



Military Family
Advisory Network

POWERED BY



WOUNDED WARRIOR
PROJECT®

Caregiver & Family Well-Being White Paper

November 2023



ABOUT MFAN

The Military Family Advisory Network (MFAN) envisions a world where all military-connected families are empowered to thrive. MFAN's mission is to understand and amplify the needs of military-connected families and inspire data-informed change.

MFAN creates programs that deliver impact, fill gaps, and address needs by introducing military families to information and resources. MFAN's programmatic efforts are grounded in scientific data and leverage best practices in program evaluation to ensure maximum impact. This approach, coupled with MFAN's authentic understanding of the military community, has allowed us to earn the trust and confidence of those we serve, as well as the government leaders charged with supporting them.

Everything we do is grounded in data, and each data point tells a story. Survey responses aren't just numbers to us. Each represents a life, a lived experience. Our research presents us with an opportunity to learn, and, ultimately, work with others to design develop programs, policies, and best practices for military and veteran families to thrive.



ABOUT WWP

Wounded Warrior Project® (WWP) is a nonprofit 501(c)(3) veterans service organization that is transforming the way America's injured veterans are empowered, employed, and engaged in their communities. Because each warrior's path to recovery is unique, WWP serves warriors wherever they are in their journey. The programs and services that WWP provides augment existing resources available at the Department of Defense (DoD), Department of Veterans Affairs (VA), and other agencies and organizations. These services in mental health, physical health, peer connection, career counseling, and financial wellness change lives. Warriors never pay a penny for these services — because they paid their dues on the battlefield. WWP's direct service programs, advocacy efforts, and collaboration among best-in-practice veteran and military service organizations advance WWP's vision: to foster the most successful, well-adjusted generation of wounded service members in our nation's history.

INTRODUCTION

The complexities of military life are well known, yet gaps remain in our understanding. One major gap involves the lives of caregivers (both formal and informal), those individuals who offer aid and support to a service member or veteran who requires care for injuries, illness, or impairments. Previous research by organizations in the military and veteran family space found that there are 5.5 million military-connected caregivers in the United States,¹ with nearly one-fifth (19.6%) caring for someone who served since September 11, 2001.² Often these caregivers are family members, specifically spouses, who sacrifice to care for their service members. The realities of those responsibilities often take a toll on the caregiver and extended family unit. Recent research has brought to light the impacts of caregiving responsibilities on caregivers, and the 2.3 million children under the age of 18 in the U.S. who live with a disabled veteran.³ The well-being of American military caregivers is at risk, especially post-9/11 caregivers. Though their services offset societal costs of care and allow wounded veterans to live at home, their caregiving role often leads to worse health outcomes, lower-quality family relationships, and more workplace challenges than non-caregivers.³ Through their own research efforts, the Military Family Advisory Network (MFAN) and Wounded Warrior Project® (WWP) aim to deepen the understanding of all military-connected caregiving experiences.

MFAN and WWP have a shared commitment to understanding these caregiving journeys and creating data-informed solutions. With the generous support of its partners, including WWP, MFAN conducted the 2021 Military Family Support Programming Survey. The collaboration with WWP allowed MFAN's research to grow in both content and applicability, including new and expanded topics such as family well-being, health care satisfaction, telehealth, and financial readiness.

Likewise, WWP fielded the 13th iteration of the Annual Warrior Survey (AWS) in 2022. This research aimed to accurately predict the effects of life and societal events and to identify emerging health trends among warriors over time. The first AWS was administered in 2010 and has been revised over the years to collect the most pertinent information as the needs of warriors evolve.

As a key area of interest, WWP also conducted 2023 Caregiver Discussion Groups to enhance understanding of caregiver experiences. Through small group and individual discussions, WWP captured the perceptions, feelings, and experiences of respondents on several critical caregiver topics. With a flexible, open-ended format, deep and meaningful themes emerged that reinforced the nuances of the military caregiver experience.

This report, made possible with WWP's support, takes a deep dive into the data collected in the 2021 Military Family Support Programming Survey, the 2022 AWS, and the Caregiver Discussion Groups. Through further investigation of these complementary research studies, the understanding of military-connected caregiving families at large is extended by taking a closer look at the experiences of military caregiving. By examining the insights of each research project alongside one another, this white paper aims to provide deeper understanding of the nuances and needs of the post-9/11 military-connected caregiving family.

METHODOLOGIES

Despite ample opportunities for comparison of findings, the studies mentioned above each operate on different methodological frameworks. This section provides an overview of the methodology used for each research study. The methodologies and demographic makeup of analyzed studies, described below, contextualize the findings that follow, as well as highlight the differences in approach, further enriching findings about the experiences of these military and veteran families.

The collective research findings presented in the remainder of this white paper offer insight into the lived experiences of caregiving families that can inform future program development to best meet their particular needs and foster improved well-being.

What do we mean by 'caregiver'? Outlined below are the different definitions of 'caregivers' used across the three projects presented in this report:

- **2021 Military Family Support Programming Survey:** MFAN allows respondents to self-identify as caregivers who assist in caring for a service member or veteran who is ill, wounded, injured, or otherwise impaired. No reference definition is provided, or follow-up questions asked regarding their caregiving activities.
- **2022 Annual Warrior Survey:** WWP warriors self-report whether they currently receive the aid and attendance of another person due to their injuries or health problems experienced while serving in the military, or if they require an aid but do not currently have one. The survey responses are self-reported and no formal definition, such as from the VA, was used to identify caregivers.
- **2023 Caregiver Discussion Groups:** Individuals who are identified as 'caregivers' by WWP. No formal definition, such as from the VA, was used to identify caregivers.

Throughout this report, 'warrior' refers to the military service member/veteran who requires caregiving support.

2021 Military Family Support Programming Survey²

MFAN's research is primarily qualitative and generates data, rich with perspective and experiences, which provide a greater diversity of topics to understand and evaluate. While quantitative data can explain the "what," qualitative data can explain the "why" and "how." MFAN works tirelessly to analyze the stories families share to illuminate challenges, identify solutions, and catalyze change.

First fielded in 2013, the Military Family Support Programming Survey is the cornerstone of MFAN's research portfolio. This biennial, mixed-methods survey provides insight into a wide range of the support needs of military and veteran families serving around the world. Expanding from a rigorous foundation in qualitative methodology, recent iterations of the survey leverage validated scales such as the Family Health Scale, UCLA Loneliness Scale, USDA Short-Form Food Security Scale, and the HUD Housing Burden Scale, which enable comparisons with other population groups. To MFAN's knowledge, the 2021 Military Family Support Programming Survey was the first time that the Family Health Scale was used to better understand the military and veteran family space. This validated measure of family well-being examines the health of the family unit by measuring health care, relationships, lifestyles, financial health, and housing. MFAN shares this research with others to inspire action. These survey results lead to data-informed programming from MFAN and others, and edify public policy, yielding positive outcomes for military-connected communities.

The 2021 Military Family Support Programming Survey was fielded online from October 4 to December 15, 2021. Military and veteran families from all over the country were asked to tell their stories and, during that time, 8,638 people participated. In order to participate in the Military Family Support Programming Survey, respondents must identify as an active duty service member or spouse, reserve member or spouse, activated reserve member or spouse, National Guard member or spouse, an activated National Guard member or spouse, military retiree or spouse, veteran or spouse, a surviving spouse, or a divorced military spouse. Respondents came from all 50 states and included Washington, D.C, two U.S. territories, and 22 countries.

The 2021 Military Family Support Programming Survey was distributed through purposive and chain referral sampling. MFAN leverages its network with these widely used qualitative research techniques for the identification and selection of individuals who can elaborate on themes relevant to the research within subpopulations of interest. When MFAN invites participants to share their thoughts in its research, it often uses a sampling technique in which participants invite others who are also connected to military life to join. Invitations to participate are also sent out via social media and through partners in the military and veteran family space who hope to learn from the data. This ensures the participants come from every branch of service, every rank, and from a variety of geographical locations. Not only was this referral sampling driven by MFAN's efforts, and the efforts of its past and present advisory groups, but it also included assistance from other organizations that serve military and veteran families.

The data are analyzed with Qualtrics Survey Software, cutting-edge software that not only allows methodologically sound qualitative coding but also comparisons with other data within the sample. MFAN's research team carefully read written responses from more than 8,600 participants and identified themes and subthemes, when present. The team then evaluated all those themes to explain what military and veteran families are experiencing. The software also allows those themes to be sorted by demographics and geographics, among many other potential measures.

By combining insight provided by validated scales with the rich lived experiences of service members and their families, MFAN's research contributes to, and deepens, the holistic understanding of military and veteran families. These results are not meant to predict behaviors or perceptions of all military and veteran families. Instead, this research is meant to uncover and describe what families are currently experiencing. Looking beyond numbers and statistics, the findings are highlighted with real comments and experiences shared by participants.

[2022 Annual Warrior Survey \(AWS\)⁶](#)

The first AWS was administered in 2010 and has been revised over the years to collect the most timely and pertinent information as the needs of warriors evolve. As part of this evolution and WWP's commitment to understanding warriors' most pressing needs, the survey transitioned in 2021 from a cross-sectional census to a longitudinal sample survey. This shift in design and methodology was retained for 2022 and will remain for future iterations. The primary advantage of a longitudinal design over a cross-sectional design is that it allows WWP to observe changes in individuals over time. This allows WWP to predict, with greater accuracy, how aging and life events impact warriors.

The AWS gives WWP warriors a platform to be heard by individuals and organizations who have the power to initiate change. This data provides a 360-degree view of the warriors WWP serves and allows us to understand and address warriors' most pressing needs in areas such as mental, physical, and financial wellness. It guides WWP's efforts as well as the efforts of those who share and support their mission of honoring and empowering warriors.

The 2022 AWS was the 13th administration of the survey. The 2022 AWS included survey questions addressing warrior demographics, military experience, service-connected injuries, whole health, access to health care, financial wellness, social connection, and support. The survey is not intended to measure the impact of individual WWP programs; however, WWP uses AWS data to determine how it can better serve its warriors through direct-service programs and advocacy efforts.

Part of the 2022 AWS asks WWP warriors whether they require the aid and assistance of another individual. The data points from these questions are included in this report. Furthermore, WWP evaluated quality of life with the Veterans RAND 12-Item Health Survey (VR-12) as a measure of physical and mental health, where a higher score in each category reflects a higher quality of life.⁵ The tool provided a touchpoint for evaluation against other scales and topics surveyed, examining the connections between dimensions of health and wellness with feelings of fulfillment in the various domains of the warrior's life.

The 2022 AWS was administered by NORC at the University of Chicago and was sent to 94,781 WWP warriors. Data collection lasted for 10 weeks, from June 15 to August 24, 2022. A multimodal survey recruitment approach was used for the survey. The final response rate for 2022 was 20.4% (19,303 completed surveys among 94,781 eligible WWP warriors in the survey population) and represents the 165,967 warriors registered with WWP as of April 2022. As a longitudinal sample survey, the AWS is sent only to a preselected portion of the warrior population. This group is selected using random sampling to ensure the results of this report can be interpreted as statistically representative of the entire WWP warrior population. Oversampling of women and young adults was implemented to ensure their representation in analyses. Please see the 2022 AWS report for further details on the methodology.

Through their research efforts, WWP aims to understand the factors that impact the ability of warriors to live life to the fullest. Deeper understanding informs the path forward for programming and support that WWP provides for warriors.

[2023 Wounded Warrior Project Caregiver Discussion Groups⁷](#)

WWP also conducted the Caregiver Discussion Groups to deepen prior survey research, using qualitative methods to understand the experiences of caregivers as well as warriors, and the impact of caregiving duties on the interpersonal dynamics between them. The key aim of this research was to understand the current gaps in and need for support among these caregivers.

As partners in this research effort, MFAN and WWP worked together to develop a flexible group guide for the Caregiver Discussion Groups, to facilitate meaningful conversations and generate valuable findings about caregiving experiences. MFAN's recommendations included methods for recruiting participants, group size and facilitator ratios, participant preparation, and conversation structure.

Overall, 10 caregivers of WWP warriors participated in the Caregiver Discussion Groups between May 19 and June 6, 2023. The Caregiver Discussion Groups consisted of two group sessions and three individual interviews. The completion rate was 83% (12 caregivers signed up for one of the sessions, and ten caregivers completed). Caregivers were invited to participate in the discussion groups via email sent to caregivers known to WWP. A discussion group guide was included in the email invitation to help answer any potential participant questions. Caregivers interested in taking part responded to the email invite and signed up for one of the scheduled Caregiver Discussion Groups. Individual interviews were arranged with those who could not meet during the scheduled sessions.

During the sessions, a facilitator led the discussions using the semi-structured interview guide to gain caregivers' perspectives on family well-being; concerns about the future; support services or programs; gaps in support; and support from WWP. A second facilitator was present during the two group discussions and monitored the chat for additional comments. A WWP mental health teammate was present to introduce themselves at the start of each session and sent a follow-up email at the end in case any participants required further support.

The Caregiver Discussion Groups were audio recorded and transcribed verbatim to facilitate qualitative analysis. The transcriptions were analyzed separately by two members of the WWP research team. Once the findings were coded, the results were sent to both WWP researchers to validate the results. Differences were discussed and adjusted to reach a consensus.

WWP's research highlights how a caregiver's needs intersect with the warrior's needs, as well as showcasing the distinct and separate needs of the caregiving individual. WWP seeks deeper insights to elevate the awareness of those needs and enhance support for caregiving families.

Limitations

Unfortunately, no methodology is without limitations. Despite the valuable insight provided by the research presented below, the findings are not predictive. The Caregiver Discussion Groups consisted of a small sample of spouse caregivers. These discussions added important perspectives to the conversation but do not characterize all caregiver experiences. Similarly, breaking out caregiving populations from the 2022 AWS and 2021 Military Family Support Programming Survey also results in small sample sizes, which may not be reflective of the wider population. While the survey results capture an important part of the military-connected caregiver story, they are not meant to represent all military-connected caregivers. Further, the analysis for the present paper focused on key areas of interest to the study, shining a light on only these selected topics. Although these limitations exist, the findings below provide insight into the military caregiver family experience and act as a foundation for future data-informed solutions. It is important to note the samples include a mixture of active duty and veteran families, therefore different resources may be available depending on the military status of the individual families and how this may impact their circumstances.

STUDY DEMOGRAPHICS

Comparative demographic considerations can be made between the caregiving populations reflected in the data from MFAN's 2021 Military Family Support Programming Survey and WWP's 2022 AWS. As stated above, caregivers are primarily family members, and most often spouses. The high proportion of spouse caregivers is also reflected in the composition of the 2023 Caregiver Discussion Groups.

2021 Military Family Support Programming Survey²

Of the total respondents to the 2021 Military Family Support Programming Survey, 21.8% identified as post-9/11 veterans, retirees, or their spouses, referred to as MFAN's "warrior population" for clarity in this report. MFAN identified warrior respondents who were serving as caregivers for a service member who was ill, wounded, injured, or otherwise impaired (24.9%). When examining MFAN's 2021 warrior caregiver population, 17.3% were male and 79.9% were female. MFAN's 2021 Military Family Support Programming Survey data also showed that more than half (64.3%) of those caregivers have children in the home.

When narrowed to examine this subpopulation of warrior caregivers, 85.8% were from the enlisted ranks, 9.9% were officers and 4.3% were warrant officers. While the full respondent population distribution in MFAN's 2021 Military Family Support Programming Survey was closely aligned with the size of the branches in 2021, caregiving respondents reported their military affiliation with higher proportions from the Army: Army (56.4%), Marine Corps (14.9%), Navy (13.2%), Air Force (12.4%), and Coast Guard (2.8%).

2022 Annual Warrior Survey (AWS)⁶

Within the 2022 AWS, 31.2% of warriors reported needing aid and attendance of another person due to service-connected injuries or health problems; however, 49.3% of those respondents reported they were not currently receiving that aid. WWP found that 62.3% of the warriors needing aid or assistance have at least one child (aged 17 or under) living in the household; 75.6% of warriors listed their spouse as their caregiver. Parents, children, friends, and other caregivers were also reported in smaller proportions.

Table 1. Breakdown of 2022 AWS WWP warriors who need the aid and attendance of another person and how many are currently receiving aid.

ALL WWP WARRIORS	
Do you require the aid and attendance of another person due to your service-connected injuries?	
Yes - 31.2% <i>This includes those who need aid but are NOT currently receiving it (15.2% of all WWP warriors) and those who are currently receiving aid (16.0% of all WWP warriors)</i>	No - 68.8%



WWP WARRIORS WHO NEED AID FROM ANOTHER PERSON	
49.3% of those who need aid and attendance are NOT currently receiving any aid	50.7% of those who need aid and attendance are currently receiving it

Table 2. Caregiver relationships of 2022 AWS WWP Warriors

Caregiver Relation to Veteran	WWP Warriors (receiving aid from another person)
Spouse	75.6%
Parents or siblings	10.5%
Children	2.9%
Other	11.0%

Warriors who had a caregiver were a subset of the full sample. The full set of 2022 AWS respondents were primarily enlisted (91.4%) and male (82.7%). The largest group represented was the Army (64.5%), followed by National Guard/Reserve (31.9%), Marines Corps (16.8%), Navy (13.3%), Air Force (12.5%), Coast Guard (1.0%), and Space Force (0.2%).

2023 Caregiver Discussion Groups⁷

The Caregiver Discussion Groups consisted solely of female spouse caregivers to male WWP warriors, with a total of 10 caregivers participating. Most of these caregivers had been in their role for over 10 years and nine out of the 10 caregivers reported being the primary and sole caregiver to the service member.

Most caregivers who participated in the Caregiver Discussion Groups mentioned having children, including instances both before and after their spouse's injury. Across the 2023 Caregiver Discussion Groups, there was representation of warriors who had served in the Army, Navy, Air Force, and Marine Corps.

CAREGIVER FUNCTIONS AND HOUSEHOLD DYNAMICS

As noted above, in a 2014 report, RAND highlighted how crucial the caregiving experience is to these warrior families' stories.³ The essential role that caregivers play in caring for wounded, ill, and impaired veterans can enhance their quality of life immensely; however, those responsibilities can impact the caregiver in compounding physical and emotional ways that have a ripple effect on the entire warrior family. This section will begin by exploring wounded warriors' caregiving needs and caregiver identity and will then examine how dynamics in the household can create challenges that can impact the entire family.

Caregiver Functions

The warrior's well-being intersects with the caregiver's, making it important to examine warrior needs when framing a comprehensive picture of overall family well-being. The 2022 AWS examined the topic of caregiving from the warrior's perspective, specifically the warrior's needs. Instrumental support is characterized as having someone in your social network that you can call on to help with daily tasks and provide tangible, material, or functional aid, and was measured in 2022 AWS by the NIH Toolbox.⁴ Encouragingly, 66.5% of WWP warriors reported normal or high levels of instrumental support, though 33.5% reported low instrumental support.⁶

The 2022 AWS findings further showed that 31.2% of WWP warriors identified as **needing** caregiving from another person due to service-related injuries or health issues. Of the WWP warriors who are currently **receiving** aid from another person (16%), they report needing an average of 55 hours of care per week with daily activities and tasks. The 2022 AWS asked about the caregiver's relationship to the WWP warrior and the number of hours of support provided in an average week. Spouses were the highest proportion of caregivers and provided on average 59 hours of caregiving per week. The lowest proportion of caregivers were children of the WWP warrior, delivering an average of 40 hours per week of aid and support. For those who reported currently receiving aid and attendance from another person, 78.8% reported normal or high levels of instrumental support.⁶

Yet, 49.3% of WWP warriors who report needing caregiving do not currently receive aid and attendance from another person.⁶ The 2022 AWS findings suggest that more hours of aid and assistance provided to these warriors could promote higher levels of instrumental support as well as positively impact other dimensions of warrior health and well-being. One of the key themes that emerged from the Caregiver Discussion Groups serves as a reminder that caregivers are often serving as the primary and sole caregiver. Caregiver respondents in the Caregiver Discussion Groups also highlighted feelings of isolation in their roles, feeling like there was no one else to help, and that they needed to be "everything to everyone."⁷

Another key theme from the Caregiver Discussion Groups was "caregiver identity," where caregivers felt they had a dual identity as both spouse and caregiver to the warrior, and the impact caregiving had on their own well-being as well as the impact on their relationship with the warrior, intimacy, and sleeping arrangements.

The interconnected, and sometimes competing, demands in the caregiving household, makes providing additional hours of warrior support especially challenging for some caregivers. This gap leaves many warriors without needed care and many caregivers feeling at a loss as to how to meet their family's needs. Some examples of competing demands that were raised during the Caregiver Discussion Groups included having to adapt to the evolving needs and capabilities of the warrior as well as the needs of other members of the family. Additionally, a key sentiment shared by caregivers was how having "another pair of hands" to help with the never-ending list of chores helped ease some of the burden on the caregiver.

Household Dynamics

In addition to considering caregiver functions, dynamics within the household play a role in understanding the warrior caregiving family experience, including financial well-being, spousal employment, and family relationships. When examining relevant data on post-9/11 caregiver families for these elements, the quantitative data offer a valuable framework for understanding and a wealth of qualitative data offer complementary details that enhance the context.

In 2021, more than a third (33.7%) of MFAN's caregiving warrior families who shared their annual gross income reported \$50,000 or less, which can create financial hardships for these households and significantly impact family well-being. Households that require caregiving support often incur extra expenses for the warrior's care needs and frequently have less financial security.

A significantly higher proportion of post-9/11 caregiver respondents reported high financial stress (36.7%) compared to their post-9/11 non-caregiving counterparts (25.0%).²

Additionally, MFAN's 2021 Military Family Support Programming Survey data show that 60.5% of warrior caregivers are employed with another 25.4% who are not employed but want to work. These interconnected factors can compound challenges within the caregiving home. One spouse of a Marine retiree echoed employment challenges that stem from the need for flexible employment options, "My veteran requires 24/7 supervision with active interventions. I can't find an employer who can accommodate his disabilities." A spouse of an Army retiree explained further obstacles to employment that center around caring for multiple members of the home, her need for "[c]hildcare for special needs children and respite care for my husband that is a wounded warrior."²

The realities of caregiving also impact family relationships, and some of those impacts emerged as unique themes in the Caregiver Discussion Groups. The spouse caregiver often has conflicting roles as both spouse and caregiver. Their lives have many moving parts; inclusion of the warrior into the many milestones and transitions are both achievements and obstacles.⁷

The complexity of a caregiver's role is shaped by the many factors within their home life, just as their home life is shaped by caregiving. Amidst the unique life stories that caregiving families have are the commonalities found in the challenges they work through daily.

Caregiving and Children

The complexity of a caregiving household is felt by children as much as the caregiver and warrior. The 2022 AWS findings showed that 62.3% of warriors needing aid and support from another person had at least one child under 18 living in the household⁶, and MFAN's 2021 Military Family Support Programming Survey research found that 64.3% of caregivers had children under the age of 18 living in the home. When MFAN asked caregivers about the impacts of caregiving on their children, 38.2% of respondents characterized those impacts as positive. In their own words, many of these respondents described the empathy and compassion their household fostered in their children.²

An Air Force retiree's comments highlight these top themes that emerged from MFAN's 2021 Military Family Support Programming Survey,

"It has taught them compassion and empathy for others. It has also taught them how to work as a team to care for others who cannot care for themselves. It has also given them a commensurate amount of responsibility and ownership caring for others."²

Also, in the 2021 Military Family Support Programming Survey, many respondents explained that they recognized both the positive and negative impacts that the caregiving household had on their children. A spouse of an Army retiree shared,

"There are plusses and minuses. My husband has PTSD, suicidality, depression, anxiety, and unfortunately that has been a negative impact on my daughter's own mental health. The positive is what she has seen me do in advocating for my husband, myself, other caregivers, and our children."²

Respondents who found the impacts of caregiving on their children to be neutral were in similar proportion to those who found it positive in MFAN's 2021 Military Family Support Programming Survey. The smallest proportion (23.9%) found the impact on their children's lives to be negative or very negative. Respondents shared stories of children struggling to understand the limits or behaviors of the wounded warrior. They also shared stories of their children having to grow up fast, or as one spouse of an Army veteran explained, "My children shouldn't have to worry about taking care of their dad at such a young age. They need to be kids at their age, not caregivers."²

Caregiving concerns emerged in another area of MFAN's 2021 Military Family Support Programming Survey, where parents were asked what support they desired for their children. Mental health needs emerged as a top theme across children's age groups over 6 years old and embedded in these responses were several specific comments noting mental health needs for children navigating the challenges of living with a wounded warrior. Respondents highlighted the difficulty that children have in understanding how to live with a parent who has disabilities, including Post-Traumatic Stress Disorder (PTSD), leading to their own mental health challenges.²

The Caregiver Discussion Groups offered further insight into the caregiver family experience. Some children of caregivers internalize their parent's struggles, taking on the obligations or societal impacts that come with their parent's disabilities. The impacts on children in a caregiving household extend beyond the home itself.⁷

One Caregiver Discussion Groups respondent shared, *"My youngest one, we went through a period of resentment for a long time. She got tired of people asking her 'Why does your dad have a service dog? He looks fine. Why does your dad yell sometimes? Why does he yell, why can't he just talk?'"*

The collective data from these studies are a reminder of the interconnected elements of the caregiver family that can compound the challenges faced. Analyzed together, these three distinct studies reinforce the critical role that caregivers play in the family unit and the significance of understanding the whole wounded warrior family.

SUPPORT SERVICES AND PROGRAMS FOR CAREGIVERS

When examining resources and support for caregivers, patterns emerged across the qualitative data. Military-connected caregivers carry a significant mental load, from providing physical caregiving duties, serving as emotional support to their warrior, and often tracking all the details of care services. Support services are available for warriors, even if challenging to locate or navigate.

Interconnected Care Needs

Distinguishing between the warrior's needs and the caregiver's needs presents challenges, particularly when they are concurrent. The spouse of an Army veteran who responded to the question on caregiver needs in MFAN's 2021 Military Family Support Programming Survey captured the realities of long-term caregiving, contextualizing the scope of caregiver needs: *"Caring for the caregiver, the long-term version: when aid & attendance just isn't enough."*² Addressing those needs can be particularly challenging, as highlighted by the 2023 Caregiver Discussion Groups finding that the caregiver often prioritizes the warrior and masks their own needs.⁷

Amongst the WWP warriors who both need and are currently receiving aid from another person (16.0%), 30.1% are participating in the Department of Veteran Affairs Program of Comprehensive Assistance for Family Caregivers (PCAFC). The PCAFC provides benefits including a stipend, CHAMPVA health insurance, access to respite care, and mental health counseling,³ but findings suggest gaps in understanding the eligibility criteria and access to PCAFC program. Due to data limitations with the 2022 AWS, we are unable to determine how many of the 69.9% are eligible for PCAFC.

Gaps in Support

A closer look at the findings from MFAN's 2021 Military Family Support Programming Survey, sheds more light on the utilization of caregiver supports. MFAN asked all caregivers and warriors open-ended questions about the support they used most often and the support they wish they had. Caregivers' comments often centered around support for their warrior, though both groups brought up a need for care for the caregivers.²

The findings across the analyzed studies show that caregivers are either unaware of programs available to them or that they are not using them. With the focus more often on supporting the warrior, the needs of the caregiver are frequently overlooked or unmet, which became the second clear pattern in the data.

Thematic analysis revealed that 2021 MFAN caregiver respondents believed there was no help available, or they were not aware of different options or avenues for them to seek help. Those respondents, who reported that all types of support were missing, may not be aware of the help available. Some respondents wished for simplified resource lists available to all service members and their caregivers to help navigate options.²

The Caregiver Discussion Groups conversations echoed these sentiments of simplified support, clarifying that “resource overload” can be a challenge, as well as the burden of independently navigating the potential options. They explained that specific examples of resources and support would be more helpful than open-ended offers of general support or “what can we help with?”⁷ Caregivers are often at a loss for what to request or what might be feasible, and as MFAN’s 2021 Military Family Support Programming Survey data show, sometimes respond in similarly vague terms, simply responding that they need assistance. Further resources tailored to their needs, location, and access levels were frequently brought up by respondents.²

The spouse of an Air Force retiree expressed the needs felt by caregivers with multiple family responsibilities in response to questions about caregiver support in the 2021 Military Family Support Programming Survey:

“I think many programs think that a full-time caregiver means someone who isn’t working full-time, which is often not true. I work full-time, but a portion of my day is dedicated to phone calls, emails, and communication with providers, programs, and my spouse, so it takes away from my work. Therefore, I end up working more hours in a day just to make up the time I’m distracted. And then, that time away from home adds up. It’s a tough cycle to be in. There is also a focus on the service member, but caregiving involves the whole family. Kids are affected; spouses are affected; and many of these programs just talk about how to support the service member. This is fine and great, but not enough. Self-care is also not just going to get your hair cut or taking a break once a month. I think the focus on self-care should be a daily activity, not just when you start feeling burnt out.”²

Further unpacking MFAN’s 2021 caregiver responses, caregivers who did use support systems mentioned two main forms of support: generalized military-connected support and nonprofit support. They shared stories of support from nonprofits, both for themselves and their warriors, often commenting in generalized terms. Positive support was mentioned from organizations that support service members and their families such as WWP, Hidden Heroes, and Elizabeth Dole Foundation. Some also highlighted support from the Department of Veterans Affairs (VA), including services like physical therapy and mental health programs, as well as specific healthcare programs such as TRICARE and telehealth.^{2*}

Some 2021 MFAN caregiver respondents brought attention to insurance coverage issues for care needs, or other financial challenges to care. Respondents noted a need for specific treatments like physical therapy or other medical procedures. Caregivers shared their frustrations with getting approved for healthcare needs by VA or other programs that they referred to generally, as well as the long wait time to get help. An Air Force veteran who is a caregiver to another veteran explained, “The fact that many of us caregivers are being kicked out of the program even though our veteran still needs care.”²

The spouse of a Marine Corps veteran offered further detail about the challenges surrounding care, and the additional hurdles that caregivers face to help support their warrior when MFAN asked about caregiver support in 2021. One spouse caregiver lamented the differences in support between medical centers, even within the VA healthcare system. Other 2021 MFAN respondents felt that programs were insufficient; or not tuned in to their specific needs, as captured by the comments of one retired Air Force spouse:

*"I've been incredibly disappointed in the VA Caregiver program, especially after the recent changes. I'm told to attend meetings or events, but I don't feel like they are convenient or helpful to what I need. The only one I've found remotely meaningful is Project Sanctuary, but it is just a weekend."*²

Participants from the Caregiver Discussion Groups expressed the need for a dedicated case worker who could tailor advice and resources to their family's needs. While some participants noted that they have learned lessons or learn about certain resources over their years of being a caregiver, coupled with consideration of caregivers sharing in the groups that "no two days are the same," makes clear that support in navigating their role as a caregiver as well as addressing their family needs is still necessary. Notably, 70.0% of these respondents reported 'some concerns' about their caregiving role in the future, 20.0% expressed 'a lot of concerns' and 10.0% 'a little'.⁷

The Caregiver Discussion Groups also brought attention to the need for a support network for caregivers. Participants expressed a desire to connect with others who could understand their unique struggles, as well as a wish to attend events while not performing their caregiver role. Some of these conversations also brought up the challenges of remote locations, suggesting virtual formats to facilitate peer networks. Feelings of helplessness and isolation emerged among the Caregiver Discussion Groups themes,⁶ echoed by MFAN's 2021 caregiver respondents when asked about their experiences with support for caregivers.²

A related concern was raised by MFAN's caregiver respondents, who desired more mental health programming and respite care, which were an intermingled set of responses for their own needs and those of their warrior.²

Accessible resources that support the warrior are an essential component of caring for the caregiver, minimizing their worry and mental load. As important are resources that recognize the caregiver's individual needs as they address their warrior's needs.

FAMILY WELL-BEING AND THE FUTURE

Bringing the needs of a caregiver to light is imperative to bolster support for post-9/11 military and veteran families. Their need for resources and specific support must also be contextualized by a more holistic understanding of their family well-being and mental health needs.

Taking a deep dive into data from the 2022 AWS, it is unsurprising that warriors who need aid and assistance from another person due to their service-connected health status have compounding health hurdles. Compared to WWP warriors who do not need aid and assistance, WWP warriors who need support score lower on mental health components of Quality of Life (QoL) measures.⁶

When WWP warriors are divided into two groups, those who receive needed care (16.0%) and those who need it but do not currently receive aid from another person (15.2%), the lower mental health scores of the latter group reflect a connection between unmet care needs and lower mental health scores. Also telling is the divide between these separated groups of WWP warriors in terms of their loneliness scores. Interestingly, the resilience scores of those two groups are the same, even if lower than the resilience scores of those who do not need aid and assistance. Notably, WWP warriors with moderate to high instrumental support (66.5%) were found more likely to have mental health Quality of Life scores above the median of the general U.S. population and veterans.⁶

TABLE 3. Average Physical and Mental Health Component Scores, Loneliness and Resilience scores amongst 2022 AWS WWP Warriors and the U.S. Military Average and General Population Average.

	Warriors who received aid & assistance	Warriors without aid but need it	Warriors without aid & do not need it	WWP Warrior Average	US Military Average ¹⁰	General Population Average ⁹
Physical Component Score (PCS)*	36.5	36.5	39.2	39.0	40.7	-
Mental Component Score (MCS)*	33.8	31.9	36.7	35.7	42.9	-
Lonely [†]	70.9%	79.7%	63.1%	6.2	-	-
Resilience [‡]	4.3	4.3	5.1	4.8		6.9

WWP’s 2022 AWS data is complemented by MFAN’s 2021 findings that military family members who are caregivers were more likely to report loneliness and moderate or poor family health than those who are not caregivers.² Themes from the 2023 WWP Caregiver Discussion Groups echoed these sentiments, where respondents shared a sense of identity loss, and that they forgot who they were before their caregiving began.⁶

The intersection of caregiving and well-being is apparent, leading to further analysis of MFAN’s 2021 data. Of post-9/11 warriors, caregivers reported seeking mental health services for themselves or a member of their immediate family at a significantly higher proportion (70.0%) than their non-caregiving counterparts (51.5%). Warrior caregivers also reported seeking emergency mental health crisis resources for someone in their immediate family at a higher rate (31.4%) than non-caregiving warrior family respondents (10.8%). The spouse of an Army veteran shared some of the experience with a veteran in mental health crisis which captures a shared sentiment: *“If you aren’t suicidal, there isn’t such a thing as crisis care.”* This sentiment was felt during the 2023 WWP Caregiver Discussion Groups with caregivers sharing the lack of emergency care or on-call care for unexpected situations; for example, if the warrior is unwell during the night and needing emergency care for looking after the children.

This missing support was expanded by another spouse of an Army veteran, *“Everyone points you to someone else to handle the situation and no one actually wants to help.”*²

Data from MFAN’s 2021 Military Family Support Programming Survey showing that 18.1% of warrior caregivers have had suicidal thoughts in the past two years is further cause for concern. With these smaller, narrowed sample sizes, this should not be generalized to full populations. This is an insight among the respondents to this research. Further study among caregivers is encouraged.²

The data across the studies examined here reflect critical challenges to the well-being of the entire post-9/11 caregiving household. The increased likelihood of loneliness among warriors and caregivers is compelling data, made more poignant by the expressed need for mental health support among these families. This critical area is one of the most pressing needs to support the overall well-being of caregiving families.

* The Physical and Mental Component Scores comes from the VR-12,⁷ where higher scores indicate better health.

† Lonely measure comes from the Three-Item Loneliness Scale;⁸ scores were grouped as not lonely (scores 3 to 5) or lonely (scores 6 to 9). The first 3 columns include the percentage of warriors who scored as lonely, and the average includes the average loneliness score.

‡ Resilience was measured using the Connor Davidson Resilience Scale 2-Item (CD-RISC 2).⁹ The final summary resilience score ranges from 0 to 8, with higher scores indicative of greater resiliency.

KEY FINDINGS & RECOMMENDATIONS

Efforts to better understand military-connected caregivers are of the utmost importance to all who serve the military and veteran community. The analysis of family dynamics further adds to the understanding of the military caregiving home. By examining demographic considerations and examining support programming from their perspectives, this white paper has helped identify support needs and gaps in support for caregiving families.

The findings from these three complementary research endeavors suggest that caregivers need deeper and broader support systems like peer networks, health and well-being services, financial support, and special consideration for caregivers who are also parents. This analysis makes clear the importance of the following recommendations to expand and enhance caregiver support:

Military-connected caregiver families face complex hurdles, and with these findings in focus, MFAN and WWP recommend the following tactics to expand and enhance caregiver support:

1. Individualize caregiver support and increase access to caregiver resources

Caregivers of post-9/11 veterans are primarily family members, and most frequently spouses of the warrior, whose family responsibilities often go beyond the full-time caregiving needs of their warrior. A caregiver's service often starts when the warrior's service has ended, resulting in multidimensional hurdles. Likewise, their needs are layered. Of critical concern to them is the ability to find and access support for their warrior. Alongside a desire for help navigating health services or treatments, caregivers need programs that are tailored to the unique needs of their warrior. Finding these resources is a daunting task, particularly when they often are unaware of their options. Amplifying and education around existing resources, like PCAFC or Program of General Caregiver Support Services (PGCSS) and providing support to navigate available health benefits could minimize the stressors that caregivers face, such as lack of cross-entity coordination and release of information to create ease in access to resources and services. Development of support and resources around employment and education options for caregivers as well. Across data analyzed, findings further reinforce the need to explore more individualized support for caregiver families.

2. Increase the accessibility of mental health services and promote wellness

The research examined here also shines a light on the need for enhanced mental health support for the whole caregiver family. Post-9/11 caregiving family members are accessing mental health services in higher proportions than their counterparts, but their stories also reflect the limitations of those services. Warrior families have experienced limited crisis care, support tailored to children who experience the challenges of being raised in a military caregiving home, and caregivers themselves often deprioritize their own needs behind the warrior and their children. Mental health services should be expanded and accessible (including the use of technology innovations) to enhance support for these families who continue to sacrifice. Respite care opportunities should also be more accessible so that they may step away from their caregiving duties to care for themselves. Further development in public-private partnerships and continued engagement from non-profit organizations to serve this community and address some of the gaps in support are critical, especially for children caregivers.

3. Build and strengthen caregiver communities

Connecting with other military-connected caregivers was a common need expressed by respondents that could combat their feelings of isolation, with considerations for access challenges for those who live in remote areas or have difficulty stepping away from their caregiving responsibilities. Peer support networks and caregiver community-building are examples of ongoing support services that parallel the long-term commitment that caregivers fill.

4. Provide additional support to caregivers who are also parents

Further, the compounded challenges faced by caregivers who are parents should be addressed. They need time to raise their children, address the challenges their children may face as part of a caregiving household, as well as simply connect as a family and foster full-family well-being.

5. Continue and expand caregiver research

It is of critical importance to continue research efforts to better understand, and thereby support, the nuanced needs of military caregiver families. The sacrifices that caregivers make are often overshadowed by the sacrifices made by their warrior, yet the findings throughout this paper highlight the interconnected elements of family well-being that hinge on the caregiver.

CONCLUSION

The findings of the 2021 Military Family Support Programming Survey alongside the 2022 Wounded Warrior Project Annual Warrior Survey (AWS) and the 2023 Wounded Warrior Project Caregiver Discussion Groups have offered insight into the current lived experiences of military-connected caregivers. These findings are most valuable when used through tangible solutions for military and veteran families. Through their longstanding commitment to military and veteran families, WWP and MFAN will continue collaboration that elevates caregiver needs and works toward meaningful solutions for their well-being.

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