALTH AMONG CAREGIVERS IN MILITARY FAMILIES
% of military family respondents reporting a current diagnosis



in comparison to 16% of non-caregivers in military families. Additionally, one in five (22%) caregivers in military families indicated they would like to receive mental health services but do not, compared to 17% of their non-caregiver peers, and a greater number of caregivers (24%) than non-caregivers (14%) report receiving mental health care. Therefore nearly half (46%) of caregivers in military families receive or want to receive mental health care in comparison to less than a third (31%) of their non-caregiving counterparts.

One in five (22%) caregivers in military families indicated they would like to receive mental health services but do not, compared to 17% of their non-caregiver peers

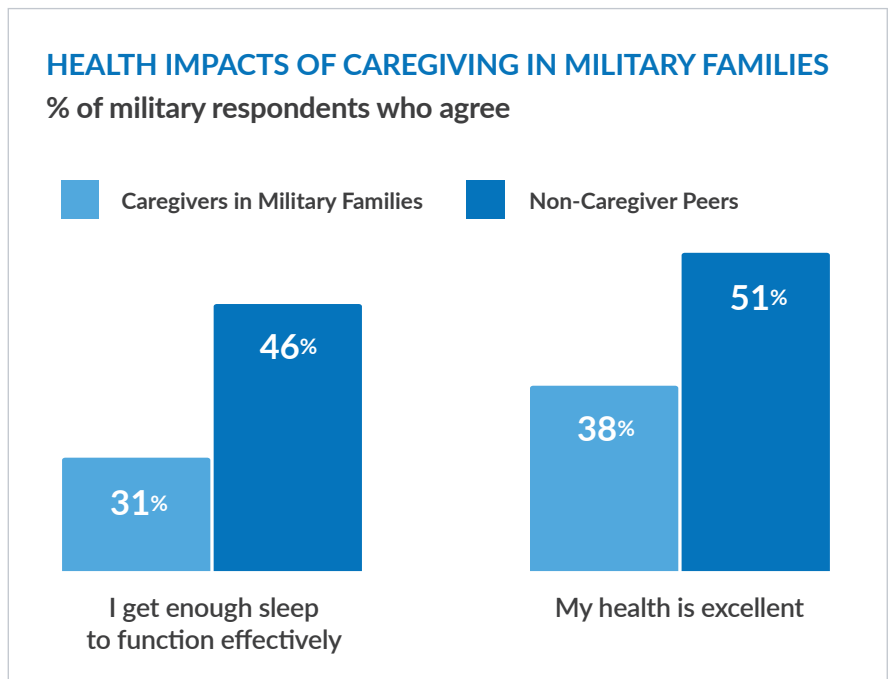


Quality, restorative sleep is important to both physical health and mental health,¹⁸ but caregivers often report shorter sleep durations and poorer quality of sleep than non-caregivers.^{19,20} Caregivers in military families report similar negative impacts on sleep; less than a third (31%) of caregiving respondents agree they are

getting enough good quality sleep to function effectively. In contrast, half (46%) of non-caregiving respondents said they are getting enough sleep.

Furthermore, slightly more than a third of caregivers (38%) report their health as being excellent, while more than half (51%) of non-caregivers report the same. Lack of sleep, amongst other unmet needs, has been shown to impact overall health outcomes for

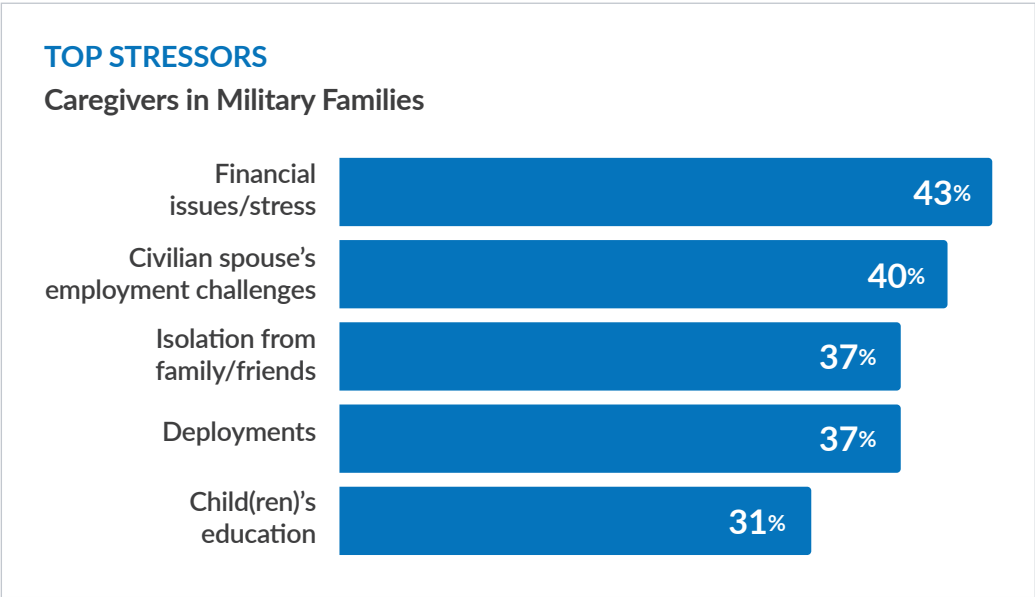
caregivers.²¹ Despite younger age and the ability to receive reliable health care and mental health care, caregivers in military families continue to demonstrate greater challenges to their health and mental health than their non-caregiver peers.



Finally, military families' connection to the local civilian community impacts their resilience, and mental health.^{22,23,24} Building and maintaining resilience, though, can be challenging for military caregiving families when frequent relocations, deployments, and perceptions of a civil-military divide²⁵ can leave them feeling isolated and alone. A sense of belonging to the local civilian community is associated with resilience²⁶ and may also impact the perception of stress. Caregivers in military families who agreed that they feel a sense of belonging to the local civilian community reported significantly less perceived stress than their caregiver peers who disagreed, or even felt neutrally. Programs that can successfully support military caregiver connections and sense of belonging to the community, then, may have the capacity to improve caregiver resilience and mental health.

Finding 7: Caregivers in military families report more financial stress than military non-caregiver peers.

Financial concerns have been routinely identified as a top stressor for military-connected families as a whole²⁷ as well as for caregivers in the general U.S. population.²⁸ Military-connected caregivers have previously reported



more pronounced financial stressors than their non-caregiving counterparts, indicating that the caregiving role may come with additional economic burdens.²⁹ “Financial issues/stress” was the top stressor for caregivers in military families. While the top factors that contribute to financial stress are

| TOP FACTORS CONTRIBUTING TO FINANCIAL STRESS FOR CAREGIVERS Caregivers in Military Families | |
|--|-----|
| Un/Underemployment | 29% |
| Student Loans | 29% |
| Out of Pocket Housing Costs | 24% |
| Out of Pocket Relocation Costs | 24% |
| Excessive Credit Card Debt | 23% |
| Major home repairs | 11% |
| Which of the following contributes to your family's current financial stress? Please select your top 3 choices. | |

similar in caregiver and non-caregiver respondents, two thirds (67%) of caregivers in military families reported that their family’s current financial situation causes them some or a great deal of stress, while more than half (53%) of their non-caregiver peers reported the same. Financial stress levels are similar across all currently-serving caregiving families, with “some or a great deal” of stress reported by 68% of caregivers in active-duty families, 69% of caregivers in National Guard families, and 59% of caregivers in Reserve families.

A review of respondent overall household incomes for the year 2019 revealed that a greater proportion



of military caregiving families (42%) reported a household income less than \$75K/year compared to their non-caregiving counterparts (37%). Unpaid caregiving responsibilities add an additional layer of difficulty to finding employment that aligns with education level and skill set yet also allows for the flexibility that is necessary for military families. Caregivers in military families report un/underemployment as the top factor contributing to their financial stress (29%), with student loans as the second contributing factor (29%).



Caregiver financial concerns may be at least partially attributable to spouse employment concerns for both caregivers in military families and those in the general population.³⁰ Difficulty finding employment that allows a caregiver to balance employment and caregiving responsibilities within the military lifestyle, which essentially prioritizes military service obligations over family and caregiving needs, can limit the available income in caregiver families. Addressing military spouse under- and unemployment and ensuring opportunities for flexible work may alleviate some of caregivers' financial stresses.

More than half of caregivers in military families (53%), however, are engaged in paid employment; 37% are employed full time, and another 16% are employed part time. Another third (33%) are not employed but report they need or want paid employment. As respite and support services are often unavailable or unreliable,³¹ caregivers in military families who are employed may need time off from their paid employment to fulfill their caregiving role, potentially impacting overall household earnings and therefore leaving caregiving families financially disadvantaged.

Finding 8: To adequately balance military life and caregiving responsibilities, caregivers in military families need flexible commands and supportive community programming.



The balance between service obligations and family responsibilities is a source of stress for the majority of military families,³² but it may be more so for caregivers. A greater percentage of caregivers in military families (78%) reported that their or their service member's overall Operational Tempo (OPTEMPO) — the daily workload, deployment load, and training load experienced since January 1, 2019 — as being stressful or very stressful for a healthy work/family life balance. In comparison, 66% of their non-caregiving counterparts said the same. Military units/commands play an integral role in supporting the military family as a whole, not just the service member. While nearly half (45%) of caregivers in military families reported that the service member's day-to-day job obligations make it difficult for them to provide care or assistance, the majority of all respondents agreed that the unit/

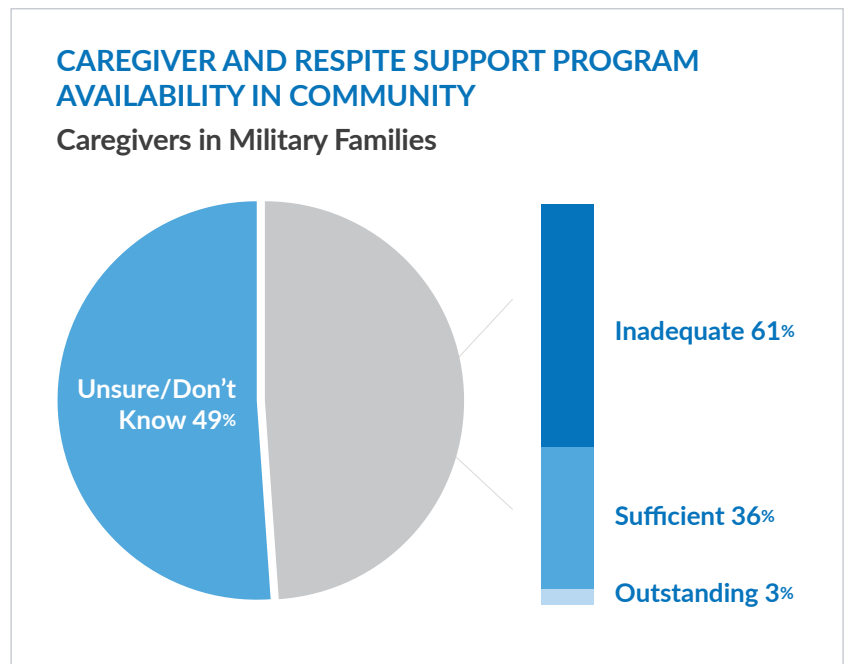
command makes reasonable accommodations (time off, schedule changes, remote work, etc) when needed to manage home/family obligations. Differences in levels of agreement were noted, however, with fewer caregivers agreeing that commands made reasonable accommodations (55%, vs. 60% of non-caregivers).

Deployments, another fact of military life, can further complicate the provision of care. More than half (52%) of caregivers in military families report that their or their service member's deployments make it difficult for them to provide care. Deployments bring long periods of separation, uncertainty, and often an inability to communicate with loved ones and care recipients. Additionally, for military caregiving families, deployments may take away either the person providing care or another adult who is able to provide backup/substitute care. Half (52%) of caregivers in military families disagreed that they have someone who can serve as a backup/substitute to provide care for their care recipient if needed. For the caregivers left on the homefront during a deployment, supportive service like respite



care can be a lifeline. A quarter (26%) of caregivers in military families who are anticipating or have recently experienced a deployment identified caregiver respite and support as a top need during deployment. However, fewer than a third (30%) of those families who identified respite care as a necessity during deployments know how to access caregiver respite and support in their community.

The availability of high-quality respite care is a challenge for caregivers nationwide, regardless of military affiliation.³³ Fewer than a quarter (22%) of military caregiving families agree that over the last 12 months^h they have been



able to take respite from providing care as often as they needed. When asked to rate the availability of resources in their communities, half (49%) of caregivers in military families reported that they were unsure/don't know about caregiver respite and support programs. Of those caregivers in military families who were able to provide a rating, nearly two thirds (61%) indicated that caregiver respite and support programs in their community were inadequate, 36% reported programs as being sufficient, and just 3% reported that their communities resources were outstanding and should be used as a model for other communities to emulate.

Caregiver respite is recognized as a “vital but scarce” resource necessary for caregivers in general³⁴ and for caregivers in military families in particular.³⁵ The Exceptional Family Member Program (EFMP) is intended to ensure access to special needs support for military families who have a family member with special educational or health care needs.³⁶ While there is considerable overlap between families who have children with special needs, caregivers, and families enrolled in the EFMP, not all families who are eligible are enrolled.³⁷ Furthermore, military families are ineligible for support through EFMP if their care recipient is not a military dependent.³⁸ The findings from this report indicate further research, funding, and programmatic efforts are needed to address respite and support shortfalls for caregivers in military families.

^h The 2020 MFLS was fielded from September to October 2020, during the COVID-19 pandemic. Caregivers may have had less accessibility to respite care during this time due to pandemic restrictions.

Recommendation 1: Recognize the diversity in caregiver experiences within military families, develop more inclusive approaches to identify caregivers through active screening, and incorporate these inclusive approaches into daily operations.

Identifying caregivers is complicated, but it is the first step to improving support for this population.³⁹ Those who self-identify as caregivers are not necessarily the same people who say they are “exceedingly burdened” by caregiving tasks (such as assisting with normal activities of daily life, helping through emotional “storms,” frequently missing work to care for someone else, etc.). Many of the individuals who confirm they are doing care tasks do not identify with the term “caregiver.”

We therefore recommend all caregiver support programs (e.g., DoD, VA, other public sector, and nonprofit) review their definitions of “caregivers/caregiving” and consider including broader and more inclusive language. Such a definition might include both caregivers that identify themselves as such and those who are doing the tasks of caregiving without the recognition, including those who are providing care to children with special needs. This definition should then be used across the space, both for program eligibility and for discussions regarding “caregiving,” in order to normalize a more comprehensive definition of the term among the military and general populations. In the long term this will help ensure that caregivers who do not currently self-identify are more willing to seek and use existing support structures, and will improve understanding among those who help facilitate referrals to such services. Additionally, to reach caregivers in military families that do not self-identify as such, resources designed for caregivers should be shared at non-caregiver events, including welcome briefings or packets. Discussion of caregiving responsibilities should also be included as part of routine conversations regarding service members’ personal and professional needs.

We also recommend that organizations actively seek to identify caregivers within their memberships or populations using this expanded definition and track programmatic and other outcomes to better support them. For example, within the military, this includes identification of caregivers in military families on DEERS and TRICARE records, separate from the EFMP identifier. This identifier can also include details on the persons for whom care is being provided (e.g., a parent or grandparent) and can be taken into consideration when making decisions regarding installation assignments, etc.

Caregiving in military families does not fit perfectly into current assumptions about caregiving. Most caregivers in the U.S. population are caring for aging adults,⁴⁰ while the largest group of care recipients among caregivers in military families in this sample are children with special needs. Furthermore,



military-specific caregiver programs are generally designed for caregivers of service members or veterans. For example, DoD's Warrior Care Office offers support for caregivers of service members only, excluding the majority of caregivers in military families. Alternatively, programming designed for caregivers of aging adults may not resonate with many caregivers in military families.

Numerous studies have demonstrated clear improvements in well-being and quality of life for caregivers, care recipients, and even other family members in caregiver support programs,⁴¹ including for example the REACH II intervention,⁴² and the Operation Family Caregiver program.⁴³ Although these interventions have been focused on targeted caregiver groups, lessons learned from these programs may be adaptable to caregivers in military families. The successes from exceptional caregiver support programs can also be adapted and incorporated into existing programs that naturally touch military caregivers in military families, such as the Exceptional Family Member Program.



CONGRESS

- Request a study on the demand for various caregiver support options among military families, as well as to evaluate the effectiveness of programs supporting caregivers (including the EFMP and DoD's Warrior Care Office), and identify solutions from these programs that can be adapted to serve a broader community of caregivers in military families.



DEPARTMENT OF DEFENSE

- Adapt the established programs like DoD's Warrior Care Office⁴⁴ to a broader audience, as well as integrate successful practices such as peer support and coaching into the Exceptional Family Member Program, which naturally reaches military families with children who have special needs.
- Continue to monitor caregiver programs and incorporate recommendations from the National Academies of Sciences' Report⁴⁵ and findings from the Congressional study.

Recommendation 2: Focus on upstream solutions to financial difficulties among caregiving military families.

The economic burden of caregiving is well-established in the general population.⁴⁶ Among caregivers in military families, financial concerns are the top stressor, and the greatest contributor to financial stress is under- or unemployment, followed by student loans. Caregivers often face challenges obtaining and retaining employment that they can balance with their caregiving responsibilities, particularly when military obligations such as service-member day-to-day job demands or deployments become an obstacle. Solutions that will significantly impact military spouse employment, therefore, are likely to also alleviate caregiver financial concerns.

While under- and unemployment is the most common contributor to financial stress for caregivers in military families, lack of affordable child care has been and remains a top barrier to employment for military spouses.⁴⁷ For caregivers in military families, this is expanded to include not only child care for children with special needs, but also adult care services for dependent adults. The Military Child Care in Your Neighborhood and Exceptional Family Member Respite Care programs have served as a model for increasing the capacity of affordable child care for military families.⁴⁸ A similar program could be established for the smaller number of military families who have a dependent adult for whom they are providing care.



CONGRESS

- Support legislation that addresses the root causes of financial stress among caregivers, such as spouse employment initiatives or student loan forgiveness efforts like the Military and Veteran Caregiver Student Loan Relief Act, which would make Veterans' caregivers eligible for federal student loan forgiveness;⁴⁹ HR 3641, which would defer student loan repayment for dislocated military spouses;⁵⁰ or the Credit for Caregiving Act,⁵¹ which can provide a tax credit for eligible family caregivers.



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- Address spouse employment barriers and alleviate stress for caregivers by encouraging commands to support reasonable accommodation for service members who need to balance home and family obligations, addressing affordable child care shortages, and expanding efforts to allow military families more agency over relocations, such as the Army Marketplace.
- Improve both employment issues and caregiver support programming by hiring caregivers to serve as care navigators for military families, particularly those caring for children with special needs.
- Invest in peer support programs, such as the Defense Health Agency's Warrior Care PEER Support Coordinators,⁵² which can create connections, belonging, and opportunities for informal respite for caregivers.
- Continue respite care programs for EFMP families, including typically-developing siblings, as many caregivers in military families are caring for both children with special needs and children who do not have special needs.
- Continue to expand the availability of child care suited for children with special needs, as families who have children with special needs report more difficulty finding child care that works for their situation.⁵³



NON-PROFIT AND CAREGIVER SUPPORT ORGANIZATIONS

- Support opportunities to alleviate financial pressures on caregivers, such as increasing financial literacy among military caregivers, both by incorporating caregiving-related expenses into existing military financial literacy curricula and expanding awareness of new resources like AARP's *Financial Workbook for Veteran and Military Family Caregivers*.⁵⁴

Recommendation 3: Increase awareness of and expand access to caregiver respite and support programs, including local community support.

The majority of caregiver in military families respondents did not know about caregiver resources in their local community and did not know how to access respite care, despite frequently noting that this was an important need during a current or upcoming deployment.ⁱ Limited caregiver awareness of support programs has previously been identified as a barrier, though focused on caregivers for aging care recipients.^{55,56} Because there is likely considerable overlap between caregivers in military families and families served by the Exceptional Family Member Program, there is an opportunity to use this program to meet the needs of some caregivers in military families. To this end, as recommended in a recent RAND report on the EFMP,⁵⁷ the DoD and military leadership can ensure that all military families have information about the EFMP and what services are available through this program and in the local civilian community.

The DoD also can raise awareness of and expand access to the Career Intermission Program (CIP), which allows eligible service members to transfer out of the active component and into the Individual Ready Reserve for up to three years while retaining full health care coverage and base privileges.^j During their sabbaticals, service members might choose to take care of a dependent, attend college, or pursue other personal/professional goals. This program was designed to boost retention by providing service members with an opportunity to focus on personal matters without having to separate from the military. Unfortunately, lengthy application timelines and limited accessibility make CIP an unworkable option for many service members who might otherwise wish to use the program to attend to a dependent's care or in response to a family emergency. Service members are currently required to apply to CIP six to 12 months in advance of their projected rotation date (PRD) or "soft" end of active obligated service.^k Moreover, access to the program varies by service. Only 22 people — 10 officers and 12 enlisted soldiers — have participated in the Army's CIP since 2014.⁵⁸

ⁱ Respite care through EFMP is dependent on funding and availability, and is not guaranteed. It may be offered at some locations but not at others. Families must be enrolled in the EFM program to receive respite care.

^j See, for example: OPNAV Instruction 1330.2C, N13, March 12, 2018, <https://www.secnnav.navy.mil/doni/Directives/01000%20Military%20Personnel%20Support/01-300%20Assignment%20and%20Distribution%20Services/1330.2C.pdf>

^k See, for example: OPNAV Instruction 1330.2C, N13, March 12, 2018, <https://www.secnnav.navy.mil/doni/Directives/01000%20Military%20Personnel%20Support/01-300%20Assignment%20and%20Distribution%20Services/1330.2C.pdf>.



DEPARTMENT OF DEFENSE/MILITARY LEADERSHIP

- Provide information about the EFMP and services available through EFMP to all military families.
- Expand access to the Career Intermission Program and create a fast-track application to expedite processing for acute or imminent caregiving needs (e.g. when a family member's diagnosis is terminal and imminent or acute).



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Methodology and Respondents

This report is a focused exploration of caregiving in military families, drawn from the data collected in Blue Star Families' 2020 Military Family Lifestyle Survey (MFLS). The MFLS is the largest, most comprehensive annual survey of military and veteran family lifestyle issues, and has been fielded annually since its inception in 2009. The 2020 survey instrument was designed by BSF in collaboration with Syracuse University's Institute for Veterans and Military Families (IVMF) with input from military family members and advocates, subject matter experts, and policymakers on many areas of military and veteran family life. Subject matter experts from the Rosalynn Carter Institute for Caregivers provided specific guidance on caregiving questions for the 2020 MFLS instrument.

2020 MILITARY FAMILY LIFESTYLE SURVEY METHODOLOGY



The survey was conducted online with approval from Syracuse University's Institutional Review Board (IRB) and administered using Qualtrics' survey system (Qualtrics, Inc., Provo, UT) from Sept. 8 to Oct. 16, 2020. Survey participation was considered voluntary, and the information provided was confidential. The survey uses a convenience sampling method.

Respondents for the MFLS were recruited through a variety of methods, including email distribution from Blue Star Families' mailing list, which accounted for the largest proportion of responses, as well as social media dissemination (e.g. Facebook, Twitter, Instagram, LinkedIn). A group of military- and veteran-serving organizations (MSOs/VSOs),

including the Rosalynn Carter Institute for Caregivers and AARP, which hosts specific resources for caregivers, also served as outreach partners, sharing information about the survey and amplifying recruitment efforts through their own membership, accounting for 25% of responses.

Blue Star Families provided an explanation of the study's objective (provided to each possible participant in a consent form whether they subsequently completed the survey or not) to minimize potential self-selection bias toward any single focal issue and, thus, mitigating any respondent propensity to participate based upon any specific, issue-based self-interest (e.g., benefits, employment, wellness, etc.). All responses allowed respondents to select "prefer not to answer" on questions with which they felt uncomfortable, and many questions allowed respondents to select all applicable responses.



Recruitment and outreach were designed to enhance representation from historically underrepresented groups, such as Black and Hispanic/Latino/a/x respondents, junior enlisted families, and National Guard and Reserve families. During survey fielding, recruitment messaging in media and social media outreach was adjusted to enhance recruitment of subgroups, such as calling for specific service branches' response, to obtain a sample that was largely representative of the active-duty military.



Sampling, however, was not stratified, nor were results weighted to be precisely representative. Possible biases were introduced through the use of a non-probability sampling method, particularly dealing with gender, marital status, age, rank, and/or race/ethnicity representation among service member and family member respondents. For example, female service members make up 17% of active-duty personnel⁵⁹ compared to the 50% of service members respondents they represent in this year's survey. Similarly, approximately 10% of veterans are female⁶⁰ compared to the 28% of veteran respondents they represented in this survey. Without reweighting, this over- or under-representation means this sample cannot be generalized to the entire military and veteran-affiliated community. Nonetheless, this sample provides both directions for research and exploration and perspectives of subpopulations such as female service members that would be marginalized in more representative samples.

Many sections of this survey were only available for completion by specific subgroups: military spouses, spouses of veterans, veterans, or service member respondents. Survey branching and skip logic techniques were also used to allow the survey to target certain respondent groups with questions that may be pertinent to them. For example, sections related to the needs of military children were only shown to those who reported they had children. Therefore, including missing data considerations, the actual number of respondents per question varied throughout the survey.

The survey questions were a combination of multiple-choice and open-ended questions to allow for diverse responses from participants. Quotations from open-ended questions are used throughout this report to bring depth and context to understanding the numbers behind this survey. Responses of "Does not apply" and "Prefer not to answer" were usually excluded from analyses. In addition to original questions, this survey also includes measures aimed at providing standardized and scientifically validated instruments, such as the Perceived Stress Scale (PSS).⁶¹



SUBSAMPLE SELECTED FOR SPECIAL REPORT

Using the terms defined within this report, a subsample of survey respondents was created to include 3,777 active-duty, National Guard, or Reserve service member or spouse respondents who answered the relevant caregiver-related questions, including 1,619 caregiver respondents and a comparison group of 2,158 non-caregiver peers. This robust sample, while not generalizable to the entire military caregiver population, provides an unparalleled view into experiences of military caregivers.

DEFINITIONS

Military Identity

The 2020 MFLS recognized that many members of the military community have multiple military affiliations, such as a veteran service member who is a current spouse of an active-duty service member. Survey respondents were asked **first** to identify *all* their current affiliations with the military. For example, respondents could identify themselves as a “spouse/domestic partner of an active-duty service member,” “National Guard service member,” and/or “veteran/retired service member.” A **second** question then asked participants to select the *primary* role that best identifies their current relationship to the military.

For the purpose of this report, however, “military identity” is defined as the affiliation a respondent chose as one of their (potentially multiple) military affiliations **and** as their primary identity. As an example, respondents identified in this report as “active-duty spouse respondents” were those participants who selected both “spouse/partner of active-duty service member” in the initial question of all their affiliations **and** as their primary current identity.

Caregiver

The definition of a “caregiver” is complex and varied. It includes considerations of relationships between the caregiver and the care recipient, the type of care provided, the needs of the care recipient, and even the age of the care recipient and the living arrangements of the caregiving dyad. The term “caregiver” is also culturally charged; some will identify easily as an “unpaid caregiver,” while others see the care they provide as an inherent and inseparable part of their role as a child, spouse, or parent. Furthermore, there is emotion and moral value attached to the definitions. What some would consider “caregiving,” others would consider simply “parenting” or “being a good daughter/son.”

The definition of “caregiver,” then, must be broad enough to include those who are doing the work of caregiving without identifying themselves as caregivers, but limited enough to focus on those who are providing caregiving work beyond the range of care that exists in “typical” family and human relationships, such as a typical parent-child relationship. This report explores that concept of caregiver identity, and to this end, defines “caregiver” somewhat broadly. “Caregiver” in this report includes both self-identified and



task-identified caregivers,¹ but excludes those providing care only to children under 18 without special needs (“parents”). In this report “caregivers in military families” include active-duty, National Guard, or Reserve service members or spouses who identified as caregivers by this definition. Respondents who were either self-identified or task-identified as a caregiver, but were providing care only for children without special needs (n=510) were excluded from the caregiver sample, because these respondents did not report providing caregiving beyond the scope of the typical parent-child relationship.

SPECIAL REPORT SAMPLE RESPONDENTS

Military Affiliation of Subsample Respondents

In the subsample of respondents selected for this report, the largest group of respondents primarily identified as a spouse/domestic partner of an active-duty service member (70%), followed by an active-duty service member (20%), a Reserve service member (4%), a spouse/domestic partner of a Reserve service member (3%), a National Guard service member (3%), or a spouse/domestic partner of National Guard service member (4%).

| MILITARY AFFILIATION OF SUBSAMPLE RESPONDENTS Active-Duty, National Guard, and Reserve Service Member and Spouse Respondents | | |
|---|-------------------------|----------------------------------|
| | Caregivers (n=1,619) | Non-Caregiver Peers (n=2,158) |
| Spouse/Domestic Partner of Active-Duty Service Member | 68% | 72% |
| Active-Duty Service Member | 16% | 15% |
| Reserve Service Member | 5% | 4% |
| Spouse/Domestic Partner of Reserve Service Member | 3% | 2% |
| National Guard Service Member | 4% | 2% |
| Spouse/Domestic Partner of National Guard Service Member | 4% | 4% |
| <i>While we recognize that many people have multiple ties to the military, please select the most central relationship, and answer the survey questions from that perspective. Which relationship best describes your primary relationship to the military?</i> | | |

The largest proportion of military respondents identified themselves as Non-Hispanic white (74%), followed by Hispanic or Latino/a/x (10%), Black or African-American (5%), Bi-racial or Multi-racial (5%), Asian (4%), Native Hawaiian or other Pacific Islander (1%), Other (0.9%), and American Indian or Alaska Native (0.4%).

¹ See Finding 1 for detailed description of “self-identified” and “task-identified” caregiver.



RACE / ETHNICITY OF SUBSAMPLE RESPONDENTS

Active-Duty, National Guard, and Reserve Service Member and Spouse Respondents

| | Caregivers (n=1,560) | Non-Caregiver Peers (n=2,067) |
|---|-------------------------|----------------------------------|
| White/Non-Hispanic | 72% | 75% |
| Hispanic or Latino/a | 11% | 10% |
| Black/African-American | 5% | 6% |
| Bi-racial/Multi-racial | 5% | 4% |
| Asian | 4% | 3% |
| Other | 0.8% | 0.9% |
| Native Hawaiian or other Pacific Islander | 2% | 0.8% |
| American Indian/Alaska Native | 0.7% | 0.2% |
| <i>What is your racial/ethnic group? Please select one.</i> | | |

Within the subsample for this report, the majority of respondents were female (87%), and a small proportion of the sample identified as LGBT (4%). Of all subsample respondents, the single largest age group was Millennials aged 24-39 (62%), followed by Gen X, aged 40-55 (34%), Gen Z, under 23 (3%), and Baby Boomer/Greatest Generation, 55 and older (2%).

AGE/GENERATION OF SUBSAMPLE RESPONDENTS

Active-Duty, National Guard, and Reserve Service Member and Spouse

| | Caregivers (n=1,619) | Non-Caregiver Peers (n=2,158) |
|---|-------------------------|----------------------------------|
| Gen Z: Under 23 years old in 2020 | 2% | 3% |
| Millennial: 24 to 39 years old in 2020 | 62% | 63% |
| Gen X: 40 to 55 years old in 2020 | 34% | 33% |
| Baby Boomers, Greatest Generation, Silent Generation: 56 or older in 2020 | 2% | 2% |
| <i>What is your age?</i> | | |



DEMOGRAPHICS OF CAREGIVERS IN MILITARY FAMILIES

The military family caregiver subsample, which consisted of active-duty, National Guard, and Reserve respondents, may have represented a greater proportion of field-grade officers and a smaller proportion of junior enlisted families than are present within the active-duty force.⁶² Junior enlisted (E1-E4) spouses make up 21% of active-duty spouses, but make up only 6% of the sample, while field-grade officer spouses make up 11% of active-duty spouses, but comprise 26% of the sample. Senior enlisted (E5-E9) and company-grade officer respondents (O1-O3) were represented at rates similar to those in the active-duty population. Warrant officer family respondents (W1-W5) made up 3% of the sample, and the general grade officers (O7-O10) were the smallest group at 0.4% of the sample.

The sample of active-duty family respondents from the Military Family Lifestyle Survey represents a greater percentage of married, older, and senior-ranking respondents than in the active-duty population as a whole, and this may also be reflected in the subsample of caregivers in military families. The services were represented at rates within three percentage points of the active-duty force for active-duty caregiver families,⁶³ except for the Navy, which was oversampled, and the Army, which was undersampled. Army respondents were sampled at 30% compared to 35% of the total active-duty force; Air Force respondents were sampled at 25% compared to 24% of the total active-duty force; Marine Corps respondents were sampled at 11% compared to 13% of the total active-duty force; Coast Guard respondents were sampled at 6% compared to 3% of the total active-duty force; and Navy respondents were sampled at 29% compared to 25% of the total active-duty force.



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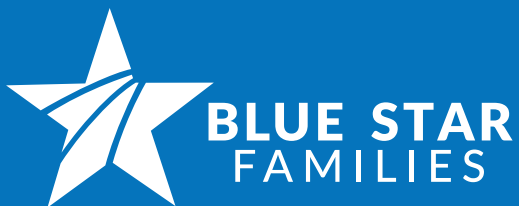
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