

Exceptional Adults

Examining the Experiences of Adults in the Exceptional Family Member Program



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Executive Summary

For the past three years, Partners in PROMISE has heard from many adults enrolled in the military's Exceptional Family Member Program (EFMP) while conducting our annual special education surveys. Many of them are also parents of children enrolled in EFMP whose qualitative responses highlighted a lack of data collected on this population. Therefore in 2022, we opened our annual survey to include EFMP adults to better understand their unique experiences.

There is very little publicity surrounding the lived experiences of adults enrolled in the Exceptional Family Member Program (EFMP). This was noted in a report sent to Congress in 2018.[i] According to an Army report, Exceptional Family Member Program Survey: Assessing the Needs of Exceptional Army Families, "41.9% (n = 1,268) [of survey takers] have a Spouse EFM" in 2019.[ii] Partners in PROMISE reached out to the Office of Special Needs to determine how many EFMP enrollees were adult dependents vs. minor dependents. At the time of publication, they did not have the authority to release these numbers. Without a clear understanding of how many adult military family members participate in this program, it is unclear if the level of support and specialty services are sufficient to meet the needs of this population.

According to a 2021 RAND study, "It is important to remember that children are not the only family members who might have special needs. The needs of adult dependent family members could also require EFMP enrollment and be eligible for EFMP support and services. Adults may have different needs than children or youths. Spouses with disabilities, for example, may have greater needs for education or employment accommodations, or vocational rehabilitation. We noticed that neither DoDI [Department of Defense Instruction] nor department/service branch policies address different services and coordination requirements that may be required for different family members with differing needs."[iii] Military OneSource provides a few resources[iv] that are designated to assist EFMP adults. These resources include access to nonclinical case management, referrals to mental health services and public benefits, and a provision of assistive technology and adaptive equipment to help with overcoming limitations.

OUR TOP FINDINGS

- EFMP adults may be out of the workforce (not working, not looking/volunteering) at higher rates than the larger military spouse population.
- Similar to children in EFMP, EFMP adults struggle to access needed medical care with 59.62% reporting they experienced a delay in receiving services after their most recent PCS (Permanent Change of Station) move.
 - Of those under the care of a mental health professional prior to their most recent move, 80% reported delays in accessing mental health care at their new location.
- Over half of EFMP adults surveyed indicated they are unsatisfied with the Program.

Recommendations

Employment

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"The jobs I've been offered at new location pay more than 30% lower than my previous salary."
- 2022 Survey Participant

FINDING 1:
EFMP MILITARY
SPOUSES MAY
BE OUT OF THE
WORKFORCE
AT HIGHER
RATES THAN
OTHER MILITARY
SPOUSES.



Finding 1

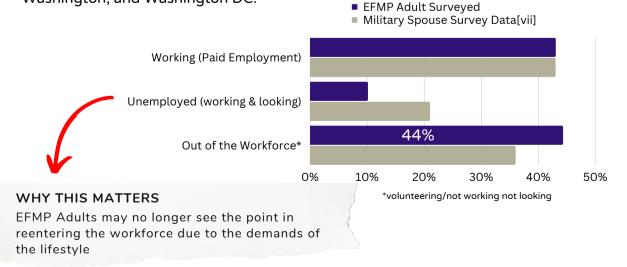
Employment

In surveying military families with children enrolled in EFMP over the past two years, we observed that over half of military spouses reported being unemployed and out of the workforce (64% in 2021[v] and 52.23% in 2022[vi]). Survey takers cited educational and medical caregiving as their primary reason for not working as paid employees. EFMP adults may be out of the workforce at higher levels than their civilian counterparts or even other military spouses[vii].

Overall, 42.94% of EFMP adults who were also military spouses indicated they worked as paid employees (34.81% reported working as a paid employee, 7.59% were self-employed, and .63% reported also serving on active duty), 54.44% were not employed in a paid role (looking for work, not looking for work and volunteering), and 2.53% preferred not to indicate their current employment status. Of those who reported being out of the workforce (not working in a paid role), 59.3% reported they were not working and not looking, 22.09% were working as unpaid volunteers, and 18.6% were unemployed (not working and looking for work).

It is important to note that although a military family member may indicate they are not looking for work, we often hear from families who do not see the point in looking for work because they have tried it in the past and either could not find a job in their field or their income could not offset child care costs. *This is why for the purposes of this paper, we define "out of the workforce" to mean not working in a paid role, nor looking to find a paid role (not working not looking or volunteering). We asked those who indicated they were not working as a paid employee why they believed they were not working in a paid position. Their answers were similar to those provided by the parents of children enrolled in EFMP (Read the Report).

However, EFMP adults were not statistically more likely to report being out of the workforce compared to EFMP parents (n=525; p=.907). Though not significant, we found that more spouses who reported living in military-dense states were working as paid employees than those who did not live in a military-dense state (n=129; p=.067). We identified the following military-dense states: Virginia, Texas, North Carolina, California, Florida, Maryland, Washington, and Washington DC.



Delays Receiving Medical Care

"I became
overwhelmed after
my [family member]
died and I couldn't
get out of bed. I
knew I needed to
seek help not only for
myself but for my
family."

-2022 Survey Participant



FINDING 2:

ADULTS ENROLLED IN EFMP NEED ACCESS TO BOTH ACUTE AND LONG-TERM CARE, BUT REPORT EXPERIENCING DELAYS IN RECEIVING BOTH TYPES OF ESSENTIAL CARE.

Finding 2

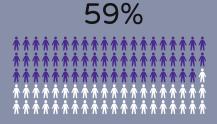
EFMP Adults Experienced Delays in Receiving Needed Care

We asked: "Did you experience a delay in receiving MEDICAL services after your most recent PCS move?" Over 59% of survey takers indicated they experienced a delay. Of those, 89.07% waited a month or more with 6.25% reporting they "have never received services." We asked survey takers why they believed they experienced a delay. Responses included: couldn't make a provider request until after seeing my new Primary Care Manager (PCM) (29.31%), provider waitlists were very long (28.45%), no providers in my area were accepting new patients (14.66%), unable to get a referral from a PCM (12.07%), no providers in my area (3.45%), and moved to a rural location (3.45%).

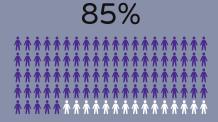
Roughly 26% of EFMP adult survey takers indicated they had a mental health diagnosis. We asked these individuals to "briefly describe the circumstances that led you to seek mental health care." Participants were given the opportunity to provide open-ended responses. We categorized the qualitative responses to see what their primary motivations were for seeking mental health care.

Our first area of focus was whether their need was acute or long-term. During the categorization/coding process, we ranked their answers with "acute," "long-term" or "unclear" if their responses did not indicate the nature of their mental health needs. We found that over half (56%) cited a long-term need; either because they had a long-term personal/family history of the condition or if they indicated they have been dealing with these issues for a prolonged period of time (trauma, PTSD, etc.). Twenty percent indicated they were dealing with an acute need like postpartum depression or grief after the loss of a loved one. While these acute needs could certainly extend into long-term needs, we coded them as acute because the type of care may not be life-long. This distinction is also made by Military OneSource's Military and Family Life Counseling Program which "offers free short-term, non-medical counseling."[viii] This program offers "12 sessions per person per issue"[ix] at no cost following a qualifying triggering event, like postpartum depression or anxiety triggered by a deployment, etc. The remaining 24% of responses could not be coded as acute or long-term.

Other categories were assigned to responses. These categories indicate the reason survey participants cited needing mental health care: Suicidal ideations/attempts (8%), needs were exacerbated by military lifestyle (5%), preventative/routine care (9%), history of mental health issues (3%), anxiety (25%), depression (20%), wanted to be a better parent/spouse/friend (8%), postpartum depression (6%), or they experienced a traumatic event (17%).



Of those surveyed experienced a delay in receiving medical care after their most recent PCS move.



Of those diagnosed with a mental health condition indicated they were receiving mental health support prior to their latest PCS move.

WHY THIS MATTERS

EFMP is tasked with ensuring timely medical and mental health care after military relocations

Anxiety and depression were the most commonly cited reasons for adults with a mental health diagnosis to seek mental health care. For those who indicated they had a mental health diagnosis, 84.91% indicated they were receiving mental health care services prior to their most recent PCS move. Of those who received mental health care prior to a PCS, 80% indicated they experienced a gap in mental health care after a recent PCS. The majority of those who ultimately received care waited 2-3 months (30.77%), followed by 19.23% who waited 12+ months. Over 23% indicated they were "still waiting for services." The location they lived in did not play a role in reported wait times as living in military-dense locations did not have a relationship with delays in receiving care (n=36; p=.650).

Historically, the DoD's Exceptional Family Member Program focused on ensuring eligible family members do not experience a disruption in medical care due to frequent military moves. Based on this data, it may be that adults enrolled in the program may not be receiving the care they need in a timely manner. Additional research is needed to determine if these experiences are representative of program effectiveness in assigning enrolled individuals to locations that can meet their care needs, or if these delays and gaps are solely a result of the nationwide provider shortages experienced after the COVID-19 pandemic.



"NEEDED HELP WITH THE STRESS OF BEING A PARENT TO A CHILD WITH SPECIAL NEEDS. NEEDED HELP WITH THE CONSTANT CHANGE AND INABILITY TO PLAN THAT IS THE MILITARY. IT HAS CAUSED ME TO HAVE AN ADJUSTMENT DISORDER."

-2022 SURVEY PARTICIPANT

Program Enrollment & Satisfaction

11

"The human aspect has been removed...
They simply saw I had seen a specialist and decided to auto-enroll me."

- 2022 SurveyParticipant

of EFMP-eligible adults reported being enrolled in EFMP

FINDING 3

EFMP ADULTS
REPORT BEING
UNSATISFIED WITH
BOTH ACCESS TO
THE PROGRAM AND
THE INCONSISTENT
SERVICES THEY
RECEIVE ONCE
ENROLLED.

Finding 3

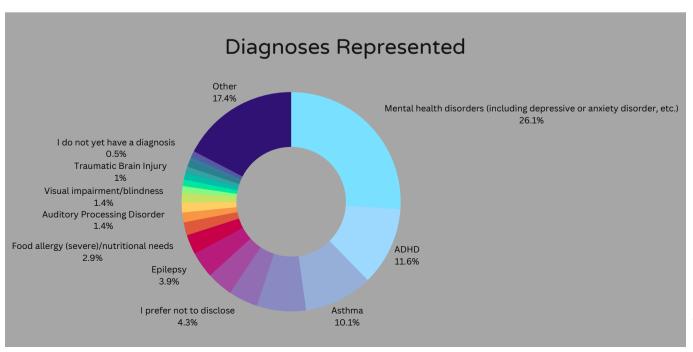
EFMP Program Enrollment Experiences

Forty-four percent of adults enrolled in or eligible for EFMP also cited they had a child eligible for EFMP. Of those eligible children, 83.65% were enrolled in EFMP. EFMP adult survey participants were enrolled at similar rates with 78.91% of adult survey takers indicating that they, too, were enrolled. The primary reasons cited for not enrolling in EFMP were: "Don't see the benefit of enrollment" (25.64%), "Impact on service member career" (20.51%), and "Stigma surrounding EFMP" (15.38%). The number one reason military children were not enrolled was "Don't see the benefit of enrollment" (22.22%).

Adults enrolled in EFMP were most likely to be told they should enroll in EFMP by a military-connected medical professional (18.28%), followed by 12.9% who were flagged for enrollment during an overseas medical screening. EFMP Coordinators/staff were the third most cited referral source (12.37%).

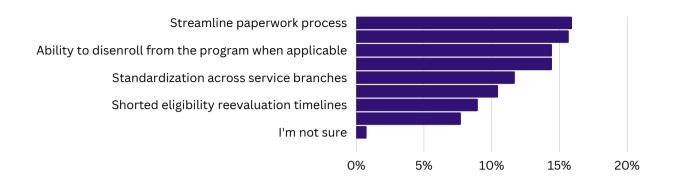
Survey respondents who were told they should enroll by a military medical professional were significantly more likely to be enrolled in the Program than those who were referred for enrollment by another individual (n=107, p=.001). Those who were identified during an overseas medical screening were somewhat more likely to be enrolled, but not significantly so (n=107; p=.079). Those identified by an EFMP coordinator/staff were significantly more likely to be enrolled (n=107; p=.023). While somewhat obvious, those who reported that "no one told me to enroll in EFMP" were significantly less likely to be enrolled in the Program (n=107; p=<.001).

We looked at which common diagnoses were more likely to have a relationship with EFMP enrollment. While some diagnoses were more likely to be enrolled than those others, none were significantly more likely to enroll or not enroll based on their diagnosis.



EFMP Program Satisfaction

"What, if anything, would you like to see changed within the EFMP (select all that apply)?"



Roughly 53% of adults who are either enrolled in EFMP or have a condition that qualifies them for enrollment indicate that they are unsatisfied with the Program. Thirty percent were neither dissatisfied nor satisfied, and 16.66% were satisfied with the Program. Those who also reported having a child enrolled in EFMP were significantly less likely to report being extremely dissatisfied, with 24.56% of those who have children who are enrolled being extremely dissatisfied as compared to 54.54% of extremely dissatisfied EFMP adults who did not have children (n=90; p=.045).

Since the Program is implemented differently across each service branch, we wanted to better understand if satisfaction levels were significantly different across branches. We learned that no branch reported significantly higher or lower levels of satisfaction for adults enrolled in EFMP.

Navy-connected survey participants were more likely to report being dissatisfied (52%) or neutral (38%) (n=90; p=.626). Air Force-connected survey participants were more likely to report being extremely dissatisfied (43.58%) than other options (n=90; p=.634). Army-connected survey participants were more likely to report being neutral (36%) or satisfied (20%) than other options (n=90; p=.784). We did not hear from enough Marine Corps or Space Force-connected adult EFMP survey participants to allow us to responsibly report their specific satisfaction rates.

We asked EFMP adults: "What, if anything, about the Exceptional Family Member Program (EMFP) do you find most challenging (select all that apply)?" The most commonly cited response was "making appointments with specialists" (13.44%). While this is not specifically a function of the program, the purpose of EFMP is to ensure that EFMP families are stationed in areas where they can receive the needed medical care and education (in the case of military children) they need. This may indicate that EFMP adults may not be living in areas that can provide the care they need. Other responses included paperwork (14.34%), limited duty stations (14.34%), lack of adult EFMP community (14.34%), unable to disenroll (13.11%), lack of adult programming (10.66%), TRICARE coverage (8.61%), and applying for EFMP (6.56%). Only one person selected "n/a - satisfied with the EFMP."

Finding 3

We observed two qualitative themes related to Program satisfaction. We learned that families encountered the Program in phases and that these phases have the potential to impact satisfaction:

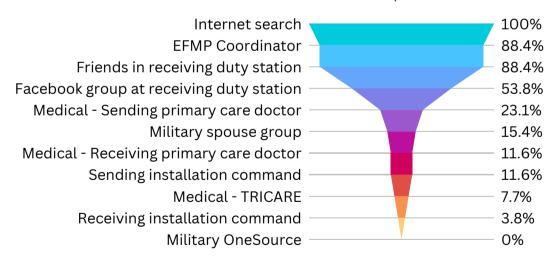
- · Access to entry
- Program delivery

Themes that examined satisfaction with the Program access indicated that the EFMP application process lacked transparency; was inconsistent across service branches and locations; people did not understand how a diagnosis in one service branch would trigger enrollment seemingly without their knowledge or consent. These processes were important to adults enrolled in EFMP. Families accessing the Program rely upon information sharing within informal communities, like Facebook, to figure out how to navigate the system.

Satisfaction, as it related to program delivery, was more straightforward. In these instances, survey takers reported being sent to a particular resource that wasn't sufficient, that wasn't relevant, or that no longer exists, resulting in lower than desired satisfaction rates.

Accessing Resources

How EFMP Adults access resources and which resources they select help inform how we can best serve their unique needs.

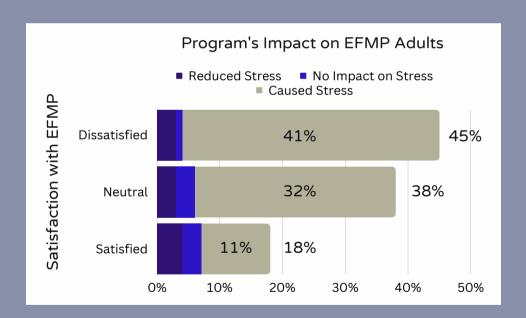


We asked EFMP adults to "rank the following EFMP-related resources in the order of who you contact after receiving PCS orders." They start with searching the internet as their primary resource for information (24.76% ranked it as their number one resource). The least popular resource was Military OneSource (0% ranked it as #1).

Conclusion & Recommendations

Although the majority of adults in EFMP indicated they had a negative experience with the program, the majority of EFMP adult survey respondents indicated the Program had no impact on their family's desire to continue serving. It did, however, have a negative impact on their family's stress levels. Those who reported being dissatisfied with EFMP were significantly more likely to report that EFMP had a negative impact on their stress levels (n=88; p=.004).

Since conducting this survey, the DoD has released DoDI 1315.19 which is intended to mitigate many of the challenges and concerns reported in this paper. These positive updates include allowing service members to review duty assignments in advance, which may help alleviate disruptions to medical care; the standardization of enrollment/disenrollment policies; and the "warm hand-off" process between EFMP Offices that is initiated prior to a military move.[x]



Improving Access

• Both EFMP adults and the parents of children enrolled in EFMP have indicated that they struggle to access care. We recommend the DoD/Tricare widen access to care providers and resources. Therefore, we recommend the Department of Defense survey in- and out-of-network specialty care providers to determine what barriers exist to offering care to military families (including accepting Tricare insurance, accepting new patients, preventative processes, etc.). In addition to establishing their satisfaction with serving this population, data should be collected to determine how Tricare could improve various interactions, applications, paperwork, payments, etc. We also recommend that the DoD examine and report on how the latest DoDI impacts access to care by studying the experiences of families who have been granted stabilization (remain in one location for up to four years).

Program Evaluation

- EFMP adults, like the parents of children enrolled in EFMP, struggle to see
 the value in the services offered by the Program. As such, we recommend the
 EFMP assess areas that could improve installation programming and
 support, specifically geared for adults in EFMP. Suggested programming
 improvements that would benefit adults enrolled in EFMP include one-onone assistance for medical specialist referrals and employment, mental health
 wellness, and respite care. Where such programs exist, we recommend:
 - A concerted effort to promote these services among this population to ensure maximum participation
 - Regularly conduct program evaluation to assess the EFMP family satisfaction of the Program overall, and specific features of the Program.
- The 2023 DoDI[x] requests the services collect data on EFMP families. We recommend that this information be made public to help increase program transparency and reduce the stigma associated with enrollment.

Enrollment Procedures

- Like EFMP parents, EFMP adults are often flagged for enrollment during the overseas screening process. Since this can cause significant disruption in the execution of orders, we recommend all branches review their overseas screening processes and make these processes transparent for military families, disseminating requirements widely. Reissuing unaccompanied orders rather than canceling accompanied OCONUS orders due to EFMP status should not be standard practice. We suspect the 2023 DoDI[x] update may inadvertently result in an overall reduction in accompanied orders in order to avoid incurring costs associated with providing needed care. While this may solve the problem of the availability of care, it simultaneously creates new family readiness struggles by forcing a family to live geographically separated for an extended period. Instead, the services should seek to maximize available care.
 - A possible solution is to expand U.S.-based telehealth care opportunities for those stationed overseas.

Demographics & Limitations

In 2022, we conducted our EFMP and special education survey and, for the first time in the three years of conducting surveys, we opened it up to adults enrolled in the Exceptional Family Member Program (EFMP). We elected to extend this survey to this sub-population because we kept hearing from parents of children enrolled in EFMP who told us they, too, were in the program and needed assistance navigating related processes. We heard from a total of 160 adults enrolled in EFMP. Most of our survey takers were aged 36 - 40 (29.13%), followed by 23.62% aged 41 - 45, 22.05% aged 31-35, 12.60% aged 26 - 30, 7.87% aged 46 - 50, 2.36% aged 56 - 60, 1.57% aged 51 - 55 and .79% aged 21 - 25. The majority of survey takers identified as Caucasian (75.28%) followed by: Hispanic or Latino (6.18%), Black or African American (5.62%), American Indian or Alaska Native (2.81%), Asian (1.69%), Native Hawaiian or Pacific Islander (0.56%), and a race/ethnicity not listed here (2.25%)/Prefer not to say (5.62%). Unsurprisingly, the vast majority of adults enrolled in EFMP identified as female (98.73%), with 1.27% identifying as male. Of those, 1.27% indicated that their current gender identity was different from the sex they were assigned at birth.

Over 81% reported that they are currently stationed within the Continental United States (CONUS) with 18.87% residing Outside of the Continental United States (OCONUS). The majority of adult EFMP enrollee respondents were spouses of active-duty members (70.85%). While overall we heard from a cross-section of military service branches, there was a higher than anticipated response rate from Air Force enrollees (35.71%) with Army (27.98%), Navy (25.60%), Marine Corps (5.36%), Space Force (2.38%), Coast Guard (1.79%) and Department of Defense (1.19%). The majority of survey takers were from more senior ranking families of both enlisted and officer ranks hearing from the following: O4 - O6 (34.01%), E4 - E6 (27.89%), E7 - E9 (27.89%), O1 - O3 (7.48%), W1 - W3 (1.36%) and W4 - W5 (1.36%). This is in line with our special education and EFMP participants who often are plugged into the community than more junior military families.

Unlike military children enrolled in EFMP who primarily cite diagnoses of autism as the reason for their enrollment in the program, the majority of adult enrollees cite mental health diagnoses as their reason for enrolling in the program. Roughly 26% of adult EFMP survey takers indicated they had a mental health disorder (including depressive or anxiety disorder, etc.), 11.59% reported Attention-Deficit Hyperactivity Disorder (ADHD), 10.14% reported an asthma diagnosis, and 7.25% reported a long-term physical condition (including cerebral palsy or spina bifida, etc.).

Because we do not know how many adults are enrolled in EFMP overall, it is hard to know if our survey sample can be considered representative.

Methodology

Because of the lack of data surrounding the experiences of adults enrolled in EFMP, Partners in PROMISE wanted to understand how their experiences compared to the experiences of parents of children enrolled in EFMP. We asked parents of enrollees, and the enrollees themselves, questions about their satisfaction with the program, the types of diagnoses represented, demographic information, and other relevant questions. We began to compare their experiences, but because the majority of EFMP parents were dealing with educational issues, their experiences were not directly comparable. We did ask questions related to the availability of mental health care and medical services and were able to compare those findings.

To analyze these variables, Chi-Square tests were conducted via Statistical Package for Social Sciences (SPSS) with a special focus placed on the relationship between the three primary dependent variables:

- Mental health care diagnoses & availability of care
- Employment rates for EFMP adults
- Reported EFMP satisfaction rates

Qualitative methods of discourse analysis were used for constructing the survey and analyzing results. Discourse analysis is particularly useful for examining how people conceptualize and respond to what they perceive to be social inequalities.[xi] Adults enrolled in EFMP must navigate at least two discourses: that of EFMP and that of the health care system/TRICARE.

Data Collection Instrument

Because the military population is diverse and located throughout the world, the most effective and common data collection instruments are online surveys. Due to the lack of existing secondary data on military children in special education, Partners in PROMISE drafted its own data collection instrument in collaboration with the Ohio State University (IRB: 2021B0171). The survey covered many topics, from medical/special education wait times, Likert scale satisfaction questions, number of military moves, demographic data, and long-term educational outcome goals. Qualitative questions were interspersed throughout the survey to allow families to share the details of their special education experiences. Units of analysis included the number of military families who filed complaints with a school district and familiarity with military and civilian special education services and concepts. There are approximately 140,000 individuals (adults and children combined) enrolled in EFMP. [xii] The survey instrument collected 728 responses, with 160 coming from adults enrolled in EFMP or service members whose spouse is enrolled or meets program eligibility requirements.

The instrument consisted of 294 possible questions (EFMP adults were asked a total of 60 possible questions) and took roughly 5 minutes for parents to complete with a 63.5% completion rate. Because the distribution strategy focused on a combination of purposeful and snowball sampling,[xiii] which is the military family nonprofit standard, it is difficult to measure the response rate. Partners in PROMISE sent the survey via direct email campaign to 861 recipients including partner organizations who previously agreed to distribute the instrument.

Citations

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