

2021-2022

INAUGURAL
SURVEY
REPORT



Exceptional Families of
the Military



One Community,
One Voice

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EXECUTIVE SUMMARY

In the 2020 Exceptional Families of the Military's (EFM) Assignment Process Report, statistics showed the need for sweeping change across all branches of the military in regards to the Department of Defense (DoD), the Department of Homeland Security (DHS) Exceptional Family Member Program (EFMP), and the United States Coast Guard Special Needs Program (USCG). In the previous 2020 survey, there were 194 respondents, and findings revealed a majority of TRICARE beneficiaries did not receive care within the allotted time frame. In fact, half of the respondents reported they waited 120 days for care, and a small percentage went without care. EFMP was created with the purpose to ensure families moved to duty stations that could provide medical and mental health care. From the sample gathered in the 2020 survey, families are still struggling to receive care.

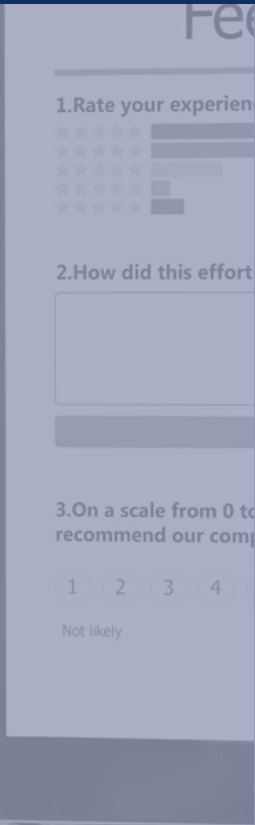
Due to the outcome of the 2020 survey and the Autism Care Demonstration (ACD) survey released by EFM in 2021, questions continue to arise in regards to EFMP families and whether or not the program is meeting the needs for service members' and their beneficiaries. For the current research, EFM decided to expand the survey and question currently enrolled EFMP families. Also included in participants are retirees who use TRICARE for their former EFMP families to gather more data on the EFMP program.

EFM's 2021-2022 survey found EFMP families struggle due to multiple barriers such as: medical wait times and families moving to installations where services are not offered. More barriers included housing not accommodating needs or offering hazardous homes and/or food insecurity due to EFMP expenses. Results also found both TRICARE ECHO respite and branch specific respite programs need better oversight in order to accommodate families' needs and to better assist dual military families.

**AUSTIN CARRIGG,
REBECCA EMERSON,
JENNIFER BITTNER**



METHODOLOGY



The data collection was a Google Forms survey with the option for participants to answer open ended questions at the end of each section. The open-ended questions allowed participants to offer up their experiences with various EFMP related policies or programs military families go through during their time in service. By offering participants places to express any concerns or experiences in EFMP, EFM can identify any areas, or themes, to improve upon in EFMP for both children and adults enrolled.

HISTORY OF EFMP

In 1979, the Army introduced EFMP to provide assistance for family members who needed specialized medical care, and other service branches implementation of the program followed. The program initially had voluntary enrollment, but over the course of the years, advocacy groups banded together and voiced concerns about these family members' unique needs. Congress then created the Military Family Act of 1985, which in turn caused the DOD to create the Office of Family Policy. The Office of Family Policy's purpose was to assist military departments in creating activities relating to military families (Congressional Research Service, 2022). Enrollment is no longer optional, and families who qualify for EFMP are required to enroll (DoD Instruction 1315.19, 2017).

After these policies and programs were created, Congress continued to see a need for these families in the military. The 2010 NDAA brought The Office of Community Support for Military Families for Special Needs into effect with the intent to oversee EFMP. This office was later renamed the Office of Special Needs (OSN) in 2016, and the focus was to "standardize, enhance, and improve DOD support around the world for military families with special needs (whether medical or educational needs)" (Congressional Research Service, 2022).

EFMP ELIGIBILITY

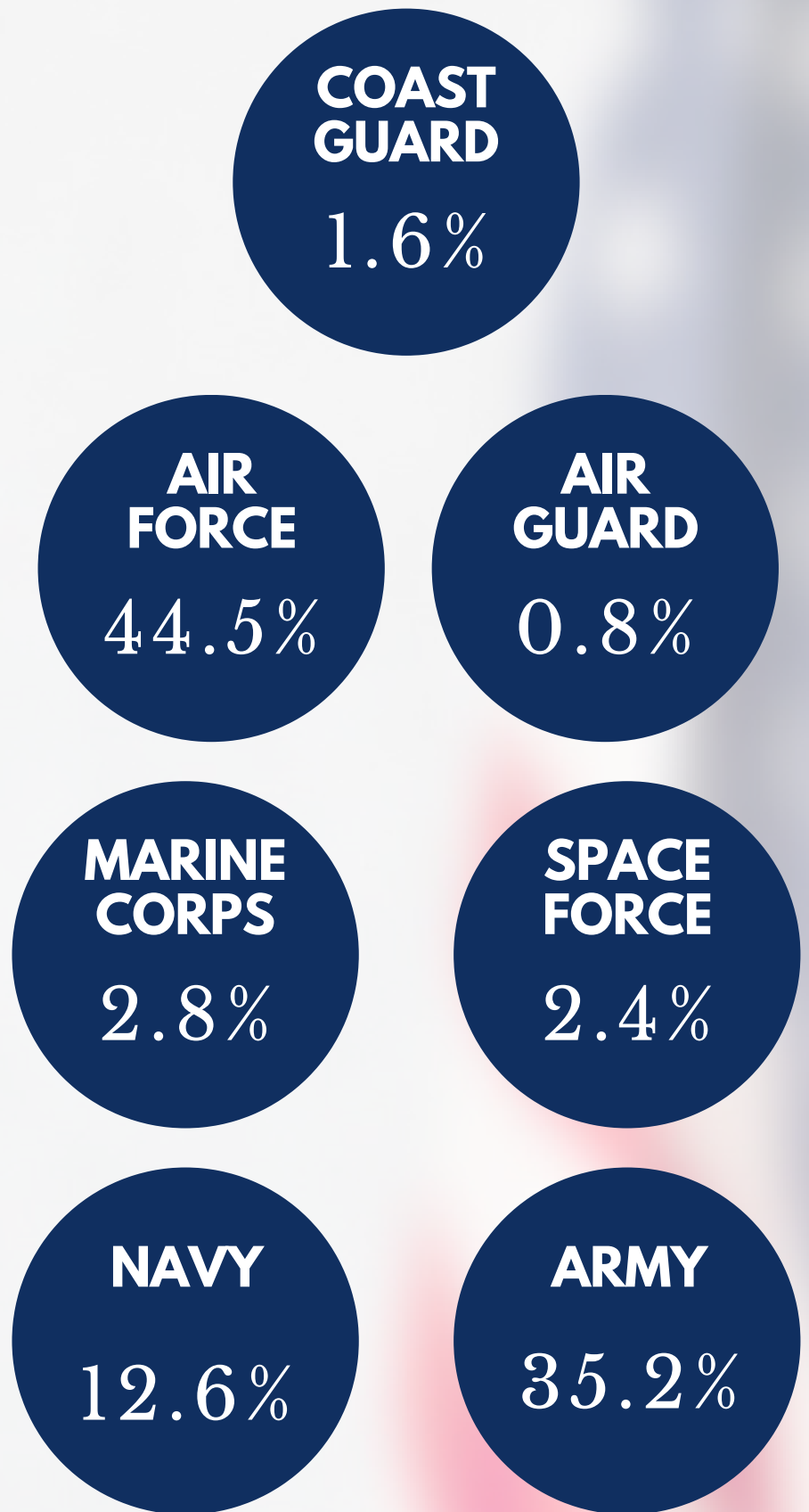
While OSN is responsible for DOD policy, each branch is responsible for monitoring and implementing EFMP for their service members. There are specific requirements for EFMP enrollment that involve one or more of what is listed below:

- Life-threatening or chronic condition requiring special care
- Current and chronic mental health condition
- Asthma or other respiratory related diagnosis
- Attention Deficit/Attention Deficit Hyperactivity Disorder
- Chronic condition requiring adaptive equipment, assistive technologies, or environmental/architectural considerations
- Special education needs (Congressional Research Service, 2022)

In 2021, the Congressional Research Service reported 146,824 dependents of service members in the Exceptional Military Family Member Program. This is an increase from years prior.

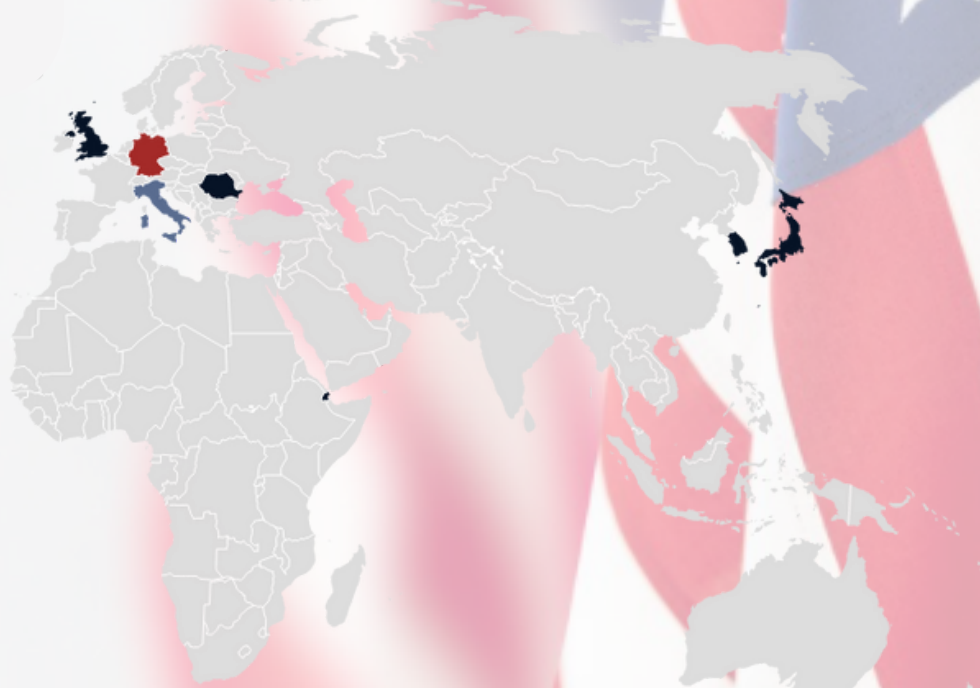
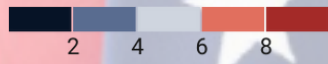
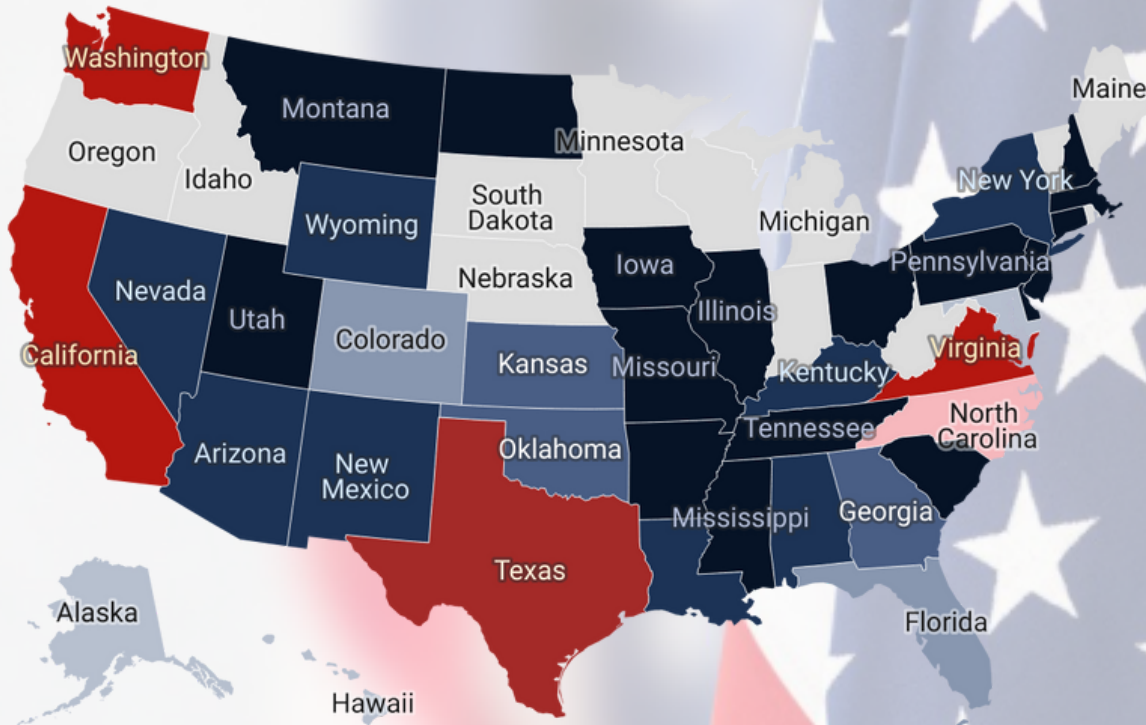
DEMOGRAPHICS

EFM ASKED: "WHAT IS YOUR SERVICE MEMBER'S BRANCH OF SERVICE?"

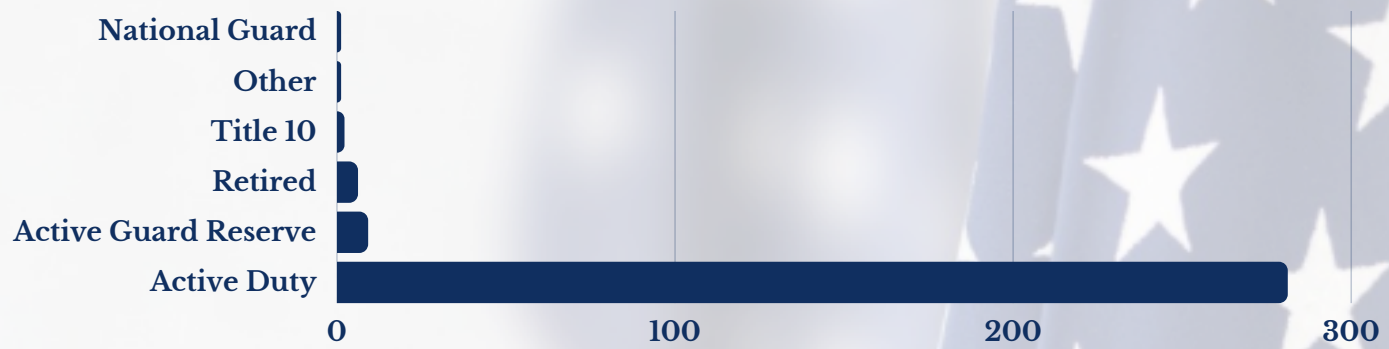


EFM ASKED: WHAT IS YOUR CURRENT DUTY STATION?

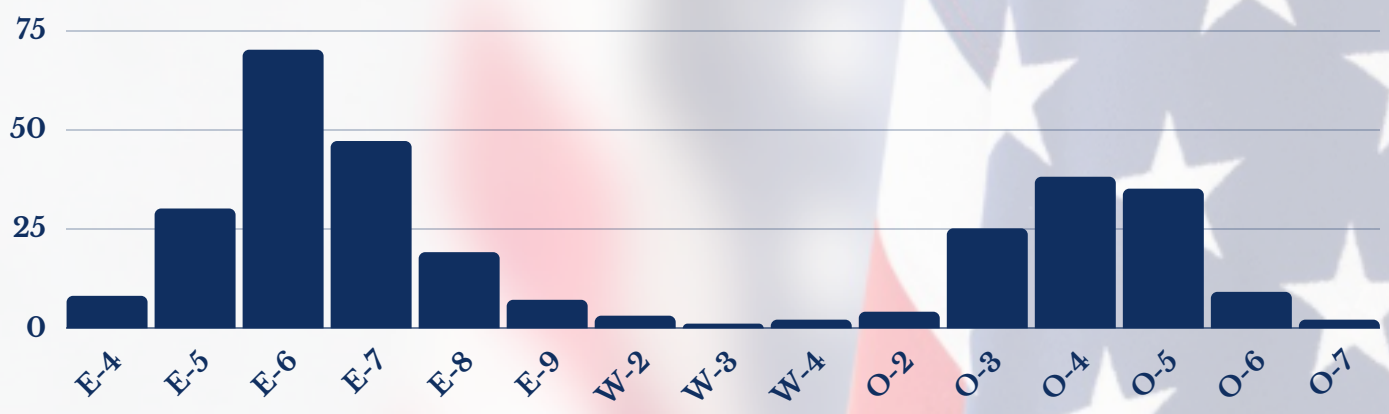
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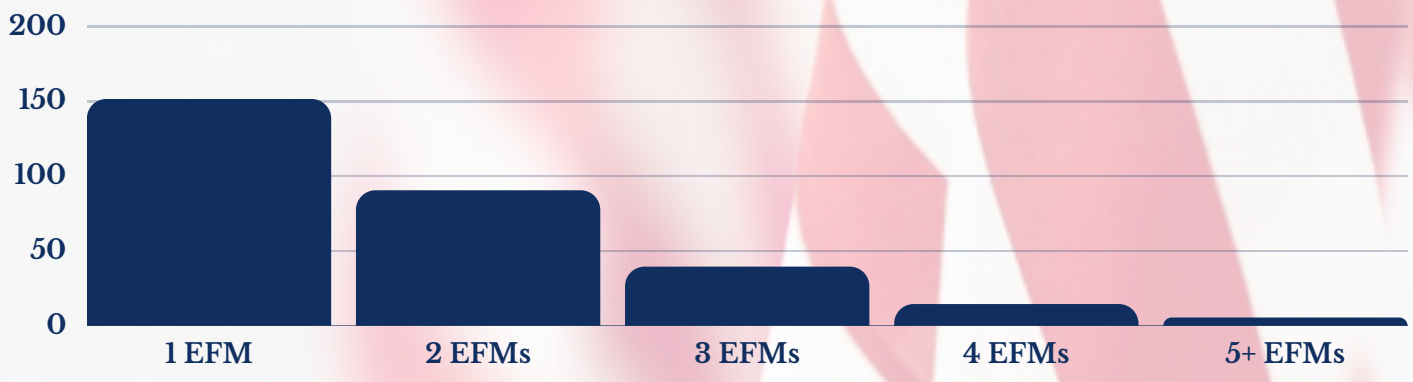
WHAT IS THE DUTY STATUS OF YOUR SPONSOR?



WHAT IS YOUR SERVICE MEMBER'S PAYGRADE?



HOW MANY DEPENDENTS (INCLUDING SPOUSE) ARE ENROLLED IN EFM(P)?



IN EFM'S 2020 SURVEY RESULTS, OVER HALF OF THE RESPONDENTS STATED THAT THEY WAITED OVER 120 DAYS FOR CARE AT THEIR CURRENT DUTY LOCATION.

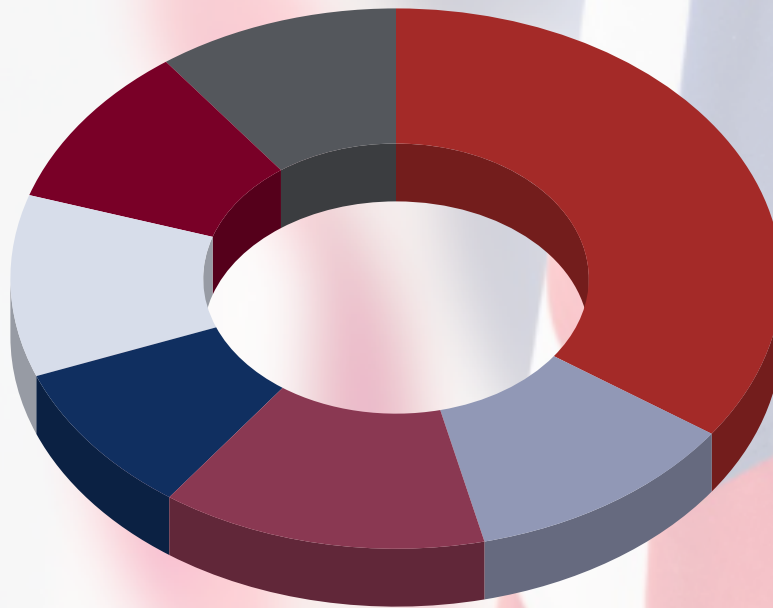
EXCEPTIONAL FAMILIES OF THE MILITARY IS LOOKING TO SEE HOW THOSE WAIT TIMES HAVE CHANGED, IF AT ALL, FOR 2021.

89%

of respondents waited longer than TRICARE's standard of care. TRICARE's standard of care is 28 days.

MEDICAL CARE ACCESS TO

Of the 300 survey participants, 34.7% responded they had a five or more month wait for services for their EFMP family member when they moved to their new duty station. Of the responses, 10.9% of participants reported there were no services available for their EFMP family members when they arrived at their new duty station.



- 5 or more months
- Services are not available
- 3 months
- 4 months
- 1 month
- 2 months
- less than a month

EFM asked an open ended question, “If your wait was longer than one month, please explain the specialty and the reason for the wait.” EFM received 224 responses for this, and below are a few reasons why families had to wait for services:

The data was broken down into various categories on why families had to wait for services, specialties, or therapies. The survey showed families waited for care due to: lengthy wait time(s), availability of services, TRICARE barriers, COVID restrictions, and respite wait time(s). Housing, school, and EFMP issues also played a part in this wait.

From the 224 people who commented, 76 specialties were shared with extended wait times to obtain services, if services were obtained. In addition, 77 respondents gave reasons without naming the services they were attempting to obtain. It should be noted, comments often listed multiple specialties. The most reported specialties with delayed care were: Applied Behavior Analysis (ABA) (22%), Speech Therapy (14%), Occupational Therapy (13%), Mental Health Providers (10%), Developmental Pediatricians (8%), Physical Therapy (6%), and Neurology Related Specialists (8%).

Speech Therapy and Occupational Therapy Delays

Thirty-one families reported they waited for speech therapy services. Wait times ranged from two months to over a year, because clinics did not have enough providers, families needed time slots after school, TRICARE authorizations approval issues, or they had to travel further out of town to seek services. Thirty families reported similar wait times for occupational therapy. One family, in particular, reported a delay with their referral because no pediatricians in their county accepted TRICARE Prime anymore.

ABA Delays

Of the 224 respondents, 50 families reported waiting for Applied Behavioral Analysis (ABA) for their Autistic child/children to begin when moving to their new duty stations. The general consensus for waitlists for ABA providers in the survey ranged from the shortest being four months (5%) to the longest being three years. The new requirements for the Autism Care Demonstration (ACD) from March 2021 are overwhelming for families because the Defense Health Agency (DHA) changed the requirements for services. EFMP families reported struggles with “jumping through hoops” in regards to the referral process. Families reported appointments with their primary care managers were difficult to obtain.

Families reported COVID restrictions were still causing barriers for them to obtain services. Of the 50 responses provided, reasons for ABA delays, 70% mentioned long wait lists, lack of after school appointments and providers who take TRICARE; or the civilian community lacking ABA providers, in general, for the population numbers requiring treatment. A top reason shared by 22% of commenters referenced TRICARE barriers to services.

Neurological Specialist Delays

Fifteen reported the need for neurological specialties, and 53% of those families stated there were no appointments available. A reported barrier, which 20% of families reported, said their PCMs made getting necessary referrals to specialty care a problem. One family shared their new PCM would not give them the needed referral despite their medical history. They received a referral months later from a different provider when the issue became chronic and began interfering with daily life. Another family reported delays because they needed authorizations to be seen by providers off post. Wait times ranged from three months to over a year.

Unspecified Specialist Delays

Of the 77 families who reported long waits but did not specify for what specialties, 47% reported long wait lists and no appointments available as, well as lack of providers in the community or a lack of providers who accept TRICARE. They also reported difficulty obtaining appointments to see a PCM to get their referrals or other referral delays. Several people listed PCM's Temporary Duty Location (TDY) or deployment as the reason they could not get seen to get their referrals in a timely manner.

The second open ended question for this section asked respondents to report anything else they would care to elaborate on to explain their situation. There were 171 comments, and below are some comments:

“There isn’t any support for activated reserve families in navigating EFMP or ECHO. We had to get the Developmental Ped involved in order for anyone from the (corporate) office to call us back or process the paperwork they sat on for months.”

“Cannot get ABA therapy for autistic child because tricare won’t allow virtual visits and our child is high risk.”

“The EFMP system is broken. We have been repeatedly sent to locations that lack availability because they are larger bases and it is assumed that will have the services we need while being denied family travel to smaller bases that actually had immediate availability for services because of the incorrect and baseless assumptions of both HRC and EFMP.”

“We were denied to move as a family, we were told services were not available in Hawaii for our EFMP so the service member had to go alone or lose position even though I found services that would accept us.”

“ABA therapy is very hard to find, so when we are forced to PCS when care is established it greatly hurts the child being displaced.”

“We have never had a problem with services, our problem is waiting forever for efmp to approve our clearance.”

“Being ignored when trying to coordinate a move and securing housing, schools, and a follow on job while trying to maintain current duties is almost impossible. Adding this layer of approval for things that have been approved before and being dismissed left a last minute struggle that was very unnecessary.”

“No help from base, no interest in the situation, support personnel couldn’t care less.”

RESPITE CARE CAN BE HELPFUL FOR CAREGIVERS' SUPPORT. CAREGIVERS, ESPECIALLY THOSE WITH SPECIAL NEEDS CHILDREN, OFTENTIMES NEED ASSISTANCE AND SEEK OUT RESPITE HEALTHCARE OPTIONS (WHITMORE, 2016). BOUNDARIES TO RESPITE CARE CAN BE LINKED TO CAREGIVER BURNOUT AND DIFFICULTY IN CARING FOR THEIR LOVED ONES' NEEDS (COOKE, SMITH, & BRENNER, 2020).

Due to the stress of caring for a child/children with significant medical and mental health needs, families are at risk for having a lower quality of life than their peers without children with medical or mental health needs. Having access to consistent and quality respite care can contribute to an increase in a better quality of life for caregivers and their family members they take care of (Remedios, et al. 2015).

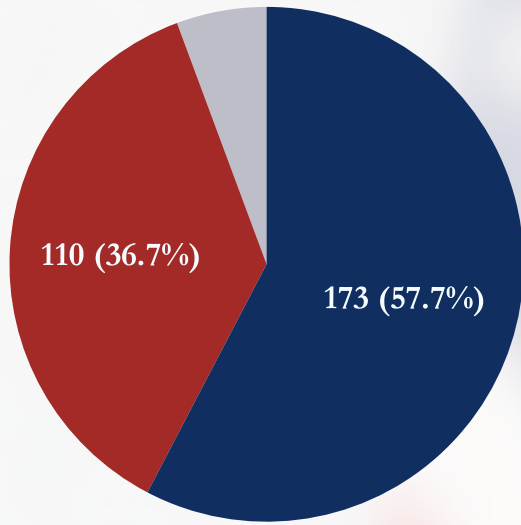
Respite is not only beneficial for those with disabled children. The role of caregiver carries over to spouses and extended family members when veterans come home and require caregiver assistance. Adults enrolled in EFMP reported they have their own medical and therapy appointments to attend to and need assistance around the house. They would like to be able to rely on respite services for their dependent children since most military families do not have immediate family nearby to assist them with activities of daily living (ADLs), picking children up from school, driving to appointments, etc. The burden then falls on the SM, driving aged children or friends.

Respite can provide relief for many caregivers when their service members are working long hours, in the field training, TDY, and/or deployed. However, 42% of 281 participants responded they could not utilize their branch of service respite care program. Of the 281 participants who noted they qualified for respite, 52% indicated they are not able to access the program.

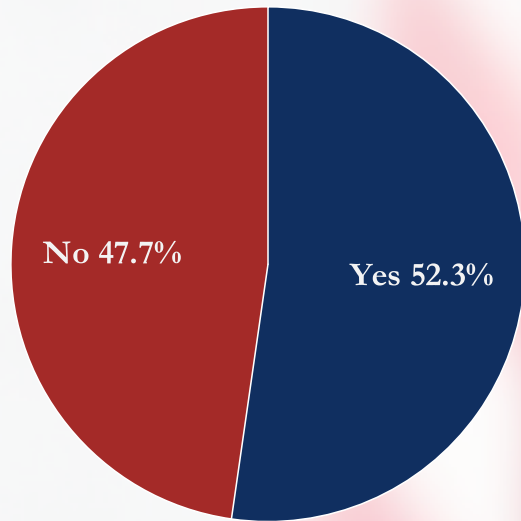


RESPIRE

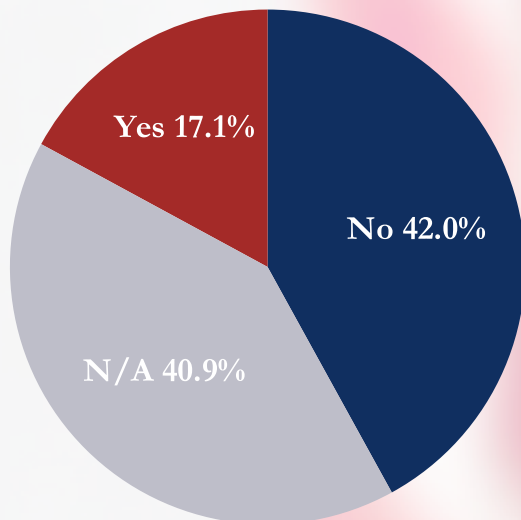
BRANCH OF SERVICE RESPITE CARE



Does your Branch of Service (Air Force, Army, Navy, USMC, Space Force, Coast Guard) have a respite care program for EFMP families?



Do you qualify for your Branch of Service respite care program?



Are you able to utilize your Branch of Service respite care program?

EFM asked an open ended question, “If no, why are you not able to utilize the Branch of Service respite?” There were 151 responses to this question:

Many responses communicated confusion about the program: how to apply for respite and then how to use the services offered. From the comments provided on the survey, there is a need for a more streamlined process on how to access respite care for qualifying families. To add to the burden of the process, obtaining qualified respite providers appears to be difficult for families as well.

“No idea how to utilize it with 3 children that don’t qualify.” Air Force Family Quote

Difficulty getting providers added to the program “No providers in the area, and too cumbersome of a process for someone “off the street” to get qualified/credentialed.” Air Force Family Quote

There were 115 responses to the open ended question, “Would you like to share any additional comments?”

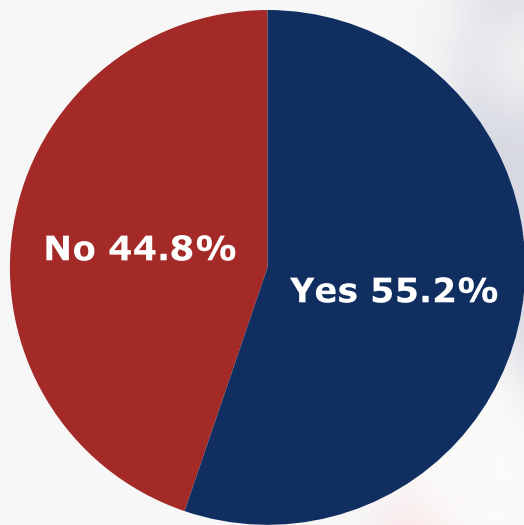
“The Air Force took over the respite care program and have not been very good implementing the respite care program. Due to this there are not enough respite care providers, non military provider do not have base ids or contractor badges. It is a complete mess.” Air Force Family

“We are authorized 40 hrs a month through EFMP respite and 16 hrs a month through ECHO respite. There are 2 respite providers here at JBER to provide care for our hundreds of EFMP families. It has become increasingly difficult and almost impossible to schedule care with anyone experienced to our watch our child. We need respite providers and when we find our own, we need them to be cleared swiftly!” Air Force Family

“Because there are no providers. We were given a list of 4 providers, 3 of them didn’t actually take pediatric patients and the 4th didn’t take children with autism, as their exact words were “we aren’t babysitters.” We are still approved for respite with ECHO, but we can’t get it due to no providers” Navy Family

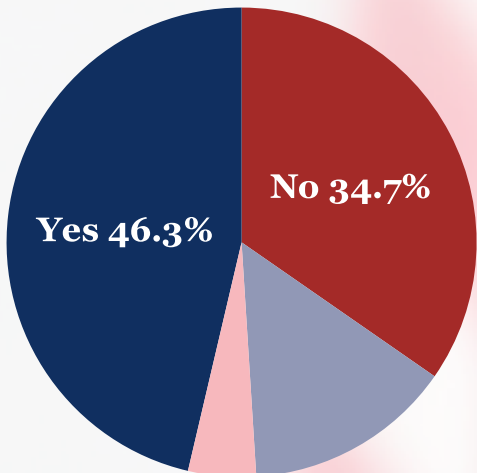
“I’m able to utilize it, and it’s been fantastic (after the initial wait period). The biggest obstacle to fully utilizing it is lack of providers. I realize this is not an EFMP issue, but wanted to paint a full picture of why the benefit isn’t fully utilized.” Navy Family

TRICARE ECHO RESPITE CARE

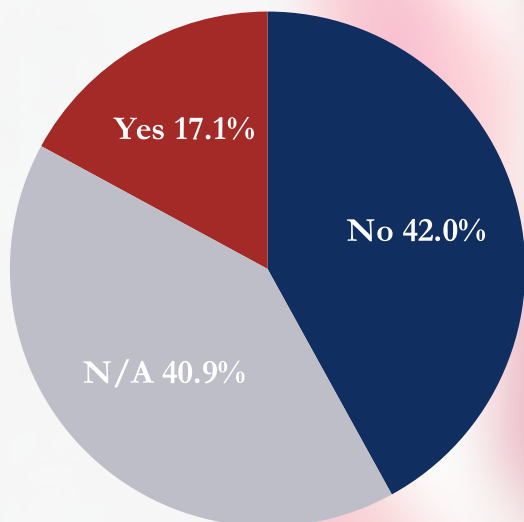


Do you know about TRICARE ECHO respite?

● No ● Unsure ● No Answer ● Yes



Do you qualify for TRICARE ECHO respite?



Are you able to utilize TRICARE ECHO Respite?

**EFM asked the open ended question:
“If, no, why are you not able to utilize TRICARE
ECHO respite?”**

For this, EFM received 81 responses:

A requirement for TRICARE ECHO respite is one guardian must be in the home while the respite worker is in attendance. The guardian cannot work or complete school work while the respite worker is present. This can be a barrier for military families who are dual military, single parent homes, or dual working homes. However, a recently published Government Accountability Office (GAO) report stated, “DHA officials told GAO that this is not a TRICARE policy, rather that some home health agencies require this out of concern for the dependent’s safety,” (2022). Many families would like to utilize respite care, but are unable to due to provider shortages, strict guidelines of use imposed by the DHA, and the few hours offered of respite.

In fact, in the NDAA FY 2021, TRICARE ECHO respite hours were increased for families from 16 hours to 32 hours. The increase in hours has yet to be implemented. The GAO report also stated:

As such, DHA cannot assess why, in 2021, only about half of ECHO enrollees authorized to receive respite care (175 out of 341) ultimately utilized this benefit and cannot identify strategies for increasing access to this benefit. (2022)

Families continued to express concerns and frustrations with the process in this section. They expressed concerns about their EFMP family members' future(s) once the SM leaves active duty and they lose access to ECHO benefits. Here are some of the comments EFM received below:

"I am still not clear on our cost to utilize ECHO respite."

"Our children are permanent dependents. We have full guardianship responsibilities. The ECHO services would be very helpful to the retired family as well."

"These hours are different from what I've told we're allotted."

"Respite care is geared toward parents of EFMP children, or those caring for a disabled spouse. Tricare lacks programs to assist disabled EFMP spouses with daily tasks. We're expected to just bumble along."



INCAPACITATED ADULT CHILD

EFM WANTED TO BETTER UNDERSTAND FILING FOR INCAPACITATED ADULT PROCESS IN DEERS AND MILITARY FAMILIES. THERE WERE NINE RESPONSES:

“It was VERY confusing with multiple forms asking similar yet minutely different questions. Even after DEERS was updated we discovered none of the medical providers were notified and even when we discovered the problem Tricare had issues verifying. It was frustrating. AND, the local office did not have the information we needed. We thought we were done then found out there were many more forms.”

“Not started yet. Deers didn't know what I was supposed to do.”

“We have an amazing developmental pediatrician at Nellis who started and completed the process for us.”

“Due to government shutdowns the short period before 22 when applying is allowed led to a lapse in Tricare. Eventually back pay was provided but it added unnecessary additional stress and time.”

“Was told that we could not start process until 6 months before he turns 21”

“For friends, they had to go outside of the military. It was confusing and expensive.”

“Efmp office had no idea as to what I was talking about or how to complete the process. I had to figure ever(ything) Out on my own. I haven't found the efmp office extremely helpful.”

If families did not file for incapacitated adult, why not? These were the responses:

“No one ever told me it was a thing.”

“We were told we have to wait until he is 20”

“One issue was the forms all being different depending on the Branch of Service. Standardization of this process would be so helpful.”

“The process is very intense and hard to understand all that needs to be done.”

“I have heard from other families and after speaking to the representative for this program that it is very difficult process. Also that even if your child is permanently disabled you must redo it constantly. Seems like it is just one more program that the military makes extremely difficult to receive when we already have a lot on our plate.”

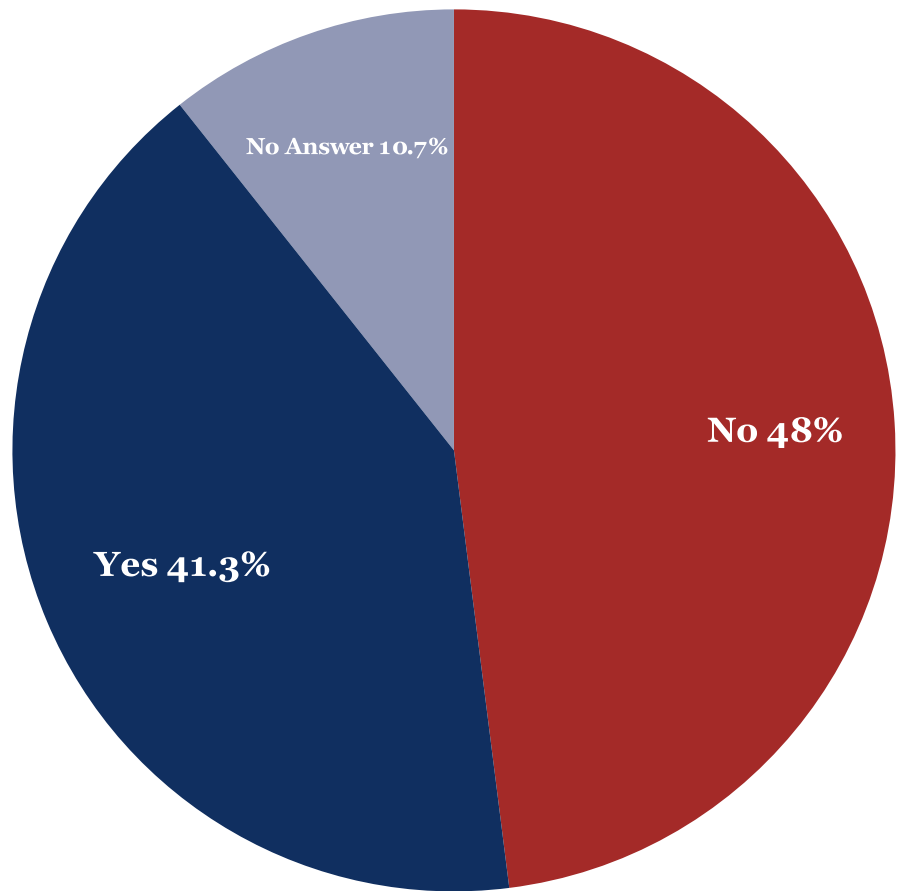
“This process (is) scary and deers doesn't seem to know the steps. This should be easy for efmp enrolled kids with profound disabilities”

“No one has answers for incapacitated child”

WEBSITES & APPLICATIONS

EFMP ELECTRONIC

DOES YOUR MILITARY SERVICE DEPARTMENT HAVE AN ELECTRONIC EFMP WEBSITE OR APPLICATION?



71

RESPONDENTS HAVE USED THEIR BRANCH WEBSITE OR APPLICATION

The Air Force has EFMP Family Vector as their online resource for families enrolled in EFMP. The website contains resources for AF families to upload their EFMP screening forms for PCS along with moving and educational guides for families to access. The intent is to have a website where AF families can upload their documents for travel screenings to PCS and save a trip to the EFMP office. They have the ability to check the status of their screenings from home and to send emails to ask questions when necessary.

Of the people who responded, 29% had negative responses about online experiences, while 12% had positive feedback. Many participants expressed frustration with backlogs from the AF MyVector website. They were able to upload their documents into their portals but then had extensive wait times. Some people reported issues with the website and, when they were in the process of uploading important documents, the website would fail to complete importing their documents.

A few participants reported they participated in the Army's pilot program for their new EFMP online portal. One participant reported their experience was positive, and they enjoyed being able to manage their own care. Another reported they received no information at all and were unable to get information from official sources.

In general, electronic resources would be helpful for families, but the information needs to be up to date on the platform the DoD chooses to launch a program through. What Families would like in a website is updated information on bases they can PCS to, wait list times for medical, resources, etc. Participants responded they would like to be able to track the progress of their paperwork submissions once their packets have been uploaded and employee's contact information should any questions arise. AF families stated their PCS orders were "held up" because they switched to MyVector, but there were not enough employees on the other end to keep up with the applications coming through.

HOUSING

HOUSING QUESTIONS ABOUT MILITARY HOUSING ON YOUR INSTALLATION

85.7%

of respondents indicated they have applied for ADA housing at their current duty location.

50.8%

of respondents indicated they have a family member in their household that should qualify for ADA Housing.

20.3%

of respondents indicated they believe a member of their household may qualify for ADA Housing.

69%

of respondents that have applied and qualified were told there is an ADA Waitlist

EFM asked the open ended question for survey respondents to add any additional comments in regards to housing:

In 1996 Congress established the “Military Housing Privatized Initiative” (MHPI) to help military families have access to better housing on military bases. The MHPI agreement was to bring in stakeholders from the private sector to assist in developing housing quickly for service members. The MHPI chooses private companies to maintain military housing on installations and these companies include: Balfour Beatty, Corvias, Liberty Military Housing, LendLease, Liberty Military Housing, and Hunt Military Communities (acq. osd.mil/housing; AFHA, 2022).

According to the Office of the Assistant Secretary of Defense for Sustainment, the MHPI works with the DoD to maintain military housing on installations and has the responsibilities below:

- Obtain private capital to leverage government dollars,
- Make efficient use of limited resources, and
- Use a variety of private-sector approaches to build and renovate military housing faster and cheaper for American taxpayers (acq.osd.mil/housing)

EFM found the following themes for those who attempted to reside on base such as housing wait list times, availability of ADA homes, conditions hazardous to health, and those who settled for housing that did not meet their needs. A few respondents stated they decided to not live on base in order to meet their needs.

ADA housing. 20.3% of families reported housing wait times for ADA homes negatively impacted their PCS. There were not enough ADA homes available at their installation which was mentioned by 23.7% of families. Also, 5.1% reported they did not have ADA homes available due to their rank.

Hazardous Conditions. Participants reported potentially hazardous conditions with housing on base and were denied accommodation at 11.9%. These families were told they had to accept housing even though they had mold. Housing would not accommodate a family who qualified for a fenced yard. Housing also denied accommodations for windows and denied deadbolts for their doors.

Special Considerations. Survey respondents, at 25.4%, mentioned they needed a one story home or air conditioning for their accommodations.

Expenses. Various participants reported that housing told them they would have to pay for their own accommodations. Survey respondents, 8.5%, reported they had out-of-pocket expenses regardless because they had to pay for lodging while waiting for ADA housing to become available or they decided to move off post. In the NDAA for 2022, legislation passed stating all MHPI companies **must provide reasonable accommodations and/or modifications at no cost to the military family tenants.**

Outlier responses. At 32.2%, there were various comments from participants explaining their displeasure with housing on post in regards to ADA houses and/or accommodations. Some families reported their EFMP children required their own room, but housing would not provide them with a home to meet their needs. Families are reporting the current housing market off base(s) is putting financial strain(s) on them, so the need to live on post is a must in order to financially provide for their family. Some responses complained about the housing offices and “to be jerked around by housing was such a horrible experience.” (Direct quote from a survey participant)

The Armed Forces Housing Advocates (AFHA) conducted their own housing study in 2022 and received similar responses and showed similar results as to what EFM found. AFHA found current issues with:

- Environmental Hazards
- Window safety
- Faulty construction
- Disability Rights violations
- Homelessness
- Fire hazards
- Toxic Gas

Hazards to health with housing are important to address, along with violations of ADA rights, safety concerns, etc., for EFMP families. Two non-profit organizations, EFM and AFHA, are finding similar information in regards to concerns about military housing, which shows there could be a trend of unsafe living situations for service members and their families.

FOOD INSECURITY

EFM ASKED: IN THE PAST YEAR HAS YOUR FAMILY FACED FOOD INSECURITY?**17%****OF RESPONDENTS STATED THEIR FAMILY HAS FACED FOOD INSECURITY IN THE PAST YEAR.****EFM ASKED: IF YES, WHAT RESOURCES DID YOU UTILIZE TO FEED YOUR FAMILY?**

Families sought out multiple resources to feed their families during their time of need. With this, 50% of the respondents to this question stated they sought resources from local food banks, food drives, etc. 22% of the respondents who sought out resources from local churches, city, council, and private charities, while 7% sought assistance through their school. Some families, 17%, were able to seek help through WIC and food stamps while 17% also reported their family either went without, used savings, budgeted, or sought second employment to assist with food insecurity. There was a small percentage of respondents, 2%, who reached out for assistance and received none. It should be noted that respondents possibly reported seeking out multiple avenues of resources such as food banks, WIC, local churches, etc.

EFM asked: "If yes, did EFMP related costs contribute to your food insecurity?"

78.7%

**OF RESPONDENTS
STATED EFMP RELATED
COSTS CONTRIBUTE TO
FOOD INSECURITY?**

EFM asked: If EFMP related costs contributed to your food insecurity can you share with us what those costs were?

EFMP related costs did contribute to food insecurity, according to survey respondents. Below are some of the major themes respondents stated. There were six themes gathered from the qualitative data.

Extra Medical Expenses. Having EFMP family members can apply extra financial pressure to families when they are already experiencing stress in other areas of their life. Of the survey participants who answered this section, 45.71% stated their extra medical expenses purchased contributed to their food insecurity. This means families are paying for medical supplies such as diapers and supplies (for both children and adults), food when their loved ones are in the hospital, testing TRICARE does not cover, services TRICARE does not cover, procedures, and paying out of pocket for “things” when there are billing issues.

Travel Costs. Travel costs contributed to EFMP families' food insecurity, and 28.57% of participants responded in this way to this particular open-ended question. EFMP families often travel to medical and therapy appointments multiple times a week, thus spending large amounts of money on gas due to miles driven. Some families have to drive over an hour to see providers because they cannot receive the care they need at their local MTFs. Families also travel to take their EFMP family members to different schools, such as charter or private schools, since some public schools or schools on post cannot accommodate their child's needs.

Geographical Separation (Geo Bach). Geographical separation, or commonly known in the military community as "Geo Bach," refers to when the Service Member (SM) lives separately from their family. Oftentimes, SM will live at the military installation they are assigned to while their family will live separately, thus the need to maintain two households. Due to this financial strain of handling two households, 11.43% stated being geographically separated from their SM contributed to their food insecurity.

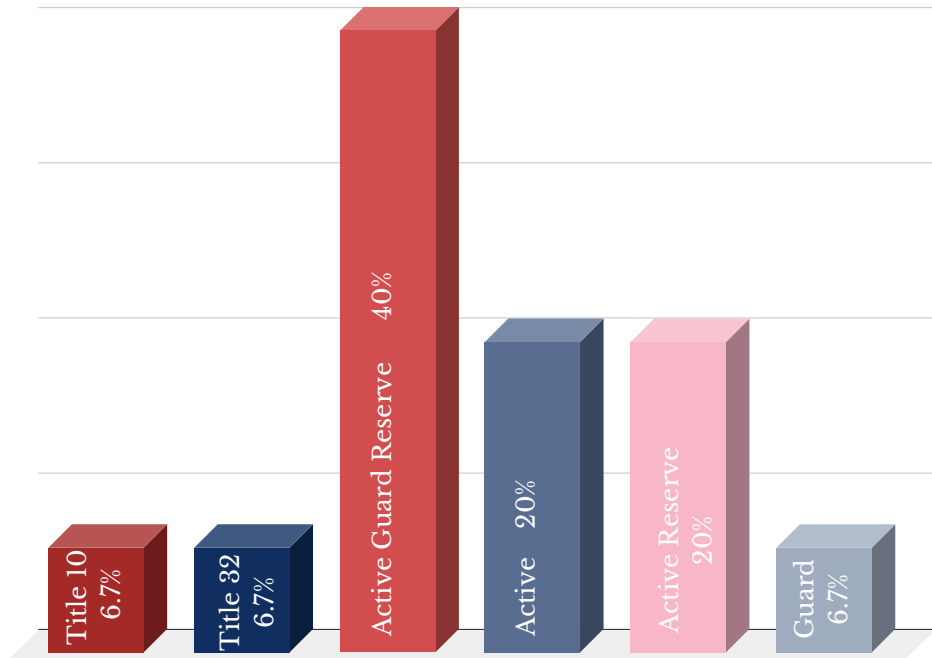
Childcare Costs. Families reported at 11.43% that childcare costs contributed to food insecurity in their household. Childcare costs were from COVID-related events. Families were unable to bring children to scheduled appointments because of COVID restrictions, so the family had to pay for childcare. Also, families reported daycares turned their EFMP children away for enrollment stating the center could not meet the child's needs.

Outliers. There were 28.57% of outlier responses from the open-ended responses where families reported various contributing factors to their food insecurities. Some families reported purchasing sensory items for their children. Sensory items are important to individuals with sensory processing disorder (SPD). In Jewel, et al. (2020), "Children with either SPD or ASD can have difficulties with processing sensation from tactile, auditory, visual, gustatory, olfactory, proprioceptive, and/or vestibular systems."

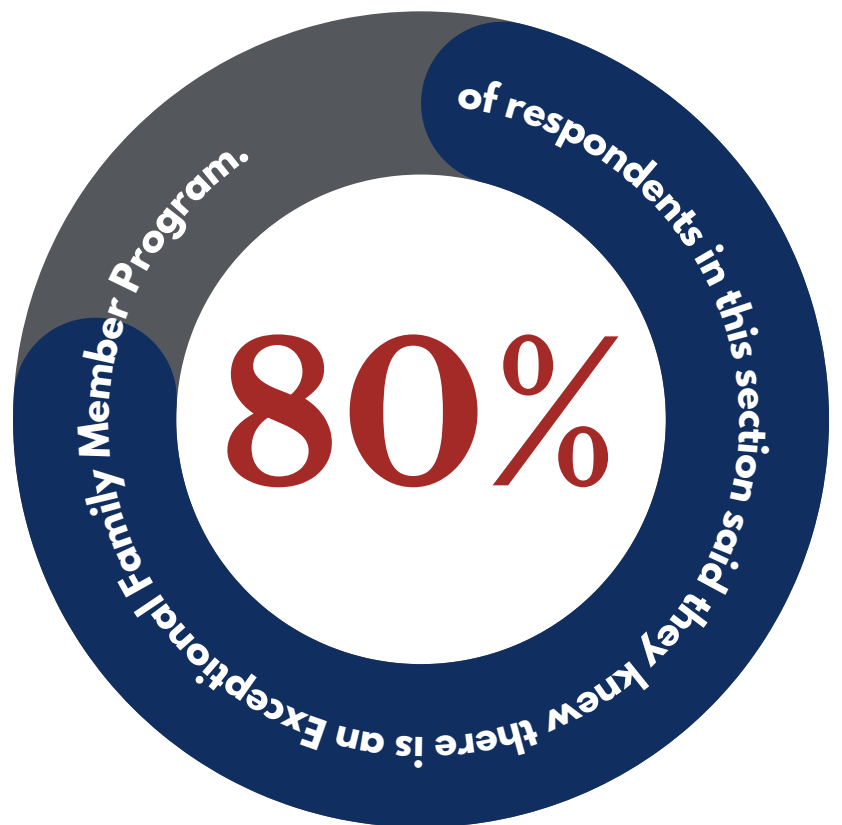
Participants also reported they had to pay out-of-pocket expenses for ABA because of the 2021 Autism Care Demonstration (ACD) changes and the coverage the demonstration would no longer assist families with. Participants are also paying for out-of-network providers since in-network providers are not available. Finally, there were comments in regards to not having access to ECHO respite services.

RESERVE AND
GUARD AND
EFMP

WHAT IS YOUR GUARD OR RESERVE STATUS?



EFM ASKED: DO YOU KNOW THERE IS AN EXCEPTIONAL FAMILY MEMBER PROGRAM (EFMP)?



EFM asked: If yes, how did you find out about EFMP?

Based on comments from 15 respondents associated with the national guard and reserves, various methods were used to identify potential need for enrollment. These included but were not limited to, word of mouth, social media, and medical or educational providers.

What services are available through EFMP enrollment?

EFM asked Guard and Reserve participants if they knew what services were available by enrolling in EFMP. There are some “blank/unclear” answers to this question, 33.3%, which means Service Members may not know what is available for them and their families enrolled in EFMP.

EFM asked: Are you enrolled in EFMP?



60% OF RESPONDENTS WERE ENROLLED IN EFMP

33.3% OF RESPONDENTS WERE NOT ENROLLED IN EFMP

6.7% OF RESPONDENTS LEFT THIS QUESTION BLANK

EFM asked: how did you find out how to enroll?

Based on the 15 responses received, the majority of the members were either contacted by an EFMP office coordinator or a medical facility/doctor. With just over 12% learning via word of mouth or personal research.



NEW RECRUIT

New Recruit Questions (Less than one year in service)

EFM asked questions for New Recruits (less than one year in service) and according to the demographics for this section, no new recruits answered this section.

Adult EFMP Child

The data from this section was not statistically significant and, therefore, EFM was unable to use the data. One reason the data could not be significant is families did not understand the demographics question.

EFM WANTED TO BETTER UNDERSTAND FILING FOR INCAPACITATED ADULT PROCESS IN DEERS AND MILITARY FAMILIES. THERE WERE NINE RESPONSES:

“It was VERY confusing with multiple forms asking similar yet minutely different questions. Even after DEERS was updated we discovered none of the medical providers were notified and even when we discovered the problem Tricare had issues verifying. It was frustrating. AND, the local office did not have the information we needed. We thought we were done then found out there were many more forms.”

“Not started yet. Deers didn't know what I was supposed to do.”

“We have an amazing developmental pediatrician at Nellis who started and completed the process for us.”

Continued on next page.

“Due to government shutdowns the short period before 22 when applying is allowed led to a lapse in Tricare. Eventually back pay was provided but it added unnecessary additional stress and time.”

“Was told that we could not start process until 6 months before he turns 21”

“For friends, they had to go outside of the military. It was confusing and expensive.”

“Efmp office had no idea as to what I was talking about or how to complete the process. I had to figure ever(ything) Out on my own. I haven’t found the efmp office extremely helpful.”

EFM WANTED TO BETTER UNDERSTAND FILING FOR INCAPACITATED ADULT PROCESS IN DEERS AND MILITARY FAMILIES. THERE WERE NINE RESPONSES:

“No one ever told me it was a thing.”

“We were told we have to wait until he is 20”

At the end of the section, EFM asked survey participants to add any additional information. All responses are included here.

“One issue was the forms all being different depending on the Branch of Service. Standardization of this process would be so helpful.”

“The process is very intense and hard to understand all that needs to be done.”

“I have heard from other families and after speaking to the representative for this program that it is very difficult process. Also that even if your child is permanently disabled you must redo it constantly. Seems like it is just one more program that the military makes extremely difficult to receive when we already have a lot on our plate.”

“This process (is) scary and deers doesn't seem to know the steps. This should be easy for efmp enrolled kids with profound disabilities”

“No one has answers for incapacitated child”

SUMMARY

Exceptional Families of the Military (EFM) has goals of supporting EFMP families and identifying areas needing improvement within the EFMP program. The 2021-2022 survey identified several areas where improvements can be made to help EFMP families and military readiness. These are some of the areas EFM's research identified EFMP families are suffering either from the PCS process or from the EFMP program: medical wait times after a PCS, access to respite services, housing, and food insecurity.

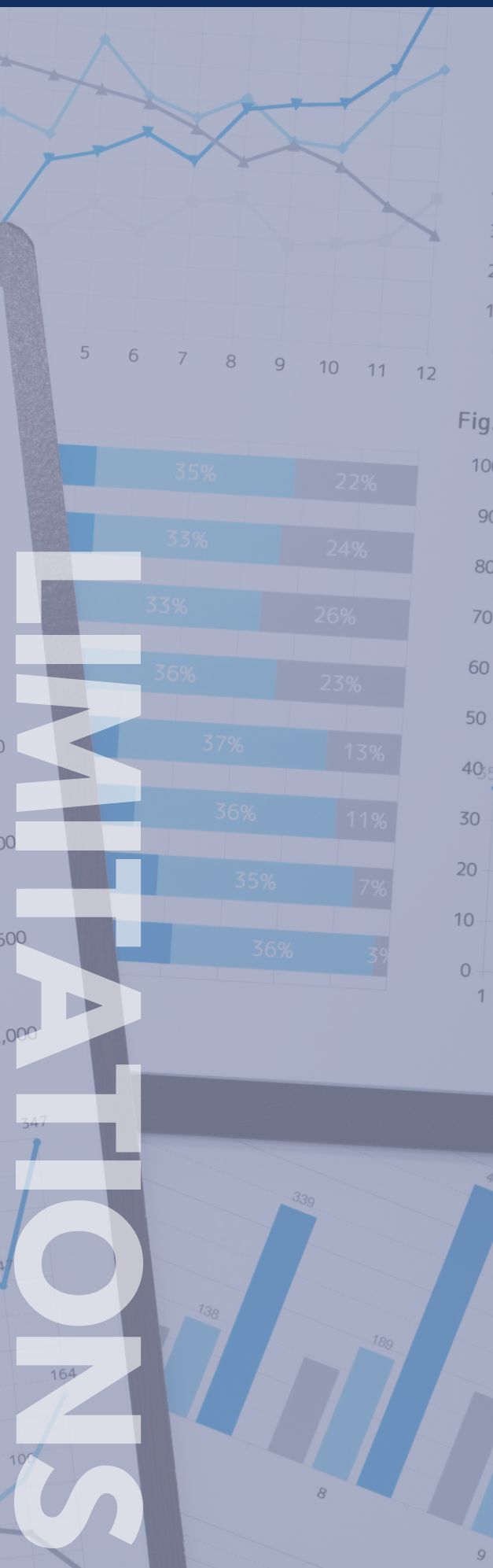
Medical wait times reported at 5 months or more at 34.7% by survey respondents. The process of waiting for medical therapy providers at new installations can be hard on families when they are arriving at new places because they are already adjusting to leaving behind providers they are accustomed to who know their medical and/or therapeutic backgrounds. Now, they arrive at a new place where families may or may not know anyone, and they have to wait for months to meet with new providers in order to receive new referrals to get treatment(s) started. Some families reported at 11.6%, the new installations did not have any services at all when they arrived.

Respondents who are a part of the ACD expressed extreme frustration from the March 2021 changes, especially with wait list times. Another stressful component is ABA providers dropping TRICARE due to the 2021 requirements. Families reported the evaluations required for the ACD are difficult to obtain because providers have long wait lists and they have their own hurdles to jump over. Survey respondents also stated TRICARE made things difficult on them when they requested paperwork they already had.

Respite care is important for families who have children with extensive medical and developmental needs. Caregivers need support to be able to unwind and take time to themselves so they are able to care for their loved ones. Also, caregivers need access to quality respite caregivers. Survey respondents reported at 42% they cannot access their branch respite programs. Also, at 53% of respondents reported they cannot access TRICARE ECHO respite. The reasons for not being able to access these services are multiple reasons, but the main one is provider shortages. Participants reported they had been given the option to have their providers approved as respite caregivers, but the process was too difficult to get the providers approved. Some adults reported they would like their own assistance with respite as well as being in the EFMP program because they felt the emphasis was placed on children.

Lastly, various housing concerns were reported by participants. Long wait times for ADA homes were reported by participants at 20.3%, and 23.7% reported there were not enough ADA homes at their installations. There are over 146,000 family members enrolled in EFMP, so there could be a bigger need for ADA homes at military installations to give families more access to the accommodations. Participants reported at 11.9%, they were told by housing on post they would not be accommodated for their EFMP family needs. For example, if the family needed a specific lock for their home, they were denied. If the family needed a fenced yard, they were denied. Some families were told they could pay out of pocket for these accommodations. Families were also told to move into mold-infested homes, or they would not be given air-conditioned homes despite having the necessary medical paperwork showing they needed AC.

EFMP families are struggling because the program has many barriers, such as medical wait times, families moving to installations where services are not offered, housing not accommodating ADA needs or offering hazardous homes, or food insecurity due to EFMP expenses. The respite program, both branch respite and TRICARE ECHO needs to be overhauled in order to accommodate families better and to assist dual military/ single parent families as well. The purpose of this survey was to identify the areas where EFMP can improve in order to better provide for service members and their families.



There are limitations to this survey from EFM. First, there are over 146,000 members enrolled in EFMP though we know this number does not equate to the total number of families enrolled. Only 300 families responded to the survey either as the EFMP members themselves or on behalf of their EFMP beneficiary(ies). The sample size is small. The rank representation does not represent the widespread enrollment of EFMP, and service breakout could not be a true representation of the EFMP population. There are no demographics of the families enrolled in EFMP: rank, branch of service, number of EFMP members enrolled, or the average number of enrolled EFMP beneficiaries per sponsor. Second, the survey was distributed through Google Forms which can be a limiting form in regards to data analysis.

Third, the question for New Recruits was answered by respondents who were not new recruits, so data analysts had to go in and remove the unnecessary answers. There is always the possibility two respondents from the same family answered the survey without knowing the other responded to the survey. A final limitation is that volunteers from EFM participated in the survey as well. Despite the limitations, the data presented in the report represents the information reported in the survey by participants.



RECOMMENDATIONS

Recommendations from the survey are to assist EFMP families. Respondents expressed frustration with PCS issues, housing accommodation problems, the respite program, and the implementation of EFMP websites/applications. EFMP families appear to be frustrated with the barriers in regards to their medical care at MTFs and the wait lists they have to endure at new installations. Some respondents reported they arrived at their new duty station only to have no services offered there. Imagine moving an entire family across multiple states, leaving a care team aware of the needs the EFMP family member needed, only to arrive and have no care available.

EFMP has been around since 1979 and continues to be a significant pain point for families enrolled, despite the intent to help families. As a final recommendation, due to the findings from the current survey, EFM advises there be an outside look into the program as a whole for process improvement. The Department of Defense should create an independent commission, consisting of subject matter experts from the public and private sectors, to recommend best practices to support military families impacted by medical and/or mental health diagnoses and disabilities.

EFM HAS MULTIPLE RECOMMENDATIONS BASED ON THE OUTCOME OF THIS SURVEY:

- Streamline the EFMP system for enrollment, maintaining paperwork once enrolled, and for PCS
- Remove barriers to access to respite care and allow families to utilize providers to help families with school and work
- Provide more ADA-compliant homes for EFMP families or require that all new homes be built in a manner that allows any family to utilize it regardless of disability
- Hold the housing companies accountable when they violate the Tenants Bill of Right
- Improve the current AF MyVector website process for EFMP families and launch the other websites for the remaining branches. Hire the appropriate staff to manpower the influx of paperwork coming through electronically so the EFMP process will not get backlogged.
- Identify and provide resources targeted for EFMP families who experience food insecurity or provide FSSA to EFMP families of certain ranks
- Survey current EFMP enrollees DoD-wide on these issues.

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APPENDIX A

Quotes Related to Timing

“Don’t meet the status requirements for long enough period of time” quote from Air Guard Family

“By the time we were approved my husband was back from deployment.” quote from Navy Family

Quotes if EFM is Adult

“Because respite is not offered unless the child is the family member with a special need. I wish having a spouse with a special need would qualify families for some respite care.” Quote from Air Force Family

I’m a spouse and the EFMP. There are literally no special programs for us. “ Quote from Air Force Family

“Respite care is only for adults who have EFM children. I’m the adult spouse who is enrolled in EFMP. I get no assistance or respite care at all.” Air Force Family

Process is Unknown/Unclear Quotes

“I don’t know how to use respite care or where the resources are to start it. My PCM wasn’t much help for information “ quote from Army Family

Medically Complex Quotes

“They have no nurses and my child is Medically Complex” quote from Army Family

“Was told they only had one caregiver who was not experienced with medical complexities. Told to go ahead register but they would need time to find a caregivers we would be more comfortable with.”

Provider Shortage Quotes

“There are only 3 providers here. Two are full and the one we utilize she has a full time job already so booking in hours can be difficult.” Air Force Family

“There are no providers willing to work. It took me two years to get a provider to provide respite, she moved after 6 months and I was left with no provider again. I then tried getting THREE people qualified to provide Respite and the process is so long and ridiculous none of them were able to finish. The communication from HQ was nonexistent and when you finally get ahold of someone there are no answers. This program is broken and has been for several years.” Air Force Family

“As I stated prior, there is no respite care providers in the entire state of Iowa. There are also no FCC providers meaning that any of our dual mill, or single mill drilling guardsman have no access to child Care on drill weekend.” Air Force Family

“As I stated prior, there is no respite care providers in the entire state of Iowa. There are also no FCC providers meaning that any of our dual mill, or single mill drilling guardsman have no access to child Care on drill weekend.” Air Force Family

“In each duty station the wait for respite care was nearly 1.5 to 2 years. That’s entirely insane considering the average military family moves every 2 to 3 years.”

APPENDIX A CONTINUED

Provider Shortage Quotes

“There are only 3 providers here. Two are full and the one we utilize she has a full time job already so booking in hours can be difficult.” Air Force Family

“There are no providers willing to work. It took me two years to get a provider to provide respite, she moved after 6 months and I was left with no provider again. I then tried getting THREE people qualified to provide Respite and the process is so long and ridiculous none of them were able to finish. The communication from HQ was nonexistent and when you finally get ahold of someone there are no answers. This program is broken and has been for several years.” Air Force Family

“There are many respite rules that hinder a dual working household to access respite. There are also not enough providers and the providers that do exist prefer to take on families with multiple EFMP members so they get paid more. This causes families like ours where only one child is EFMP and the other is not to be at a disadvantage because the providers are paid significantly less for sibling care and many will not agree to sibling care because the pay rate is so low. Also, most families want care after school, evenings, and weekends so you have a high population “fighting” for the same time slots “ Air Force Family

“As I stated prior, there is no respite care providers in the entire state of Iowa. There are also no FCC providers meaning that any of our dual mil, or single mill drilling guardsman have no access to child Care on drill weekend.” Air Force Family

“EFMP respite care gives adult parents a break, but since I have no children enrolled in EFMP, I receive no assistance at all. However, I have disabilities that affect my ability to function on a daily basis and would love help. Why are parents the only people offered assistance?” Air Force Family

“Wright-Patterson AFB has a fantastic EFMP program. The program is well run and everyone works together, from FSS to Medical. All the doctors and providers work together for the EFMP dependent, everyone is a team and it makes living a stressful life just a bit easier.” Air Force Family

“The respite care program, when it works, is amazing. We had our full entitlement of hours when we lived in Kansas. We have not had any respite in the last 18 months since moving to Iowa. The process is completely broken, no one cares, and finding child care and this environment is nearly impossible. We have been through five babysitters in the last 18 months just trying to find someone qualified and willing to watch our special needs children. The process for becoming a respite care provider is so monumentally broken I'm surprised anyone ever gets approved. Over 4 months to get a response from the people in San Antonio? Are you kidding me? That's not even getting the application started, that's just trying to find the application to begin with. And then once the application is submitted, it's radio silence until eventually your paperwork is simply thrown out for failure to respond even though they never got in touch with you in the first place. It's all a joke!” Air Force Family

APPENDIX A CONTINUED

Not Otherwise Classified Quotes

“My children (all autistic) struggle with separation anxiety as well as having non family in the house. I was also told there is a 2 year wait list.” Navy Family

“When applying for respite care since both kids are efmp and each have their own appointments going on, we did not qualify because they are not considered “severe”.” Air Force Family

“Respite care is only for adults who have EFM children. I'm the adult spouse who is enrolled in EFMP. I get no assistance or respite care at all.” Air Force Family

“We have 2 boys with autism they both qualify but we are in able to use because they want our boys to use at different times with different respite providers I've also been told I could not be in my own home while the respite provider was with either of our sons so it's un beneficial if I have to take two kids out for a few hours while one receives care because I cannot be in my own it also is a little strange how the parent can't be around to monitor this respite provider who is spending time with their child .” Army Family

Questions about the survey?



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