

Compiled Submissions to the
Military Family Readiness Council
February 2017

by Military Families and Advocates regarding challenges in obtaining care for their children,
particularly those with complex and chronic conditions

Shared with the Defense Health Board
Spring 2017

For its consideration in completing its task to review and recommendations to the Defense
Health Agency regarding pediatric healthcare improvements

(please accept apologies, due to redacting of personal info and scanning of
documents, some formatting quality is impaired)

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To whom it may concern,

My name is Daniel Hult, and I am a Technical Sergeant in the Air Force. My 11 year old daughter has Rett Syndrome; she is currently in hospice where we are currently stationed in Maryland.

In 2015, I received a 3 year assignment to Hawaii. Through the EFMP process, my daughter was denied travel. I quickly applied to have the assignment cancelled due to my daughter's severe condition, and my application was approved. 3 months later, I received the same assignment. I applied to have the assignment cancelled again; but this time, my application was denied. I was told I would have to serve the 3 year assignment unaccompanied. Considering my daughter's condition, this is basically asking me to miss her last few years of life. I fought it, and I began researching the way EFMP policies are written for Air Force members.

We successfully found a way to avoid the assignment when somebody offered me a one-year unaccompanied assignment to Korea instead. I leapt at the opportunity. 6 months later, right before I left, that assignment was cancelled by the gaining MAJCOM. Nearly out of options, I began working very hard to bring attention to the issue that I now faced- I was going to receive the Hawaii assignment again, I would not be able to bring my family, and there was no policy to protect me when it happened. There were only loopholes and temporary deferments, none of which actually guaranteed I could be here for my daughter.

In December 2016, as expected, I received the assignment again. It would be 3 years in Hawaii. I am now applying for a humanitarian deferment- hoping to kick this can a little further down the road. I do not know what will happen in one year if I get this deferment. Maybe my daughter will still be alive and I will have to fight this tired battle again. EFMP is not working for me in this case, and because of policies like "equal distribution of overseas assignments", the Air Force is trying to send me on an extremely long routine assignment away from my family. This is not a contingency. This is just a routine PCS. There is no emergency that requires my presence in Hawaii. I can do my job right here, where my daughter is on hospice, just as well as I can in Hawaii; but my career might be ended if that is what has to happen for me to stay

with my family. There ought to be some relief for families like mine, because the burden of a terminally ill family member simply ought to warrant some reprieve from an unthinking assignment system. The current Air Force system offers me only one year of deferment for a terminally ill family member. I have tried to accept another assignment, one that would reduce the time away to one year. It is my opinion that a three-year separation is far too long when you aren't talking about a contingency, and that is not even considering my family's special circumstance.

"Equal distribution of overseas assignments" hurts special-needs families. The assignment system could be more logical, and EFMP protections that keep families together could be more effective. Please address this issue so that special-needs families do not have to worry about things like this happening. Please protect special-needs families from facing choices like the one I am now facing- between ending my career and possibly missing the end of my daughter's life.

Submission from

, Friday, January 12, 2017

O002-Feb2017 o/

Good Morning-

I saw on one of the Autism support Facebook pages I'm a part of that we could submit concerns to you all for the upcoming conference. Some background information about me is I am currently active duty as is my husband and we have a 10 year old son that is on the spectrum (I know that they said the spectrum wasn't really a thing any longer but I still say that)

Our son was diagnosed when he was about 2 and since then it has been a bit of a challenge to say the least in the way of services and care. We were stationed at Seymour Johnson AFB, NC when he was first diagnosed and to be honest we didn't have a sense of direction on where we needed to go in regards to getting him the services he needed. I think that we knew about EFMP early on and we were in constant contact with the POC and she offered as much as she could; but she too had a child on

the spectrum (that subsequently went to the same school with our son) but when she left Mr Freeman the school liaison took over that job as well and he was very hard to reach, also a lot of the stuff that we got in the way of correspondence was in regards to functions and such that were recreation capacity.

We didn't find out about the ECHO program until close to the end of our time at Seymour Johnson and that was when we enrolled in ABA therapy. I believe had we had that knowledge sooner that perhaps it would have made a difference in his care and development. By the time he started to get this service he was already 6 and had been diagnosed 4 years.

Here are some things that I would like to see in the program for children with special needs. We were told that children are cleared medically for PCS but nothing else. The issue with that is this, being medically cleared is fine but there are other things that need to be considered like wrap around care(daycare), medical care outside of the clinic services like therapy and nursing assistances services amongst other things.

Having the EFMP program in theory is great but there seems like there should be more for the families that fall under that umbrella like support and relocation help, schools that are the most beneficial for the needs of that child(ren) and where they can get the care and therapies that they need. When a person finds out that something is different about their child they sometimes are in shock; sometimes it's hard to navigate through what to do next; that support is missing in the EFMP program. Now, I can't say that for every location but the ones we've been to it has been.

When we first got here to Offutt AFB, NE it was a challenge yet again trying to find childcare for . due to discrimination laws no daycare could deny us at least a trial for admission for

We felt air11ost in every place that mannerisms and quirks were proving to be too much for every care provider that we encountered. So in addition to losing money for some of the childcare places that required us to pay for the time that he was there, we were burning leave to keep with us because we couldn't find anywhere for him to go.

went through about 6 daycares in several months. There should be an incentive in place for people who work in base childcare to have extra experience in ABA, special Ed, special needs and the like so that people who have children that have special needs they can be accommodated also. I know that in saying that it's a really tall order but I think that because the military is a one stop shop encapsulating all that we could need (

medical, housing etc) this is something that is really needed.

I have found that not having childcare and resources is a daunting experience. Thank God I met my friend .

She gave me more information than I could ever have thought to ask for. My suggestion or medical clearances is when a child is cleared to PCS that their actual needs be considered. If they have autism, special feeding needs, a tracheotomy, downs, fragile X whatever. I don't know if this is something that can even be considered; when we came to Nebraska it was so new for - and his stress and disorientation was compounded more so than ours because not only was he dealing with major change but he was also dealing with himself and not being able to articulate to us how this was all making him feel.

With children with special needs, sometimes time lost is opportunities lost. Time that resources could have been established and skills and functions could have been honed and cultivated, improving a child's overall quality of life. Overall it would be nice to have more help and more support. Sensory movies and events for our kids are great but since most people have children that don't have a special need in addition to their special need child; we normally just assimilate into the activities in society.

I know that I had a lot to say and I'm sure there are things that I may have forgotten but all in all we just need a program that give us a feeling that its for us, to help us not something created just so big Air Force can say they're helping us (an old co worker was told this by someone at AFPC).

Thank you for reading this and thank you for your time.

I've been asked to submit an issue I have as a military family with a complex military child for the upcoming DOD Military Family Readiness Council meeting.

My daughter has an extremely rare syndrome that has several rare diseases that fall under it. PCSing is always a troubling time in our family, even if we are moving to an area with every specialist she needs, because as we move from region to region we are put into a situation where we don't have her medical specialists already set up at our incoming location for IMMEDIATE care. If she were to be stable, it would not be an issue, we would wait to be enrolled in our new region, we would wait for an appointment to see our new PCM, and then we would wait for her PCM to refer us to, more often than not, outside civilian specialists.

Rarely is there little to no wait to see new specialists, most of the time there's a 3 to 6 month or even more wait for the specialists to see new patients, and that's on top of the weeks that have already passed waiting to get in to see the new PCM and waiting for your referrals. I need to be clear that a PCM, whether it be a pediatrician or a family practice doctor is not at all equipped to handle my child's medical needs.

Two of our last three PCSs, we ended up in the emergency room with life threatening complications/ illness and no specialists who are familiar with her history and her diseases. An ER trip that turns into a hospital admission is not unusual in our lives and we are grateful that we have that option, but when there is not a doctor familiar with her diseases and her treatments, who can act immediately her very life is at stake.

The most recent PSC hospitalization had the worst communication and treatment, and unbeknownst to us the hospital we were told to go to had none of her specific specialists with privileges at that hospital (a fact that I stated above was unknown to me as it is advertised as a Children's Hospital), and no specialists at all in the state or region who were familiar with her case. This meant delays in my child getting the proper treatment that she needed. This is NOT acceptable.

Tricare, EFMP, personnel, I don't know who, but somehow, somehow these kiddos with fragile medical needs need to be coded, preapproved, pre-authorized so that they are set up months in advance with the new specialists so **they are.** **Care** from someone who is a specialist at the gainmg location who will know their history and treatment, should there be a crisis.

I'm writing to ask that you do not take away respite care for military families with special needs children.

Thank you

Submission from:

Thursday, January 5, 2017

t)000reb 20/7/21 -

To Whom it may concern,

wanted to say thank you for asking for opinions from military families with special needs kids. It is so nice that so many people in the upper levels of government are taking time to listen to military families. I cannot begin to say what a blessing the military health care has been to us. My husband is a physician at USAFA and works long hours taking care of cadets here, which is stressful enough. Adding into that the stress of having two children with autism makes our lives very busy. Having access to good quality ABA therapy and respite care has been very helpful to our marriage and family. Thank you so much for taking care of our special needs children in this way.

am also writing this letter to follow up on a comment that Mr. Jeremy Hilton made at the end of the EFMP forum with the Secretary of the Air Force. He made a comment about expanding the ECHO program to mirror the medicaid waiver programs that are offered in each state. This is something very near and dear to my heart, and I wanted to explain how this problem has affected my family.

My son was diagnosed in Ohio at that age of 2. My husband and I were overwhelmed with the diagnosis and asked other families for advice on what to do for treatment. Several people mentioned that there was a medicaid waiver program to apply for. We tried to apply for the Medicaid waiver program in Ohio and did not make any progress due to the long wait list and paid out of pocket for therapy in attempt to get our son early intervention. A few months after his diagnosis, my husband got a new duty station in Texas. While in Texas we received the heartbreaking news that our second son also has autism. We got on the wait lists in Texas, and due to my husband's education in the military, we were able to stay in one duty station for 6 years. However, even though we were there for such a long time, we still never made any progress on any wait list in Texas. Our next duty station was Colorado.

By this point I was very discouraged from the process of applying in each state for services, for nothing to come of it. Please know that the process of applying is a long, emotional, and complicated process. The medicaid offices always seem to need more documentation than I have on hand so it takes time to get the needed paperwork and the process is very taxing emotionally because you have to go through and highlight all that is wrong with your child. I started to process to apply in Colorado but the process was very hard to figure out where to apply, who to apply to, and what all was needed to apply. It took me another 2 years to go through the application processes and 9 months for the process of my application (Colorado happens to be a state with "no wait list"). I am happy to say that my son is now on the medicaid waiver in Colorado, but now we are moving again in 6 months. Do you see the source of my frustration? Creating a benefit that could move with us from state to state would do a world of good for our and other EFMP families. The system seems stacked against military families who have so much already on their plate. Anything you could do to help would mean so much.

Warmly,

Submission from: , **Sunday, December 18, 2016** *ooo7reh20171u* *R.*

What can be done to quickly move forward expanding the ECHO benefit to mirror state by state medicaid wavier programs?
The wavier program is discriminatory for military families.

have two special needs children and have never been able to access services till our recently assignment. When we move this summer, we will again loose services as we move out of state. In the 9 years that I have tried to get services, we have received 1 months of medicaid wavier services so far, due to frequent moves mandated by the military. The process takes so long each time we move. It is really discouraging.

0008 Feb 2017 mtgk

Submission from: , January 2017

On December 11th, 2016 my daughter, [redacted] was discharged from the hospital following her third brain and spinal surgery with the instruction to start physical therapy immediately. We are still waiting to start services even though we have had a Tricare approved authorization in hand for weeks.

My family is currently stationed in Bremerton, WA- one of the few Navy bases designated to help families with kids with needs like [redacted]. The system from the outside looks solid- put families in an area that is rich with military and civilian resources that can fill the needs of these special families however this system isn't without its flaws; the two major flaws being the geographic hardships when accessing care and services being spread too thin by overcrowding in the area.

Currently, there are 75 Tricare approved physical therapists within a 25-mile radius, 7 of which specialize in the type of physical therapy that Josie needs. Those therapists per Tricare's website are 17 miles away but what Tricare fails to take into consideration is that 12 of those miles are directly across the Puget Sound. Travel around or across the sound becomes a financial hardship, especially when multiple appointments are needed each week. Families like mine are then forced to choose between the financial burden of traveling for the right type of specialist or to use a local provider that doesn't specialize in the type of care needed.

There are programs put in place by Tricare that help cover the financial hardships acquired if travel exceeds 100 miles but that is 100 miles as the crow flies, not physical miles traveled. From our door to the closest clinic that meets [redacted] needs is 77 miles meaning we wouldn't qualify for assistance to cover gas and the numerous tolls along the way.

When families do find a provider that will work for their child's needs, they run into long waitlists. Currently, the wait for an initial evaluation for a pediatric occupational therapist in our area is three months. Three months from the time a physician states there is a need for additional care before the child can even be evaluated for services. With a steady influx of new EFMP families moving to the area and established EFMP Category 5 families being homesteaded, the local service pool has become diluted and, as a result, the waitlists get longer and longer, delaying needed services even more.

If flaws in the EFMP system, specifically those used to move families to areas with resources, aren't addressed, the benefits of the program will become obsolete as families will no longer have access to local resources.

Submission from:

, January 12, 2017

0009 Feb 2017 MGR

This submission is
from Autism
Advocate.

is an Air Force Spouse, Autism Parent and Military Child

Concerns with EFMP

1. Face to Face Requirement

We are on our third time moving as an EFMP family. While it was never required (or maybe just never done) in the past, families now have to bring in their EFMP dependent for a "face to face" meeting before the PCS can be approved. No one has been able to give us (or other families) a reason as to why this is necessary, only that it is in the AFI so we have to do it. We already have to submit every medical summary, IEP, and treatment plan to the EFMP office, so I am not sure what someone looking at my child will accomplish. Does the government not trust the professionals that signed off on all of the required paperwork? My child has an invisible disability (autism). A physical examination {which is most of the time not even attended by a doctor} will not benefit anyone. Our son and many special needs children have a very hard time with transitions and an appointment of this kind seems like an unnecessary experience for him to go through. We also have to pull our kids from much needed therapy and school to accomplish such a meeting. It would nice to be given an actual reason as to why it is necessary. And if the only reason is that it "is the rule", perhaps the rule should be changed.

2. EFMP Efficiency

EFMP offices nationwide do not have the experience or resources for EFMP to be carried out in an effective manner. Staff are constantly changed out so there is no continuity or accountability. After our second EFMP move we found out that the first base we moved from had never sent our paperwork and ECHO enrollment to the second base. We had go back and make numerous phone calls to bases from two assignments past to be able to get into the new system and continue getting the services our son needs. And of course nobody working there had worked there when we were there, so the paperwork took weeks to find. If families are required to go through the EFMP process it needs to be more streamlined and efficient.

EFMP offices rarely have updated databases as to what type of providers are in the area. There could be therapy providers with openings but because no entity researches available area resources families are denied assignments that could work for their EFMP child. Parents who have researched potential assignments get no input as to what medical provider/ school district services are available. Parents also may have input as to what services their child no longer needs or no longer needs to the same degree as autism is a developmental disorder and level of development and necessity for therapy is ever-changing.

EFMP offices will only refer out to in network providers so many times families whose children could be benefitting from therapy get waitlisted while out of network providers that no one is aware of have openings.

EFMP does not check area availability as far as waitlists are concerned for certain therapies and medical services. This is evident in the automatic approval to the DC area (which has many families without services because the waitlists for therapy is so long due to the influx of military autistic children to this area). EFMP will clear families to areas that do have specific medical specialties available but waitlists

are so long those families will never access those services. Without checking real availability the purpose of EFMP is negated. The same goes for the EFMP clearing families to areas with school districts that are not following minimal federal educational requirements. Some bases have area schools with well-documented deficiencies for disabled children and EFMP is only basing clearance on medical providers (we found this to be true for Maxwell Air Force Base).

3. Case Manager Deficiencies and Overload

Families enrolled in ECHO and EFMP are supposedly assigned case managers to help them navigate services and Tricare issues in their new area. This process is inconsistent at best. Many families are never assigned a case manager and when they call to request one they do not hear back or do not hear back in a timely enough manner for the case manager to be helpful. Our case manager when we first arrived at the Pentagon called my husband's cell phone. His cell phone has to be turned off during the day. I called the number back and left a message with my number so that I could make contact with the case manager. She once again called my husband's number back. I left four more messages and never heard from her again.

Concerns with TRICARE's new ABA Policy:

The last names and therapist's names have been left out of this article to protect the children and parent's quoted. If any further information is needed regarding these specific incidents most of those quoted were open to elaborating to the council their concerns. Article originally published here: <http://fromthebowelsofmotherhood.blogspot.com/2017/01/military-autism-families-fear-loss-of.html> < Caution-
<http://fromthebowelsofmotherhood.blogspot.com/2017/01/military-autism-families-fear-loss-of.html> >

Military Autism Families Fear Loss of Services Amidst New TRICARE Policies I

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with a military child on the spectrum.

It's the same fight, different year for many autism families across our country. As TRICARE rolls out new policies the ABA and military autism communities are scrambling to figure out what it all means and unfortunately it doesn't look good. ABA is an autism behavior therapy that is currently one of the only treatments endorsed by the medical community to address maladaptive behaviors, help overcome deficits and delays, and provide autistic individuals the tools they need to communicate their wants and needs. This therapy has been known to do everything from giving a nonverbal child words to reducing severe aggression. It can reduce dangerous behaviors such as bolting and self-injury. It can potty-train an 8 year who is still in diapers. It can teach an autistic child how to feed and dress themselves.

Many autism families will attest that ABA therapy is value added. Bonnie K. (military spouse and autism parent) describes what a game changer ABA has been for her family: "ABA was a huge help for our family. My son went from combativeness and aggression to cooperative and able to attend school." Because of similar testimonies and clinical findings most healthcare and state services are moving in a

direction that will get more families covered (thanks to the tireless lobbying efforts of Autism Speaks< Caution-<https://www.autismspeaks.org/advocacy> > and other organizations 45 states have now signed on to autism insurance reform). While most state and private insurers are moving towards more coverage for autism families, TRICARE is making it more difficult to access the autism services it already covers. TRICARE requires more ABA provider credentialing than any other insurance, which is costly and time consuming for providers making TRICARE patients harder to serve. Their new policy (which was released at the end of November and started implementation on January 1st of this year) mandates providers administer and submit a behavior inventory every year for services to continue. This is in addition to the re-authorizations that need a specialist referral and severity level to be submitted every six months that families are already burdened with acquiring. Many families have already had reauthorizations rejected in the new year due to the short notice for the required behavior inventory. Thus military kids are already losing services due to the new ill-planned policy changes.

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A military child with autism works on gross motor and transitions with his therapist.

And that's not the worst of it. The policy that most worries providers and families alike is the new requirement that already diagnosed kids will need to have diagnosing evaluations re-administered every two years to continue services. The evaluations must be administered by an autism diagnosing specialist, many of whom have waitlists 12-24 months long for an initial evaluation. And many of whom will not entertain the idea of taking up a valuable 2 hour evaluation slot for a child who already has a diagnosis when so many kids are awaiting initial diagnosis so they can start receiving services. The new requirement that seems to be seeking a new diagnosis for a lifelong disorder has everyone pretty confused. Military spouse voiced her frustration with the changes: "I'm just dumbfounded at

re-diagnosing every two years. Are they supposed to outgrow autism?! The need for ABA may change, but the diagnosis itself will never change if they were initially correctly diagnosed by a qualified provider."

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An ABA therapist practices walking in the "wrong" direction with her client. He has struggled for months with rigidity as to which way they can walk from his Caution-home.
Despite military health care facilities' continual pleas that they are undermanned and unable to carry out such testing, TRICARE has moved ahead with the new policy. Military families are already facing waitlists every time they move, possible regression every time they move and nationwide provider shortages. Provider and autism parent' . states, "As a parent, waitlists are already long. My children have been without services for 6 going on 7 months since we moved." Advocates point out with the new testing requirements access will only be further restricted.

While families wait to be retested many fear they will lose services during critical times. Autism parent Kimberly G. cannot

imagine what such a loss would mean for her son. "ABA has changed our lives. I went from having a non- verbal, angry, unresponsive child to a verbal, happy, connected child. We went from not being able to leave our home due to meltdowns and anxiety to being able to go grocery shopping and go to church.

My child went from not interacting with peers to being a kid that loves being around others and asks to play with friends. He is thriving...Losing services would be detrimental to him right now because he is on such a good path. He loves his therapists and the change in him is remarkable. We live in a small town with one ABA provider. They are overloaded as it is. Having to deal with re-testing and re-authorizations, especially as slow as TRICARE moves, would be a disaster for us."

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An ABA therapist practices nice play with a military autistic child who has had severe aggression towards his siblings.

This action on behalf of TRICARE and the DoD has families wondering if the government is intentionally trying to limit access to covered services. This isn't the first time TRICARE has slashed autism services and military families have paid the price. In 2014, TRICARE planned to cut autism provider reimbursement rates in half. (Caution-<http://thehill.com/policy/defense/220201-pentagon-to-cut-autism-healthcare-payments-in-half>< Caution-<http://thehill.com/policy/defense/220201-pentagon-to-cut-autism-healthcare-payments-in-half>>)
Many providers would have shut down, downsized or stopped taking Tricare clients leaving families with no option for services for their autistic children. Due to the outcry from military families and the media attention, the Pentagon back-peddled and postponed rate reductions. They later came out with a lesser rate reduction based on cost of living. (Caution-<http://thehill.com/policy/defense/272749-pentagon-under-fire-for-proposed-cuts-to-autism-care>)
< Caution-[https://www.blogger.com/\(Caution-http://thehill.com/policy/defense/272749-pentagon-under-fire-for-proposed-cuts-to-autism-care\)](https://www.blogger.com/(Caution-http://thehill.com/policy/defense/272749-pentagon-under-fire-for-proposed-cuts-to-autism-care))> These reductions hurt families in low cost of living areas the most as smaller providers collapsed under the red tape and lower rates. Because of all of these changes and the surrounding uncertainty many military families' services went on hold or disappeared. The most recent NDAA (after many senators and organizations' advocacy efforts) reversed these rate cuts, but for some providers it was too late and those areas are now without services altogether.

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are calling their Senators and reaching out to the powers-at-be in hopes that their voices will be heard. But how long will it take the DoD to realize how detrimental these changes will be for families? And how many military autistic children (who already face a great deal of challenges) will go without critical services in the meantime?

To Whom It May Concern:

We are an EFMP CAT 5 family who has had experienced pediatric hospice care twice for the same dependent. The way hospice is handled with Tricare is outdated and causes an immense amount of undo stress in an already unimaginable situation. When a child is admitted to hospice, the family has to make the decision to relinquish all curative care. That family is then at the complete mercy of the hospice company. Tricare is no longer involved. Tricare no longer covers meds, doctors appointments, equipment, most importantly, the specialists. When we had to admit our child to hospice care a second time the company we were with refused to allow him access to his physical therapist, occupational therapist, and speech therapist regularly. They refused to upgrade his feeding tube to the type that was necessary to nourish our child. And Tricare does nothing. Once you are admitted to hospice, Tricare relinquishes their responsibilities for that child. Tricare will no longer cover follow up appointments with specialists, they no longer cover equipment the child needs. We had to make a very difficult decision. Do we choose the much-needed nurses and doctors that can come to our house and prevent our child from being exposed to further illness in a hospital setting or do we give that up in hopes of continuing to treat his symptoms and allowing him to maintain his already extremely limited communication and mobility? This is a decision no family, especially those that serve our great nation should have to make. The emotional strain of having a terminally ill child is difficult enough without having to pick and choose his means of care.

Hospice does receive a stipend for caring for the patient through the insurance but clearly when children are concerned, this is not remotely close to the type of care a child and their family need during the end of life care.

purpose that Tricare does not force the family to choose between hospice services and their current doctors. That we are not left in the lurch to be completely at the mercy of a hospice company that, in many cases, does not have protocol for treating children. That Tricare continues to follow the child and allow as needed visits to the established specialists and cover reasonable treatments for that child.

Submission #2 from

, February 3, 2017

0011 Feb 2017 MtgR

To Whom It May
Concern:

Our family is an EFMP category 5 in the Navy. While I understand the premise of having the EFMP program, it has proven to be much more of a hassle and career limiting program than any benefit to our family. The one good thing that has come from the program is our respite hours.

Having to disclose our child's terminal status to the military has prevented my husband from doing his job, prevented him from {reasonable} duty stations that are required for advancement of his career and have essentially trapped us in a location that is not in the best interest of any of our children nor the service member's career.

We are currently attempting to negotiate orders to a shore duty that will significantly help his chances of advancement and have been blocked at every turn. Blocked by the EFMP department in Millington who are trying to implement rules that do not exist and are unreasonably impossible to follow. We were told in order to move to Charleston, SC we would have to contact every specialist our child would need there, getting letters from them, on their letter head saying they agreed to treat our child while we are there. This is unreasonable on every level.

First, the "suggestion" of the five duty stations that are generally CAT 5 areas, prevent my husband from furthering his career as none of those stations provide the titles that are critical for his advancement. I understand the five duty stations are based on MTFs that can handle the treatment of a medically complex dependent. Nevertheless, that unreasonable stipulation forces the service member to make unnecessary choices between their family and their career. Why is it not expanded to include the civilian hospitals that can handle medically fragile dependents? For our situation, The Medical University of South Carolina is located in Charleston and has more than adequate medical care for complex individuals. In fact, it is closer than the MTF we are considered under here while attached to Kings Bay. Civilian hospitals and treatment centers should be more readily considered when the service member and their dependents are negotiating orders CONUS. Instead of the only option being unaccompanied orders and causing hardship by forcing the service member to leave their dependents behind. Keeping the family together whenever possible should be of utmost importance to the powers that be.

-----second, we have been told it would be re obtainable-----+

every specialist our child requires, on their letter head, signed by them stating they would treat our child while we are at the new duty station. I understand the need to ensure a dependent can receive adequate care when relocating. However, this approach is not only unreasonable, it is impossible for several reasons. No {decent, upstanding} doctor is going to agree to see a patient, let alone a terminally ill/ medically complex patient, without their records and a face to face visit. Who is going to pay for the travel associated with this and the time that would be required for the service member or the spouse to miss work to meet with these doctors? What doctor is going to sign off on agreeing to treat a patient they haven't met? All of the extra travel this would require would put unnecessary stress on the EFMP dependent. No doctor can guarantee they will be at their current practice for the duration of a set of orders. Jobs change, medical needs change, patient and doctor's wishes change, part of the reason Tricare standard is the option we choose is the freedom to find doctors who truly understand that our EFMP member is outside the box. So much time was wasted trying to jump through these impossible hoops. Unnecessarily unreasonable time because of

the disconnect of the Powers that be trying to make

sure their bases are covered and that translating to impossible regulations, which are not a written instruction in the first place, causing undo stress and discrimination for the EFMP community.

Instead, I purpose you allow the service member and their family to research and ensure that the gaining duty station does have doctor's civilian or military that can accommodate the needs of their dependent. And allow them to write a letter stating that they have contacted these offices on these dates and they can accept new patients and we have made an appointment for such and such a date after our PCS. I would go so far as to suggest a statement saying that the service member and their family have done the research and would not ask for a military move for the duration of the current orders in the event these statements turn out to be false and the proper leg work was not done. In adopting a model such as this to determine adequate care, it opens up so many more options for service members with medically complex dependents.

Submission from:

, Monday, January 2, 2017

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Dear President Trump, General Mattis and the Family Readiness Support Council,

Thank you for giving me opportunity to make a statement to this Council. Unfortunately, I cannot attend this support council meeting because our family resides at Camp Pendleton in Southern California.

Please let me introduce myself-- my name is "I am the mother of a category 3 Exceptional Family Member (EFM). I am also the Lead Family Representative for the Exceptional Family Member Program (EFMP) Support Council of Camp Pendleton. In these quarterly meetings, I represent military families and bring up issues they are having regarding their EFMs to the CG, SgtMaj of Camp Pendleton as well as Marine Corps Community Services (MCCS,) Resident Energy Conservation Program (RECP,) and other representatives from major programs based here on Camp Pendleton.

My mission is to make you aware of the issues that we have here at Camp Pendleton, which I am sure are issues over the entire military community.

1. Homesteading: Homesteading should be an official option in situations of critically ill/mentally ill EFMs. In my personal situation, my daughter has numerous chromosomal defects that have caused autism, bipolar disorder, brain abnormalities, health problems, severe behaviors including self-harm and suicidal ideations. She is only 7 years old. She sees numerous specialists: developmental pediatrician (quarterly or as often as needed), neurologist, pediatric ophthalmologist, ENT, pediatric psychiatrist (monthly or more as needed.) She has speech therapy (2hr/wk,) occupational therapy (2hr/wk,) physical therapy (as needed) and Applied Behavior Analysis (12+hrs/wk.) She must have a 1:1 aide at school. Our family is currently awaiting orders for my husband, and trying to find a base that can accommodate all her needs without long wait lists is proving to be a daunting experience. In the case of high special-needs children like ours, we should be permitted to reside at our current base where, as a family, we do not have to make that difficult choice between our child's healthcare needs or our spouse's career.

2. Housing: On Camp Pendleton, American with Disabilities Act (ADA) compliant housing has a 6+ month waiting list. Lincoln Military Housing should not be allowed to offer an ADA compliant home to a family without disabilities just because the house is empty. All military housing facilities should be required to save the ADA compliant units for people who need them. When an ADA compliant home is not readily available, the families are given a temporary house which could be hazardous to the EFM. It also puts a huge financial burden on the family because the military will only cover the cost of the permanent change of station (PCS,) not moving from a temporary house to an ADA compliant house.

3. EFMP: Even though Camp Pendleton is a base that is comprised of mainly Marine Corps personnel, it also has a large Navy presence as well as Army and Air Force. EFMP "benefits" are different for each branch of the military. Each branch also has their own exclusive EFMP data bases, which none of the other branches have access to. This informational exclusivity situation needs to change; help for these families should never be denied. For example, the Navy EFM parents cannot get help from a Camp Pendleton case worker, because they do not have access to the Navy EFM database; so the family calls the 32nd St Naval Station and they refuse to help, because the family is stationed at Camp Pendleton. If there was some type of shared access to the data bases, these families would be receiving the help that is so desperately needed.

4. Respite care: In the USMC, category 3 and 4 EFMs qualify for respite care. We must use an Registered Nurse (RN,) Licensed Vocational Nurse (LVN,) Certified Nurse Assistant (CNA,) or ABA therapist to provide respite. Respite care rates are based on

the base Child Development Center (CDC) day care rates. In our case, we are approved for 20 hours/month at \$12/hr. Unfortunately, in Southern California, an average babysitter charges \$20/hr. It is next to impossible to find a respite provider willing to be paid only \$12/hr with all the qualifications that EFMP requires. Respite rates need to be based on the prices that respite care companies in the specific area charge. Another problem with the respite care program is that care is required to be paid as an out-of-pocket expense, making the families wait (sometimes months) to be reimbursed by EFMP. Many respite programs pay the providers directly, rather than the client paying and waiting to be reimbursed.

5 Tricare: Tricare needs to be consistent with coverage for special-needs families. Tricare changes their Autism coverage and/or requirements approximately every 3 months, if not more often. Their multiple changes result in interruptions of therapies because the families, patients, doctors, insurance and therapy providers all get confused on what they need from one other. Everyone involved ends up getting a different answer of what is needed from Tricare, and the most frustrating part is that even Tricare customer service agents are confused.

Thank you for listening to the concerns of my family as well as the other families at Camp Pendleton. If you would like to ask questions about my statement, or have my statement personally via video call, please feel free to contact me. My personal cell number is 843-263-3316.

Submission from , **February 3, 2017**

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To whom this may concern,

I'm writing on behalf of my family in support of programs and services for DoD Family Members with Special Needs, including healthcare and the Exceptional Family Member Program.

I am an active duty Army officer with 14 years of service including 3 operational and combat deployments. My wife is a 10 year veteran of the US Army with 4 operational and combat deployments. In 2014 {while I was deployed in support of a Presidentially mandated mission), my son, was diagnosed on the autism spectrum. Since that time, he has received weekly occupational therapy, speech therapy, and both in home and in school ABA therapy. To say that these therapies have been life changing for is truly an understatement. Through these Tricare provided services, my son has developed into a high functioning young boy who is slowly but surely catching up to his age group peers. For the first few years of his life, was often labeled as "too difficult to handle" and "never following directions" by those who had to interact with him. Through an intense regimen that Tricare services has provided, my son has grown and evolved into a child whose potential is unlimited. But the road is long, and the journey is not over.

Due to recent policy and statute changes, my son's services are in danger. Changes such as:

- 1) Tricare requiring additional testing for ASD diagnosis (requiring ADOS2 and re-testing every two years; and if a patient shows growth with testing, will they reduce the services that have helped to get them to that growth point, potentially causing regression);
- 2) Discontinuing ABA therapy for any diagnosis other than an ASD diagnosis;
- 3) Tricare not allowing educational goals for ABA therapy {ABA therapy is meant to help treat the patient as a whole, and for a school aged child, appropriate educational interactions should be allowed to be included on the treatment plan);
- 4) Cutting funding and reimbursements to ABA providers while increasing operating and training requirements for the same companies; thus creating a smaller pool of companies that can provide services to an ever growing number of patients that need ABA therapy.
- 5) Tricare not paying for orthotics for children (unless they have diabetes)- despite having dx with low muscle tone and needing Occupational therapy.

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"Power to Influence!"

Submission from : , **February 3, 2017**

Sincerely,

Dear Council Members,

I'm writing today regarding the recent changes in Aba coverage and how unrealistic they are for military families. Would you please provide further clarification/explanation on the issues I've noted below:

- referring to question 2, you state that a child who was diagnosed prior to October 2014 DOES NOT need to be re-diagnosed. As long as the child "conforms" to the DSM-5 criteria for ASD and the proper documentation is provided by one of Tricare's approved specialists. Yet, that statement is not made clear with regard to the new testing requirements and reviews. So, my question is twofold, in the above context what does "conform" mean and do children diagnosed prior October 2014 need all 3 tests done, specifically the Ados-2? What documentation are you requiring from the doctors?

Secondly:

- According to the following,
"AAP guidance states that a new diagnosis of autism is not necessary unless clinically warranted. Why is the ADOS-2 testing required at the 2 year review?"
"I understand the NDAA requirement for TRICARE to report on patient outcomes. What evidence is DHA relying on to support the use of ADOS-2 and IQ evaluations to show patient outcomes?"

I have an appointment for my son in February and don't want to waste the doctors time nor put my son through unnecessary testing. Additionally, it's imperative that the doctors be given further clarification as to why they are being asked to re-diagnose. Many doctors are refusing to do the testing or feel that it is a waste of time.

Thank you for your hard work on behalf of our families. I look forward to seeing some changes as these concerns (and many others) get the attention of senior leadership.

I cannot stress enough how once again the burden is put on the EFMP families to make calls, write letters, try and get referrals...The one thing that EFMP parents don't have is TIME.

Submission from:
January 12, 2017

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Dear Sir/Ma'am,

Thank you for the opportunity to submit a statement regarding the DoD's services for special needs family members. I am a retired Army officer, military wife and mother of a 10 year old son who is autistic and non-verbal. I would like to express my gratitude for the outstanding Applied Behavior Analysis (ABA) therapy that he has received through TRICARE since his diagnosis eight years ago. He has made tremendous progress, which would not have been possible without ABA therapy.

One of my greatest concerns and frustrations, however, is the lack of continuity of services for my son whenever my family PCSes. For instance, when we PCSed from Joint Base Lewis-McChord, WA (TRICARE West) to Fort Sill, OK (TRICARE South) in 2013, my son went without ABA therapy for 11 months because of the waiting list. Had we been able to get on that waiting list a few months before we moved, the lengthy gap in therapy could have been

shortened. Incidentally, we also had to wait four months to resume occupational therapy and five months for speech therapy. This is not just a problem for my son and our family. It is a problem for every military family, particularly when they PCS to a different TRICARE region. I have outlined the issue below.

Issue:
TRICARE Referrals. Currently TRICARE does not allow inter-regional specialty care referrals for Service Members and their families, who are relocating due to a Permanent Change of Station (PCS) move, thereby adversely affecting continuity of care.

Scope: The inability to obtain inter-regional specialty care referrals in advance of a PCS move is extremely problematic for military families who have Exceptional Family Members (EFMs).

Presumably, this inability/restriction is due to the fact that each TRICARE region is serviced by different contracted providers, whose databases and systems do not interface with one another. As a result, Service Members and their families must wait until they arrive at their new duty station to restart the referral process. In many cases, the waiting lists for specialty care and services at the gaining installations are months long. Allowing primary care providers from the losing installation/station in one TRICARE region to make referrals to specialists at the gaining installation/station in another TRICARE region would significantly reduce the time on waiting lists; facilitate a smoother transition; eliminate unnecessary bureaucracy; and improve the continuity of care for Service Members and their families in advance of a

move .

Recommendation(s): It is my recommendation that TRICARE establish a program that allows inter-regional referrals to

be made 30-90 days in advance of a Service Member's report date to the gaining installation/station.

Thank you in advance for your consideration of this issue.

Respectfully,

**Submission from
2017**

February 3,

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February 3, 2017

DOD Military Family Readiness Council and Special Needs Military Families:

I am writing this letter as a military spouse and mother to _____, a special needs child that is enrolled in the Exceptional Family Member Program (EFMP). _____ has been diagnosed with Autism and has sensory processing issues. Autism spectrum disorder (ASD) is a complex developmental disability that affects a person's ability to communicate and interact with others. ASD is a spectrum disorder that can affect people in varying degrees. This results in unique needs for my child. Evan receives special services at school and also requires therapy outside of the school both in the home and in a clinic.

_____ is a four year old that has delays in expressive/receptive communication and developmental delays. We struggle with many daily challenges and he spends the majority of his time in school or in therapy. He goes to a Special Needs Pre K program full time. When he is not in school, he goes to 3 Speech sessions a week, 1 Occupational Therapy (we are switching providers as 1 time a week is not adequate) and has ABA therapy 34-35 hours a week. He has made amazing progress, largely due to the support system he gets through therapy. _____ The thought of the loss of these programs and the effect they will have on my child are frightening. As a parent, to know that the programs work and the thought of those programs being taken away, would result in my child suffering. Regression is always a parent's fear when their child loses a service and unfortunately for military families this could soon be a reality.

In addition to the education, medical and therapeutic needs, as military families we face other unique challenges. Our families are required to move every few years finding new schools, doctors, therapists and friends. Our family units are separated for months at a time, leaving one parent to care for the children solo while worrying about the safety of their loved one. We often live thousands of miles away from our support network of family and close friends. All of this creates additional hardships on top of stress and dedication that is already required to raise a special needs child. As military families, we deplete our military benefits for the care of our children. They require additional care that exceeds the standard Tricare benefits. The extended care health option (ECHO) allows for us to receive care that is not covered such as ABA therapy and durable equipment. It is necessary for our children to receive proper medical care and the therapies that they need to continue their progress.

We are asking that you protect the services for our children. We have recently received the cut to our respite care system, and the rates to our ABA providers have also been cut resulting in losing some providers. Respite care was a very important service for many families and the only opportunity that many families received help with their special needs child. Many families depend on ABA services for their children, they have made progress with this program that they have not made with any other program. To have this therapy cut or to chance losing providers

is the devastating to families. We are devastated that we will be losing our Respite Care for effective July 1, 2017.

This year we cannot allow more cuts to our programs benefiting the families that are often stressed and stretched to the max. More changes to the ECHO program are being considered and need a second look with family input and input by the providers servicing families. A new policy requiring a new autism diagnosis and IQ testing every 2 years in order to receive ongoing care is being implemented. Developmental pediatricians were not allowed to weigh in regarding this new policy. The required testing is a lengthy process, has long waitlist and there are limited providers available to conduct such tests. These new requirements could result in families having a lapse in services that they depend on for the wellbeing and progress of their children.

We cannot halt the progress of these children that fight weeks, months or even years for what others can see as the smallest goal. We ask that you reconsider the proposed changes to the ECHO

ne,ed and deserve. The ECHO program should be closely looked at for the benefit of the EFMP families, these programs should not be cut nor should the new testing requirement be put into place.

Respectfully,

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January 25, 2017

Dear Military Family Readiness Council,

I write today as a wife of a Marine and mother of two sons. Our oldest son has Autism, ADHD, a degenerative and rare form of Epilepsy which required brain surgery in 2013, Aortic Valve Stenosis and Celiac Disease. He currently takes eight medications in the morning and seven at night, in addition to being on a medical Ketogenic diet which requires that we weigh every bit of food he put in his mouth down to the gram. He was recently accepted into a medical study, the Undiagnosed Disease Program, to further help us understand and diagnosis the medical pieces that are missing. This study was recommended to us because the genetic testing that was recommended to us is not covered by Tricare. We are fortunate to have him selected for the study.

Today I write to you regarding the January 2017 Tricare ABA (Applied Behavioral Analysis)/ Autism policy. In accordance with the new policy, children diagnosed prior to October 2014, regardless of whether the child was diagnosed under the DMS-V, are required to be "re-diagnosed." Additionally, if a child was diagnosed initially using the DSM-IV, they are also required to be re-diagnosed or will lose ABA services. Autism clinics and Developmental Pediatricians that specialize in Autism diagnosis using the ADOS test (the gold standard for Autism diagnosis) have wait lists anywhere from 4-10 months long. These wait lists are for initial evaluations, for children JUST being diagnosed with autism. These wait lists do not account for the children that are now being required to be re-diagnosed to continue ABA services. In fact, most clinics will NOT re-evaluate those children already diagnosed because Autism is a life long disorder. Autism does not disappear or go away over time. While children utilizing ABA therapy typically make great gains and successfully master skills previously unattainable, they at no point are no longer autistic.

Our son has been receiving ABA services since his initial diagnosis in 2010. He has learned how to make better eye contact and more appropriately socialize with peers. He has worked hard to learn sight words and learn self help skills. He can now shower on his own and get dressed by himself. He is now able to articulate his frustrations and process his feelings on most occasions after a meltdown. These are just a few of the things we have seen our ABA therapists help us with to push forward.

Our developmental pediatrician at Duke in Durham, NC said it's absolutely absurd to require re diagnosis using ADOS. Children can be reconfirmed as autistic through many other means. The wait time and extensive money on re diagnosing" these kids has us all scratching our heads. The time that could be lost for these kids with therapy because of this new policy is terrifying.

Furthermore, the idea of Tricare seemingly trying to decrease the amount of money spent on our special needs children and the services they need is mind boggling when Tricare covers gastric bypass surgery and now sex change surgery for transgender military members.

Please, please, please reconsider the damage being done to these children. They sacrifice so much being military children that the very least they deserve is the therapy they need to possibly live a somewhat "normal" life.

Respectfully,

Submission from

: January 11, 2017

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DoD Military Family Readiness Council,

Unfortunately, due to geographic limitations, I'm unable to attend the 26 JAN meeting. In lieu of personally attending this event I would like to submit a statement for consideration by the council.

I'm the mother of two, one of which was diagnosed at birth with Down syndrome, plagiocephaly, torticollis, nystagmus, laryngomalacia, tracheomalacia, hypotonia and two holes in his heart (Patent Foramen Ovale and Patent Ductus Arteriosus) that are now closed. Despite early testing during pregnancy none of these diagnoses were discovered until birth. We immediately joined EFMP and we have been extremely pleased with the services provided to military families. However, we believe there is always room for improvement.

1. Tri-Care coverage of cranial helmets:

At four months of age we received the scans of our sons skull to identify plagiocephaly and the need for a cranial helmet. The physicians were extremely optimistic that a cranial helmet would be 99% effective in correcting the plagiocephaly. We began the process to obtain a cranial helmet and to our surprise we were notified that our Tri-Care insurance did not cover a cranial helmet. We were denied coverage and asked by the hospital if we wanted to continue care. How could we not continue care, especially after seeing our son's cranial scans? How could a one income military family also pay for a cranial helmet? Our son required two helmets that cost between \$1500-\$2500 per helmet. Thankfully we received financial assistance from the state of Arkansas and family. We are happy to report our son's skull is now considered "normal". The problem with this scenario is that our family should not have endured the stress and pain caused by not having the adequate medical coverage for something prescribed by a physician. Why are cranial helmets an automatic denial?

2. Therapy (vision and ABA therapy):

At almost two years of age my son has had nystagmus or "dancing eyes" since birth. Nystagmus is a condition of constant involuntary eye movement that may result in reduced or limited vision. Nystagmus is NOT curable, but is treatable by vision therapy and medication. Unfortunately, vision therapy is NOT covered by tri-care, which is furthering limiting and potentially reducing the ability for my son to see.

~~Additional~~ - my son received traditional speech therapy, but was denied Applied Behavior Analysis (ABA) therapy, which is commonly used to treat Autism, because he does not have an autism diagnosis. Tri-care only allows individuals with an Autism Spectrum Disorder diagnosis to receive ABA therapies. However, ABA therapies have proven to effectively develop social and communication skills, reduce inappropriate behaviors and facilitate meaningful inclusion. Research has shown effectiveness of ABA therapy interventions for individuals with Down syndrome and my son's therapist and physicians have recommended this therapy as a treatment option. Unfortunately, once again it's a treatment not allowable under tri-care.

Why are these services not available and who determines what services are approved?

3. Access to American Disabilities Act (ADA) Accessible Play At one years of age I took my son and then three-year-old daughter to play at an on base playground. I remember having a moment, not a good moment, but a moment of realization that my child with special needs had no opportunity to play with his peers. I remember enjoying the playground when I was a child, do you? Maybe you remember seeing who could swing the highest? Those opportunities can be lost for a child whose disability keeps them

from using a playground. I felt helpless for my child and upset that he did not have the fair opportunity to play with his peers. Thankfully with the help from the Force Support Squadron and the Airman and Family Readiness Office the landscape of one base

playground was changed to include an accessible therapeutic

swing designed to support children with physical disabilities and limitations. How can we ensure children have access to play at all installations?

Submission from:

January 11, 2017

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Thank you for taking the interest in the Exceptional Family Member Program (EFMP), the program is dear to my heart. My name is _____, and we were a Marine Corps family with a child with profound special needs from 1978 to 2003, I worked for federal grants through the Department of Education at Southern California's Parent Training and Information Center and developed the California Military Outreach program from 2002-2008. After moving to Virginia, I worked for the Marine Corps EFMP at both headquarters as the EFMP Advocate developing policy and at the installation level as the Training, Outreach Specialist implementing new policy from 2008-2014.

I was proud to be a part of the policy and program changes in the Marine Corps under the guidance of Commandant of the Marine Corps General Conway and sincerely feel the lessons learned as we transformed the program was successful and can be implemented by the other armed forces. Over a five year period of time, the Marine Corps was able to reform their Marine Corps Order, change their funding mechanism, implement new human relations hiring models, streamline their assignment process, develop computerized case management system and provide direct family support through case management and self-advocacy family training. These actions saved the Marine Corps funds by reducing their humanitarian transfers due to lack of support services, provide increase of assignment opportunities to Marines with family members with profound needs, and provide direct family support services to dependents allowing our Marines to focus on their jobs.

Leadership team that was critical to the transformation for the Marine Corps EFMP was General Larson, Mrs. Kerry Lewis, and Mrs. Rhondavena LaPorte.

Key changes to the program that made the transformation successful included changing the programs funding mechanism from Category A to Category C. This allowed profits from the exchange to be used for funding our social programs to include EFMP. The employee positions were changed from GS/contractors to NAF employees allowing for the ability to adjust salaries and dismiss ineffective employees. When congressional cuts started to occur, USMC was able to not only sustain their

Next critical changed included the development of a computerized Case Management System that allowed HQ to communicate to Installations effectively, transfer important documents, and provide

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transformed the system into a
working model.

The final change included reform of the Marine Corps order which focused on streamlining the assignment processes, adequate staffing, real family support, advocacy for state agencies to pay for local services, legal support for families to advocate for state services at two main installations, and family advocacy training on transition, special

education services, state Medicaid. The family support section of the MCO was first modeled after California's Regional Center regulations.

I hope you have the opportunity to reach out to the Marine Corps, the transition was difficult, the transition team made some hard decisions that were not popular, but within a 5 year period of time, the program was reformed and not only saving funds, but provides support to our families.

Thank you,

20 Feb 2017 mtg R

Submission from , **February 2017**

Hello, as a ABA provider currently in the North region we are concerned with the transition to the East. We have been contacted by Humana Military to to join their network but we are hesitant to do so because of the 35% in-network deduction that they will take from provider billable rate. Is Tricare and the EMFP aware that this will cause many providers to leave and become out of network providers? Families are already have problems find ABA providers in many areas. Thank you for your time.

Submission from , February 2, 2017

21 Feb 2017 Altgr

Hello, as a ABA provider currently in the North region we are concerned with the transition to the East. We have been contacted by Humana Military to join their network but we are hesitant to do so because of the 35% in-network deduction that they will take from provider billable rate. Is Tricare and the EMFP aware that this will cause many providers to leave and become out of network providers?

Families already have problems finding ABA providers in many areas. Thank you for your time.

Follow-on email to MFRC from Mr. Abner:

We have a number of families that are concerned about this.

We have had families that have not been able to go to certain posts because there are not enough providers in those areas or because the wait lists are very long.

Many of our families are concerned that when Humana Military takes over more providers will leave the network due to the 35% deduction. This concern does ring true because last year when ABA provider rates were cut a great deal left the Tricare network. We are not sure but it seems this 35% is for all types of providers. Many families in our area already have problems finding doctors that take Tricare to do assessments. There are shortages for certain types of doctors already that help our clients with autism. We have had families compassionate care to our area for services and had others use it to leave. Providers leaving will most likely happen again and the options for families will decrease. Families feel that being limited to certain bases where there are enough providers could hurt their careers.

Thank you for your time and work for the families.

Tampa Recruiting Battalion

U.S. Army Spouse

Edit: my husband feels that someone should evaluate military children's IEP's and school services on a yearly basis to ensure students are receiving a fair and appropriate education.

Plus, he thinks support groups should be tied to the# of EFMP at an installation, NOT THE SIZE OF THE INSTALLATION.

He suggests that the EFMP process should be streamlined so that when updating the EFMP, there is no need to address all of the old diagnoses on the old EFMP. All current diagnoses on the update should automatically overwrite the old information.

He also suggests that the EFMP system should be integrated into the Army medical database system so that military doctors could make updates to the EFMP information directly instead of going through a paperwork process that is laborious for the doctor and time consuming for the family.

Additionally, Tricare should evaluate providers on a monthly basis to determine which providers have availability and which do not. A list can be created from this data to help doctors and Tricare representatives assign available providers. Many providers on the provider database have long wait lists, no availability, or have stopped taking Tricare patients at all. Parents do not find out this information until we try to call the provider listed on the referral, which causes us to have to do research to find a new provider, and contact the doctor or Tricare to get the referral changed. This wastes the parent's time, the doctor's time, and Tricare's time.

Submission from

, January 26, 2017

I hope I got this turned in within the time limits. I am sick with a nasty sinus

infection. Here is what I think is needed:

* A special needs support center at every base, not associated with EFMP, that has trained advocates and a staff of consultants (special education lawyer, \$SI/Medicaid lawyer, PT, OT, SPEECH, and ABA consultants) to help families.

* Allow ABA therapy in the schools. Our kids need the support, plus ABA therapy and curriculums can be seamlessly integrated, as many private schools have shown.

* Monthly support groups at every military installation with a population greater than 20,000, so that parents can learn from and advocate for each other.

* Change the Medicaid Waiver, because the constant military moves often leave military family members at the bottom of the list, never receiving Medicaid services.

* Reevaluate the ECHO program, as it does a poor job of bridging the gap for those who cannot receive Medicaid, but don't stop services in the interim. Make it easier to get needed items, like diapers, weighted blankets, platform swings, etc.

* A Tricare representative who checks on availability of providers, including those no longer taking Tricare and long wait lists, as well as openings. Compiles the data and submits to Tricare so that phone representatives, ECHO case managers, and military clinics can recommend providers who can provide help in a timely manner.

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Submission from

February 7 2017

Hello,

My name is _ 1 and I am Military Spouse. I currently live in Norfolk, VA and would like to attend the Family Readiness Council Meeting on Feb. 15th.

I have a dual mental health diagnosis of Generalized Anxiety Disorder, and Major Depressive Order. My mental health condition has been a barrier for me when it comes to employment.

Living the military lifestyle is challenging as we all know, but doing so with a mental illness is extremely painful and difficult.

There are many wonderful programs provided to us as spouses. Unfortunately, when it comes to providing support and resources for military spouses dealing with mental illness, I haven't found much.

I'd like to attend this meeting to be a voice and advocate for military spouses and families dealing with mental illness.

Upon much research, I've found that currently no one is tracking the statistics when it comes military spouse suicide or mental illness. This is a huge problem. I know from personal experience many spouses and families that suffer from mental illness. By not tracking or monitoring this problem properly many people are suffering and we are not aware of the breadth of this problem.

Warm Regards,

Submission from [REDACTED] February 3, 2017

It is important to focus the MFRC on many issues that impact the majority of military families. Financial readiness, spouse employment and education, military children's education, child care, transition, relocation and PCS moves, are just a few that come to mind that have not received sufficient review by the MFRC.

Comments regarding the special health needs of military children should be transferred to the Defense Health Board since this body has the expertise and authority to address these concerns. Tackling the special health needs of military children at the right venue will help ensure these issues are resolved and help promote an inclusive MFRC with sufficient time to review the many challenges facing military families.

MILITARY 'VETERAN PEER FAMILIES

WHAT WE DO

Military Veteran Peer Family Program (MVP Families) is a family and caregiver focused branch of Vets4Warriors. Vets4Warriors (V4W) provides 24/7 confidential, personalized peer support to all service men and women, veterans and their families/caregivers across the nation and around the world. The discharge status and military experience are not variables that would disqualify a veteran or their caregivers. Anyone who has worn the uniform will be provided the support they deserve.

MVP Families provides real-time, peer based support for Military families including those with family members overseas as well as military families with special needs children. Each call is answered within 30 seconds by a live peer without automated systems or voicemail.

LOOKING AHEAD

Our needs are six-fold:

First, support to 'get the word out' about MVP Families to employees, customers and others to ensure no one falls through a gap and improve overall wellness;

Second, deliver hope, encouragement, and social support to reinforce resilience through peer connection and role modeling to the family members of veterans;

Third, encourage, advocate, and support self-care through wanted or needed medical, mental health treatment and other professional service;

Fourth, strengthen military families: including all military caretakers, military

and military partners to deliver integrated care;

Fifth, near-term operational funding which predominately supports our veteran peers who are paid employees and will allow us to continue growing; and

Sixth, a long-term goal of establishing an endowment that will ensure MVP Families is around for the decades ahead to meet the needs of those serving in our nation's military, our veterans and their families.

This will allow us

1. To continue upstream support to curtail crisis escalation by providing effective, peer support and referral services to our families and caregivers prior to the point of crisis.
2. Expand our programmatic capacity to all family members, veterans and service members by conducting a major marketing and awareness effort to ensure others know about our services.
3. Ensure all know that our peers are always available, 24/7 where MVP calls rollover to Vets4Warriors, especially during transitions; no one is ever alone.
4. Reduce the stigma associated with seeking mental health care or help in general.

MVP FAMILIES REAL OUTCOMES INCLUDE

1. Improvement in the overall well-being; mental/physical health of care givers family members.
2. Increase and more effective use of on base/post, community and family specific support services and programs nationwide.

EXAMPLES OF CURRENT PROGRAM MVP FAMILIES IMPACT

- Spoke with single mother of three children, two with special needs. As an Army Reservist and police officer, her schedule was changed from afternoons to day shift to better care for her children.
- Mother of two children; one in the LA National Guard and 5 y/o with autism. Initial call was to help her son transition back to civilian life. PTSD was from
-----Prev 01::ts---ae1::tse--b-y-her-ex--htiS-ban&.--=J=h-rough-peer-conn-ec-tion-we-were-a-ble explore the client's lack of self-care and address her feelings about her overall changing situation. Client was able to express her anxieties and concerns in a peer environment without feeling judged but supported. She was able to help both sons with referral agencies provided by our agency to feel better supported in their community.
- Spouse of disabled veteran not receiving benefits. She was later diagnosed with PTSD from the untreated combat PTSD her husband endured. Spouse is working on reestablishing her relationship with her estranged children. She has become more open. Spouse has agreed to try treatment, with a referred counselor to help resolve some of her issues that she has stated "haunt" her now.

MVP FAMILIES PROGRAM OVERVIEW

The need of support from family members became apparent when Vets4Warriors noticed an increase of calls from parents, significant others, friends and caretakers of service members. Similar to Vets4Warriors, MVP Families strive on the confidentiality, connection and follow-up support provided to our audience.

According to the RAND Corporation, there are 5.5 million military caregivers in America and discovered that twenty percent of care

givers are for post 9/11 veterans. The RAND study displayed that those caring for post 9/11 veterans experience more health problems, financial instability and unstable relationships.

MVP FAMILIES HISTORY

MVP Families was initially dubbed MilitaryMom2Mom and established in April 2015. Military Mom2Mom focused on the needs of Military parents who dealt with not only stressors in the military, but as parents of a special needs child. After a year of seeking the population and lacking the necessary numbers, MVP was created. Vets4Warriors realized the support that family members needed as well. In order for our veterans and service members to improve, the whole family had to overcome the obstacles together as a single unit.

In 2015, MVP had over 2,000 contacts which include veterans and family members, which focused in generally 3 counties in New Jersey, but expanded their services to any caretaker in need. Veterans provide personalized peer support nationally and internationally to assist our biggest supporters of the service members who have served, and continues to serve.





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Significant Findings in Report to Congressional

Defense Committees:

Study on Health Care and Related Support for Children of Members of the Armed Forces

Office of the Secretary of Defense July 2014

Element 1: A comprehensive review of the policies of the Secretary and the TRICARE program with respect to providing pediatric care .

1. Review processes for evaluating emerging technology in use in the general community but not supported by the hierarchy of evidence required for the TRICARE purchased care program.
2. Review regulatory provisions for TRICARE program cost-sharing of care that appears to have gained acceptance in the larger medical community but does not meet the TRICARE-specific definition applicable to the purchased care component.
3. Analyze use of health care benefits by children ages 6 to 21 years to assess if developmental - and age-appropriate care is being delivered as compared to AAP-recommended periodicity schedules and guidelines, the 2010 Patient Protection and Affordable Care Act, or Medicaid's Early and Periodic Screening, Diagnosis and Treatment benefit.
4. Determine the extent of use of special metabolic formulas by children with complex metabolic or digestive disease to maintain essential nutrition and medical food.
5. Assess the benefit of nutritional counseling and management when provided by nutritionists and/or registered dietitians as authorized providers for children with complex medical and metabolic medical conditions.
6. Determine if the current benefit of habilitative care authorized under ECHO only for ADFMs promotes age-appropriate and developmental support for children along with skill attainment and sustainment that is distinct from rehabilitative care, and whether legislative changes to remove the current statutory exclusion of habilitative care from the Basic program-would be appropriate.
7. Usage of compounded medication for pediatric beneficiaries and review the impact of the DHA decision on coverage for compounded medications in compliance with Public Law 113-54, Drug Quality and Security Act, once the FDA provides direction on implementation of the new law.
8. Reimbursement policies and their flexibility for safe and effective care of the pediatric beneficiary as pediatric health delivery models change.

Element 2: An assessment of access to pediatric health care by dependent children in appropriate settings.

9. Future assessments should focus on more finely tuned access metrics, including wait times and referrals, reasons for higher rates of non-network ER use, and availability of providers . Evaluate currently available metrics and data sources to assess if they effectively address adequacy of access for pediatric beneficiaries.
10. Specific analyses of the pediatric population in the annual Evaluation of TRICARE Programs: Access, Cost and Quality would provide a comprehensive review of adult and pediatric ER utilization rates in the MHS.

11. Strategies are needed to accurately differentiate between utilization of freestanding versus hospital-based ER utilization and cost differences, which could inform assessment of access of services.
12. Potential recapture of pediatric ER visits through review of diagnoses and acuity of visits would inform access of services.
13. Study of regional contractor required reports to evaluate the need for contract modifications to have data available for finely tuned access metrics, including wait times and referrals, reasons for higher rates of non-network ER use, and availability of providers.
14. Evaluate the need for contract modifications to develop NARs that would reflect availability of providers on a monthly basis.

Element 3: An assessment of access to specialty care by dependent children, including care for children with special health care needs.

15. Potential methods for coding that will more easily identify pediatric specialty or subspecialty providers, or allow for dual (adult and pediatric) coding.
16. Further define diagnosis for high-utilization specialty providers and access standards between referrals and appointments.
17. Collecting data on pediatric access and provider specialty in the annual MHS TRICARE survey could be a useful tool for tracking pediatric access and satisfaction, including use of specific questions on CAHPS to assess family satisfaction specific to pediatric care.
18. Determine the components of a consistent NAR for direct and purchased care component that identifies for referrals and consultations the participating pediatric subspecialty providers.
19. Regional contract requirements for NARs to include network adequacy as measured by utilization of pediatric subspecialty providers.
20. Consider the inclusion of the pediatric population in the annual Evaluation of TRICARE Programs: Access, Cost and Quality report to provide a comprehensive review of adult and pediatric care in the MHS.

Element 4: A comprehensive review and analysis of reimbursement under the TRICARE program for pediatric care.

21. Periodically review reimbursement policies in order to collaborate on innovative processes needed to continue to meet the unique health care needs of children as health care delivery models change.

Element 5: An assessment of the adequacy of the ECHO Program in meeting the needs of dependent children with extraordinary health care needs.

22. Review the ECHO program to ensure that all eligible beneficiaries who continue to be eligible for services, and current ECHO-enrolled beneficiaries who due to changes in condition are no longer eligible for ECHO services. Collaborate with the MHS Beneficiary Education and Support Division, the Military Departments, TROs, the Office of Special Needs, and contractor partners to provide information to all eligible families and track ECHO enrollment and utilization.
23. Develop satisfaction or outcome measurements for all ECHO programs with regard to impact on beneficiaries and family readiness.

Element 6: An assessment of the adequacy of care management for dependent children with special health care needs.

24. DoD collaborative review to establish a formal family-focused process to evaluate the adequacy of care and case management in meeting complex individual health needs and promoting quality cost-effective outcomes.
25. Develop a formal collaborative process in and between direct and purchased care to define and review outcomes for appropriate care/case management of pediatric beneficiaries and their families.
26. Develop outcome/efficacy metrics for the impact of case management in direct and purchased care for beneficiaries with significant medical/behavioral health issues.

27. Future longitudinal study on the impact of PCMH on pediatric beneficiaries in the MTF setting.

Element 7: An assessment of the support provided through other Department of Defense or military department programs and policies that support the physical and behavioral health of dependent children, including children with special health care needs.

28. Develop a common core of programs/benefits that support families available at all installations with criteria for evaluating effectiveness of programs and outcomes.

29. Evaluate a process for a "one-stop-shopping system" to support families in evaluating the multitude of services available in the Military Departments, DoD, and community to meet their needs.

Element 8: Mechanisms for linking dependent children with special health care needs with State and local community resources, including children's hospitals and providers of pediatric specialty care.

30. Future study to develop and test consistent processes of communication and collaboration between nonclinical and clinical support for the family's network of needs.

Element 9: Strategies to mitigate the impact of frequent relocations related to military service on the continuity of health care services for dependent children, including children with special health and behavioral health care needs.

31. Formalized collaboration of EFMP Military Department medical and regional contractors in determination of availability of medical resources in complex medical case prior to relocation.

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Submission Cover Letter from

TRICARE for Kids Coalition

Dear MFRC Members:

On behalf of the Tricare for Kids Coalition I would like to express our appreciation for the Council's continued engagement and interest in the Tricare for Kids issues raised throughout the last several years.

It is our great hope and request that you continue to engage on children's health issues as you are developing expertise in these complex and important family matters. As you educate yourselves and your constituencies, it increases awareness of the needs of children and their families, particularly those children and families with special needs who live and interact across the spectrum of DoD programs, MHS/Tricare, community providers, Medicaid, and special education programs on and off base. It is the responsibility of the Council and us as stakeholders to ensure meaningful support, and accountability for that support, is in place for families as they continue to endure frequent moves, deployments and a high operational tempo.

The Coalition applauds the Council for its 2016 recommendations to the Secretary of Defense, and particularly appreciates the request that the Department "Address the recommendations in the TRICARE for Kids Coalition Report in a timely fashion." For the Council's convenience I am attaching an overview of the report findings that need to be addressed.

Among the findings are issues related to the EFMP, ECHO, Medicaid waivers, and related support services. Therefore we are pleased to see the focus areas for 2017 include "EFMP, healthcare and special education components of services which support special needs families."

To further the discussion around that focus area, please accept the following comments and attachments for submission to the Council for its January 26 meeting:

Generally

1. The Tricare for Kids Coalition urges the Council to remain engaged in its oversight and review of DoD and DHA programs essential to the health and wellbeing of children, including those children with special, emotional, chronic and complex needs. We ask the Council to exercise its authority to view to the DoD Senior Leadership to make children's health needs, and special health needs, a priority.

2. The oversight and review of the Council is especially critical in the current environment in which the 2017 NOA has prescribed a myriad of healthcare reform and infrastructure changes. It is imperative that children's health needs not be lost in the shuffle of "reform." There can be no real reform that does not improve and protect the needs of children. Any reform should ensure that pediatric stakeholders, both internal and external, have a seat at the table.

3. Families of children with special needs touch the health care services and supports system at many points on the spectrum; they deserve a system that communicates and interacts intelligently regardless of where it is accessed. MFRC oversight and review can help to ensure that DoD/DHA/Tricare program "owners" work together internally to ensure that families have seamless access to information and services externally.

4. As is evident among the submissions to this Council, problems with children's health and special

needs programming churn for years without resolution. MFRC recommendations for all children's health programs/improvements should include, as discussed among the members at the last meeting, the need for accountability along the lines of "someone in charge and a deadline."

Specifically

1. Family and stakeholder submissions to this Council demonstrate the ongoing and desperate need for changes in so many issue areas. These examples are necessary to tell the story of the pattern of misalignment of programming with children's health needs and especially children's special health needs. Among the discussion areas that need immediate and ongoing attention are hospice, EHHC, ECHO, ABA and special education.

2. ECHO is a critical program for families of children with special needs. It is not achieving its purpose or potential. (See additional stakeholder submissions for this and previous meetings for discussion). There is a thoughtful and targeted solution path to ensure that ECHO regains and maintains efficacy and provides meaningful support to families as intended. The Military Compensation Retirement and Modernization Commission suggested alignment with Medicaid waiver services and provided DoD the state by state analysis necessary to make the changes. The Coalition urges the Council to adopt and help further implementation of the MCRMC recommendations for ECHO. See attached for more detail.

As stakeholders of this community, the TFK Coalition offers its collaboration, expertise, and input if the Council would like any further information.

Thank you so much for the opportunity to submit and participate.

Tricare for Kids Coalition

ECHO Alignment with Medicaid Waiver Services

Military Compensation Retirement Modernization Commission (MCRMC) Findings and Recommendations

Findings

- Access to Medicaid home and community-based services (HCBS) waiver benefits provided at the state level is an ongoing issue for military families with exceptional family members (EFMs)
- Many Service members encounter HCBS waiting lists that exceed their time assigned to a location
- The average waiting period in FY 2012 across all HCBS enrollment groups and all states was 27 months, and 47 months for EFMs with intellectual or developmental disabilities
- An FY 2013 DoD-commissioned study found that military families with special needs rely on Medicaid to obtain specific supplementary services that are either not provided or not fully covered by TRICARE

Recommendations

- Increase services covered through TRICARE Extended Care Health Option (ECHO) to more closely align with state Medicaid waiver programs
 - Examples include custodial care and respite care hours that match state offerings
 - Expanded services should be subject to the existing ECHO benefit cap of \$36,000 per fiscal year per dependent
 - Modernizes program to better serve current demographics of the Force

Analysis/Discussion

MCRMC findings are on point with the Coalition's experience and concerns. Aligning ECHO with Medicaid waiver services is something we identified as a positive and necessary step as part of our TRICARE for Kids Initiative.

The TFK Coordinated Response included this short term goal:

- Implement internal ECHO reforms and increase flexibility of ECHO benefit to ensure that it aligns with the Centers for Medicare & Medicaid Services (CMS) standards for community based supports and provides improved access and continuity of care to families.

With a long term goal of:

- Ensure qualified EFMP beneficiaries have access to Medicaid waiver services through Medicaid reform.

The Tricare for Kids analysis of the DoD Section 725 2013 NOAA report on pediatrics also supports

the MCRMC recommendations:

Medicaid's structural incompatibility with military family lifestyles stymies access, hence the need to ensure that military children are not inappropriately penalized for the service of their parents in the military. A recent West Virginia University study conducted for the DoD Office of Community Support for Military Families with Special Needs analyzed concerns of under participation and lack of capacity of military support services to assist families with Medicaid access. Providing evidentiary support and guidance for ECHO reform. The ECHO program is a creature of DoD, unlike the fifty state Medicaid program, and therefore, DHA has broad latitude in its structure and implementation, as well as responsibility for ensuring its adequacy.

As part of determining adequacy, DHA officials should work with parents, beneficiaries, and advocacy groups to:

- Examine ECHO regulations versus outcomes, to include metrics to discern whether or not ECHO is meeting its primary goal, assisting "in the reduction of the disabling effects."
- Compare the benefits provided by a "typical" Medicaid waiver (or other "state resources"...for which the ECHO program is supposed to be a substitute) to the benefits provide by the ECHO program.
- Ensure ECHO policies are person-driven, inclusive, effective and accountable, sustainable and efficient, coordinated and transparent, and culturally

Transition Recommendations

Because ECHO is only available to active duty families, additional thoughts would be to assist families moving from active to reserve component, or retiring/ separating from service by providing a transitional benefit for a period to match the average or actual wait time for Medicaid services.

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Submission from

February 3, 2017

Sir/Ma'am-

My name is . My husband is a Lt. Col. in the USAF, and I served five years in the Air Force as well. My son, ' is moderately to severely autistic. I would like to share with you my story, because the direction that Tricare and our education system is concerning to me.

In 2011, we were stationed at Wright Patterson AFB, OH. My son was integrated in a classroom with an educational aide. We received orders to Eglin AFB, FL. We were out and out lied to by the school district. When we enrolled him in school, he was placed in a self contained classroom with a teacher ill equipped to handle him. The first week of school, the teacher started to make accusations. The most severe was that my son had solicited a sexual act from another student. My son did not have the sophistication, or verbal skills, to make such a solicitation. We attended a meeting at the school. I was fully expecting to see the principle, the parents, and perhaps the resource officer. It was just my husband, myself, and the teacher. The teacher insisted that my son wear pants from now on. This is August, in Florida. My son was born in Germany, spent the majority of his life up to that point in North Dakota. It was hot, and he was on risperadone which affects the body's ability to regulate body temperature. He started to have severe tantrums. At one point he had a such a severe tantrum, he had banged his head against a desk 14 times. I signed a waiver allowing the teacher to intervene if he is injuring himself or others, she elected NOT to stop him. He complained that he couldn't see. He was not sent to the nurse's office, I was not informed until I picked him up. I took him to the ER, and it was determined that during the tantrum he had a suspected seizure. I pulled him out of the classroom as soon as I could.

Pulling him from the classroom, I waived my rights to a Free and Appropriate education, and any educational standards to claim the state special education waiver called the McKay Scholarship. The scholarship covers \$11K of my son's education. The ONLY school in the area that would take my son costs around \$SOK. So I have the choice of leaving him in a school district where he is neglected, or he can go to a school where the teachers LOVE him, but since Tricare is no longer covering ABA therapy during the school day, he gets NO academics. I kept at the school for six years. In those six years, he has made no grounds academically. He cannot read, he cannot write, and he cannot do simple math. We are PCSing in about 15 weeks. I don't know where we are going, though I'm hoping we will go to DC

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see meeting both my son's needs and my needs). My husband has another 5-6 years before he can retire and we can pick a forever home that will be the best of all needs (if I live that long- so far my life span with cancer will probably be around another 4-8 years).

So I am begging you for the sake of my son that you do something for the education of our children. Vouchers don't work, and tying the hands of parents living in areas where educational options are sub-par isn't cutting it either. I understand the desire to cut costs, but don't do it at the expense of my child. He didn't sign up to be a military brat, he shouldn't be punished for his daddy's choice of employment.

Thank-you for your consideration,

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Submission from · , February 2017

Dear Family Readiness Council,

I have started a petition to HELP MILITARY FAMILIES WITH SPECIAL NEEDS CHILDREN. I am trying to get as many signatures and shares to raise awareness that military families across the country, such as ours will be losing this positive and beneficial program that helps parents and children who live with autism and other related handicaps.

As you have sent out, the Department of Defense is experiencing fiscal constraints and reductions, which means military families across the country will bear the burden of losing a program that helps thousands tremendously on June 30, 2017.

There are active duty military families with one or more children with special needs, that are scraping by and are dealing with so much strain trying to get therapy and a lot of the time they are doing it as one parent while their spouse is somewhere else on orders. Our family lost therapy for our son over two months ago and have yet been able to begin therapy for his autism due to a shortage of therapists.

When this happens, a child such as ours, has and will regress extremely and cause even further strain on them and the family.

The Exceptional Family Member Program (EFMP) has a program for those who qualify with a child that has a mild to severe disability, such as autism, have a trained care taker come to the home or on center on base. This program allows the parent to get a break, time to recharge, time to clear their mind. It allows the child time to play, have fun, be social with a caretaker who genuinely has the best intentions.

Our son has moderate AUTISM/SEVERE ADHD/SPD/ODD, expressive and recessive language disorder, anxiety and battles depression. So much for an 8 year old to handle and it can be an overload for a parent who loves them to the moon and back.

I tell you this, exposing so much that is private because I am advocating for Robbie and thousands of children and families who serve our country and will lose something that is so good and so helpful.

We have lived in El Paso, not knowing anyone to babysit our son. No family. Robbie did not have one

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- center and play with kids his age, while being watched by a teacher who knew his needs and didn't judge him. It give us time to just take a breath and be the parent he needed us to be. We are now stationed at Ft.Bragg and not much has changed, we still don't have the people we need to lean on and our respite care provider is the only person we can count on.

I think of families that have it much worse than us and I fear for their welfare and my heart aches that these kids will not get that tiny bit of sunshine when they need it too.

So, if you would be so kind, please understand from the sincerest part of my heart, I ask you to sign and share this petition that I have created and help be the change that will make a difference.

With sincere thanks and appreciation,

See below please...

Caution-<https://www.change.org/p/attn-ltg-kenneth-r-dahl-don-t-take-respite-care-away-from-military-families-with-special-needs-children> < Caution-<https://www.change.org/p/attn-ltg-kenneth-r-dahl-don-t-take-respite-care-away-from-military-families-with-special-needs-children> >

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Re: Changes to requirements to obtain and retain ABA therapy

When word first came down about the drastic change in requirements for ASD (Autism Spectrum Disorder) children to acquire and continue ABA therapy (a therapy PROVEN to help improve the quality of life for those on the Autism Spectrum), I wish I could say I was surprised. When such extreme changes were rolled out by simply posting them to the DHA website during most people's block leave period, I wish I could say I was surprised. When these extreme changes in requirements were put into effect without so much as a letter sent out to families explaining the changes, I *wish* I could say I was surprised. BUT, like nearly every ASD military family, I wasn't.

We've been here before.

Again, and again, and *again*, "someone" makes a decision that *again* causes physical, mental, emotional stress on our already *worn* families, on our *children* who already battle so much as military kids, and quietly rolls it out for us to deal with.

I have two boys on the Autism Spectrum - one diagnosed at the age of 3 (turning 7 next week) and the other diagnosed at the age of six (turning 9 in April). Autism has been my world for the last four years. This is my third duty station since my younger son's doctor first said "Autism". I have handled the asinine amount of steps it takes to get ABA therapy started or changed from one provider to the next half a dozen times. I have moved my children through *four* schools in that time frame. Here, at our most recent duty station, my husband deployed within nearly a month of arrival. My children had moved states, homes, schools, and their dad was gone. Even though I took every step required by Tricare, it still took three months just to start up therapy again. NOT because of lack of care by the providers, but due to mismanagement by Tricare.

More times than I can count, I have been notified that my children will lose services for failure to enroll them in ECHO. My children have been enrolled in ECHO since

-----being-enrolled-in-E-FMP-I-WIEE,+have-been-inf"OrmetHhcr-my-child:rrrs-diagnoso-c-----
were missing. Multiple times, I worked to send those back in. I never once received a call back from their case manager while at our last duty station but I figured out what to do despite it. Hilariously, nearly a year after being at our NEW duty station, I received my first call from the case manager assigned at our LAST Tricare region/duty station "checking in".

Now, knowing how confused and chaotic the system already is for these kids, I have to take my child - who has already been through so much - and have him REdiagnosed for a disorder that *does not have a cure*. I had to take him out of school to go to his PCM for a referral for testing that he has *already* had done so that he can retain therapy he has received for over three years due to a disorder that has *already* been diagnosed. Our PCM had difficulty finding a provider who can perform all three required tests in a reasonable timeframe as these providers are now being

flooded with referrals. We do not know if this provider will be able to fully help get this new process done. Some providers are refusing to perform such tests because they feel it is unethical to charge for and perform the same testing for a child who has already received the diagnosis via the same testing criteria. Whenever my child finally gets his turn on the waitlist (*if* we haven't PCSed by then), I will have to remove him from school up to three or four times for these tests. I may have to drive up to an hour to an hour-and-a-half meaning I may need to remove *both* of my children from school to make the time work

If we PCS, we start the entire process over while fighting through *every* multiplied struggle that a PCS represents. If we PCS and then face a deployment while trying to jump through these hoops ... I cannot begin to

I love being a military family. I am *grateful* for the care my children receive after we jump through every hoop and cut through every piece of red tape. I cannot understand how the decision to require these children and our families to undergo this *expensive*, time-consuming, resource-draining process, *helps* us. Autism does not go away. Even on really, really good days, it doesn't mean they are no longer autistic. My dad tests on the spectrum. He's a scientist - incredibly brilliant, incredibly kind, incredibly successful. Approaching sixty years old, successfully married to my mom for nearly forty years, he is *still* autistic. It doesn't go away.

We rarely stay anywhere for longer than two years which puts us having to restart the process, at the "back of the line" so to speak, every *single* time. It will *hurt* my children. It will *hurt* our family. It will *hurt* our military's readiness.

When our kids need help the *most* the very healthcare that is supposed to provide it, ***fails*** them.

I strongly encourage Tricare to have decisions about autism care made by professionals who *understand* autism. This change in procedure causes disorder, confusion, and makes many families strongly consider whether watching our kids

-----suffer from the lack of tricare is worth it---

—,

This hurts our kids. This hurts our families. This hurts our military.

0033 Feb 2017 mtg

Submission from , **February 2, 2017**

To Whom It May Concern,

I wish I could be there to provide input, but am not able.

My husband is currently deployed on his 11th deployment. We have a handicapped child who has had countless surgeries and Autism. ABA therapy has been most helpful for our family and due to multiple moves, we are not always able to accept benefits through the state that he would otherwise be eligible for had we not moved so much. Please know, I fully support my husband's career choice and am very proud of him for it, but please know that respite, medical, and therapy is very important to many families. Anything that can be done to support that is appreciated.

Best Regards,

0034-Feb2017M

Submission from: , **January 12, 2017**

Dear Members of the Department of Defense Military Family Readiness Council (MFRC):

I am a parent of a child with Autism, and am writing to express my sincere and sustained concerns with the policies regarding the treatment of military dependents with Autism. In addition to the rate cuts and often-changing requirements for documentation to continue treatment for Applied Behavior Analysis (ABA) that have substantially increased the administrative and financial burdens on providers to unsustainable levels, I want to express my profound concern about the psychometric testing requirements currently being required to continue ABA therapy. I strongly feel that these requirements are medically inappropriate, present an impossible administrative burden to patients and autism service providers, and will not yield desirable results for patients.

The ADOS is a diagnostic tool and is not designed or validated for assessing symptom progress in patients. As such it is medically inappropriate to require the repeated ADOS for this purpose. In addition, I know of no other condition for which re-diagnosis (the only appropriate use of the ADOS) is required in order to continue medically indicated treatment. I strongly feel that my child is being discriminated against by continually requiring a re-diagnosis in order to continue receiving ABA. I understand ABA is expensive, and that treatment for Autism can be a long, sometimes slow process. But I ask that you not allow Tricare to impose medically inappropriate and possibly discriminatory requirements under the guise of providing appropriate care for military dependent patients, most of whom are children.

For many of the same reasons, I object strongly to the use of intelligence tests to evaluate symptoms or treatment progress for children with Autism. There is no medically validated use of these assessments for this purpose. My child in particular has a verbal expressive disorder, making his responses in these particular tests invalid for measuring his symptoms, intelligence, or anything else.

I appreciate your attention and action on these inappropriate requirements and policies on the part of Tricare, and I hope that you will take whatever actions are in your power to protect the access to medical care and the rights of my child to receive this care free of discrimination based on his medical condition.

- - - _ - ---+Thank you for your time-aHQ-f.)le-a-se feel free to contact me at----yGl:.lftoovience if I can p ffrfM:HW -----
further information.

0 35 Feb 2017 AltgR

Submission from: , **January 12, 2017**

Dear Military Family Readiness Council:

I am an active duty army spouse with a twenty year old with special needs. His current diagnosis is autism spectrum disorder; although upon entry into the program, his diagnosis was bipolar disorder and he had experienced numerous psychiatric hospital admissions through the years.

We became active duty in 2010 and have had many successes and hardships related to EFMP.

EFMP is a necessary program and it has helped ensure that my son has been able to receive the services that have been needed; however, there are some significant issues with the program.

We were denied two duty stations (Carson and Lewis) due to the inability to get in to see a child psychiatrist within 30 days. EFMP does not take into consideration that it usually takes sometimes up to 3 months or longer to see a child psychiatrist nationwide because there are not enough providers. If one has orders months before traveling, they can make the necessary appointments and still receive services in a timely manner. In addition, sometimes the EFMP office just looks at the needs and does not even attempt to see what the service load is. I suspect that was the case for Carson as we made some phone calls and could have had an appointment within 2 weeks.

Where EFMP has been an even greater struggle for my family is when our son became an adult. Our son has not lived with us since he was 17. He was in a residential facility, then moved to a group home, and has now been on his own in his own apartment. He did not move with us because he has a Medicaid waiver. These Medicaid waivers do not move across state lines and he would have a 5-10 year wait for these needed services in another state. Medicaid waivers cover much more than Tricare, such as things like independent living skill workers and employment supports, so for a young adult, it would be a huge impact in his care to move across state lines. Our son does not need us with him, does not even need guardianship anymore, but we cannot remove him from EFMP because he is still receiving counseling services that Tricare is paying for. The only reason Tricare is paying for them is because Tricare is primary over Medicaid. Once Tricare goes away when our son turns 21, Medicaid will cover all the needed services. We cannot remove our son from EFMP because Tricare is still paying for his therapy. We cannot remove him from TEERS because he is EFMP. Our son does not qualify to receive regular Tricare after the age of 21 because we do not pay for any of his expenses and he is not in college. He turns 21 in September, we are scheduled to move in August and we will probably be denied the assignment that we are wanting because we are still flagged as EFMP. I am currently working with the local EFMP office who is in communications with the regional office, but so far, things are not sounding promising.

EFMP needs to have some sort of exception to policy or something in the case of young adults. Sure, something could happen and he may need to have extra help, but our son cannot leave the state he is currently residing in because he would be denied all the services he needs to transition to adulthood. Thankfully, the waiver service covers things like group homes and alternative family living homes if that ever should happen, but EFMP does not consider this. It would be

even greater if Tricare would consider covering the same services that state Medicaid waivers cover for those families with family members who struggle more than our son does.

It would also be nice if incoming EFMP offices would reach out to families before denying an assignment and allowing family feedback in the decision to approve or deny a particular EFMP member. Some instances, such as psychiatric services and occupational therapy, the norm is to wait for services due to lack of providers.

Thank you for your consideration.

36
0026 Feb 2017 A

Submission from

January 2017

To whom it may concern.

We are a military family with one special needs child. I am shocked about how little resources are available on base for our child. The school is not able to provide education for our child, so we have to bring her to a school off base. The pediatrician is rather clueless about her needs and I have to educate him and his staff on what we need, which makes it very difficult, because I have to do hours and hours of research. At our last station, the doctor refused to even acknowledge that there was a problem, even though it was obvious.

The EFMP program here is good. The coordinator, Mrs. Venetia Waters of the MacDill AFB EFMP department, is amazing and she goes above and beyond for the EFMP families. We have never seen a coordinator this involved and willing to help. She is the heart and soul of the EFMP program here.

The respite care that is offered through the EFMP program is a great resource, but as you already know, the hours each branch gets vary widely, but we were informed that there is a change in the works, where the Air Force Families will get the same hours as the Navy families. That will be great.

The education our daughter receives at the school off base is great, but highly dependent on the teacher we get each year. The school makes an effort to include the special needs kids where they can. They are also very understanding about the special circumstances military life brings. We got lucky with the school our daughter is in, but there are many others that didn't get as lucky. There should be resources at the school on base, so that all kids are able to attend school there. It would be important for inclusion and building community.

Thank you.

Military Spouse and Special needs mom

37
2027 Feb 2017A

Submission from ' , January 12, 2017

Good evening,

I have been a family member with special needs, served at the Marine Corps HQ level for the Exceptional Family Member Program (EFMP) and served as the East Coast, Europe and Africa Regional EFMP Program Manager for the Marine Corps. I am currently serving as the EFMP Program Manager for USAG Bavaria.

Through my career with the program I have been fortunate to work with the EFMP of many branches of the military and see the variations in the processes and delivery of the program.

I am currently working with the Army and I see glaring differences on how the Army administers the program from the way the Marine Corps, Navy and Air Force.

Many bases are moving to Joint Bases where you see a mixture of the services on one base however many processes on how EFMP is administered still remains quite different. Use of additional forms for enrollment even though the standard is the D02792 and 0D2792-1, antiquated or no case management systems for Army, different terminology for each service for EFMP related services, different position description titles for EFMP staff, major respite care process differences and more. For example, the Army does not allow the ACS side of EFMP to have any information regarding the EFMP enrollment. ACS EFMP staff have to completely rely on enrollment verification and information from the medical side of EFMP however the ACS EFMP staff must try to secure services for a family that they are not allowed access to their medical or educational records. Additionally the Army ACS EFMP staff have accreditation responsibility for the medical side of EFMP as well as other areas that they do not actually have authority over. This is very confusing for service members and providers...especially on joint base.

My Question is: What efforts are being made to actually make the program "purple"? Same forms for all services, same terminology for all services, same position description name for all EFMP staff and overall the same process for enrolling and accessing services?

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0028 Feb 2017 mtg R

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January 11, 2017

As the Director of the Specialized Training Of Military Parents Program (STOMP), which was first established in 1985 through a grant from the US Department of Education, Office of Special Education Programs, I appreciate the opportunity to provide comment to the committee as you seek to identify concerns and strategies for supporting our military families who have children with disabilities and/or special healthcare needs.

It has long been recognized that our military community is not like its civilian counterparts. Our families are more mobile, face more separations into harm's way, and have the need for supports within the military community since extended family is not readily available for many of the families. Add to this our average age for enlisted personnel and the higher percentage of families who have children with more significant disabilities and we find the need for a robust system of support and service as critical. For this reason, we would like to make the following recommendations to the committee:

- The Exceptional Family Member Program still has variances in how it is implemented from Branch to Branch and from location to location. This can be attributed most frequently to the lack of "fenced funding" for these programs. We still find EFMP Managers and Coordinators who wear more than one hat and who have minimal experience in working with the population. Because of this we have found that the role of EFMP Managers has been seen more as a springboard to other opportunities rather than a position that will sustain a knowledgeable and skilled provider. There is a need for consistency across the branches on what services are available and training requirements for the personnel who will be assisting the families. STOMP provides training for military families and professionals through a contract that we currently have with the Army and Navy. We also have a small contract to provide webinars for Air Force families as well. These trainings cover a wide variety of resources to include Special education rights and responsibilities, Tricare and ECHO as well as TRICARE ABA for children and youth who have autism, IEP and IFSP (the two documents that drive services within special education for children birth through age 21), Wills, guardianship and special needs trusts, Record keeping and transition support, as well as many other topics that the families and professionals have identified as critical to assisting them. Funding for ongoing training and support needs to be put into place and maintained to assure continuity of services and support
- Consistency in tracking of services is critical. We have families who frequently must reinvent their support systems time and again when they PCS. There are waiting lists for therapies, especially ABA, Physical Therapy and Occupational Therapy. For families who are assigned overseas the waits have been as long as 18 months. This is time lost for children that can't be regained. We do not recommend denying overseas assignments for families who have an EFMP family member as this contributes to the belief that being enrolled in EFMP is a detriment to the military member's career. Instead we feel a clear study and plan of action needs to occur to assure that systems are in place and that long delays in vetting providers is eliminated. A good example of how this has hindered access occurred in Japan. The need for a speech therapist has taken over three years. By the time a person was offered the position and then go through the full vetting process they had taken a different position as they could not wait indefinitely for access to employment. If this had happened only in one location or only in one incidence it could be considered an anomaly but it has happened on numerous occasions and at numerous locations.

- While an IEP can be implemented (to the extent possible for children 3-21) at a new duty station until evaluations and services are put in place at the new duty station, the case is not the same for children birth to three who are receiving services through early intervention services. These little ones, who need continuity in service and little or no break in service have to requalify every time the family has a PCS move to a new location either within CONUS or OCONUS. In some instances, this causes a 45 day delay in even starting the process let alone the length of time it takes for the child to be assessed, a plan to be written, and providers to be assigned. This is time the children can ill afford to lose. There needs to be a push to assure that the children will immediately be placed into services instead of waiting for new evaluations and funding streams to be established.
- Families will get moved up the Medicaid Waiver Lists only to find that by the time they are finally able to access Medicaid Waiver services, they are facing a PCS move. There are efforts moving forward to establish a system of support to sustain waiver services for military families who PCS. However, these efforts are not happening in every location nor are the options for waivers consistent across locations. There needs to be fenced "Military Medicaid Waiver" funds to sustain families when they PCS to a new duty assignment until they are eligible for that State's Medicaid Waiver services. With this consistency across duty assignments there will be less impact on families and state resources. Families who have resources in place are far more resilient and able to deal with the stressors associated with military life.

These are four major issues we hope you will consider. We feel that by addressing these areas, other challenges will be lessened and satisfaction and stability will be brought forward. The military life is a good one for families who have an exceptional family member. The resources, once in place, can cover needs that would not be as easily addressed within the civilian sector. While funding levels for services such as ABA and therapies is low, this can be identified and addressed as consistent services are in place.

The STOMP program and our staff are themselves spouses of active duty and retired military personnel and we have walked the path of accessing services for our own children with disabilities and special healthcare needs. We stand ready to continue to support the work of the committee and hope we will be called upon as needed

Sincerely,

LETTER SUBMISSION TO DOD MILITARY FAMILY READINESS COUNCIL

Date: January 12, 2017

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To the members of, DoD Military Family Readiness Council- MFRC:

Submitting my writings of comments in behalf of our beloved enrollee's EFMP child (ren) and for families like mine who continue to fight the military medical system in receiving appropriate un-bias medical and behavioral health supports for their loved one with medical chronic/acute needs and or medical needs. It is a repetitively struggle as military dependents/beneficiaries' to establish continuity of care for our EFM.

I am a parent with children within the EFMP system for over ten years. I would like to take this life moment in informing how challenging families are still having when seeking medical, behavioral supports from Military Family Treatments Facilities, EFMP, and medical and or behavioral health working alongside professionals inside the military medical sector.

It seems as dependents our medical care comes second which means [the] children and spouses within the EFMP are second in receiving what is in their best medical interest to exist and maintain quality medical care of their own during the time of their service member duty time to serve within the Armed Forces.

It's too late to fix the EFMP program it's been broken far too long within the military sector we need to re-create the EFMP where it is healthier outreach to your soldier's and their families. This program is there to support not burden the soldier and the families in receiving their civil right of medical care and Educational support not stir away families' from seeking/asking for help or support as an EFM enrollee.

EFM children and families are still in the back burner of funding, services, and supports where it becomes stagnant in continuing the services and supports especially as our military EFM become EFM adults. There is a huge disconnect in staying proactive with an EFM family through a life-span as the soldier is in the active duty status quo of the Armed Forces. Perhaps creating a DOD policy/ regulation in ensuring when the EFM reaches 18 and is still enrolled EFMP program and or military EFM soldier retires that our EFMP will connect with the families in sharing, networking, offering gov't resources in that regard for the family to be aware of or enroll into the TRICARE Adults Special Needs Program and so forth.

I, as a military spouse to my husband/soldier and a Special Needs Parent Advocate I am still encountering military families not familiar with Tricare Case Management Program. Military parents and families trying to understand, "What is the purpose of EFMP, really"?

I, myself continue to advocate for myself, my soldier and our children in ensuring safety in receiving quality un-bias medical care by highly trained, educated military medical professionals. We, currently reside once again in San Antonio, Texas attached to Wilford Hall for our medical care with JBSA, medical treatment facilities.

All, EFM families' should all be well informed in what is, EFMP and how can it support soldier's families during their duty time and mong-mititafrchain-of-c:ommam:J-arrd leadersrip. I feel there is a negative barrier in reaching out to EFMP families and low tolerance in accepting families within EFM within commands. This only adversely affects the family and the children lives but also the life of the service member per their military assignments and career within the Armed Forces.

It seem like EFM Families'..... have to come and outreach to the hired GS EFMP staff people in order to get help or needed military resource in trying to connect with state and federal programs that are available and appropriate to the individualized special needs of their loved one with a disability and or medical/behavioral health diagnosis where it should be the opposite for families.

Minorities' families can be afraid or timid to ask for support if un-friendly or un-welcoming that is why it's important to continue the Tricare Case Management Program and the System Navigator program on your federal installation. EFM, not only have their own hardship with a loved one with special needs or medical chronic conditions daily however EFM families are resilient in overcoming life crisis and adversities. I, have met EFM families who have shown strength, duty to serve, courage, and perseverance for love of their family where they continue to navigate the rigors military health care system for love of their children and family.

LETTER SUBMISSION TO DOD MILITARY FAMILY READINESS COUNCIL

Personally, our children have been under EFMP as a child and now both are becoming young adults. I am advocating for more support in creating a policy/regulation where EFMP will inform families of DOD programs that would benefit them as they transition to adult with special needs. Tricare to inform us parents with POA- Power of Attorney of what insurance programs are beneficial to our loved ones with special needs who age out of the system when they reach age of adulthood in hopes of keeping EFM and their family well-

The urgency need of oversight of EFMP program is still critical in areas of, Educational, EFM Civil rights within federal installation MTF in receiving and maintaining medical services. Continue urgency in the DODEA schools and the public school entities ensuring EFM received the best educational services, supports in which school staff professionals do not discriminate against or do not tolerate AD military EFM family as their service member works in the assigned duty assignment station.

For the military families' I would like to share keep in mind how impactful this program is for so many families who need and depend on these programs. EFM, will age out of Pediatrics to Adulthood Medical Services and Programs. The, ECHO program, Case Management, Behavioral Health, Respite, ASA therapy, specialized therapy services, special needs recreational program, special needs camps, special needs specialized dental care, specialized vision eye care medical diagnosis need coverage for EFM families is still a hard system to receive coverage and how to get it covered for EFM families dependents.

Families need to understand how that system of coverage really works. I, have navigated the system in behalf of my children I know firsthand by walking the walk in propelling the military system, and the Tricare system. Honestly it is hard, time consuming, challenging where it becomes discouraging for beneficiaries and EFM parents whom are trying to obtain medical coverage, referrals, physicians that are in-network, out of network, co-payments deductible, bookings of appointments, booking of surgeries for a EFM and the understanding of medical coverage on or off post. Coverage of medical eye diagnosis eye care, special needs glasses, special needs dental medical care and regular medical/dental coverage and so forth....etc.,

In, my/our life as an active duty military family we have been denied numerous times to travel aboard with our soldier because we are enrolled into the EFMP perhaps it is because it would be costly to have us aboard along w/ the need of ASA for our son which cannot be provided per the recommended hours or ASA therapist available per offered duty stations which are shared by Human Resource Command.

In closing, I hope I have shed some insightful comments which are helpful but regardless we are proud to be completing our end of the two year un-companied assignment with the 44th Signal Battalion where our soldier and our beloved husband/father is serving in Grafenwohr, Germany and we are a EFM family. Thank you for this opportunity to share and submit my comments respectfully with you all. I, only hope the very best for all those in the Leadership roles who will enforce the changes of policies and regulation of our many people/families enrolled onto the Exceptional Family Member Program continue to be mindful of the wide impact this program holds for many lives of families and generations to come.

As our younger EFM families serve in the military they will experience the newly changed EFMP for what it is today in their

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- - - - -< needs but in EFM Adults needs within the system of care in the military sector. I, only
hope EFMP continues its mission to assist
our EFM Armed Forces special needs children with passion, and dignityas we all deserve per our sacrifices.

Most Respectfully,

Special Needs Parent Advocate, Army Military Spouse, Latina Advocate, Autism Warrior Mother

0040 Feb 2017 mty R

Submission from , January 30, 2017

Dear Members of the Family Readiness Council,

I am writing to you today to provide insight on the obstacles faced by families with special needs. I will outline my experiences with the heartfelt desire to improve programs and quality of life of our special needs community.

I have fought to obtain services, had services, lost services, endured painful feelings of inadequacy while witnessing her significant regression, fought for services again, 6+ month waiting list (please keep in mind Fort Bragg is a compassionate assignment), more testing, re-obtained services, lost services at school, regression= family unraveling. I am mentally, emotionally and physically exhausted for fighting and grieving for my daughter. This journey is difficult on its best day, let alone these added obstacles that needlessly make it more difficult and costly on many levels!

Our daughter is nine years old with moderate Autism. It was an excruciating process of obtaining her diagnosis, as too many doctors are still to this day, saying "let's wait and see." In this day and age doctors, nurses, clinic staff are not even informing patients of Pediatric developmental specialist, early intervention services and resources, warning signs, etc. Our daughter was almost four at diagnosis even though I knew the day she was born from the gut curdling screams something was very wrong. The intolerance of formulas, projectile vomiting, avoidance of human contact and interaction, minimal sleep and virtually inconsolable did not even raise red flags of concern for our daughter; only towards her parents of repeated visits begging for help and guidance. We had a healthy son that we only took to the doctors as needed; they had our track records of our entire family's visits to the doctor ;why were they not listening? We literally wore gun muffs to survive the screaming and had to become reclusive for some sense of sanity.

The deployments were long and frequent. Our family was unraveling. Our son suffering of severe depression and anxiety from a classmate's father death in Afghanistan, watching continuing to vomit, watching Mom and sister sleep on couch covered in towels because she would choke on her vomit. My sweet, precious son at the tender age of six would ask me, is Daddy going to die? Is going to die? Are you going to die? This was so beyond brutal and cruel that I cannot put into words how this affected all of us.

Dismissals after repeated dismissal of our concerns were finally validated after almost four years of pleading. Not only did she have moderate autism; she had pica, sensory processing disorder, brain damage from lack of nutrition and undiagnosed gastroparesis for 4 months during critical developmental months of 14-18 months. There are one and a half pages of diagnosis for our daughter! This was nothing shy of medical abuse, plain and simple.

We wait almost 6 months for ABA services. We had in speech twice a week for 18 months and we had 13 words. We brought ABA on board and we had 36 words in less than 2 months! That is profound! I learned things I was doing wrong; not intentionally, but you simply don't know what you don't know. I learned how to develop and nurture what I fondly refer to as my core team (therapists, teachers, family and all that touch our lives) how to share information in a positive, collaborative manner and keep everyone on the same sheet of music for this beautiful orchestra.

All of this took its toll.... in time, money, commitment, discipline, hard work-both mentally and physically. It was extremely difficult to manage this journey and we had to come to the painful decision of my husband retiring or I was going to be admitted for a nervous breakdown since I had been clinically diagnosed with PTSD, depression and anxiety disorder.

Upon retirement, we lost all ABA benefits for our daughter. Almost two years later of advocating and pleading, retirees obtain ABA services for their children. We had numerous test requirements and it took almost another six months before services began again. Per mandate, we (retirees) could only have BCBA's (top tier service provider which made no sense to me). With such mandate, we could only obtain four hours of service [(2) 2 hour sessions] per week and that was in the clinic setting. The co-pays were high and did not go against our catastrophic cap. We have come a long way and I thank you for that. We can now have any tier level of provider overseen by a BCBA, co-pays now are lower and do go against our catastrophic cap which helps so much. There have been improvements! But, we still have so much more work to do. Our children regress so quickly. What can take us a year to achieve can unravel in less than a month with interrupted services.

This past July our school district disseminated a memo stating no outside service providers were allowed on school property. This new policy was put into place because the former policy left it to Principal's discretion and therefore inconsistent across the county. I made attempts and pleas to our school board with no overturn. I retained counsel and was assured, not to worry, this IS happening; you will have your ABA in school. I was so excited I drove immediately to our t3CBA's office with the great news. She looked defeated and said I hate to tell you, but Tricare will no longer be covering ABA in school. I cannot have 15 minutes of victory of desperately needed, prescribed and authorized services for my daughter.

I am begging for consistent and effective policies and legislation to protect our children and families that have already sacrificed so much for our beloved country!

I, and countless other families, are utterly exhausted; mentally, physically and emotionally from the constant requirement of being placed into combat mode to obtain consistent continuity of care for already authorized services. Families thrive and flourish with needed uninterrupted services. Streamlining the process, revamping approach and implementation of special needs program would be a huge improvement in child thriving outcomes, inclusion, mental health and overall health dollars!

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The following steps will have profound and life changing positive impacts!

1. Create Pamphlets/campaign on Early Signs of Autism, developmental milestones (partner with Autism Speaks and pathways.org < Caution-http://pathways.org > < Caution-Caution-http://pathways.org/ < Caution-http://pathways.org/ > > } and Navigating an Autism Journey in the Military

2. Establish an annual EFMP Action Plan and Resource Fair at each military installation to include LOCAL resources and partnerships.

3. Revamp respite. It is a desperately needed service that needs streamlining and an outside the box approach.

focusing on those with and affected by disabilities would be priceless!!!

4. Establish a pilot program to nurture and empower families with disabilities. Just as there is CVS, a similar program and own building solely

5. Establish pilot program to help serve special needs families. Similar to Army Family Team Building

(AFTB) but solely focuses on special needs children and families.

6. Establish an online community of video/podcasts on special needs topics.

I am willing to drive to DC to testify (VA native, both parents born, raised and retired from DC area), provide documentation and/or input, support; simply anything to assist!

Signed with heartfelt gratitude and appreciation of your time and efforts regarding this matter,

Parent, Disabled Retiree Spouse

Former FRG Leader, AFTB
Instructor, AFAP Facilitator, Volunteer of the Year Nominee, WAMC Patient and Family Advisory Council, Governor appointed Parent Advocate and Chair for NCICC representing birth to age 5 with or at risk for developmental delays

1.1 Feb 2017 MtzR

Submission from

January 31, 2017

31 January, 2017

DOD Military Family Readiness Council and Special Needs Military Families:

I am writing this letter as a veteran, a military spouse and a mother to 4 children, 2 of which are enrolled in the Exceptional Family Member Program (EFMP). Both of my children have fragile X syndrome (FXS), and are autistic. Symptoms of FXS include a range from learning disabilities to more severe cognitive or intellectual disabilities. Delays in speech and language development are common, as are a variety of physical and behavioral characteristics. Autism spectrum disorder (ASD) is a complex developmental disability, and like FXS it can affect a person's ability to communicate and interact with others. Both FXS and ASD are spectrum disorders can affect people in varying degrees. This results in unique needs for my children. They both receive special services at school and my son also requires therapy outside of the school both in the home and in a clinic.

nonverbal, has cognitive and developmental delays. He will be 5 next month and functions below a 2 year old in several areas. He does not respond to his name, has no concept of danger, anxiety, trouble maintaining sensory regulation and we are still working on potty training. As a result, we are in therapy with days week doing ABA, speech, OT and any other Dr appointments. G

In addition to the education, medical and therapeutic needs, as military families we face other unique challenges. Our families are required to move every few years finding new schools, doctors, therapists and friends. Our family units are separated for months at a time, leaving one parent to care for the children solo while worrying about the safety of their loved one. We often live thousands of miles away from our support network of family and close friends. All of this creates additional hardships on top of stress and dedication that is already required to raise a special needs child. As military families, we depend on our military benefits for the care of our children. They require additional care that exceeds the standard Tricare benefits. The extended care health option

----- (ECBora1rowsTor--ustoTece1vecare--mans noCcovere-a-suchas ABA therapy-and - -----
durable equipment. It is necessary for our children to receive proper medical care and the therapies that they need to continue their progress.

We are asking that you protect the services for our children. We have recently received the cut to our respite care system, and the rates to our ABA providers have also been cut resulting in losing some providers. Respite care was a very important service for many families and the only opportunity that many families received help with their special needs child. Many families depend on ABA services for their children, they have made progress with this program that they have not made with any other program. To have this therapy cut or to chance losing providers can be devastating to families.

This year we cannot allow more cuts to our programs benefiting the families that are often stressed and stretched to the max. More changes to the ECHO program are

being considered and need a second look with family input and input by the providers servicing families. A new policy requiring a new autism diagnosis and IQ testing every 2 years in order to receive ongoing care is being implemented. Developmental pediatricians were not allowed to weigh in regarding this new policy. The required testing is a lengthy process, has long waitlist and there are limited providers available to conduct such tests. These new requirements could result in families having a lapse in services that they depend on for the wellbeing and progress of their children.

We cannot halt the progress of these children that fight weeks, months or even years for what others can see as the smallest goal. We ask that you reconsider the proposed changes to the ECHO program. Please consider the difficulties that EFMP military families face and the rights that they need and deserve. The ECHO program should be closely looked at for the benefit of the EFMP families, these programs should not be cut nor should the new testing requirement be

put into place.

Respectfully,

C042 Feb 2017 MFR

Cover Email for Three Submissions to the MFRC Council Meeting Jan 26 2017

Good morning,

The purpose of the upcoming DoD Military Family Readiness Council meeting on the 26th of January, 2017 is "to receive information related to programs and services for DoD Family Members with Special Needs, including healthcare and the Exceptional Family Member Program.". I am submitting the following information for the council's consideration.

First, to add context, it is important to note that in October 2009, President Obama signed the 2010 National Defense Authorization Act (NDAA), creating the Office of Community Support for Military Families with Special Needs (otherwise called the Office of Special Needs (OSN)). Its legislative purpose, as set out in 10 U.S.C. § 1781c, is,

"to enhance and improve Department of Defense support around the world for military families with special needs (whether medical or educational needs) through the development of appropriate policies, enhancement and dissemination of appropriate information throughout the Department of Defense, support for such families in obtaining referrals for services and in obtaining service, and oversight of the activities of the military departments in support of such families."

Unfortunately, it took over six years for DoD to propose regulations implementing the 2010 NDAA (background, Caution-<http://www.military.com/daily-news/2015/11/11/pentagons-special-needs-program-to-take-years-longer.html> < Caution-<http://www.military.com/daily-news/2015/11/11/pentagons-special-needs-program-to-take-years-longer.html>>). The comment period for these proposed regulations ended Feb 9th, 2016. It has been almost 11 months since the end of the comment period for the proposed regulations, with no notice as to when the final regulations will be published.

Around a hundred public comments were collected (and a handful of internal DoD comments). The vast majority of the public comments were made by military parents, heartfelt and responsive to their life stories. Seven military service organizations and non-profits submitted lengthy commentary, with excellent feedback specific to the proposed regulations. So that council members do not have to explore the hard-to-navigate federal registry website, five were cut and pasted into two attached pdf files.

While many of the parent comments may not have been specifically germane to the regulation change, they are very relevant to the Military Family Readiness Council's charter. I hope council members take the time to review these comments and hopefully they will help the MFRC in both its mission and ensuring the upcoming meeting on the 26th of January is beneficial to our EFMP families.

Finally, I would ask the council to reconsider the attached input from the Military Family Advisory Network, previously submitted in 2014. Very few military families know that the Military Family Readiness Council exists, when it meets, or how and who represents them on the council. While I have done my best to advertise these council meetings, I am one person with limited reach, while DoD has an entire infrastructure it currently does not utilize to make military families aware of this council or its mission. I think it's safe to presume most military families do not read the Federal Register, where details of these meetings are published by DoD, including how to attend and submit comments. My latest, with apologies to General Mattis: Caution-https://www.linkedin.com/pulse/dod-military-family-readiness-council-special-needs-families-hilton?trk=pulse_spock-articles < Caution-https://www.linkedin.com/pulse/dod-military-family-readiness-council-special-needs-families-hilton?trk=pulse_spock-articles>.

Thanks so much for your time. All of our military families are worth it; but the stakes for some of our

vulnerable special needs military families are so much higher. The time the council puts into its deliberations and recommendations may determine whether these military families fail or succeed.

Sincerely,

0043 Feb 2017

Submission from :

Cover Memo, January 11, 2017

Good afternoon,

Please find my submission attached regarding the impact of special education on military children in preparation for the upcoming DoD Military Family Readiness Council Meeting on the 26th of January.

I've also created a blog piece on the same subject, accessible here: Caution-
https://www.linkedin.com/pulse/military-kids-special-education-jeremy-hilton?trk=pulse_spock-articles
< Caution-https://www.linkedin.com/pulse/military-kids-special-education-jeremy-hilton?trk=pulse_spock-articles >.

In case anyone asks, that is my daughter on the first page and I provide permission for her picture in this article and the link above to be shared publicly.

Thanks so much for your continued efforts and I look forward to the meeting on the 26th.

V/R

An Analysis of the Extended Care Health Option

By Jeremy Hilton

The Extended Care Health Option, otherwise known as the ECHO benefit, is, according to 32 CFR § 199.5, (codified in Section 1079 of Title 10, United States Code),

"a supplemental program to the TRICARE Basic Program . . . [whose purpose] ... is to provide an additional financial resource for an integrated set of services and supplies designed to assist in the reduction of the disabling effects of the ECHO-eligible dependent's qualifying condition."¹

The 2013 NDAA, in incorporating portions of what was originally the TRICARE for Kids Bill (H.R. 4341), directed the DoD to conduct,

"An assessment of the adequacy of the ECHO Program in meeting the needs of dependent children with extraordinary health care needs."

This request differs from the one presented by the 2013 Senate Armed Services Committee Report (SR 112-173), which directed DoD,

"to assess participation in the ECHO program by eligible dependents with special needs, and to explore options to provide more flexible benefits under that program without increasing costs to the Department."²

Before analyzing either of these questions, it's important to have background on the history of the ECHO program. Living a military life while raising a child or caring for a spouse with a disability presents extraordinary circumstances. The Program for Persons with Disabilities (PFPWD, created in 1996) and the Program for the Handicapped (PTH) existed for over 50

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"was established to provide additional financial support to families of active duty personnel in recognition of (1) the high cost of caring for seriously disabled family members and (2) the limited access to care for many specialized services because of long waiting lists for public services and state and/or local eligibility restrictions (such as residency requirements), which adversely affect military personnel."³

¹ <http://www.gpo.gov/fdsys/pkg/CFR-2012-title32-vol2/pdf/CFR-2012-title32-vol2-sec199-5.pdf>

² <http://tricare.mil/tma/congressionalinformation/downloads/ExpansionEvaluationEffectivenessTRICAREProgramECHO.pdf>

³ <http://www.gao.gov/products/HRD-92-15>

As of July 26, 2013, DoD's official position regarding ECHO is as follows:

"Congress thus gave DoD much more coverage of ECHO benefits than it has concerning medical benefits provided under the Basic Program. ECHO enables DoD to provide additional support services for Active Duty Family Members who are subject to frequent relocations to geographic locations that lack sufficient state resources for individuals with special needs. ECHO includes the authority to provide home health care supplies and services, respite care, training, special education, and other services....It is important to note that most services covered under ECHO are non-medical in nature....Apart from the possibility of coverage of proven medical care otherwise not covered under the Basic Program in limited circumstances, ECHO for the most part covers any "other services and supplies as determined appropriate by the [Director, TMA], notwithstanding the limitations in [10 U.S.C. 1079(a)(13)]." These non-medical services are not subject to the Basic Program reliable evidence standard required by 32 C.F.R. § 199.4(g)(15) for medical care. Instead, such ECHO non-medical services as respite care and behavior modification need only be determined by the Director, TMA, to "assist in the reduction of the disabling effects of the ECHO-eligible dependent's qualifying condition." ⁴

The flexibility inherent to the ECHO program supplies a critical function to appropriately provide for children and spouses with significant disabilities. TMA holds clear discretion to make these decisions and therefore must be held accountable for appropriately formulating policy.

We must ensure appropriate resources for these vulnerable military families, not only as the right thing to do, but also as a military readiness concern. Helping families to "assist in the reduction of the disabling effects" for a child or spouse allows the service member to succeed with their unique mission. State Medicaid resources in civilian communities have long been available to individuals with disabilities, while a military family living in the same community is unable to access those resources because of state-specific rules. Military children should not be penalized for the service their Mother or Father renders to the nation (spouses included). The DoD State Liaison Programs recognizes the lack of comparable access for military families as a top ten issues, but little progress has been made in addressing this issue from a state perspective.

Two primary items should be considered in discerning whether or not the ECHO program is operating as intended;

- 1) Examining ECHO regulations versus outcomes, and

⁴ http://issuu.com/jeremyhilton/docs/supplementary_to_26_july_2013_filin

⁵ <http://www.usa4militaryfamilies.dod.mil/pls/psgprod/f?p=USA4:ISSUE:0:::P2:ISSUE:6>

2) Comparing the benefits provided by a "typical" Medicaid waiver (or other "state resources" . . .for which the ECHO program is supposed to be a substitute) to the benefits provide by the ECHO program.

The TRICARE Policy Manual, at change 946, outlines the eligibility requirements, services provided, and exclusions by the ECHO program.

According to ECHO policy, services provided include the following:

- Assistive services (e.g., those from a qualified interpreter or translator)
- Durable medical equipment, including adaptation and maintenance equipment
- Expanded in-home medical services through TRICARE ECHO Home Health Care (EHHHC) up to eight hours per day, five days per week (generally only the most serious cases where the individual would otherwise be institutionalized)
- Rehabilitative services
- Respite care (during any month when at least one other ECHO benefit is received) up to 16 hours of care
- Training to use special education and assistive technology devices
- Institutional care when a residential environment is required
- Transportation to and from institutions or facilities in certain circumstances
- Applied Behavior Analysis (ABA) reinforcement services under the Department of Defense Enhanced Access to Autism Services Demonstration
- Special Education Services
- Vocational Training
- Parent and Sibling Training
- Institutional Care
- Equipment adaptation and maintenance
- Durable Medical Equipment (not covered by the TRICARE Basic program)
- "Other" services as deemed necessary by the D1rector _____
ofTMA

In analyzing this list, deficits do exist compared with many Medicaid waivers but none-the-less, the number of benefits appear extensive and impressive. However, an impressive list falls short if these benefits are not truly available to military families, which directly correlates to the original question posed by the NDAA, of "the adequacy of the ECHO Program in meeting the needs of dependent children with extraordinary health care needs." If these benefits are indeed

⁶<http://manuals.tricare.osd.mil/DisplayManualFile.aspx?Manual=TP08&Change=94&Type=AsOf&Filename=C9>
[TOC.PDF](#)

accessible, beneficiaries should be accessing them with much higher frequency. Or, perhaps these benefits are only as good as the paper they are written on.

Despite the lack of published data for public access, the data we do have is valuable. In answering the question posed by the SASC Committee Report, TRICARE provided a report on the 30th of May 2013, titled "The Department of Defense Report to Congress on Participation in the Extended Care Health Option (ECHO)".⁷ In this report, the following was noted;

"in FY 2012, there were 7,478 beneficiaries that accessed the ECHO program."

This data derives from purchased care claims with a special "PF" code, indicating that it was an ECHO claim. Presumably, there were a percentage of ECHO beneficiaries who didn't file a claim during that period. Also, the 7,478 number indicates usage, not access for services. The study fails to provide a clear count as to how many individuals are actually enrolled in the ECHO program. According to DoD figures, these 7,478 beneficiaries account for approximately 6% of those reported enrolled in the Exceptional Family Member Program (EFMP). Numbers vary but 125,000 is a generally accepted number.

According to the DoD study, there were 6,560 beneficiaries with a diagnosis of Autism Spectrum Disorder (ASD) with costs associated with Applied Behavior Analysis (ABA) at \$110,700,000. There were 918 non-ASD beneficiaries, a little over half, who were responsible for annual ECHO Home Health Care costs of \$45,784,000. Total costs for the ECHO program were \$157,900,000. Considering these expenditures and what the ECHO program "covers", it would be more appropriate to call the ECHO program an "ABA/EHHC program".

⁷ See Footnote #2.

Not to deter from the importance of ABA and EHHC, but this ratio exposes a telling fact that those two benefits account for over 99% of all ECHO costs, while the long list of other benefits account for less than one percent of the costs.

The critical question for analysis is whether or not any of these numbers are actually fulfilling the mission of the ECHO program, which again, is to "to assist in the reduction of the disabling effects of the ECHO-eligible dependent's qualifying condition."

In this DoD study, which was directed to work towards that solution, TRICARE worked with ECHO case managers and families to discern what the issues were but with the caveat that revisions could not entail additional cost to the DoD. It's important for the record to note that when the Senate report language was originally conceived, "not increasing costs" was meant in the context of the already authorized \$36,000 for each ECHO beneficiary per year. Was there flexibility within that \$36,000 authorized cap to meet the needs of military families? Vague language in the report allowed TRICARE the flexibility to interpret the study in a manner advantageous to their interests. For example, TRICARE was informed that beneficiaries

"do not understand why they cannot access this benefit [respite] alone and would like the policy relaxed to make the respite care benefit more flexible. This is a source of discontent among ECHO families."

The answer to this ECHO family discontent was

"Requiring other ECHO-authorized benefits to be in-place as a condition of receiving ECHO respite care is a reasonable demand management tool. It is not recommended a regulatory change be sought to eliminate this requirement, as increased costs to the Government will likely occur."⁸

Respite care provides an essential tool in helping families cope with a child or spouse's disability or chronic condition. Responding to valid concerns about respite flexibility with a bureaucratic equivalent of "because we say so" illustrates a fundamental misunderstanding by the authors of this study, as this was not the intent of Congress when they noted the obvious need to ensure flexibility in the program. This scenario provides a resounding example of written policy that doesn't align with the intent of underlying legislation.

Medicaid waiver programs provide an example of what could potentially be covered by the ECHO program, but this comparison process is not without frustration. Every state has multiple Medicaid waiver programs (there are 435 active waiver programs). Just to illustrate waivers in

<http://tricare.mil/tma/congressionalinformation/downloads/ExpansionEvaluationEffectivenessTRICAREProgramECHO.pdf>, pg 6.

general, consider three states, recently considered by the 2013 UCP "Case for Inclusion" study⁹ to be in the top ten worst states in "outcomes for Americans with intellectual and developmental disabilities" (ID/DD); North Carolina (#45), Virginia (#47), and Texas (#49). Incidentally, each of these states possesses large military populations. These three states, via the NC Comprehensive Waiver ([NC Comp Waiver](#)), the VA ID Waiver ([VA ID Waiver](#)), and the Texas CLASS Program ([Texas CLASS Program](#)), each retain services that are more robust than the ECHO program. As an example, the NC Comprehensive Waiver provides for the following:

"adult day health, day supports, personal care, residential supports, respite, supported employment, behavior consultant, community transition, crisis respite, crisis services, home and community supports, home mods, individual caregiver training and education, individual goods and services (self-direction only), long term vocational supports, PERS, specialized consultative services, specialized equipment and supplies, transportation, vehicle adaptations". This program is for individuals with autism, developmental disabilities and intellectual disabilities of all ages."

For our military families, we recommend that TRICARE and DoD model their programs after the same initiatives funded by the Center for Medicaid and Medicare Services (CMS). Per its website,

"CMS is working in partnership with states, consumers and advocates, providers and other stakeholders to create a sustainable, person-driven long-term support system in which people with disabilities and chronic conditions have choice, control and access to a full array of quality services that assure optimal outcomes, such as independence, health and quality of life.

The programs and partnerships contained in this section are aimed at achieving a system that is:

Person-driven: The system affords older people, people with disabilities and people with chronic illness the opportunity to decide where and with whom they live, to have control over the services they receive and who provides the services, to work and earn money, and to include friends and supports to help them participate in community life.

Inclusive: The system encourages and supports people to live where they want to live with access to a full array of quality services and supports in the community.

Effective and Accountable: The system offers high quality services that improve quality of life. Accountability and responsibility is shared between public and private partners

⁹ <http://www.ucp.org/the-case-for-inclusion/2013/index.html>

and includes personal accountability and planning for long-term care needs, including greater use and awareness of private sources of funding.

Sustainable and Efficient: The system achieves economy and efficiency by coordinating and managing a package of services paid that are appropriate for the beneficiary and paid for by the appropriate party.

Coordinated and Transparent: The system coordinates services from various funding streams to provide a coordinated, seamless package of supports, and makes effective use of health information technology to provide transparent information to consumers, providers and payers.

Culturally Competent: The system provides accessible information and services that take into account people's cultural and linguistic needs." ¹⁰

Combining these goals with the charter to "assist in the reduction of the disabling effects" should be TRICARE's first step as it assesses "the adequacy of the ECHO Program in meeting the needs of dependent children with extraordinary health care needs".

Now more than ever, it is essential that our leadership focus on getting this right. DoD and TRICARE have an opportunity to lead on these issues, ensuring military families have access to the necessary non-medical services and supports necessary to provide for their family member impacted by a disability.

If you have any questions, please contact me at _ _

¹⁰ <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Long-Term-Services-and-Support.html>

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Medicaid waiver programs provide an example of what could potentially be covered by the ECHO program, but this comparison process is not without frustration. Every state has multiple Medicaid waiver programs (there are 435 active waiver programs). Just to illustrate waivers in

<http://tricare.mil/tma/congressionalinformation/downloads/ExpansionEvaluationEffectivenessTRICAREProgramECHO.pdf>, pg 6.

general, consider three states, recently considered by the 2013 UCP "Case for Inclusion" study⁹ to be in the top ten worst states in "outcomes for Americans with intellectual and developmental disabilities" (ID/DD); North Carolina (#45), Virginia (#47), and Texas (#49). Incidentally, each of these states possesses large military populations. These three states, via the NC Comprehensive Waiver ([NC Comp Waiver](#)), the VA ID Waiver ([VA ID Waiver](#)), and the Texas CLASS Program ([Texas CLASS Program](#)), each retain services that are more robust than the ECHO program. As an example, the NC Comprehensive Waiver provides for the following:

"adult day health, day supports, personal care, residential supports, respite, supported employment, behavior consultant, community transition, crisis respite, crisis services, home and community supports, home mods, individual caregiver training and education, individual goods and services (self-direction only), long term vocational supports, PERS, specialized consultative services, specialized equipment and supplies, transportation, vehicle adaptations". This program is for individuals with autism, developmental disabilities and intellectual disabilities of all ages."

For our military families, we recommend that TRICARE and DoD model their programs after the same initiatives funded by the Center for Medicaid and Medicare Services (CMS). Per its website,

"CMS is working in partnership with states, consumers and advocates, providers and other stakeholders to create a sustainable, person-driven long-term support system in which people with disabilities and chronic conditions have choice, control and access to a full array of quality services that assure optimal outcomes, such as independence, health and quality of life.

The programs and partnerships contained in this section are aimed at achieving a system that is:

Person-driven: The system affords older people, people with disabilities and people with chronic illness the opportunity to decide where and with whom they live, to have control over the services they receive and who provides the services, to work and earn money, and to include friends and supports to help them participate in community life.

Inclusive: The system encourages and supports people to live where they want to live with access to a full array of quality services and supports in the community.

Effective and Accountable: The system offers high quality services that improve quality of life. Accountability and responsibility is shared between public and private partners

⁹ <http://www.ucp.org/the-case-for-inclusion/2013/index.html>

and includes personal accountability and planning for long-term care needs, including greater use and awareness of private sources of funding.

Sustainable and Efficient: The system achieves economy and efficiency by coordinating and managing a package of services paid that are appropriate for the beneficiary and paid for by the appropriate party.

Coordinated and Transparent: The system coordinates services from various funding streams to provide a coordinated, seamless package of supports, and makes effective use of health information technology to provide transparent information to consumers, providers and payers.

Culturally Competent: The system provides accessible information and services that take into account people's cultural and linguistic needs."¹⁰

Combining these goals with the charter to "assist in the reduction of the disabling effects" should be TRICARE's first step as it assesses "the adequacy of the ECHO Program in meeting the needs of dependent children with extraordinary health care needs".

Now more than ever, it is essential that our leadership focus on getting this right. DoD and TRICARE have an opportunity to lead on these issues, ensuring military families have access to the necessary non-medical services and supports necessary to provide for their family member impacted by a disability.

If you have any questions, please contact me at _____

¹⁰ <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Support/Long-Term-Services-and-Support.html>

0045 Feb 2017 mtg R



Military Kids and Special Education

Prepared for the 26 January, 2017 Meeting of the DoD Military Family Readiness Council

Dear Members of the Military Family Readiness Council,

The purpose of the [upcoming meeting](#) of the Military Family Readiness Council (MFRC) is

"to receive information related to programs and services for DoD Family Members with Special Needs, including healthcare and the Exceptional Family Member Program."

Reviewing the minutes from the [14 Sept 2016 MFRC meeting](#), I noted the importance the council put on *"special education program objectives, initiatives, and pilots."* The purpose of this letter is to inform the council members of the impact of special education on military children and provide historical context for military parent led efforts in advocating for our kids.

This information is particularly important as renewed focus on states, such as Texas, with a large military population, are discovered to have systematically denied special education services. This [seven part series](#) by the Houston Chronicle; comes on the heels of [significant discrepancies](#) noted in the special education program in Killeen ISD (serving Ft. Hood, Texas), where many of the children are from military families. One family's voice,

"We fight for (least restrictive environment) everyday," said Laura Thomas, a parent of a special-needs Killeen ISD student. "He deserves to be in a classroom with non-disabled peers. When we moved here, they threw out our (individualized education plan). ... As a veteran and current military spouse, I am so angry that I was forced to move here and go through this. This is terrible; shame on you.";

For historical perspective, in 2009, a [Washington Post article](#) highlighted the difficulties noted by military families needing to access special education. The article noted a new Marine Corps program (still ongoing) that provided three staff lawyers assigned to help military families with special education issues. The other services vaguely mentioned they were considering additional help, but I am not aware that any specific actions were taken since then on this topic.

In 2010, I was part of a three-man briefing team; all dads of military kids with disabilities (two active duty, one veteran(me) ...how often does that happen?). We were one of the very first to have the pleasure to brief the then newly formed Congressional Military Family Caucus, hosted by Rep. Cathy McMorris Rodgers, a military spouse herself and mom to Cole, a young boy who happens to have Down Syndrome. Here is an excellent debrief of that caucus meeting, much of it specific to special education : <http://www.wrightslaw.com/info/mil.children.barriers.htm>

One of the things I advocated for in that meeting and subsequent discussions was an education tuition voucher for military kids with special needs, which was subsequently included in the [Senate Armed Services Committee language](#) for that year's National Defense Authorization Act (NDAA). Predictably, the National Education Association and other unions pushed back hard and had the language removed from the conference committee version of the NOAA.

As a compromise, a DoD study was ordered, directing an eleven-part report,

"describing the needs of military families with children with special education needs and evaluating or enhance benefits available to such families and children."

The report, published in late 2011, titled ["Enhancing Benefits Available for Military Dependent Children with Special Education Needs"](#), had little to do with enhancing benefits; rather it raised more questions than answers and in my opinion, did little more than kick the can down the road; concluding

"Although anecdotal information shared by military families suggests the listed issues are significant, little systemic data exists to verify their pervasiveness. Consequently, conclusions drawn regarding the need for the proposed changes or their effectiveness are limited."

DoD Action Steps from that report:

1. *"DoD will create and implement a comprehensive plan for collecting more detailed data related to the items in this report. One feature will be to utilize existing work groups in NASDSE, CADRE, and other organizations that focus on educational issues for military children. Collaborating with education agencies to obtain this data is consistent with the MOU signed by DoD and the Department of Education in 2008."*
2. *"DoD will develop a comprehensive plan for increasing military parent understanding of IDEA and the Department of Education's implementing regulations, particularly IEP requirements, and their utilization of IDEA procedural safeguards. Rather than creating new tools or initiatives, OSN [DoD Office of Special Needs] staff will collaborate with representatives of all military services to provide information and resources to military parents to help inform their decision-making regarding their children's special education programs."*
3. *"OSN staff will collaborate with OSEP staff to explore possible information sources for the proposed military complaint documentation system discussed in Item 9 on page 13 of this report."*

Potential Questions:

1. What is the specific status of each of these action steps from this 2011 DoD report? If action wasn't taken, why not?
2. With the creation of a military student identifier (see the most recent Elementary and Secondary Education Act (ESSA)), does DoD and/or the Education Department (ED) anticipate that helping provide the type of data the report states it needs. If not, why not and how might DoD senior leadership intervene to ensure that data is tracked such that the questions the Congress asked might be answerable?
3. What action(s), from local to state to federal can base commanders, the Joint Chiefs, Service Secretaries, and the SecDef take to support action on this issue? What action are they willing to take?

To be honest, I've never heard much of anything come from this study. Like many DoD studies, I fear it was put on the shelf and not considered again. If I'm incorrect, I'd love to see the information and data to prove that there have been efforts to improve special education services for military families.

Additional reports validated this DoD study as well as military parents' feelings about whether their children could access an appropriate education:

1. [March 2011 GAO Report "Education of Military Dependent Students"](#), noted the following as significant issues for military families: frequent moves, transitions, stress, fear, inadequate evaluations, inadequate IEPs [special education plans], inadequate services upon move to a new jurisdiction, all impacting special needs military families as well as school districts...*"58 percent of the school districts surveyed reported meeting the needs of military dependent students with disabilities was moderately, very, or extremely challenging".*ⁱ
2. [A Nov 2011 National Council on Disability Report](#) considered special education issues to be a significant source for military family stress,
*"EFMP families encounter obstacles to special education-related services. With great regularity, parents described feeling that they must fight schools to secure disability-related resources for their children—a lengthy process that may not be resolved before a family has another permanent change of station. This can involve incurring legal fees that the family will not be reimbursed unless they see the case to a successful conclusion."*ⁱⁱ

In 2012, I testified in front of the Senate Armed Services Subcommittee on Personnel, on issues related to special needs military families, including special education. I'd encourage council members to read the entirety of my testimony as it pertinent to the meeting on the 26th of January, but specifically [Attachment v](#) From a letter we had sent

to then Assistant Secretary of Education, Alexa Posny. Also of interest to the MFRC more generally are the [eighty letters we collected from special needs military families](#)' in the hearing.

In 2013, our efforts in working with the Department of Education and the Senate HELP committee led to publication of a [Dear Colleague Letter](#), a memo providing guidance to all State Special Education Directors from the Education Department.

In the same year, then Chief of Staff of the Army, General Ray Odierno, noted

"they (communities) better start paying attention to the schools that are outside and inside our installations. Because as we evaluate and as we make decisions on future force structure, that will be one of the criteria."

In this [same story](#) quoting General Odierno, the author noted,

"The Army is completing a far-reaching evaluation of local schools. The review-known as the WestEd study- will single out communities that meet the Army's baseline education standards while identifying those that do not. In short, the WestEd study will serve as a warning to those communities with low or inconsistent education standards: either fix the problem or potentially face the departure of Army units-and the associated economic benefits."^{xi}

Potential Questions:

What is the status of the West Ed study and were special education services or lack thereof considered in the results of that study and were they broken out as a separate issue area? If so, what were the results? If special education services were not considered, either separately or as part of the whole, why not?

Finally, I would encourage council members and military families to read this excellent article by an Air Force JAG, Colonel Elizabeth Schuchs-Gopaul: "[Legal Issues Facing Military Families with Special Needs Children](#), Twelve Things Every JAG Should Know" (her family was highlighted in the Washington Post article linked earlier). After reading it, I suspect you'll have a better understanding of the complexity of issues our military families with special needs face, specifically in special education, but also in a host of other legal situations.

Notably, I doubt many JAGs or military families have read the Colonel's article. I suspect few, if any, military families have the documentation I've provided in this piece (and this is just a small sample). I doubt EFMP Coordinators, School Liaison Officers, Commanders, and First Shirts could find this information if they were to spend a week looking for it. I also suspect less than 1% of special needs military families know that the Military Family Readiness Council will be considering issues that impact them daily on the 26th of January.

I've attempted to push this information out, but have very limited abilities and resources to do so and given Military One Source is the central hub for all things military family related, I would have expected more outreach; a link to the Federal Register on the MFRC website doesn't count as outreach. I know it's not because those in charge think these children do not matter. Whatever the reason, it's time to make changes to better inform military families, even when a report or

--1nformation_doesn't provide DoD-the best press. The more military families we have as participants in the process, the more

likely it is that the recommendations the council makes and the decisions DoD implements will be the correct ones.

I think Colonel Schuchs-Gopaul's final comment in her article is a great one for me to close with and for the council to consider as they take up this critical issue,

"Special needs and EFMP families are part of the Air Force family and we need to reach out to them. The JAG Corps, working with EFMP family service coordinators and SLOs, can make a significant difference in the lives of these families by educating them on the specific challenges they will face as they navigate the often unique medical, financial and legal issues. We can't solve every problem faced by a military family with a special needs child. However, being attuned to their unique legal issues will help us help them and, as needed, provide the best legal advice and guidance possible. In the end, educating military parents about these issues will help them as they

continue to advocate for their children in assignment after assignment. For some, this role of advocate will be a lifelong occupation."^{xii}

Sincerely,

Endnotes

i <http://www.houstonchronicle.com/denied/>

ii <http://kdhnews.com/news/education/large-crowd-gathers-as-killeen-isd-reviews-special-ed-audit/article/4c20a3fc-e4e0-11e5-a347-3398ea28f803.html>

iii <http://www.washingtonpost.com/wp-dyn/content/story/2009/12/27/ST2009122702156.html>

iv <http://www.edweek.org/media/10militaryinline.pdf>

v <http://www.tricareforkids.org/wp-content/uploads/2015/12/DoD-Study-on-Special-Educational-Sept-2011.pdf>

vi http://www.wrightslaw.com/info/GAO_mil.educ.0311.pdf

vii <http://www.ncd.gov/publications/2011/Nov282011>

viii <http://www.armed-services.senate.gov/imo/media/doc/Hilton%2006-21-12.pdf>

ix <http://www.armedservices.senate.gov/imo/media/doc/Individual%20family%20stories%20provided%20by%20Mr.%20Hilton%2006-21-12.pdf>

x <http://www.tricareforkids.org/wp-content/uploads/2015/12/July-2013-DoE-Ltr-to-Districts-Re-Military-Families.pdf>

xi <http://educationpost.org/a-matter-of-national-security-improving-k-12-education-for-military-families/>

xii <http://www.tricareforkids.org/wp-content/uploads/2015/12/Legal-Issues-Facing-Military-Families.pdf>

0046 Feb 2017 Mtg R

White Paper for DoD Military Family Readiness Council
Meeting On TRICARE for Kids and the Extended Care Health
Option (ECHO)

The purpose of this white paper is to provide an understanding of the ECHO benefit as it relates to the TRICARE for Kids Discussion at the 16th of June MFRC meeting, a recent history of relevant discussion, and recommend the Military Compensation and Retirement Modernization Commission's recommendation regarding the ECHO benefit be implemented.

The Extended Care Health Option, otherwise known as the ECHO benefit, is, according to 32 CFR § 199.5, (codified in Section 1079 of Title 10, United States Code),

"a supplemental program to the TRICARE Basic Program ... [whose purpose] ... is to provide an additional financial resource for an integrated set of services and supplies designed to assist in the reduction of the disabling effects of the ECHO-eligible dependent's qualifying condition." ¹

The Department of Defense's position regarding this program is as follows,

"Congress thus gave DoD much more discretion in its coverage of ECHO benefits than it has concerning medical benefits provided under the Basic Program. ECHO enables DoD to provide additional support services for Active Duty Family Members who are subject to frequent relocations to geographic locations that lack sufficient state resources for individuals with special needs...ECHO non-medical services such as respite care and behavior modification need only be determined by the Director, TMA, to assist in the reduction of the disabling effects of the ECHO-eligible dependent's qualifying condition." ²

The 2013 Senate Armed Services Committee Report (SR 112-173), directed DoD,

"to assess participation in the ECHO program by eligible dependents with special needs, and to explore options to provide more flexible benefits under that program without increasing costs to the Department."

The 2013 NOAA, as part of Sec 735, commonly referred to as TRICARE for Kids, directed the DoD to conduct,

"An assessment of the adequacy of the ECHO Program in meeting the needs of dependent children with extraordinary health care needs."

Neither the response to the Senate Committee report, completed in May of 2013, nor the resulting DoD TRICARE for Kids report⁴, published in July 2014, was adequate. It is my opinion that the ECHO program is in need of significant reform.

Consistent with that opinion, the Military Compensation and Retirement Modernization Commission (MCRMC), stated the ECHO program is not being administered as intended, stating,

¹ [CFR Title 32 Volume 2, Sec 199-5](#)

² [DoD Supplementary to 26 July 2013 Filing](#)

³ [DoD ECHO Report May 2013](#)

⁴ [DoD TRICARE for Kids Report July 2014](#)

"the Congress intended ECHO as an alternative to unavailable waiver benefits. Yet ECHO benefits, as currently implemented, are not robust enough to replace state waiver programs when those programs are inaccessible to Service members and their EFM's."

The MCRMC recommended significantly enhancing the benefits delivered through the ECHO program.⁵

In April 2015, Secretary of Defense Carter, in response to the MCRMC ECHO recommendation, stated,

"While the Department supports the objective of expanding services available to family members with special needs, we cannot fully assess the Commission's recommendations within their timelines for implementation. Furthermore, the Commission acknowledges that more work will be needed before determined which of the many state Medicaid waiver programs would be the most helpful and beneficial to our military families with special needs.

It will take the Department time to evaluate these programs, including any associated costs. In addition, ECHO currently does not have a process for implementing consumer directed care and that will take time to both evaluate and establish. The Department can more readily evaluate two specific services identified by the Commission: 1.) respite care and 2.) incontinence supplies. Other areas, such as custodial care, will need some additional study. The Defense Health Agency will lead the Department's review and determine the way forward in July." (of 2015)."

The MCRMC took it upon itself to conduct the additional study Secretary Carter requested and published a follow-up to their January 2015 recommendation in December of 2015.⁶ The results of that final recommendation as well as the Excel spreadsheet⁷, created to support their recommendation, are available in footnotes 6 & 7 as well as attached to this white paper (via email).

We must ensure appropriate resources for these vulnerable military families, not only as the right thing to do, but also as a military readiness concern. Helping families to "assist in the reduction of the disabling effects" for a military child allows the service member to succeed with their unique

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resources because of state-specific rules. Military children should not be penalized for the service their mother or father renders to the nation.

I strongly encourage the Military Family Readiness Council endorse the MCRMC ECHO recommendations to the Secretary of Defense for implementation.

⁵ [MCRMC Recommendation Number 7](#)

⁶ [MCRMC ECHO Recommendation December 2015](#)

⁷ [MCRMC ECHO Excel Spreadsheet](#)

Parent Comments related to DoD Proposed EFMP Regulations

Summary:

This rule establishes the Exceptional Family Member Program (EFMP) to identify a family member with special needs, providing family support to military families that include a family member with special needs, authorize travel at Government expense for active duty service family members with special needs, and, process DoD civilian employees who have family members with special needs for an overseas assignment

<http://www.regulations.gov/#!docketDetail;D=DOD-2011-0S-0127>

Comment

We are an Army family of over 20 years and my child with Autism has been in the EFMP system for over 14 years. We have had quite a frustrating and varied experience with EFMP. In the hopes of remaining brief and solution-focused, I will avoid unleashing the amount of frustration I have with the EFMP system, but instead will list the top challenges we have faced along with potential solutions.

1. Burdening families with paperwork and processes. In my instance, my daughter receives all of her services from the public schools. EFMP has provided nothing to us in the 14 years we have been in the system, except for requiring us to fill out extensive forms and provide piles of documentation. In a recent example, my daughter went through her 3-year reevaluation through the school system that included five separate evaluation reports from specialists at the school and a report from the psychologist and psychiatrist doing her medical evaluation. When I presented this to the EFMP office, I was then given a new stack of forms to fill out that requested the EXACT same information that I just handed them. However, it was not on "their" forms. I was also told I had to make a medical appointment with her PCM so he could fill out the medical form. Again, had two medical docs with a report that stated that but that was unacceptable. Her diagnosis was current in the MTF system but that wasn't good enough. Instead, had to take up a valuable appointment time for her PCM to fill out a form. I also had to take a form to the school to have them fill out the SAME information that was just handed to the office. Redundant, redundant, redundant. You are burdening families with stress and tasks that we do not need - at all!! Solution: accept school paperwork as documentation (after review of course) and have the EFMP staff fill out forms from the information that is given them.

2. Little to no oversight of EFMP offices/personnel/system. In our 10 moves to date, I have seen some amazing EFMP staff members but for the most part, I have been incredibly disappointed and frustrated. Helpful is not a word that I would use to describe most of the staff. Again, burdening families that do not need it. Most staff seems unclear on policies and sometimes seem to make them up. Lots of shrugging of shoulders and blank looks. One of the most frustrating pieces is having to submit, resubmit, and submitting once again paperwork that gets "lost in the system," "no trace of it being submitted," or "submitted incomplete" (even though it was complete when you left the office). Paperwork also gets "stuck" at regional offices, often holding up orders. No phone numbers or contact information is ever provided when asked - you just have to "wait." Who can families call when their EFMP office gives them stories like this? And who can we talk to about ineffective or just plain rude staff? Solution: provide EFMP families a way to report problems with the system, especially when orders are being held up. In 20+ years, we have not been able to find a solution to this. No one seems to know who EFMP answers to

or who can dig down into the different offices and find "stuck" paperwork. Give us the info we needed to advocate for ourselves.

3. Combine the separate EFMP offices and stop with the branch-specific offices. EFMP should be universal throughout all branches of the military and should welcome all to work with them. Nothing revolutionary there - just do it. Also, the Army (not sure about other branches) has separate EFMP offices, one at the health clinics and one at ACS. We are often unclear as to each of their roles with each PCS and to tell you the truth, I think they would do a lot better working together than separate. Too much, "Go talk to EFMP at the clinic, we can't help you" and then that group pointing you right back to the office that just sent you. Save some money - combine them and get them working together as a unified team. Sure would save us some extra trips and have everyone at the same table for once.

4. Stop taking so long to fix problems. I know, easier said than done. But working with special families in the current op tempo, you have to be responsive and flexible. Stop causing us so much stress and frustration. We have enough of that taking care of our family members with disabilities.

Comment

To Whom It May Concern,

I was hoping to be able to take the time to speak with the depth of knowledge required to make recommendations on the proposed changes but since I was only informed about this forum a couple of days prior to the Comments being closed I will instead have to simply give a more personal narrative of the impact of the EFMP program. I am extremely disappointed that I wasn't informed of these proposed changes or the option of public Comment through an official EFMP/DOD channel and instead stumbled upon them through word of mouth. If the DOD is truly seeking an open forum for change, then I'm wondering why this information wasn't disseminated directly to families by an official agency or group.

My son is an incredible, fun, bright 17-year-old who also happens to have a significant disability. He has a severe global developmental delay (attributed to an unidentified underlying genetic disease) which impacts his mobility, his communication, his self-help skills, his intellect, etc. He also has a seizure disorder. My family and I provide for and fully assist with every aspect of his daily living to include toileting, bathing, feeding, etc. It has been a JOY to serve him in his journey toward adulthood but certainly the task has been arduous and challenging at times.

It has also been a joy and an honor to serve this nation alongside my husband who is now nearing retirement. He has served 5 lengthy deployments in the past 14 years and he is preparing for his 6th after arriving at our new duty station just 5 months ago.

We currently have no respite, no agency assistance, etc. While we tend to be very capable of overcoming adverse situations, many families would not be able to sustain themselves in any aspect given the nature of the heavy load that has been placed on our shoulders. We are fierce advocates for our family and for our children however EVERYTHING in the special needs arena takes TOO MUCH TIME. It takes months of applications to get through the state program requirements and get on waiting lists that leave you waiting for years until you are approved for some services or waivers. It takes an incredibly persistent and tenacious person to negotiate through the web of community resources and agencies that might possibly help or give vital information to assist your family in simply procuring life giving medical, educational, and social supports that are absolutely necessary when raising a child with a

disability. It is common knowledge that services and supports are difficult at best to obtain, sometimes impossible depending on the child's type of need and the depth of care required, and yet it is still somehow acceptable for the DOD to perform in the same substandard manner as states that are backlogged by the thousands. My husband and I have served this Country with excellence and commitment and I fully expect that the DOD would want to implement that same excellence and commitment when serving the families of its soldiers who have unique and special needs.

My family's first duty station was a mistake. They sent us there and then decided that we shouldn't be there based on my son's medical needs. We were there for 8 months but that was still enough time for a deployment for my husband. I was left alone to traverse the system of obtaining therapies, etc in a brand new community because this wasn't a post for EFMP families so there was no one who assisted me. We were moved on a compassionate reassignment (at the request and initiation of my son's doctor) to another base. We were stationed there for nearly 10 years. I again traversed the system and we settled in. The local educational system was ill equipped for my child and I was told after many years and many struggles that the area schools were not able to keep up with the influx of children being re-assigned there for medical needs by the military. They were struggling and our children were suffering. After many years of failures and no progress, we WERE THAT FAMILY that had to hire an attorney to ensure that the district was upholding IDEA and FAPE to a cost of more than

\$50,000. The process of advocating through litigation was one of the most demoralizing, frustrating, and isolating experiences of my life.... and my husband was deployed during the bulk of the process. I'm certain that you understand not only the emotional stresses but the financial strains of a single income military family taking on this fight for justice. It should be common knowledge that many districts know of the financial limitations of military families and that the likelihood of those families holding them accountable through litigation is so small that they are willing to take egregious actions while disregarding the spirit of IDEA. Our district settled with our family after an extended and tedious game of legal extensions, etc. and literally the night before we were to head to our hearing. I hope you can understand the inherent struggle with trying to coordinate something of this magnitude over deployment phone calls, making decisions and coordinating childcare for weeks without your spouse and with no community help. While this all is certainly not the responsibility of the EFMP or the DOD, this scenario is not unique to our family. I have personally spoken with so many families that are suffering because "services are available" doesn't really mean that services are available in actual practice, in daily life, in our real lives. It is common

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local EFMP staff of the
difficulties and discrepancies (what should be versus what really is) of educational and other services provided and yet more and more families continue to be relocated. The DOD has a responsibility to make sure that if a military location has been chosen as a destination for children with multiple handicapping conditions that the local districts and support agencies are ACTUALLY supporting and providing an appropriate education and upholding IDEA and FAPE. The military legal offices are unavailable to help with this sensitive sector of law and military families are finding themselves in paralyzing positions of helplessness and desperation.

The military chose to move my family to a new duty station just a year after our settlement with the district. It also happened to be less than one year after we were FINALLY approved for waiver services from the state (after all those years waiting) and were for the first time EVER receiving consistent respite... it was time to leave all that behind and start over. Our next duty station happened to be a joint base that falls under a different branch of the military than ours. Upon arrival, the

problems started. The EFMP there told us point blank that they didn't know that we were even coming, didn't have any information on my child, didn't know we were there until we walked in their doors, and couldn't assist us in anything... but if we were the other branch they would have. They would have been able to provide respite, they would have been able to advocate for us, they would have but... they couldn't. After 6 months, we began the process of requesting a compassionate reassignment.

Unfortunately, it was our experience that the random people who review the piece of paper with your child's diagnoses' on it and then decide your future isn't the best indicator of service availability. The local districts that are assumed to be able to accommodate your child instead refer your child to a private school that is a 2-hour bus ride, each way! The medical services that aren't available on post but are "in the community" are a minimum of 3 hours of driving in traffic in an urban environment for a 15 minute, medication check in appointment. The respite services haven't been available in your new area "for some time". The social support and state agencies have "over 10,000" people on the waiting list. I'm certain that I don't have to explain what a health and safety issue it is to relocate a family to a new community and then leave them isolated, vulnerable, and without assistance and support. Even for the most well educated families it is difficult to determine this information ahead of time (prior to a PCS move) without intimate knowledge of the community, base, etc. Military families trust the EFMP and others in the DOD to be making informed decisions on their behalf and that trust many times has not been respected or earned and it therefore cannot be maintained. Our compassionate reassignment request was finally approved after OUR tireless efforts. We had to make numerous calls to local and regional EFMP coordinators, local and regional medical EFMP doctors, and even the national EFMP office. We had to work with an extra measure of diligence and perseverance. It was shocking to us when even the EFMP staff at the national level were confused as to why so many different staff and offices were involved in our request. My husband and I both spoke personally with a handful of other military families at the same duty station who were pursuing similar compassionate reassignments and facing the same difficulties. Something is critically wrong in a system when it seems more reasonable to a military family with 2 young children and a special needs child or a wife with cancer, etc to bypass the office that is a 5 minute drive from your home and instead drive more than 3 hours to visit a regional office in the hopes that you will finally receive some assistance and advocacy, in the hopes that if you show up in person they might have to actually address your issues instead of just not responding to your phone calls and emails. These families that are isolated are your best, your brightest, and your most important resource and their efforts and focus are being squandered on attempting to solve issues at home. instead of having the ability to fully focus on the important military mission they are tasked with because they can trust that someone has come alongside them and really hears and sees the solutions that need to happen.

We are at our new duty station. Unfortunately, many of the same issues have arisen. I haven't had a single day of respite care in over a year and half because they don't have a provider "in our area". Thankfully, we are adept at sustaining ourselves and rising above our circumstances. We are facing a new situation in which we would like to transition our almost adult child (nearly 18) to an independent group home living situation but have been faced with more difficult and complicated decisions than a typical family not affiliated with the military. We are not in our home state, nor a state that we will be retiring in so we are unable to transition our child here. We are also at a significant disadvantage for transitioning our child in another state in which we do want to retire to because we aren't physically living there. We MUST have guardianship before the age of 18 (to make any necessary medical and

educational decisions) at the cost of hundreds to thousands of dollars but that guardianship isn't transferrable to another state of residence.

It would seem there is always another challenge on the horizon when you have a child with special needs... but it would be my expectation and hope that within a military agency that has a budget of over \$30,000,000 someone, somewhere would be available to walk alongside my family and so many other families as we follow this noble calling in the military despite the additional challenges we face as special families. To walk alongside our families and give us a solid footing of trust and knowledge, to walk alongside us and open doors of opportunity and rest, to walk alongside us with consistency and excellence, to walk alongside us as we sacrifice so much to sustain freedom, to walk alongside us and cancel the 800 meetings scheduled this year to talk about change and actually JUST MAKE CHANGE, to walk alongside us and refrain from changing the definitions of definitions and instead engage in real, meaningful work that is tangible in OUR everyday ordinary support of the global mission.

We just want someone to walk alongside us.

Comment

My son has been enrolled in EFMP since 2009-2010. At our former duty station, the EFMP was of no use to us. I submitted the forms and didn't even receive notice that he was enrolled. I hadn't heard from anyone on the matter. My husband was deployed at the time and when he returned he noticed that we had an EFMP family member on his AKO account. When it comes to relocation, we have only relocated once since our enrollment. Due to my husband's numerous deployments, relocating just wasn't in the needs, he deployed too often for us to move. We just recently relocated and I am happy with the EFMP office here. They seem very involved and thorough as well as helpful and caring. My concerns with relocation with a family member having special needs, gears more toward the act itself. As I understand the military is my husband's career and he is of the Army's needs and our family has been very supportive of this, I do feel that families with children or anyone who has special needs, should definitely be given better consideration for more of a steady assignment. One that doesn't affect their career as far as promotion and advancement is concerned. It should not hold my husband's career serving his country back just because we have a child with special needs. We did not ask for that to happen to our son when we started our family and should not be punished for it. We relocated because my husband was told he would never advance any farther. If you don't advance in the military, you are stuck. My husband wanted to advance in the military for a long time and is extremely proud of doing so. However, just because we can't go to certain locations or he can't relocate for certain duty assignments because of our child, should not have anything to do with the soldier's career. Our son's disorders, yes plural, are rare. I have yet to find another military family with someone who has the same things as him. Moving was extremely difficult and it's only happened once so far since he was diagnosed. Routine is extremely important for our son, as well as many other things. I would be willing to bet that many people with Autism and other disabilities similar, would need the same things. Moving wipes that right out the window. New home, new place, new school, new teachers, new bus driver, new neighbors. All of those things are overwhelming to people with certain special needs. IEP meetings are frustrating starting all over, getting to know the new "team" trying to make sure your child's needs are met. When a child has issues that are rare and unheard of, it is extremely difficult to get their needs met, whether they have the appropriate teachers, equipment, learning strategies etc or not. Everything changes and everything gets flipped upside down for them and the family dealing with

the rest of the backlash. I understand the EFMP is there to ensure that when a military family with an EFMP member does move, that they are relocated to a duty station that has the means to fit all of that person's needs. You can move to a location that has MORE than what your family member needs and it will still be a whirlwind of disaster. I think this should be taken into consideration more. Way too many families deal with DAILY struggles with a special needs family member. Any kind of change can be devastating with or without all of the person's needs being met. The person with special needs as well as the people caring for them and dealing with the struggles of daily life deal with enough. Being military and going through deployments, field exercises, schools away from home - all of those also add to daily stress and somehow we manage to survive, but all the relocating and the need for it and the reasons behind the relocation, or being told you may never fully advance in your military career if you don't?

That needs to be addressed in my opinion. Nobody should ever be made to feel like they will never get anywhere in their career because of a child/family member with special needs. You can do all the research and reading you want, but you will never know what it's like until you have what we have.

on "what ifs". The current program does not prevent this type of discrimination.

Comment

I am an Air Force spouse of 22 years, the last 5 of which I have had an "EFMP" child. I don't even know where to begin with the problems of this program.

As per the Air Force Services website EFMP is to provide these services

1 EFMP - Medical (EFMP-M) provides medical information management support for EFMP enrollment functions and coordinates relocations for families who have medical or educational needs

First I have no idea what that is supposed to mean. Second, I have never had any of those services offered. We are completely on our own when it comes to receiving the medical care we need for our child as we move from duty station to duty station. When PCSing we are given no preference or easier access for enrollment, and have no choice in the MTF or PCM. We still have to wait until we are physically in the new area to enroll in the new region, MTF and PCM. Then we must make and wait for an appointment with the new PCM to get the new referrals for multiple specialists and services, many of which we have had for years and will need for the lifetime of the child, then we wait for appointments with these specialists and services, with no thought to continuity of care. This can sometimes take months:

2 EFMP-Assignments (EFMP-A) provides comprehensive and coordinated medical, education, community support, assignment coordination, and housing accommodation to families enrolled in the EFMP program.

First and foremost is the shocking difference between the services. Some have categories, some have codes. Some have detailers that know the system, some have personnel who don't have a clue. In the AF there is no hard and fast rule or continuity as far as keeping the family in an area that has the medical care or services that you need, it seems to be left up to the random whim of the person at the gaining base as to whether they can provide services, when clearly some cannot even though they have said yes. The higher in rank you go the less regard to the Q-code and any special accommodations there are, then when you are given an assignment your family clearly isn't going to be approved for, the attitude is oh well, we have no other alternatives for you. I'm a big girl and I know that not every choice is going to

be perfect and work for the family, but a little forethought and COMMUNICATION could go a long way in choosing the right assignments. Housing accommodations are also at the whim of the privatized housing and may or may not actually meet the needs of the family.

3 FMP - Family Support (EFMP-FS) provides community support function provided by Airman & Family Readiness Centers (A&FRC) and includes, but is not limited to, on-and off-base information and referral, parent training, support groups, relocation assistance, financial management, and school information.

I have no real issue with this, IF you are lucky enough to get on an email list or search out social media information. EFMP coordinators do not go out of their way to include all EFMP in their communication, but it is easy enough to find and I know there are many functions for EFMP families. However, I don't think they reach every demographic of the EFMP family, mostly excluding adults, older children and support for those with only medical needs.

Comment

I have been a part of the EFMP program for several years now and on average see four different specialists. We have lived in Texas, Germany and Guam and now Alaska. My biggest complaint/problem in the EFMP system is the lack of continuity in record keeping and transferring, especially since many of my specialists are off base. This is the third time I have gotten to a new base and little to none of my records have been transferred from the base to the specialists and each one has had to pretty much start over. There has to be a better way and a more uniformed system. Not only is it a waste of taxpayer money when tricare has to pay for tests again because the base fails to transfer all the records to specialists when a referral is approved, but it puts more pressure and work on the patient to try and keep track of (and many times pay for) additional records at off base facilities. Again, there has to be a better way.

Additionally, when I have a team of doctors it would be nice to have the option to stay at a location in order to have better continuity of care. I realize this may not always be an option, but by the choice of the member and the family it would be incredibly helpful.

Comment

My son with autism has been enrolled in EFMP since the beginning of the program. This program has done everything to help. I'm disappointed that our family is flat out denied the opportunity to go overseas. Autism is a spectrum disorder and each individual's needs should be looked at carefully before assigning a category that does indeed affect the service member's career.

No attention is given to whether the family uses TRICARE Standard or TRICARE Prime. A family using TRICARE Standard has much greater access to therapists and doctors. We choose to use civilian doctors because they are better educated concerning our son's comorbid medical disorders.

Parents do much better research than EFMP personnel for possible PCS locations. All too often I hear of families being turned down billets where the parent found all the medical and educational services available without waiting lists. And I also hear of families being sent where they have long waiting lists or very long drives to specialists. Twice after receiving orders, we were asked to write a letter stating that we understood we were going to a location without an MTF and any additional expenses we would be

responsible for ourselves. Both of these locations ended up having appropriate services with no waiting lists. The schools were wonderful and my son even received a Medicaid slot in one state in less than 6 months. Why are all families not given the option to go even if EFMP suggests the location is not in their best interest?

The current Navy Category system does not work for people with autism. Autism requires a well-funded school system, OT, speech, ABA and perhaps a dev ped and psychologist. (And many other therapies that TRICARE does cover such as chiropractic care and social skills classes). These services are usually not part of an MTF. What is important is that there are enough ABA, OT and speech professionals in the area without endless wait lists for after school hours.

I appreciate that EFMP staff sometimes do know they don't know the answers and direct people to the Autism Society. But in all my years in this program, no coordinator ever told me I could get an attendant for my child paid for by Medicaid. When my husband was deployed right after a PCS and I had young children at home, one who did not sleep at all and had explosive diarrhea which he wiped on the walls, it would have helped enormously to know about this state program.

Moving to large category 5 locations, especially for autism services, has caused severe continuity of care issues over the years for us. Wait lists for after school services can be over a yearlong in these dense military/MTF locations.

The program should be the same across all branches of service (the Coast Guard is also entirely different under Homeland Security). It needs to be more flexible in allowing families to have input in the decision making process. For example, do you want to go where a weekly service has a 6 month wait list, or where an annual appointment requires a 4-hour drive?

Thank you for your continued effort to build a better EFMP.

Comment

We are an Army family of 22 years, with 2 Children in the EFMP program. EFM 17yr old with multiple issues the most serious severe ADHD, EFM 15 yr old also with multiple issues, the serious being severe Autism. So we have been with EFMP for approx. 15 of those years. To be honest being in the EFMP program for our oldest child with ADHD has never been a benefit. It has required tedious paperwork and
.....apptsbutneveram1supportservices.

As for my 15 yr EFM with Autism, we have/had used 2 programs, one that was an ECHO demo program ABA, now it is obtained differently. The respite program is the other but currently really don't use it because the care at the current duty station is hard to come by. We have used it at previous duty stations because it was connected with home health care. Here the personnel is not trained and have no experience with children with Autism, they are just pulled off the street. It's a terrible system.

The problem with the respite program and with most the EFMP programs in general is the amount of paperwork that is required. You are asking an already taxed and stressed population of parents that you are trying to help by burdening them with an insane amount of red tape and mountains of paperwork to fill out, sign off on by several appointments and providers. It seems like EFMP wants to make the process so difficult that it will discourage the parents from obtaining the servicethey are seeking.

If you want to help, simplify the paperwork, centrally input everything into the system, parents do not need to do the leg work for each program. All programs and information can be enrolled from that data base with that information.

Besides respite, I've never really found EFMP helpful. It's been more of a pain, jumping through all their paperwork hoops requirements before a PCS. I've made suggestions, filled out forms, voiced concerns at forums over the years but nothing has changed. Navigators were hired but I didn't find that helpful. I was still doing all the researching before each pcs.

Having an EFMP child doesn't help me in any way at my MTF. I had made a suggestion early on that it would be nice if our file could be flagged. My child couldn't handle waiting more than a few minutes at an appt, in a new place (open space), he needed to be taken back to an appt room as quickly as possible, to avoid a meltdown. A lot of kids with Autism are like that (anxiety) issues. Simple things like flagging and prioritizing special needs cases for reviewed EFMP cases would be nice. Not saying every kid with Autism gets priority but a development pediatrician could determine that when enrolling them in the EFMP program. It would have made our life easier.

Lastly, I don't think EFMP should be allowed to determine whether a service member and the EFM should or shouldn't be allowed to PCS anywhere. Honestly they don't know the child or their needs really. They are looking at a piece of paper. They can present what is at that post/base then let the AD member determine it.

There could be a system put in place to score services at that duty station. Is there ABA available, what is the wait time, the school systems/special ed system/classrooms, special/medical services in the area.

That should be EFMP's job. Now that being said, a waiver should be available for a family stating I'm moving to a duty station with no ABA services and waive ABA services only while at this duty station unless they were to come available.

Too many careers are being dictated by EFMP. Too there is the other side to this. If a soldier needs to get to a place with services, then EFMP needs to continue with compassionate reassignment program.

Comment

I am a member of EFMP, secondary to an asthma diagnosis. I find the continual outreach and constantneedforcommunication.fromcaseworkerstobe.excessive.Whenmypackageisn't.updated.atthe2-year mark, email threats are made to my husband who then forwards them to me.

Unbelievable. I worked as a EFMP Coordinator many years ago, prior its "overhaul" and accompanying assignment of multiple caseworkers. While I can understand that there may have been unmet needs in EFMP, especially where children are concerned, I do not agree that the typical government reaction by overwhelming the system with employees and unnecessary programs was the answer. I find that EFMP is more of an intrusion and burden that I have to tolerate, since its mandated by order. My husband and I are both adults and know when updates are due and how to proceed through the process. We don't require dozens of emails to ensure we do what we are supposed to. In fact, constant reminder emails are somewhat of an embarrassment to me, to be reminded that I am "special" and need to seek extra help.

This constant coddling of service members isn't helpful to them or the system, and by doing so, we are perpetuating a dysfunctional environment in which veterans are mystified when they aren't told exactly how to navigate their world or reminded to do so multiple times throughout the year.

Comment

We have been on an EFMP for almost 10 years, the problem we have is there is SO much difference in every base we PCS to. We were fortunate to have two really good programs and then we PCS'd to Offut, AFB Omaha and there is almost no contact with the EFMP office. We are pretty much out there on our own with this office, and it's taken us almost 2 years to finally get squared away. I would like to see more accountability and maybe some universal programs that streamline from base to base, maybe youth center respite services and programs for our EFMP families. If the bases were to commit more to providing services themselves than to leaving the communities to provide them it would make things a lot easier for families.

Comment

I am a member of the TXARNG AGR force and my daughter is a part of the EFMP community. The problem we faced when registering her within the EFMP program was the severe lack of knowledge and continuity between the active duty force and the ARNG force. While the active duty side of the house definitely knew how the program worked, they had no idea where to place us and which AD post to assign us to. We were bounced around between two separate posts for a few months before we got the right answers. I'd really like to see an effort made to train the ARNG and individual states on this program so that other families get the care and compassion they deserve.

Comment

My spouse -- a civilian -- is on EFMP, only because participation is mandatory. This system infantilizes adults on the program to an unbelievable extent. Adult military dependents whose condition is stable and well controlled ought to have the option to acknowledge treatment limitations involved with a Permanent Change of Station move and press on.

Comment

FAMILIES NEED AN ADVOCATE! At the gaining and the losing base! The gaining base needs to have a plain language research and advocate for the families at THE GAINING BASE and with the doctor approving or denying travel!! Your "advocates" are not currently doing this! Also split the paperwork for conus and OCONUS moves. They are quite different and this causes confusion. Currently they are meshed together and the consequences for PCS'ing with a non-recommendation for travel are different conus to oconus vs conus to conus. People often confuse the two. Your data base for finding providers is grotesquely inadequate. Doctors are absent of the list mis-categorized and hence not found when searches are performed at gaining bases. People are wrongly denied. Then families are left to prove that the care is available.

Wonderful example of a stellar efmp- medical officer is [redacted Pill at Minot AFB, ND I have now navigated 5 EFMP moves. 1 denial which I successfully appealed. 4 approvals. Headed to Minot AFB in June for the 2nd time. Have 2 children enrolled in EFMP since 2009.

Comment

My name is, [redacted]. We have been enrollees of EFMP, since our children were very young in age, and now they both are teenagers. Our eldest child turned 18 last year. My concern for the EFMP program and our future EFMP military families' of our Active Duty, ARMED FORCES is continuation of supports of children, family members enrolled." How does EFMP Program support our once child(ren) enrolled onto the program differently when he/she reaches the age of, minority and a young adulthood still enrolled onto the EFMP program"? This is still a huge concern within this program. Adult Programs per EFMP Depts will differ by state, and overseas. All EFMP programs should be prepared when a EFMP family member enrollee passes away. For instance, what are the resources, military federal programs acquired to provide to soldier and the military spouse. What is the process per a 'EFMP' medical and or death on a federal installation or within the civilian sector of, a Active Duty EFMP soldier household.

EFMP Dept, should be able to provide cultural diversity programs to families per their ethnic background, as needed and requested. EFMP, should be able to respect and support family's religion cultural system of practices of all EFMP families per advocacy, state, federal, community supportive program, or legal support in native tongue understanding. Another mention, per readings, I did not see mentioned per this docket, DOD-2011-OS-0127-0001 anything written in English language EFMP Programs can be provided/support in native tongue fluent (spoken language of the soldier's family household other than English. I believe this is a key factor for all Federal EFMP, programs to provide support in interpreting all federal DD forms, federal programs, all/medical services offered and rendered to AD EFMP military family especially when military spouse is manning the Homefront as his/her soldier is deployed, training, TTY, special assignments, and so forth. Lastly, having a wraparound approach when working alongside your EFMP families is very important in addressing all needed supportive federal system of care for child, young adult and our re-tired EFMP families from the Armed Forces. Thank you for allowing me to share candid Comments. [redacted], SN Parent Advocate,

Comment

I spent five years at a location as an overage. I volunteered for any and every assignment that I could. Others were leaving that had less time on station than I. It wasn't until another location was going from contractor back to military that I was able to finally leave that location. I feel that during the assignment process, they see the Q code on MILPDS and then pass us over without looking into the situation. My

..... ifeh.c1 tose.e.ane.uJ()lggi Jeyer-y.v1:arfQr.h1:r 1:i:ztJJec:ljs.orc:l\$LiheygJ:eve.r:t.WelLc.Qt1troll d.asshe's only had two in the past 13 years. I feel that it's a waste for her to be in the program, as there are

other families with much bigger problems. I understand that the gaining location needs to approve weather or not they can accept, but there needs to be a better process for the folks that have controlled illnesses. Especially for the spouses enrolled in the program.

Comment

We have been enrolled in the EFMP for more than three years due to my son's autism spectrum diagnosis. I have two concerns. First, it is disappointing that the Services have such different ways of implementing active duty assignments for families enrolled in the program. In my branch of Service, autism automatically locks me in to a very limited pool of assignments in CONUS. A friend with a child on the spectrum is moving the entire family overseas. Others have been assigned to Hawaii. If the required

medical services (and schools) are available on a joint installation, why do some Services ignore this and limit assignments.

My second frustration is medical. The EFMP paperwork requires that the attending physician list the required specialties for treating the EFMP member. So when my family *moves*, it would seem logical that the receiving command would expect us. If we can get on a waiting list for housing, why can't we get on a waiting list for specialty doctors at the MTF when we *move*? Instead, we become a "new" patient at the MTF and it can take several weeks to get an appointment with the specialist. It would be helpful if the system would allow the EFMP member to have a "check in" appointment upon arrival at a new duty station to ensure continuity of care.

Comment

I was forced to join EFMP in 2007 when I had a physical before a *move* to Germany. The doctor who checked my records said I needed to be in EFMP because I took antidepressants for several years that happened to fall within the three-year window of my husband's Germany assignment. She did not discuss my records or health status with me before she made her decision and actually threatened me when I balked at joining EFMP. I was led to believe that I had to turn *over* some *very* personal records to her so she could examine them. This was a doctor who didn't know me from Adam and did not give me any input as to what my own wishes or needs were.

First, she said my husband would not get orders if I didn't join. I already had the orders in hand and command sponsorship and she was clearly surprised when I showed them to her. Then, she said if I didn't join, my husband could be kicked out the Army. She also added that it was a good thing we weren't going to Hawaii, since there was apparently a shortage of mental health care there. As I happen to have master's degrees in both social work and public health, I found her **Comment** rather ridiculous. She also said that I might have trouble in Germany, since my husband could be deployed (he happened to be deployed when I met with her) and/or I could be affected by the weather. I don't have issues with seasonal affective disorder, but she *never* discussed that with me. She just assumed it could be a problem for me.

That doctor spoke to me as if I was a child and made it *very* clear that she was covering her own ass. Talking to her was a humiliating and demoralizing experience. I found her *very* insulting. Since my husband was in Iraq at the time and I couldn't discuss the situation with him, I did as I was told and submitted the paperwork.

About six months after we *moved* to Germany, we got a nastygram from someone from I'd *never* met at Walter Reed, wanting to be "apprised" of my condition. My husband wrote back and let the coordinator know that I didn't want to be in EFMP and had no need for the program. We *never* heard from EFMP again. I got through our time in Germany with no adverse health incidents and my husband retired in 2014. We now are back in Germany where my husband works as a contractor. It sure is nice to have privacy and the ability to decide for myself what my healthcare needs are.

I think competent adults should have the option to decide for themselves whether or not they want or need to be in the EFMP. Aside from that, the program seems to have different rules for different people. My husband was able to simply tell the EFMP coordinator that I didn't want to be in the program and they left us alone. We have heard different stories from other people who have not had that experience.

Some have had to be reassigned and others have had to have someone "fix" their records so they could get command sponsorship for their family members. I'm sure EFMP is a fine program for those who need it and want to use it. I was not one of those people. It turned out okay for me, but I have read horror stories from others who weren't as lucky.

Comment

I have been a military spouse to an active-duty member for almost thirteen years. Of those years, the last four I have been on the EFMP program. Regrettably, I want the government to know that it is the worst program I have ever participated in or encountered.

Problem 1: It is supposed to be voluntary yet it is not.

Problem 2: The medical EFMP Coordinators on base do not actually "coordinate." Our last base coordinator's office provided me with false information, was not transparent and was over tasked. Important papers sat untouched for two weeks at a time. When it was time for me to move to a designated location, not a single person assisted in coordinating the continuity of care.

Problem 3: The most difficult and important of all the problems we have run into is that my husband's assignments are selected without consideration of where I am allowed to go. It is done backwards. First the assignment is selected then secondly it is figured out if I can accompany him. There should be an evaluation ahead of assignments so that it is already coded where I can and cannot go so that unnecessary hardships are not put on commands and families. When they figured out after the fact that I cannot accompany him to his assignment, they then have to back track and figure out a new assignment and it could most definitely impact his career progression- which the system is supposed by law not do. The end result in our case was an entire year separated as a family for the second time in his career in addition to numerous deployments. A sacrifice we make for our country- but an unnecessary hardship had there been an upfront way to know where I am authorized to go.

Problem 4: The military medical system as a whole has a larger problem than EFMP. People are being denied overseas locations that have critical assignments over common medical conditions. If you have an overseas location that allows for families to be there, then adequate health care for conditions such as high risk pregnancies, asthma, mental health, autism and so on needs to be provided.

... I finally had to have a doctor on my last assignment, a licensed doctor of many years verify and put in writing that I had a positive health prognosis and was entirely under the Doctor's medical judgment able to PCS, live and receive appropriate medical treatment in another country. That authorization was denied by another medical professional, who didn't know me, didn't know my case or condition (other than what they read on papers or forms), and said it was based on a "what if" of a future event that has to this date never happened. Essentially, our family was separated because of one person- removed from the scenario because of a "what if". Anything can happen to anyone at any time in this life. What ifs are not reality- critical career and life altering decisions should not be made based

Comment

While I understand that my husband's needs of the navy, I feel that there should be more work put in for sailors to be able to stay at a duty station for EFMP. My son is a category 5 and my husband's detailee would not work with us to stay in WA even with available orders. Our son has autism, sensory

processing disorder, developmental delay and speech delay and was actually progressing in WA with his therapies. Since we were forced to PCS to CA instead of actually being able to homestead in WA, our son still isn't receiving his therapies thanks to how long it takes to get the ball rolling and has regressed to the point that prior therapy was basically useless. He's not eating, he's back to biting himself and harming himself, he's not using any words he's been taught... it's frustrating. What good is it to have EFMP and homesteading if it's not utilized. I'm sure out of all of the sailors in the fleet, someone could take the bullet and allow sailors to homestead with their family too. For some, like my son, it would be detrimental for him to live somewhere and have his dad live elsewhere.

EFMP needs to be made a priority when negotiating orders. People that are in the homesteading category should actually be allowed to homestead and the service member should be allowed to homestead with them. Maybe allow them to negotiate sooner than non-homesteading families so there's more time to find an appropriate billet.

Comment

We have three children who have been enrolled in EFMP since 2007. In the last ten years alone we have moved to four different military installations. We have encountered numerous situations in which the EFMP office has proven to be ineffective in providing our family (as well as many others) the needed local information, resources, support and guidance that should be provided to a military family upon arrival to their new duty station and throughout the assignment.

I have had to in fact, guide EFMP representatives through their own process and have been taken aback by the lack of knowledge and trust in families to be more active participants in their own relocation process.

We are an Air Force family stationed at an Army installation for the second time and we are not allowed to speak to our local EFMP officials here on Post. We are instead instructed to direct any EFMP concerns or questions to the EFMP office at an Air Force base over two hours away from us. We are also excluded from participating in any of the Army EFMP sponsored activities, services and events strictly due to the fact that we are an Air Force family serving on an Army post. That isolates our family as well as countless other military families serving at a joint assignment from benefiting from programs that we are entitled to.

we would like to see changes to the EFMP that provide continuity and consistency among all military branches from the PCS process down to the inclusion of all EFMP families at every military installation regardless of the branch in which they serve. Each EFMP family must have the same code or category system used and there needs to be higher standards by which to assign families to their follow on assignments as far as services and available providers are concerned.

Comment

As an adult member of the EFMP I was required to sign up when I was diagnosed with stage IV metastatic breast cancer, and I not sure why, because as an adult I don't qualify for any help. I hope you would include something for adults with needs.

Comment

I believe that a by-product of EFMP would be higher morale and security with the affected service men and women, as their family member would have support in place. This would allow the service men and women to focus more on their tasks, and allow the family member to address some of their chronic conditions. I also appreciate that mental health was included.

Comment

We have been enrolled in EFMP since 2013.

About a year after we joined EFMP, we moved to a Army base. My spouse is active duty Air Force.

We can't use the local office and are instead on a remote assignment listing with a Air Force base that is 3 hours away.

This has made the program nearly useless for us as we can't attend local base EFMP programs. Also it has made their role of helping recommend different local specialist complicated as our representative isn't familiar with specialists in our area.

we also don't have a local case manager, this is a struggle as my daughter sees 4 specialists on a regular basis so continuity in records to what her PCM has and what the specialists have isn't working well.

Is it too much to ask to allow all branches use whatever base they are assigned to?

Comment

Some EFMP families are able to ask for a Stabilization (a form the S-1 can assist with) at the Post /Base they are getting the most assistance. Doctors that support your child's care, can write letters to document the success of the treatment the child is receiving at that Post.

Comment

With my husband having 34 years in the service, moving 13 times and residing on several joint or "joint community" bases both stateside and overseas, I do not understand why the DOD cannot come up with some standard and satisfactory care for all EFMP families across the board in all services. From what I have witnessed, it is very difficult for a family to move from one base to another. They are used to having care from their previous base. If there were to be some consistent and standard care, it would most likely, in the long run, save the government money, and also keep families from making the very difficult decision to "stay put" and not move with their sponsor due to inadequate services at their next duty station.

Comment

I believe that EFMP program has been good for my family, based on the two programs that I have used. The coordinators are good at reaching out and attempting to facilitate our needs. However, the EFMP program needs to be empowered with regards to TRICARE/ECHO. The Marine Corps defines EFMP, according to MARINE CORPS ORDER 1754.4B, "The primary purpose of the Exceptional Family Member Program (EFMP) is to ensure continuum of care for eligible Marine Corps family members. By identifying families with special needs and maximizing the provision of services, the quality of life provided to the Marine Corps family is enhanced while meeting the mission of the Marine Corps." In the Marine Corps

EFMP system, once enrolled, when you PCS, your coordinator sends your file ahead to the gaining EFMP department. This enables them to be able to begin working with you before your move. I would very much appreciate, as I am sure would others, if the EFMP could prepare the TRICARE region for gaining an EFMP member who has medical needs for early enrollment. If that were enabled, maybe the EFMP family could enroll in that TRICARE region ahead of time to get services started early due to waitlists.

For example; my son requires in home Applied Behavioral Analysis (ABA), Occupational Therapy, and Speech Therapy. If I PCSed to the current area I live in, there is a YEAR LONG WAITLIST for my current provider. That would cause significant regression in his disability. But if EFMP was aware of the specific issues, knew the local conditions/waitlists, and had the authority on behalf of the EFMP member's family consent to assist a TRICARE regional change ahead of their check in date, it would facilitate smoother transitions for EFMP members.

I understand that this seems unrelated with EFMP and problematic for TRICARE billing issues. But I go back to the "continuum of care" element in the Marine Corps order. I am also talking about a small number of people who would need this exemption, and the EFMP coordinator would have to use common sense for these case by case determinations. If we say that EFMP provides case management, this would be under that purview. As for billing, I as a service member go TAD/TDY to a conference out of my TRICARE region, and have an emergency and no access to military medicine, visit an emergency room. TRICARE is able to handle finding my information, address and all needed information to pay the bill. It can be done! Why can this not be done for EFMP members who would regress without this change?

EFMP should be more than helping to link EFMP families with limited government resources, and assistance with enrollment/re-enrollment. They should be empowered to actually help EFMP families with their specific issues, vice just give advice on what other families have done in the past and be powerless to help.

Comment

This is exactly what my family needs right now!!!

We've hardly had any support while my husband has been in Korea. I've been fighting with doctors and Tricare for a year now to get the services needed for my son.

Comment

We have three high need (cp, developmental delay feeding tubes) children and have been enrolled since their birth and to be quite honest I don't even know what EFMP is for. They don't help with anything we've been trying to get respite care for almost 4 years and the company SRI can't seem to get paperwork done and or Efmpr rep is either under qualified or doesn't do her job. So tell me what are you supposed to do for our families? What is the point if you don't even tell families why except to track them like our pets? At least the vet clinic spells it out for you. This program is just an acronym that has no meaning. The only time we get ANY notification is when they are threatening my husband's career because our paperwork expired!

Comment

EFMP is supposed to help when getting orders to another base however the time lapse in services is not taken into consideration. Even if a provider says a wait list is only a month, travel time, time taken to enroll in a new region, set up doctor's appointments to get new referrals is not taken into consideration. Companies are also saying there is no wait list when, in fact, there is. Moving across the country can cause a 4-6-month lapse in services which is a huge detriment! Monitors don't care that you're EFMP and need to be trained better regarding the program. We had a monitor tell us "I have a friend with a kid with autism, your kid will be fine". What training does HE have to make that decision?

Comment

My daughter has been enrolled in EFMP since 2005. Over the years the services of the program have deteriorated. We started out having wonderful support. A weekend respite program called, "Camp Special Time" that had trained staff to handle all abilities. A service for respite to help us find a suitable sitter for our daughter who has behavioral challenges. That also limited paperwork required by us to handle. When changes came to the respite program, we lost our ability to find a qualified sitter. Online sitter sites leave us with no responses due to all the challenges a sitter may face with our daughter.

Leaving our family with little or no respite even with all the ways to pay for it. We currently have no family living close to us to help out in a way of respite. Our current EFMP coordinators have been wonderful and understanding, but they are unable to really help find what our family needs in respite. Only offer resources. We would LOVE for the respite program in the EFMP to be fixed with a way to find quality care & a simpler way to track hours/payment. This would benefit families who have no family in the area that they are stationed.

Comment

I feel that it is unfair, confusing, and complicated to keep the EFMP program for each branch of the military separate. There are so many joint bases and we are ONE military. In addition to that it is unfair, that the different branches receive different benefits, for example the number of EFMP respite hours. How is it fair that one branch receives only 12 hours a month, while another branch receives 40 hours a month?

At our current base the EFMP coordinator is very active and organizes a decent number of events, which we are SO thankful for. At our last base, EFMP was basically non-existent.

Thank you for considering our Comments.

Comment

The EFMP program has been established to assist Service Members and their families wherever they are stationed. It would be beneficial to have the ACS database equipped to mark a family as EFMP in the system. With the Service Member being coded in the system as EFMP with each PCS. This would help ACS staff members during in-processing or out-processing services. We strive to provide the best possible assistance to all of Military Families with additional assistance to our EFMP families to alleviate stressors.

Comment

We have two children that are enrolled in EFMP because it is mandatory. This program has done nothing for us other than creating stress. We feel discriminated against NOT helped. We have been assigned many duty stations where speech and OT was not available for a year plus, but yet we are denied an overseas assignment because therapy is not available. Once a child is enrolled in the program it is virtually impossible to get out of the program even when the needs of the child have changed where they no longer require therapy. Because we are EFMP the process to enroll in CVS is ridiculous, and again we feel discriminated against. NOT HELPED! I would like to see this program with OPTIONAL ENROLLMENT. Let the families with significant special needs enroll and leave the rest of us alone.

Comment

I feel it is very unfair how different the resources and benefits one EFMP office can have from another based on location and service. I have spent years deployed and in the field as a Marine and we only receive up to 20 hours of respite care as opposed to 40 hours other services get, and their conditions don't have to be as severe. At joint bases, you could even find yourself to have 2 different EFMP offices with different resources and abilities to help their EFMs. Why does the DOD allow services to treat their EFMs differently?

I spent 4 months getting an overseas screaming done for my family when I was certain they would be disqualified from being able to PCS to Japan. The Process took so long as our civilian Doctors did not know how to fill out the forms creating multiple visits because they did not initial something or put NA. Now knowing my future and us having to take so much time off work was very burdensome and for no reason in the end. There should be a system in place that gives you a SET amount of duty stations your family can go to as a part of your EFMP registration, this will make our lives easier and detailers/monitors don't have to keep cutting orders.

There is not enough emphasis placed on education. Moving has caused headaches form my kids with special needs since we tend to have to start the processes all over again. My son recently lost much needed specialized education as our new school did not agree with our old school's assessments. Our new EFMP office does not have a lawyer and the Marine Corps only has one to cover the entire east coast. Services should have lawyers with licenses in every state to represent parents in IEP, Mediation

..... and due process hearings. It will be a year before we go through the entire process when a lawyer could have helped navigate a path to a quick agreement instead of the school bullying us. It will be a year before the entire rebuttal process is completed and we will have to go through this again very soon with our other child...so many meetings, so little help and not enough respite care.

Comment

We have been members of EFMP since 2008. Honestly, it is of no use when I have been able to network better, and have a better handle on services and schooling options than the resources that are supposed to work for us on post. At one point the installation was without an ACS EFMP coordinator, and the EFMP office in the MTF was contacting me when they had questions when there was a change in one particular program for families. That is ridiculous.

In our experience, the MTF and ACS EFMP offices do not coordinate to get families all of the information they need. None of them are knowledgeable about resources in the community, especially for those of

us with rare diseases, and none of the agencies communicate, like with housing when accommodations are needed, or from the MTF to HRO.

Since the respite program was changed to contractors it is inaccessible.

This is just how broken the program is when you have children enrolled. As an enrolled adult, I get no benefit whatsoever. There is no point in the program for adult dependents that I can see at this time.

Comment

The EFMP system as it is now is failing. My son was enrolled as an EFMP member when he was diagnosed with Autism 10 months ago. I PCS'd to a new duty station 6 months ago. Prior to coming; I tried to ask for assistance in ensuring I picked a good school area for my son who has autism. I received no support, I was told basically to go check the local school websites. Unfortunately, I have ended up in a school that cannot handle my child appropriately, and without any alternative schools that he can be sent to within the county. I have tried requesting assistance in finding caregivers that could handle my special needs child, and I was just told to go to some generic website for finding babysitters. I tried requesting assistance in finding someone who could be my short term caregiver on my family care plan, I was told to check with Youth Services... I can't actually name one thing that EFMP has done to help me with this PCS.

I am also dual military cross branch. The AF worked with me to put me at a duty station my husband could come to when I returned from overseas. The Army has not played so nice. I even asked if there was something that EFMP could do to assist there, as I cannot manage my son as a sole caregiver. There was nothing, no regulations or hardships or anything to assist in getting my son's second parent back living with us. The stress of an EFMP child is enormous, there should be policies in place to assist in ensuring families are stationed together to assist in continuity of care for EFMP family members. This is especially critical as I am due to go TOY for 6 weeks shortly, and you can't just interrupt an autistic child's routine and school and medical appointments to send them to another base for 6 weeks. If my husband was here stationed with me, there wouldn't be an interruption in his continuity of care.

Comment

EFMP needs to be standardized across services. There should be no difference in the services provided to the Air Force vs. the Army and so on. The EFMP staff needs to actually be a part of the disability community. We have had several staff at our base and they are clueless about the needs of EFMP families. When those needs are addressed, the staff treats the families with disdain to the point of making them cry. EFMP should not be a place that simply hands out a pamphlet and sends a family on their way. Further, the EFMP staff should know the disability services and landscape well enough to not duplicate services. They should also be willing to be an advocate for the families and not the school district. They should be willing to attend IEP meetings and stop lying to families telling them that it is against regulations for them to attend IEP meetings. Respite should be easy to obtain and you should not have to run around the base looking for multiple people to sign off on documents for respite. PCS decisions should be made after acknowledging the EFMP status of the family. The Air Force does not do this, and my family has been given back-to-back deployments to the same location and turned down each time. Note that when you give orders spouses lose their jobs. You also need EFMP staff that knows and understands the importance of wrap-around services for families. You cannot send a family

to Offutt that needs childcare for their special needs child. It is not provided by the CDC, especially after a certain age and is only provided by one location in the city that takes 40mins or more to drive to, one way. If there are not wrap around services that allow families to work or complete their mission, then what do you expect the service member or family to do to support the EFMP member? The EFMP office should also not be located in the AFRC but rather in the medical center and for children in the pediatric office: It should look like the medical home model...this would allow the entities to work together and give the parents a "one stop shop" for obtaining the supports that they need. There are excellent examples of medical home take for example the PRC program in Omaha Nebraska and it surrounding areas. It is run out of the Munroe Meyers Center by Mark Smith. That would be an excellent place to look to find ways to address how families are accessing services. You also need to consider hiring parents of special needs children as a much better option than the random professional. The families are more informed about the needs of other families as well as the services available in the area. Again, this is also present in the medical home model.

Comment

I feel the efmp program is better with the navy as we have a homesteading program. All branches should match that. MTFs should become more aware of efmp status and make it mandatory as the instruction says. So in other words, walk them from the PCM appointment to the efmp office. I have heard too many families say they have no idea or they feel it is optional. Also, this does seem to benefit enlisted personnel more than officer. Maybe there needs to be changes there. Respite care also needs streamlined, the navy program is the most liberal with hours and it is great. Also if this program becomes the same across the board then we should have no problems with SM and their families going to a sister service or joint bases.

Comment

My name is [redacted] and I am writing on behalf of my son who is in EFMP status. HE was vaccine injured at Womack Army Community Hospital. I did not receive any medical attention for him or any help after he was injured. It took me two years to find out he was getting sick from the vaccines. He developed encephalitis within a month of getting 7 shots (ten vaccines) This is normal I am told--- that he can get this many shots at one time. He clearly had a medical history of vaccine reaction that NO ONE

dared to check. I have been his advocate since the day he was born. He was born healthy, but scarred by vaccine injury. EFMP is a joke. These are flakey doctors that are like they are qualified to even assess the damage that has been done-- to my son or any other vaccine injured baby. It happens more than you would care to research. Why do you think they are in EFMP status? Have you checked their shot records and ER visits to see if they line up? My son is vaccine injured thanks to the army, and because I was never asked about his vaccine reaction history. Now I am taking care of my son for the rest of his life all because you want to keep up with the status quo of injecting children without questioning family history. There are thousands of children who have autism all because of the shots. You should research that for the military. There are thousands.

Comment

I am the spouse of an active duty Air Force member enrolled in EFMP for the past six years. I have a chronic mental health condition for which I have never been hospitalized and which has never caused me to be a suicide risk.

In reviewing the regulatory guidance for the EFMP program, I feel the government should assess the details and effectiveness of the program's implementation at the individual level. As an adult, I've found it to be inefficient, intrusive and unhelpful, and it's been the direct cause of my family being separated for a year for a remote military assignment.

By seeking regular counseling and occasional medication consults to control and manage my condition in response to the stresses normal for most military families--a spouse's long hours, frequent moves and loss of support systems, and the necessity of changing jobs myself several times--I was flagged for enrollment in EFMP.

This would be no problem if the system sought to help service members and their families, instead of simply save the government money on travel and medical expenses. I've received no offers of case management or any additional help finding counseling or doctors from the EFMP program. The employees at our local base office have not been consistently helpful and one in particular seems to be woefully undertrained.

When my spouse received an involuntary assignment for a small overseas base, I was denied command sponsorship to accompany him based on my diagnosis--again, a condition treated with readily available and inexpensive medication that I have been managing successfully for 10 years. As a result, he was diverted to an unaccompanied yearlong overseas assignment, leaving me behind to care for our infant and preschooler alone.

I expected to handle deployments and separations as a military spouse, but I never dreamed that being responsible, seeking treatment for my condition, and enrolling in EFMP as required--a program that's written as if it was supposed to be a help to service members--would be the reason for another year apart. As implemented, in my experience, the system punishes those who seek treatment or complete enrollment by treating them as an immediate liability in the case of any PCS or change of duty, especially overseas. Even an adult like myself or my husband has little recourse in the decisions made by the EFMP program, however much they may affect my military spouse and our family.

More standardization of services offered by the EFMP program from office to office and base to base, greater training for its employees, much more explanation of and transparency in the assignment process, and an honest admission of what difficulties EFMP enrollment may cause for a service member's family are clearly needed.

Comment

My family has been enrolled with EFMP for 15 years, I myself am an EFM, along with my two daughters just for me to get counseling has proven to be hard depending on what base we are at. For my two Autistic daughters it has been a rollercoaster ride up and down. Change is hard for our family and with every major change we have a major decline. EFMP members with Autism should not have to move every three years they should be homesteaded. We were at one duty station for 9 years I was finally getting help for my kids, and the Army said you have to move your homesteading. When one of your children is born different and it's a struggle to get anything done the Army should practice what it preaches! They are not family oriented, every place we have been too, we have had chain of command say your wife can deal, not have support or enough support cause you to need your spouse to help. The first year of my middle daughter's life I was her only advocate. There are not case managers that go in-

between the family and EFMP that can really help, they are not allowed to. There are children that need Behavioral Therapy that don't get it because they are not Autistic. The rules and regs don't make any sense the common sense has left the building. The people that make these rules have not walked in our shoes and given the chance I don't think they would!!

Our spouses are underpaid and overworked. Then when you retire out of the Military you no longer receive EFMP services!! The family serves just as much as the service member. There are lots of red tape that we have to go through as family member's posts look good on paper but when you get there they are not. There are many times not enough providers for the therapy for your child, or they won't approve the hours needed for that child. How does this make anything better? Yes we will give you some help with your kids but only a little and it hurts the child the most.

Comment

EFMP should be allowed to use on base providers (Primary Care) while Tricare Standard. We are paying out of pocket for coverage and when there are multiple specialty clinics it ought to be covered. I am a type one diabetic with premature twin daughters. We are not allowed to be seen on base because of the strange rules. I feel my husband being a veteran and having three family members needing medical it would be beneficial to be seen upon the base. Due to not having a primary care doctor for myself or my children, I have risked my health and jeopardized my last pregnancy. I was in and out of the ER and hospital and lost my son due to complications with my diabetes. I was 24 weeks and 5 days pregnant when we lost his heart-rate. I feel that EFMP should be allowed all the specialty clinics on base and not have to fight to find off base providers.

Comment

When we were stationed at Fort Benning, we had a great therapist off base. When we moved to Fort Campbell, we got a civilian contractor. Appointments were canceled. We didn't get as many as were needed. They tried to force my son into group therapy, we regretted ever leaving our therapist in Georgia. Then we transferred to Colorado Springs. The therapist at the Air Force Academy was quite religious. We're atheists. We gave up on trying to get therapy through the military.

Comment

I am rather new to EFMP as my son was diagnosed with Autism at age 2 while we were stationed overseas in England at RAF Mildenhall. We were too close to our PCS to try for a compassionate reassignment and chose to wait till PCS. Then we were given order for a PAX River Naval station and were told that in order to deal with EFMP issues we would have to drive the 2-hour drive to Andrews AFB in D.C. That assignment got canceled and there was a mass scramble. The part that was horrible is that EFMP can't really advise on what type of services are where. They tell you to get on Military One Source and Autism Speaks and figure it out. I think that there should be some kind of standardization among all offices and that obtaining a list of services available at every base should be an easy click of a button for the people in the office positions. We are now at JBLM and praying that we can ride out the last 6 years that my husband has till retirement here.

Respite care is another thing. We had no idea that program even existed overseas and really that is a place where it should. There are always military wives that are looking for jobs on overseas bases and it would be a great help to families over there who could use it. Yes, there is a chance that a PCS would

take away providers, but after seeing what our respite care provider gets paid here at JBLM, people would be jumping at the bit for those jobs. It is possible to provide those type of services overseas, especially at the larger bases or areas where the dependent population who is looking for work would be able to help.

The person who said there should be advocates on each side (incoming and outgoing PCS's) and that each office should be able to take all branches would save so many people so many headaches.

Comment

If EFMP is a DOD wide program, then standard operating procedures and services/programs provided should be the same across the board no matter at which location a military family enrolled in EFMP is stationed. Additionally, my family should be eligible to participate in all EFMP program offerings, to include respite, regardless of his service affiliation.

Comment

My family has been a part of the EFMP since my son was 10 months old. While he may not be considered handicapped, he is most definitely special needs. He suffers from epilepsy. Most days, no one would know anything was wrong with him, but it only takes a second for that to change. Without the care that he had received and medication to control his seizures, he could indeed be considered handicapped. I do not want that for my son or anyone else's family member.

When working in this reform, please be cognizant of the wording that is used, because many families, just like ours, could be removed from this program given a poor choice of words and how someone that doesn't even know my son or his medical history chooses to interpret that wording and policy.

Being a part of a military family is hard, but when you add a special need to the mix, it gets a lot harder. The stress and worry that a typical military family feels is multiplied by so many other factors, like will the referral for specialist be approved, will we be able to fill our prescriptions on post or have to pay an ever increasing co-pay at an off post pharmacy, will my family be split up because my son won't be close enough to a specialist at our new duty station, etc.

I am thankful for this program, and I hope that this reform only brings positive changes that will help more families face their medical and educational needs.

Comment

My biggest concern is that active guard reserves is not part of the EFMP program. My husband is looking into a full time reserves position so we can be closer to a big city with a hospital that meets my children's growing needs. I am told by the Echo case manager that if my husband is full time in DEERS then our children are eligible for Echo but would not be a part of the EFMP program. However, you have to have an EFMP certificate of enrollment to be eligible for Echo. The whole system should be working with parents and instead I spend so much time talking to different individuals in different organizations often with opposing answers. My hope for this process is better transparency. On a second note, if you continue to include children with asthma (for example), please do not limit children with a terminal illness because their parent is in a branch of service that does not recognize the program. We spoke to an EFMP coordinator about services at a potential base and she dropped communication as soon as she heard "AGR" which does not fall under her responsibility.

Comment

I would love to see EFMP standard across all branches of service. The navy seems to have the most comprehensive system with category levels, a homesteading program, and a more liberal respite program that is being utilized to the fullest.

I would also love to see the families themselves have a bit of a say so with categories. For example, an adult that has Lupus for 6 years and has been managed quite easily should have say if a category 4 (meaning staying CONUS) is adequate. If they have a condition that is being managed and it looks like a PCS move to X would be ok, a category 4 shouldn't limit an adult spouse that is capable of managing their own health care.

I also think that since this is a mandatory program the PCMs should not brush off an asthma or speech delay diagnosis, instead of telling the patient that they need to enroll, they should walk the patient over to the EFMP office and enroll them. There are still way too many people that do not even know EFMP exists.

I also think that if all of the services have the same program that it will be better for the service member to PCS to sister service bases or joint bases, thus opening up more billets for the service member and not stagnating one's career. This also gives more options before someone has to make that hard decision to geo. batch. and tear apart their family.

I would also love to see at remote bases that they bring in more experts to help the families with complex needs in our community. We are a level 5 base (so for Navy, category 5 EFM can be here) but we are isolated and the children's hospital is 2+ hours away. Too close mileage wise for Tricare to reimburse us but it is a financial hardship living this far away from the hospital, therapists, special education lawyers, you name it, it is all not around here.

I would love to see some actual money pumped into the EFMP liaison program. They are supposed to put on informational things, social things for families, train active duty POCs, etc. and they have NO BUDGET!!!! Why is a mandatory program that they want families involved have no budget!!!! That is why most bases EFMP liaison/family support never does anything and they do not help families. The one we have here at our base is great but I know that if she actually had a budget our program would even be better, sensory friendly films (remember we are isolated we don't have much here), guest speakers on different topics, even holiday parties-it all costs money.

I realize that none of these changes will happen fast. Heck, we might even be out of the military by then, but I would love for the EFM program to be better and not looked upon as a black mark on a service member's record, and do what it is actually supposed to do and help families.

Comment

The main thing to have happened since my son was placed in EFMP is that my husband is limited as to where he can be stationed. Four and a half years in we still have not received any ABA support. We're Navy but we live closest to an Army post. Everyone at the Army community centre has been extraordinarily helpful but there are some elements of support that we cannot access because we're not Army. I really shouldn't have to go all the way to Bethesda; Fort Belvoir Community Hospital is a joint facility!

Specialist care (Pediatric track for my autistic son instead of Family Health, appointments with Developmental Pediatrics) is patchy at best and frankly unobtainable at worst.

In short - it has not been a good or helpful experience.

Comment

I have twin children that are enrolled in Efmp due to autism. The program has helped us ensure we are being sent to a duty station that can meet their needs for autism related services. I believe this to be a great thing as separating families is a bad choice and causes undue hardship on both the service member and their family. I think there could be some changes made like providing better information to families about the available resources at their new duty station, streamlining the paperwork so you don't need to have several doctors plus the school fill out various portions and a proper notification system to notify you at least 3 months prior that you're Efmp paperwork needs to be updated. Also making it easier for people to get an actual appointment to complete the paperwork instead of walk in only. I think the option for homesteading would be a great use to families who have various needs and they are being met at a certain installation. It reduces the cost of constantly moving service members, gives families more support and stability and allows persons who want to PCS more to have that option. I also would like to see more services offered for siblings of Efmp and support for the spouses left behind during deployments who need help caring for efms. Currently the army offers a respite program that needs to include more than just watching a child, it should be more traditional respite and provider type services to include transportation, out of home community activities and homemaker services. Efmp is an essential part of our lives and I cannot stress how important it is.

Comment

My husband works for the Navy in a Marine Corps base. We have received services, orientation, workshops, and even recreation through the Marine's EFMP program. The EFMP representative for the Navy has only pushed paper and does nothing for us

Comment

When we got approved for EFMP it made a world of difference for our daughter. It allowed us to get ECHO under Tricare so we could start ABA therapy. She advanced in many areas that helps her in life to communicate better. It also helps us receive a lot more care options to treat her Autism and Sensory Processing Disorder. I think the key to this program is making all the bases aware we have it available to them. When it was told by us through Tricare we had to be enrolled in EFMP first in order to receive ECHO option. At the National Guard Base our daughter's father works at no one ever heard of EFMP. Once we got some information and a lot of paper work we still had to communicate to different titles who receive this program.

I think more communication about this program will help a lot of military families who are struggling with a disabled child.

It's the greatest program that should *never* go away or not push forward. Our family was the first to receive these benefits at the Base. By our awareness for this program it helped a number of military families there to get this option.

Comment

We are a Marine Corps family with two children with autism. We live in an area where the cost of childcare is high and have been told we don't qualify for respite care. To find a trustworthy, qualified babysitter we are paying at least \$15 an hour. We have friends in other branches who qualify for respite care and it's incredible frustrating that it's not universal across the board for what the qualifications are. When the medical provider tells us we should most definitely qualify for some help then the EFMP office tells us to apply for Medicaid to get respite through the state, it's incredibly discouraging. Should we go back and beg the doctor to make their diagnosis worse than it already is? Nope, we don't do that so we rarely get a break. That is my one and only complaint.

Comment

We have been a part of the EFMP program since 2006. My daughter has severe autism and intellectual disabilities. Our daughter is 12 years old and almost entirely non verbal. Besides the first experience I had with an EFMP manager, I have really liked all of our managers.

I feel that we are given adequate Respite hours. However, I really enjoyed the flexibility I used to have to pick my own respite provider, and take them with me to activities, appointments, etc... For years I was able to choose a trusted family friend to care for my child. Now I am given a list of names, and hopefully one of them is available to watch my child in my house. Many families I know have waited for months. I use Respite almost entirely when I am home doing housework, or when my 13 year old daughter is home for date nights with my husband. I do not feel comfortable leaving my daughter completely alone with someone I do not know when she has no way of expressing to me her feelings or experiences. I understand there is a need for a standard for this, however, I feel that there should still be an option for those that have the resources to use a trusted friend at an assigned base. I did this at two different posts for a total of 7 years (although they had to stop assisting me off property).

Second, I feel that the EFMP often does not have a very firm grasp on the resources in a community. It surprises me how little some of them know. I like to fully research areas where we are moving, however, I think there are many that are overwhelmed or new to the process that suffer in this department. I think there is too much paperwork. The fact that I lay my questionnaires side by side to copy down information verbatim year after year, often with an impatient daughter beside me is exasperating.

I believe that on the medical side children with autism should be flagged for visits to the E.R. or doctor's appointments. I had to take my daughter to the E.R. last year. I explained during Triage that my daughter would be patient for about 45 minutes. I had snacks, candy, as much battery in her ipad as I could manage in an emergency situation, but it would only last so long and then all Hell would break loose. I was very kind and professional in explaining this to them. Apparently no one took me seriously, an hour and a half later the meltdown began, our name was called within 30 seconds (not an exaggeration). Instead of being able to examine my daughter in a calm, compliant state, we were all struggling to calm her and do what needed to be done.

I would like a clearer understanding of where we can be stationed. I also want the option to sign a waiver with the understanding that I waive my right for a compassionate reassignment. I now know how to work with my daughter better than anyone else, and feel confident that we could, as a family, do

what needed to be done at any duty station. This may be an option, but I would like it to be something I didn't have to research, that I just knew because of easy access.

I do not like the new policy of having to get a Dr's referral every 6 mos for continued ABA. Between IEPs, EFMP, regular doctor visits, establishing services after each PCS, this is just too much. I have four children to keep vaccinated, healthy, etc... There is too much time spent at needless doctor's appointments!

I would like EFMP and TRICARE to have a better understanding of ECHO, and coordinate together. ECHO is so ambiguous. I have had one grouchy case manager after another, until this last PCS. The case manager I was assigned when we arrived took the time to explain to me, in detail, what they could and could not do. This is after 8 years of ECHO enrollment. I also believe diapers should be covered once a child reaches a certain age (6). Other insurance companies provide this benefit. We have a significant diaper cost each month.

I want part of the standard process to include examining my child's profile before it is submitted for clearing prior to a PCS. We were denied a PCS, and later discovered there were multiple services listed on my daughter's paperwork that we did not need. No one ever went through those with us to ensure they were accurate. We were in California where there were a number of optional services available that we were using to supplement and keep our daughter active.

I also want a clear understanding of my child's benefits as she ages out of childhood programs and becomes an adult. I have not started really researching this yet, I wish I didn't have to do so.

These are the significant issues I can think of at this time. If I can think of more overnight, I'll let you know;-)

Comment

I have two children on EFMP our daughter first, and we had no idea what efmp actually did. No one ever even talked to us aside from turning in paperwork. Then we were stationed else where and had no idea that because our son had an iep he also needed to be on efmp. We filed for compassionate reassignment back to jblm upon his autism diagnosis. Once here I went in person and spoke with a very welcoming lady and then place with someone else who called me from efmp the next week. This new lady was rude and short and was angry at me for not having proper documentations from our last base and she could not look up or efmp information that I'd have to drive to the lewis side and pick it up somewhere she vaguely described as inside madigan. I cried I felt so overwhelmed our last base said everything was taken care of and the new base had all of our paperwork. Obviously this wasn't the case. Luckily my husband was able to get it faxed to us. I went to take the paperwork in to have MY efmp lady say she was sorry she thought I was an army wife and that I didn't need to do any of that she already had all of our stuff.

My suggestions are

1. Make the paperwork the same across every branch.
2. Make the process EXACTLY the same across every branch.

3. Make every part of efmp accessible to its employees. I shouldn't have to go to medical records to get something when they should be able to access it.

4. Ease

5. Less stressful

6. More straight forward

7. Welcoming. With a packet or a meeting so parents actually know what efmp is and how they can help their family. Otherwise like us they will be enrolled and think it's a useless program.

If someone is already needing EFMP be they army, navy, air force. Or marine WHY should any of them be more hassle then another branch? It's already stressful enough it

Comment

When we first enrolled my son in EFMP, they told us we would be homesteading because of his autism and difficulty with re-establishing services that could cause significant regression. This was summer of 2011. Then when my husband (active duty Navy) went up for orders this past year, the rules either had changed or we were misinformed (by several people, who clearly all made the same mistake we did) regarding homesteading--instead were being asked to relocate. It has taken us two years to get a team established that works well with my son to a point where he is making improvements. We are at a command where my husband would never have to break rotation, and we have all the services my son needs. If we moved, we would even have to give up his very expensive and customized communication device because it is through the county we live in. It terrifies me that we could be expected to give up his voice. We were very lucky that we ended up being able to stay. I hate that my husband deploys and has to worry about whether our son is going to lose his ABA coverage because of the many hoops we have to jump through every year when Tricare, or the Navy, or EFMP changes the rules, usually without informing us. I have no idea how to get a case manager, or if we even qualify for one, as I have found that most of the EFMP people we are in contact with either do not stay in one place long or have not gotten back to me. I had to get someone in Millington to make a simple correction to my son's EFMP record that an EFMP office here could have done, but all three of the offices I tried contacting never got back to me (I didn't actually know where two of them WERE, so I couldn't have even gone there if I wanted to).

We appreciate the respite care greatly. That has been an amazing help to our entire family. Being away from family is difficult and the strain of an autistic preschooler and a deploying husband is intense. Our provider helps our son with his development while giving me time to do simple things like grocery shopping that are incredibly overwhelming to him. It is one program that we were informed of immediately and have been able to use. We don't typically hear about other EFMP programs.

I feel that if the program kept us better informed and did the things it was designed to do, it would be an incredible help to military families.

Comment

We are an active duty family with twins who are both EFMP due to having autism and ADHD. I honestly wish we had NEVER signed up for them to be EFMP because we feel that it hinders my husband's career

because of the hoops you must jump through from one duty station to the next. I feel like no one listens to the parents in what their needs are and how far we are willing to travel for the preferred provider we want to utilize. The so called "recommendations" from one doctor hinder a family when it is time to PCS even after I've stated we haven't seen a certain provider in years or you no longer utilize ABA therapy. Just to get recommendations removed you have to make an apt with the PCM and convince them you don't extra services for your children. It seems like they are pushing families to make up or add on stuff they don't want or need just because it makes them look better. The universal across the board way of enrolling and keeping people EFMP is asinine and needs to be rethought immediately.

Comment

I brought up the case manager idea at a recent EFMP meeting at the Family Readiness Center. It makes so much sense to have a knowledgeable individual be the go between from the Med group, EFMP, ECHO/tricare/Value Options, Referral Management, Family Readiness and the special needs families/individuals. Otherwise, the families are left to learn the go-betweens, with each of the afore mentioned subject matter experts ONLY knowing their own area-not the entire gamete of information a family would need to know.

Comment

My 9 yo son has been enrolled since he was 2 1/2 (Pdd-Nos). I must say the paperwork to get assignments approved are overwhelming! It's a job in itself to get services and then there is always wait lists and long commutes to contend with.

It would be so lovely to have an ABA therapist in all schools to work alongside resource teachers, speech pathologists, general Ed teachers, occupational therapists, etc. Needed services, in one location for our EFMP individuals would help ease the stresses families endure on a daily basis. Perhaps a central location (military clinic, family support center)

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Comment

For the first 12 years of my children's life, EFMP was just one of those hoops we jumped through every time we PCSed. I never liked the process only because it was more work (paperwork) for me with less benefit personally. When I arrived at a new base, there was no support group, no network, and I rarely knew one other EFMP family. The last 6 years I've seen a difference in the personal support and contact offered from the EFMP staff at different bases. They hold events for families to meet and connect. They hold briefings on IEPs and other EFMP-related issues. There is a POC somewhere who knows your name other than from a piece of paper, and, at my current base, even a Facebook group. So, in my opinion, it

is changing to become more positive, relevant, and personal to me rather than an arbitrary, disconnected system. If I could, I would change two things, One, I wish I could change the way EFMP affects our PCS choice. When you get orders and are denied by the EFMP, then the AD person goes back to the "bottom of the list", so to speak as far as job/location choices. Most of the good places are by then already assigned and you are left to pick up what is left. This has happened to our family more than once, adding more anxiety to an already stressful time. I also don't think the EFMP assignment approval process is always standardized. In the past, EFMP denied us going to Washington DC and then again to New Jersey, both of which are locations filled with specialized medical care. So, we could not figure out why there was a denial in the first place. We ended up going to both places but it took weeks of researching, reading up on EFMP protocol and paperwork to process--which made our stressful PCS time even more stressful. Two, I'd simplify the paperwork. It's long, tedious, and having to PCS every 2-3 years, we have to redo everything all over again--and that's times 2 kids. Why can't we have a shortened online form that keeps all relevant personal info and we just update each time we PCS? Thank you for the opportunity to Comment.

Comment

There should be a homesteading option for children with autism of service members. There is no such rule or program for the Army. Do you have any idea how hard it is to create a successful adulthood for a child who is moderate to severe on the spectrum if they have to relocate every few years? EFMP also needs to take a really hard look at special education that is available within a reasonable distance from duty stations before sending a family there. I was told last year that special education did not matter in deciding duty station. Are you kidding me? 80% of the assistance my son, who is moderate to severe and non-verbal on the spectrum is provided through the special education he receives 1:1 from the county where we live now. It was proposed we move somewhere that not only would he never be in a 1:1 situation in any county within 3 hours of the post, but that if we tried to sue the county, they knew we'd only be there 3 years, and would tie us up in court that whole time. This is unacceptable. Also, it has come to my attention that if someone is determined moderate to severe on the spectrum the D02792, the only thing the receiving duty station will look at, only lists these kids as moderate, which is absolutely ridiculous and unfair to the child. Our service members are willing to die for their country and the good of their families. Please do not continue to add to their woes by making them have to choose between their careers and their child's well-being.

Comment

We are a military family that currently has 4 children enrolled in the EFMP, so I can say that my experience with this program is somewhat extensive. This will continue to be the case for the remainder of my career as three of those children have severe, lifelong conditions. To give a bottom line assessment, the current EFMP program requires far more from us the service members than it provides to us by way of services or support. Even the current services that are supposedly available cannot be used because of bureaucratic delays or lack of personnel. Take for example the respite care program.

One of our children qualifies and was enrolled in this program but due to the lack of service providers, my son never really received any substantial respite care. Beyond this one failed service and the tedious enrollment into the echo program, which is a quagmire unto itself, the EFMP has provided us very little.

With that being said, I do have a couple of suggestions on how to improve the program beyond

just increasing general service availability.

First, EFMP service reps should be hired who have experience working from within the EFMP. These individuals should have experience as family/service dealing with the issues that family and service member with exceptional family members face.

In addition to new empathetic customer service, individual military members, preferably those experienced with exceptional family members, should be chosen to act as unit level EFMP liaisons, advisors, and advocates. Higher level commands should have a dedicated individual for this task, while lower level operational units should task this as an additional duty. To support this new military duty, an EFMP training course should be set up to enable the selected service member to truly offer realistic, timely, and useful information regarding their family members, the EFMP, and other services that may be available in the community. I would suggest that this pool of individuals be tracked so as not to lose the valuable experience that they have gained. I know that this suggestion is but one in a long list, proving a compassionate, knowledgeable, and empathetic comrade who can walk the exceptional family member journey with the service member will create a feeling of inclusion and support that is desperately lacking in the current program.,

Comment

It has been very difficult navigating the world of services for our son (ASD) who is enrolled in efmp. I have yet to find a play group for him, so that he can social with others in his peers group. There is no actual location for respite care provided outside of the home. How is it respite if we are all in the same location, siblings and all yet another adult is there? Resisted should take the former of a program where a child is dropped off for a specific amount of time then picked up. It does not make sense to me why there has not been a summer camp, after school program or social clubs, sports team created by EFMP. These resources would be wonderful and change the quality of life of not only my child but every child enrolled in EFMP. In addition what is being done for the siblings of a child with special needs? What support/activities active created for them?

Comment

My daughter was diagnosed with Autism a few days before her second birthday, our family is currently living in New Hampshire as my husband is stationed here on recruiting duty. I have found it very hard to navigate the EFMP program, since we do not live near a base it took almost 4 months for my daughter's PCM to correctly fill out the paperwork, that once submitted we only received a letter in the mail stating she was accepted into the program. Our case may be rare as I found out later that our assigned case worker was out on sick leave for 3 months and that was why contact was not established for 4 months once in the program. During this time, I was unaware of the benefits of the program and what other programs my daughter was eligible for. We tried enrolling my daughter in Tricare ECHO but it was denied because the paperwork had not been signed officially by EFMP. This was another misunderstanding; I was unaware that families do not get an official signed copy unless it is requested. This caused a lot of headache and frustration for myself and my husband and it could have been avoided had there been a procedure list or resources that explained the program in place and was easily accessible.

I would like to suggest that general information about EFMP as to who to contact, enrollment papers, and other resources and helpful tips regarding the program be compiled onto one webpage that can be attached to each recruiting station's home page. I have seen the current page and it is simply not

detailed enough. With dealing with the program I have felt that no system is set in place to help families whose family member has to be enrolled in EFMP while on recruiting duty. I think with the suggestion above it would be a great start in the right direction. I would be willing to give further insight on my experience, as I do not want another family on recruiting duty to have to deal with this added stress of the program. Thank you for your time.

Comment

Regarding EFMP, RIN # (0790-A182) and/or the Docket ID number (DOD-2011-OS-0127)

This program most likely saved my wife's life and most definitely saved my family's long term health. However, now that I'm having to resubmit after getting orders back to the base we previously were approved to leave, I find that the review process and selection criteria don't seem to take my family's wellbeing (specifically the EFMP member affected) into consideration.

We were rejected from an assignment and then reassessed and sent back to the base we came from on EFMP originally. My wife is terrified of the outcome and I'm doing the best I can to re-assure her that the system will work this out in the end. We are hopeful, but I feel the AF has some serious issues related to this program.

This in no way is a reflection of the individual support from our local efmp office, they have been cordial and as upfront as possible. The program itself has serious flaws, if the goal is to minimize hardship and enhance the ability of the AF member to focus on the mission.

Comment

I believe that EFMP was created with positive intentions, but it seems that 9 times out of 10, EFMP is nothing but a hassle and creates a lot of heartache. Our child was initially enrolled at age 1 during an overseas screening because of a onetime inhaler use a few months before. This was a RED flag for our screener and we were enrolled in EFMP against our objections. When the time came that the EFMP was expiring, the office used our child's relatively new ADHD diagnosis as a reason to keep us in the program. We have NEVER benefited from EFMP and I don't think there's much they can do since we don't require respite care or any other services. The only times we talk about EFMP is when it's PCS time and we have to jump through hoops to get orders. There is a huge disconnect throughout the military; I see that many see the disconnect between service branches, but I see the disconnect within the Army alone. Example: our child saw a child psychiatrist at one Army base because the service was available. We were happy with the services provided and had no issues. When it was time to PCS, the RFO was essentially held hostage because of our child's EFMP. The gaining post did not have a child psychiatrist (through the town had plenty!) so we either had to PCS to another post or the PCM and psychiatrist would have to sign off on EFMP paperwork that stated our child could be treated by a PCM. Both agreed and filled out the tedious paperwork and the RFO was released. That is just one example of the "jumping through hoops" that military families have to experience in EFMP. Another point that should be considered is the EFMP focus. Out office CONUS EFMP offices, only one seemed open to EFMP families from all walks of life. The other four focused, through advertisement, social media, e-mail, programs and special events, on autism. From my professional and personal experience working with Army families, autism within the ranks is a very important need that requires a large amount of resources; I believe the EFMP program needs to be restructured into entities that focus on family's needs. Larger installations for instance with

multiple staff members could have one staff member solely dedicated to autism/ECHO, one for physical EFMP and one for social/emotional EFMP (ADHD, etc). And these staff members need to be trained for their jobs often times, EFMP staff are not familiar with programs available and because of the sheer enormity of their work, they don't have time to call gaining posts to inquire about services, etc. Ultimately, EFMP is great in theory, but the execution is seriously lacking. When my spouse was working on a list of future assignments, we were hesitant to even discuss another OCONUS move because we don't want to endure the headache with EFMP which is quite unfortunate. I firmly believe that FAMILY considerations and voices should be heard. If I believe my child can thrive in an OCONUS or certain CONUS location, TRUST ME. Ask me questions, ask me for research, ask me for data guarantee you that I will have it and more because I, like you all, only want what's best for my family.

Comment

Regarding RIN # (0790-A182) and/or the Docket ID number (DOD-2011-OS-0127) I am the spouse to Technical Sergeant who is stationed at Patrick AFB and works at Cape Canaveral Air Force Station. We currently have a rip for orders that will be moving us to FE Warren in Cheyenne Wyoming. Under any other circumstances these orders would be most welcomed. Cheyenne is a wonderful place to raise children. They have spectacular schools, virtually no crime, there is much to do and it is breathtakingly beautiful. I know this because we were stationed there 5 years ago. We pcs'ed from Wyoming to Florida because I am on EFMP. I have severe allergies and asthma to the environment in Wyoming and other northern bases that require me to use a nebulizer machine and various medicines in order to breathe. When we were stationed in Cheyenne previously, I suffered numerous instances of pneumonia and bronchitis. I also underwent 3 surgeries for allergic rhinitis. I received iv steroids as well as oral steroids regularly throughout our time living in Wyoming. We applied for EFMP and the medical board and my doctors agreed that the best course of action was for us to get stationed to Patrick AFB in Florida. We have lived here for the past 5 years. I have had zero instances of pneumonia or bronchitis. I have not once had to receive oral or iv steroids. I have not had to take a daily inhaled steroid or a nasal steroid. I have not had to utilize my nebulizer breathing machine. I have not been ill while being stationed here. I am writing to make sure that my voice is being heard and documented when I say that I feel that the EFMP process has failed me. I gathered all the necessary paperwork and went through the doctor workups to try to ensure that we would not get stationed at a base that would impair my health. Somewhere along the way a decision was made to send our family back to the base that we pcs'ed AWAY from due to my illnesses. When I called our local EFMP office and spoke to them I was told that because I haven't been sick for the past 5 years, maybe the med board feels like we could go back to Cheyenne and see what happens. With all due respect, it is unbelievable to me that someone would gamble with my health and sit back and take the approach of "wait and see." I sincerely hope that my experience at Cheyenne is vastly different than the last, however I do not expect to be well there. My doctors at Patrick AFB do not expect my experience to be different either. I was recently prescribed a daily nasal steroid, a daily steroid inhaler, a rescue inhaler and I was given more albuterol mix for my nebulizer machine- all of this was done because my doctors want me to prepare my body for the environment that I am allergic to and moving to. I have been taking these medicines for the past couple weeks to build up my lungs and immunity. I love the Air Force. I love the opportunities and experiences that my family has been able to enjoy because of the Air Force. However, this last process of recertification for EFMP and receiving a new base assignment has been frustrating and disappointing to say the least. I am left to wonder if my EFMP file was even reviewed by those making these important

decisions. Greater accountability needs to exist to ensure that those that are a part of EFMP and are due for reassignment, are not being sent to duty stations that they previously had medical issues at. Had someone simply took the time to read my files, I would not be subjected to going back to a place that will cause me severe health complications. I am certain that many other EFMP families feel the same way I do. That we are merely a file. That our health and medical situations are consistently disregarded. That being a part of the EFMP process is more of a punishment than a benefit. This program that is supposed to help families in need is broken. Thank you for your time.

Comment

I have just two general Comments about the EFMP. First to start, our family members case was assigned a category 5 when most with his diagnosis are assigned a 4. His diagnosing Doctor did not agree. We are at our 3 year re-enrollment period and hope to get that down to a category 4 as it should have been to begin with. New doctors and second opinions have been acquired. This process is not easy but it had to be done.

Second, numerous EFMP coordinators have been assigned to my family member and this is at just one duty station. Often, this is without notification to us. It is extremely annoying when you call to get information and the EFMP coordinator contact info you thought you had so meticulously recorded is incorrect. On more than one occasion, I've not received a return call after leaving a message with the coordinator that I was redirected to. So, in summary, EFMP coordinators assigned to my family members case have been only 10% helpful. The program does not "help" as it designed to.

Comment

I love the efmp program but I hate the fact that we can't go overseas. The only thing that my son has to make him efmp is deafness but he has bilateral cochlear implants and because of this he can sign and speak. He doesn't really need any special accommodations. I think that this is unfair as all hospitals around the world has a deaf community. I also think that it is unfair that it is mandatory to join the efmp program. It should be the family's choice like it was so many years ago.

Comment

The current Air Force process for applying to relocate for EFMP is truly sad. The process as it stands is this: 1. The military member requests to relocate and submits the supporting documents. 2. AFPC reviews whether it's a legitimate request. If so they proceed to step 3, they look at bases that need your rank, AFSC, etc. 4. They ask the EFMP office at those bases if they can support you. 5. If one or more says yes, AFPC chooses where you go. There is a minuscule amount of say parents have in attempting to get their family member at the right base that fits them medically, academically, and socially. Parents know what their EFM needs more than an EFMP office across the country, or AFPC relocation.

My solution is to allow parents to submit a list of preferred bases with their relocation request, that they feel meet their child's need best. At this point AFPC can check for open spots as well as the off base support structure at the preferred bases. If more than one base is found, AFPC relocations should ask which base is preferred. The EFMP relocation problem is a fantastic tool, but currently parents have far too little say in where they end up, potentially making the problems worse for the child. I currently speak from experience. As the program currently stands, we are stuck at a base we didn't want to go to, with the worst school system in the country, and a severely overburdened autistic care and treatment

system off base with no chance of going anywhere that fits my daughters need appropriately. All this could have been avoided if someone just asked what we wanted for our child.

Comment

There needs to be consistency with assigning categories. It makes this program a joke when people with the exact same disease and similar progression of it, for example MS, yet they are assigned to different categories. Also it should not preclude those who wish to be stationed overseas from doing so when there is adequate medical care available. Treat people as individual cases. This is why there are many, despite it being mandatory, that do not enroll. Especially those who are of higher rank, regardless of what is stated concerning the program, it can hinder their career. Or the active duty member goes overseas which often harms the EFMP family member.

Comment

We have been a patron of EFMP since 2003. I truly believe that this is a service that is both beneficial to families and service members as well. We have both a child with ASD and asthma; and have been to five duty stations up to now. These are the observations that I would like to share.

1. There is lack of communication between medical EFMP and non-medical EFMP. There have been duty stations where one or both offices do not communicate with one another OR the patient. Suggesting that language be added for the "left to talk to the right" in order to get better continuity of care at every installation, not just the ones who can get along with one another.

2. The current paperwork (EFMP Medical) takes approximately two to three weeks to properly complete. In addition to having to make appointments with off post providers, if the codes don't match, or there are differences in the severity, IF anything from the PCM to the civilian providers don't match, then the packet is kicked back, or better still EFMP medical CHANGES THE FORM in order to make accreditation. Suggested changes include allowing for variances in providers' opinion, and specific guidance for punishment for altering documents. This process takes from six weeks to three or more months, (variances due to load at Walter Reed, OR kickbacks from chain up to Walter Reed) which unless a dependent is doing the paperwork significantly interferes with work for service member.

3. When addressing the medical side of EFMP, regulation currently requires that at 36 months, medical forms MUST be updated. HRC is now requiring that at 30 months the paperwork must be updated if within PCS window, otherwise service member will not be put on assignment. What is actually happening is paperwork that is already cumbersome needs to be filled out every two years instead of three in order to not have command/HRC issues. This is an "unwritten rule" that makes things harder for soldiers to participate, as well as the EFMP staff who may or may not be aware of what other entities are doing.

4. Rules that require stabilization...are almost non-existent in practicality. It is a running joke that "high school stabilization" carries more weight with HRC/ assignments than EFM requests do. When moving from one Tricare region to another; ALL referrals and ECHO packets have to be redone. That is AFTER the IEP's are completed by the gaining ISO, which by federal mandate they have 30 days to complete after registering for school. Depending on services needed, four to five months go by before referrals/ DME/IEP's are in place. For children receiving therapy, that is a significant setback which costs Tricare more money in the end. While there are some that request stabilization for dishonest reasons, many are

responding to the additional burden a move would cause at that chunk of time. Suggestions include requesting supporting information from the providers when addressing stabilization requests.

5. One of the many complaints heard is that EFMP medical tell HRC that services are available only to get somewhere and see that either services are no longer available OR the wait list is so long that services cannot be accessed while at the duty station. Because ACS EFMP is the personnel who work with the families, they should be the ones who can accurately let assignments know whether the services are available or not. (Medical EFMP works with families during the paperwork to enroll/update...every two years. See number three) There is also lack of communication from duty station to duty station for families, despite clear guidance from the regulation requiring this. Suggest that the language be clearer to enforce the requirement, much like the Command Sponsorship Program, or even tying into it.

6. In short, it seems as if the program intent is good, but execution at the lower levels is not as stringent as needed to meet the needs. Request "letter to" or further clarification/guidance in the regulation in order to meet the needs of service members and families without the burdens the program sometimes causes. Also suggest making changes so that the regulations are the same DOD's wide, allowing for all branches to have same access to care and support. (Much like maternity leave!)

Comments

I was wondering what help from EFMP for my daughter whom has severe allergies to which she cannot eat any meat and any nuts and some beans which makes it really hard for her to get the protein and iron she needs to grow. She was given the option to be in your ECHO program which provided her ENSURE PROTEIN DRINKS but being she did not like them we were forced to find vitamin supplements to give her the necessary nutrition she needed but being that most of the vitamins provided have or have been manufactured in or have nuts or fish oil she is again limited in nutritional factors. When we actually do find some without it, it causes an arm and a leg and when I asked ECHO they do not have suppliers that carry it. So then we are back to square one again. I just wish there was a way that EFMP could provide more for cases like my daughter to help out because having to buy extra food and supplies besides the norm for my family is taking a lot out of our budget to make sure she gets what she needs. Because with her not being able to eat what everyone else eats sometimes we have to supply her with special meals for school that they can give her if they cannot get or prepare what she needs there also.

Comment

These programs are in dire need of re-vamping. They are not made to help military families. They are not effectively communicating with the public. With what social media is today and the ability to email thousands of people by email, our Fort Hood EFMP Facebook page has posted complaints that they held workshops and no one came. No one came because no one was told about the event. The Fort Hood EFMP representatives know there's a special education debacle in Killeen, but yet they've said it doesn't affect the Fort Hood families, which is utterly impossible.

As a parent of two special needs children, many EFMP workers seem to assume that if a parent has a problem, it must be the parent that is the problem. I have also had experience with a system navigator where I was told she's really just there for moral support. As a parent and soldier, it doesn't always feel "safe" to seek help within the EFMP/CYS and army community and many military families have been left to seek legal actions without military support.

These programs are broken. They are not working. We need someone to step in and help our families without fear of retaliation.

Comment

There are some risks to these changes. What about taking into special consideration the different types of families and special circumstances and situations? This is not a one-size fits all program.

What about helping Guard and Reserve and Retired families? If my husband retires from active duty and/or chooses to go into the civilian workforce or reserves or guard, then we lose everything we worked so hard to get for our children. It is an extreme concern for families.

Also, having more provisions for those with special needs throughout the world would give more opportunities for families to go overseas, or special exceptions on a case by case basis. We have minor special needs compared to some families, and one little box checked made it so we could not go overseas- after we had an RFO and had been planning it for a year, and had sold most of our household goods. We would have been just fine going over, and do not need special equipment or extra doctor's appointments. All we needed was ABA therapy- which they have in Germany, and then orders had to be changed. It is extremely frustrating. I know we are not the only ones this has happened to.

Comment

I would love to see something put in place that would prevent interruption of services for children with autism.

Every day without service for a child (especially one under the age of five) lowers the ceiling for the child to reach their maximum potential. Services such as ABA therapy are imperative for children on the spectrum and every interruption sends them backwards. Sometimes the children will regress so much that it takes longer to regain the skills than it took to achieve them in the first place. In our experience it takes a minimum of six months to be seen by another ABA therapist once we move to a new duty station... If at all, because TriCare's website and/or provider's information isn't always up to date on services truly

available in the area.

Comment

National Guard and Reserve families that purchase tricare should be allowed to participate in EFMP.

My son has autism, EFMP would allow him more therapy, specialized schooling and devices that tricare does not cover but EFMP would allow him. This would benefit his life so much.

I would love to be contacted to provide medical proof of what the children's hospital can provide my son with tricare vs what my son would be provided with if we have access to EFMP.

Comment

We have 3 children that are special needs, & 2 are enrolled in EFMP. We are Active Duty AF. We have not really seen a situation where we've reaped the benefits of EFMP. Our children were diagnosed

almost 2 years ago, but we've not PCS'd since then. We highly support the NEED for the EFMP program, but feel that unfortunately there have been many barriers to accessing care. We've has a particular struggle accessing the EFMP Respite Care benefit, due to there not being any approved providers in the area. Child Care Aware has been contracted by EFMP to locate providers, but to date, nobody has participated in the program. We've also struggled with the coordination between the medical group/pediatrics, EFMP coordinator, Tricare/value Options/ECHO program, Family readiness. There is a general lack of all the specific nuances of what each program can offer, how they work in accordance with each other, and what are our next steps, etc. We suggested that a Special Needs Coordinator would be really helpful, but to date have not heard back about our questions related to this. We also tried accessing the ECHO respite care benefit available to us, since our children are receiving ABA through the ECHO program, but have not been able to for the same reasons. No providers are available. We have also waited for months to get in to ABA (so far we've been seen 1 day/1child this week). Lack of providers.

Comment

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Comment

Enrollment in EFMP needs to be voluntary not mandatory. I have two children in EFMP one for a IEP for speech only and one needing a specialist on growth related issues only, not development. I am fully able to determine where my children's needs can be meet. I should fully be able to say whether a location that involves travel to the specialist is appropriate for my family considering the position for my husband, the active duty member, jobs for myself and the numerous other variables may make a location worth the drive. It would be much better if EFMP served to verify when a family wishes to not be transfers to a particular location than to say where a family can be transferred, unless the family voluntarily enroll

EFMP eligibility needs to be revised to remove enrollment for any IEP in school. It is too low a threshold that requires enrollment for speech-only IEP and even gifted designations by IEP in some districts. Any IEP must be honored by federal law in another school distinct, and I understand a review of services is

done for any PCS outside CONUS regardless of whether there is a EFMP member. EFMP enrollment for IEP only is unnecessary and an unnecessary burden on families.

Also, when my son was put on a IEP for speech only, it triggered the enrollment in EFMP in which they demanded to see 5 years of medical records for the entire family. This was entirely inappropriate and a pure violation of our privacy. Technically, we 'voluntarily' handed over our records, since the medical group can basically hold up my husband getting his orders, which we need to move forward with scheduling the movers etc. I.e. hold us hostage until they get what they want. There is absolutely no legitimate rationale for demand to see an entire families' medical records because a family member is identified as EFMP eligible. Then for the EFMP meeting they demanded that the children attend. No one has a right to demand that I produce my children for them, unless it is regarding substantiated questions of their welfare. As well-meaning as EFMP thinks it is, it crossed the line regarding my rights of privacy and parenting.

Comment

I would like to see a program that is actually about the families. Currently there is a separation between what is provided for EFMP families from A&FRCs and the base clinics. Due to this separation, families are falling through the cracks. They do not know who their EFMP team is, nor the full concept behind what it is that they can do for them.

I know that services are reviewed before families arrive at the gaining base, but those services are not always offered as stated. We are currently at a base where half of the services that we need are two hours away. This is either because the services offered in our area have a long wait list or those specialties do not treat the age needed. Had someone picked up the phone to call the services before we came, it would have been discovered that this was not the best place for us to be for medical care. Especially considering that we have to drive 2 hours for services and there is a base there as well.

There should be more communication with EFMP families. Most of us are dealing with a number of medical issues on top of everyday life. There are not many support groups that not only address what is being dealt with, but also understand that there is a military life aspect. We are still relatively new to this process. I have found out more about the EFMP program as an angry parent than I have as a parent wanting information. At times it seems that in order to receive proper care or for someone to pay attention to what you are saying, you have to be reactive.

I think it would be amazing to see a program that is streamlined, across the board. To have a program in place that is the exact same, regardless of the base you are at would be a godsend. Currently, I have to write down every conversation, phone call, and notate each visit because I question how much support will actually be given when needed, especially in the form of communication.

Military and Non-Profit Service Organizations Comments regarding Proposed EFMP Regulations

Summary:

This rule establishes the Exceptional Family Member Program (EFMP) to identify a family member with special needs, providing family support to military families that include a family member with special needs, authorize travel at Government expense for active duty service family members with special needs, and, process DoD civilian employees who have family members with special needs for an overseas assignment

[http:// www.regulations.gov/ #docket Detail;D =DOD-2011-OS-01 27](http://www.regulations.gov/#docketDetail;D=DOD-2011-OS-0127)

Comment

I,

Regarding :

Agency: Department of Defense (DOD)

Document Type : Rulemaking

Title: Exceptional Family Member Program,

Document ID: DOD-2011-OS-0127-0001

To Whom It May Concern:

12

February 2016

Thank you for allowing me to submit late comments on the above noted proposed rule. I am a prior service military member (Army/Air National Guard) married to a retired disabled veteran with a disabled daughter that has high medical acuity needs. I have been a military medical services provider, a civilian medical services provider and have civilian nursing licensure and multiple military medical MOS/AFSC's. I have worked with individuals with disabilities in all my various assignments, both military and civilian, since 1976/79 and as a parent since 1985. I continue working with disabled individuals at this time.

In the last 6 months I have received a marked increase in inquiries from military special needs families AND EFMP coordinators looking for service programs and knowledgeable help. The vast majority of these contacts have been from Air Force and Army personnel/members. From where I sit the Coast Guard, Navy and Marines seem to have this situation under control.

I have had a chance to review the proposed rule document and I do have some suggestions/observations to add. I am speaking from both personal and professional experience and will bullet point for brevity.

- *All military EFMP programs, regardless of branch of service, Active Duty, National Guard/Reserve would be improved if greater program visibility, networking, and communication between EFMP offices, related offices on base (ie: personnel, pass and ID, social actions, etc.) and families served occurs.*
- *Medical case management can be best performed when case managers are local.*

Familiarity with the services available and the capabilities of medical staffs in both on base Military Treatment Facilities and civilian hospitals and clinics allows for optimal care in a timelier fashion with fewer authorization and clerical snafus. Our local case manager position was done away with some years ago. Without someone local who was familiar with both our family needs and the services available in my area I found myself, by protocol, attempting to work with 6 different medical case managers in 5 different states. Continuity of managed care did not exist. I was forced to become my own care manager and formally withdrew from the system in order to take care of our daughter's needs without contradictory interference from multiple "managers". A large majority of parents do not have the skills to do this. When medical managers are working from a distance for individuals they don't know and without local facility/program familiarity, continuity of care becomes difficult, if not impossible, and the individual is the one who ultimately suffers.

- *EFMP Coordinators should have at least some professional medical experience AND at least some hands-on experience working with individuals with disabilities in local communities. A more rigorous employment protocol for EFMP coordinators is needed.*

It is difficult for untrained individuals to assist families with high acuity medical needs identify and find services and programs that match those needs. Military medical staffs are transient and undependable due to training and deployment requirements. They exist for support of the fighting force, not the families at home. Medical staffs and case managers rely on EFMP Coordinators to know what is needed although many are ill equipped to handle the wide variety of special need idiosyncrasies seen through their office. Many families don't need the medical services as much as they need other programs. I am contacted quite often by EFMP Coordinators who have a difficult time performing a basic search for services as they often don't quite know what they are looking for. They have little or no personal experience to draw from. Yet I often can find that information from my remote location fairly quickly. This is a problem. Training needs to be increased.

- *Improved On-going Training.*

Once EFMP coordinators have been hired it is helpful to have them maintain contact with local community services. Programs change frequently or are often discontinued. Spending time in the community visiting various programs and services assists the Coordinator in understanding what is available and can only improve understanding of individual needs as seen in an active environment. This cannot happen behind a desk.

- *Mandatory inter office training regarding regulations and updated information.*

There are multiple offices families need to work with in gaining services for their children. Speaking from personal experience (and hearing this same complaint from other frustrated families on a very frequent basis) members and their families often find themselves in the middle of what feels like a ping-pong match. At one point I was shuttled back and forth between what should have been two complimentary offices for over 2 weeks over a simple form before I finally had had enough, cornered senior NCOs from EACH office at the same time, and demanded they figure out what I needed and who I needed it from while I stood there. It took a copy of the regulation and an officer to finally make a decision so I could

move on with the process I needed to work through. A lot of time is wasted by EVERYONE when this happens. Clear and precise inter-organizational communication, informational maintenance, and chain of function/responsibility is key for all parties involved.

- *Guardianship/Incapacitation questions and assistance.*

Protocol and facilitation information needs to be more broadly available to active duty members as I receive a good number of questions about this process every month.

National Guard/Reserve families seem to have this information readily available.

*Please note: Alabama and Nebraska's age of "Legal Majority" is 19. Families PCSing from these two locales to other states where the age of Legal Majority is 18 may find themselves legally behind the proverbial eight-ball in being able to represent their 18 yr. old disabled children if legal documents are not in place upon arrival at the new duty station. Standard Age where incapacitation determinations and guardianship assignments should be age 18 regardless of location.

- *Secondary Dependency Determinations "Who is supposed to be handling the information process for families"?*

In recent weeks I have had more than one EFMP coordinator contact me directly regarding, "helping a family with questions", and then proceed to try to get me to take over the full assistance process in helping the family complete this form. That's the coordinators job and many coordinators don't know what to do. If it isn't within their realm of responsibility to assist families with this process then they should know exactly who to refer these families to, so they get the help they need in a timely fashion. I am not contracted to do this.

I have had some very negative personal experiences with this process myself and, given the number of questions I receive monthly, I am not the only one. Families are often blindsided by this "news to them" requirement and often don't find out this is something they need to do for their newly adult children until they attempt to obtain an ID(USIP) card for their child and are denied by MPF or Pass and ID for lack of a *Favorable Dependency Determination Letter*.

My first introduction to this arduous process happened exactly that way. I was handed a short informational form by the airman at the ID desk and told to, "Follow the instructions". Basically, the information stated to fill out a Form DD137-5 and send it in to, "the following address". The address listed was the Denver DFAS office. The Denver DFAS office had been closed and all functions moved to ANOTHER facility 3 YEARS EARLIER! I don't work in personnel, never did, but even I knew that facility was closed. No one in that personnel office knew what to do next. I was on my own and under the gun for time. If I didn't act quickly my child would be sans ID card and medical services.

This happens frequently!

The question now is, is this an EFMP process? Or is Military Personnel and Finance responsible? Who lets families know this requirement is coming up? Who tells them they will need to gather and keep a full 12 months of substantial amounts of financial information regarding their child's upkeep along with other significant medical and legal

documentation BEFORE they can start to fill out the Form DD137-5? How do they know where to submit completed forms? Who can families contact EASILY with questions about the form and where it needs to go? Who does that?

And what about retirees who need to complete this process for their legal dependents? Who notifies and helps them?

I now know what I am doing to complete this process for my daughter and am hard pressed to complete it in the time frame given. The questions on the form are confusing and finding someone knowledgeable enough to answer questions about it is extremely difficult. I have been through this process and, as of the first week in February 2016 when I was asked to help yet another lost parent attempt to contact "someone who knows about this", STILL could not contact an actual person local OR at any given DFAS office regarding this directly. No DFAS office I contacted in the last few weeks had a recorded option for SDD or an actual live person to talk to. Online information given is for the general automated phone line. No directions to entities that may help are given. So EFMP coordinators and families often email me. This process is a "Wicked problem" for all of us.

We all know a lot of information is needed to make a determination, we get that. But it would be helpful if families could be informed ahead of time that this process is necessary, someone local should be assigned to help with paperwork or an actual *designated help line* should be created for questions families have about this long form.

My husband and I have learned from years of personal experience as special needs parents and military members that family readiness is key in managing the impact deployments and other actions have on our family and the spouse left behind to run the household. One key family support should be knowledgeable and efficient EFMP personnel who know what we need and how to get it done in a timely fashion. This service needs to be ramped up.

Thank you for allowing me to submit the above thoughts. I tried to be brief. I appreciate the opportunity given.

Respectfully,

Comment

February 9, 2016

Submitted via Federal eRulemaking Portal at

www.regulations.gov Office of the Deputy Chief Management

Officer
Directorate of Oversight and
Compliance Regulatory and Audit
Matters Office
U.S. Department of
Defense 9010 Defense
Pentagon Washington,
DC 20301-9010

Re: Comments on the Department of Defense proposed rulemaking on the "Exceptional Family Member Program", 80 Fed. Reg. 76885 (December 1, 2015); Docket: DOD-2011-OS-0127; RIN: 0709-A182

Thank you for the opportunity to comment on the "Exceptional Family Member Program" (EFMP) proposed regulations. As the leading nonprofit organization advocating on behalf of service members and their families, the National Military Family Association has for many years worked to ensure the needs of military families with special needs family members were addressed. In recent years we have been gratified to see the Department of Defense (DoD) make the care of special needs military family members a priority as well. Specifically, the establishment of the Office of Community Support for Military Families with Special Needs (OSN) represented a significant step forward in addressing the needs of special needs family members. However, the promise of an effective EFMP that fully meets families' needs has fallen short. OSN and the Services' EFMP programs must act to regain the trust of military families and prove they can provide resources and services families can rely on.

OSN and the Services' EFM Programs: More Oversight is Required

OSN was created in the Fiscal Year 2010 National Defense Authorization Act (FY10 NOAA) (Public Law 111-84) to enhance and improve DoD support around the world for military families with special needs, whether medical or educational. Despite the establishment of the OSN, gaps in support to special needs military families still exist, due in part to differences among the various Services' EFM programs.

The EFMP is intended to perform three interrelated functions:

Identify and enroll eligible family members;

- (1) Coordinate the assignment process to ensure special needs families are not sent to locations that lack adequate resources; and
- (2) Provide families with information about and referral to local resources.

While some Services take a centralized approach to EFMP, with enrollment, assignments, and case management services all housed in a single office, other Services' programs are more "stove piped." When a breakdown in communication occurs, families may find themselves assigned to locations without appropriate medical or educational services for their special needs family member or unaware of resources available to them through their communities. We often hear from families who experience a long wait before receiving services at their new installations because of a lack of communication between EFMP Coordinators at the old and new installations. Families need the reassurance they will have continuity of care and a warm hand-off as they move from installation to installation.

A 2012 GAO report, *Better Oversight Needed to Improve Services for Children with Special Needs*, (GAO-12-680, September 10, 2012) noted there are no Department-wide benchmarks to set standards for the Services' EFM programs. As a result, the Department is unable to assess the effectiveness of the branches' EFM programs and ensure improvements are made when needed. In addition, although OSN was created to enhance and monitor the military branches' support for families with special needs, it has no authority to compel the branches to comply with DoD or Service-level program requirements and it has no direct means by which to hold them accountable if they fail to do so.

DoD needs to comply with the GAO recommendations and establish benchmarks and performance goals for the EFM program. We further ask OSN develop and implement a process for ensuring the branches' compliance with EFM program requirements. We ask DoD and the Services to set a common standard of support families can expect to receive through the EFMP. Families have the right to expect a level of service for their special needs family members regardless of the color of the uniform they wear. This is especially important as joint basing becomes more common and when families from one Service live and work on installations operated by another.

Special Needs Navigators and Case Management Not Implemented

The FYIO NOAA included specific directives for providing family support and case management services to better serve military families with special needs family members. Despite the intent of the legislation, those services have not yet been fully implemented, leaving families struggling to locate resources in their communities and manage their complex medical and non- medical needs.

The FYIO NOAA directed installation EFM programs to include "Special Needs Navigators" to help families find programs and resources available in their civilian communities. In locations where Special Need Navigators are part of the EFMP, families report a high level of satisfaction with the service and support they receive. However, few installation EFMPs include a Special Needs Navigator. We are disappointed the proposed regulation does not address Special Needs Navigators and provides little detail on the most basic level of family support and coordination of resources. We urge DoD to meet the minimum level of family support coordination outlined in Section 563 of the FYIO NOAA.

Section 563 of the FYIO NOAA also emphasizes the need for enhanced case management support. Case management is specifically mentioned three times in the legislation:

- DoD requirements for resources (including staffing) to ensure the availability of appropriate numbers of case managers to provide individualized support for military families with special needs.
- The program shall provide for timely access to individual case managers and counselors on matters relating to special needs.
- Each program shall provide for appropriate numbers of case managers for the development and oversight of individualized services plans for educational and medical support for military families with special needs.

Additionally, the FYIO NOAA Conference Report language makes clear the importance of case management support for special needs military families:

"The conferees expect that implementation of this section will result in substantial improvements in identification and outreach to larger numbers of individuals who need

support and coordination of available services, expansion of case management services, more direct training and counseling for parents and families, and timely access to information and referral to both Department of Defense and other federal, State, and local special needs resources and services. The conferees direct the Secretary to examine ways to mitigate the challenges for families who may be disadvantaged by relocation during their military service, and to ensure that enrollment in the Exceptional Family Member Program, or any successor to that program, is perceived as a positive and necessary family readiness resource."

The EFMP proposed regulations provide few details on case management services. There are no specifics regarding case manager resource requirements, acceptable case management access standards, or requirements for the development and updating of individualized service plans (medical and educational) for military families with special needs. Given the critical role case managers play in the support of special needs military families, we believe the regulation should include more detail on case management resource requirements and responsibilities.

Section 582 of the FYII NOAA, Enhancement of Community Support for Military Families with Special Needs, included two provisions that are missing from the EFMP proposed regulations:

- (1) Periodic reviews of the best practices in the United States in the provision of medical and educational services to children with special needs, and
- (2) Establishment of an advisory panel on community support for military families with special needs.

Both of these provisions should be added to the proposed rule.

For many years, the Department of Defense Education Activity (DoDEA) has asked for guidance regarding special education services for children of DoD civilians stationed overseas. We are pleased the proposed regulation includes details on this important topic.

'I could you have any questions regarding our response, please contact: ... ;

The National Military Family Association is the leading nonprofit dedicated to serving the families who stand behind the uniform. Since 1969, NMFA has worked to strengthen and protect millions of families through its advocacy and programs. They provide spouse scholarships, camps for military kids, and retreats for families reconnecting after deployment and for the families of the wounded, ill, or injured. NMFA serves the families of the currently serving, retired, wounded or fallen members of the Army, Navy, Marine Corps, Air Force, Coast Guard, and Commissioned Corps of the USPHS and NOAA.

Sincerely,

Comment

Comment regarding DOD-2011-OS-0127-0001

<http://www.regulations.gov/#!docketDetail;D=DOD-2011-OS-0127>

EFMP Regulation Changes Comments: While I am pleased that these regulations have finally been proposed, there are a number of aspects which must be strengthened, added, and changed if these regulations are to meet the intent of the Congress and the President when 10 1781c was created and signed into law .

In preparing these remarks I considered the 2010 and 2011 National Defense Authorization Acts (NDAA) as well as the House and Senate Conference Committee reports from both years. The committee report language, especially from 2010, is quite damning, and given the time that it has taken to write these proposed regulations, it seems our legislators had good reason to be concerned. I would recommend those considering the history of these regulations read this story by Military.com which highlighted the issues DoD seems to have faced when creating these proposed regulations: <http://www.military.com/daily-news/2015/11/11/pentagons-special-needs-program-to-take-years-longer.html>

- o From the [2010 NDAA Conference Report](#)

"Support for military families with special needs (sec . 563} (page 738}

...The conferees believe that expanding support for families with special needs is a critical requirement for the all-volunteer force. Regrettably such programs have not been a priority for the Department...The conferees are also concerned that enrollment in the Exceptional Family Member Program, which is crucial to ensuring that the needs of eligible dependents are met, is far lower than necessary to reach the estimated 220,000 family members who are eligible for such enrollment.

The conferees expect that implementation of this section will result in substantial improvements in identification and outreach to larger numbers of individuals who need support and coordination of available services, expansion of case management services, more direct training and counseling for parents and families, and timely access to information and referral to both Department of Defense and other federal, State, and local special needs resources and services. The conferees direct the Secretary to examine ways to mitigate the challenges for families who may be disadvantaged by relocation during their military service, and to ensure that enrollment in the Exceptional Family Member Program, or any successor to that program, is perceived as a positive and necessary family readiness resource."

- o From the [2011 NDAA Conference Report](#)

"Enhancement of community support for military families with special needs (sec. 582) (page 429}

...require that the Office of Community Support for Military Families With Special Needs conduct periodic reviews of best practices in the provision of medical and

educational services for children with special needs; authorize the secretaries of the military departments to establish or support centers to provide medical and educational services for military children with special needs; and require the formation of an advisory panel comprised of military family members to provide advice to the Director of the Office of Community Support for Military Families With Special Needs on services and support for military children with special needs.

As currently constructed, I do not think these proposed regulations in fact meet the guidance provided by the Congress when they created this law nor the letter of the law, 10 U.S.C. 1781c.

In addition to the above documents, I also reviewed the following, which I would recommend others do as well when they are considering the form of these final regulations:

1. 10 U.S.C. 1781c: <https://www.gpo.gov/fd/sys/pkg/USCO DE-2011-title10/pdf/USCO DE- 2011-title10-subtitleA-partI I-cha p88-subcha pl-secl781c.pdf>
2. MILITARY DEPENDENT STUDENTS: Better Oversight Needed to Improve Services for Children with Special Needs (GAO-12 -680): Published: Sep 10, 2012. Publicly Released: Sep 10, 2012: <http://www.gao.gov/products/GAO -12-680>
3. Department of Defense Exceptional Family Member Program Benchmark Study, submitted to the Office of Special Needs by Bronfenbrenner Center for Translational Research, Cornell University and Beach Center on Disability, The University of Kansas in September 2013, accessible on Military One Source: <http://download.militaryonesource.mil/12038/MOS/ResourceGuides/EFMP-Benchmark.pdf>

Comments

- I. Recommend a definition of "adverse" or "adversely". The term is too vague as to be meaningful and the services may construe it differently without either a definition or explanation .

Used three times in the proposed regulations:

- o (3) Stabilization does not have an **adverse** effect on the mission requirements of the Military Department.
- o (4) The career development of the Service member has been considered and is not affected **adversely**.
- o (iii) Remove active duty Service members who have family members with special medical and educational needs from overseas orders if no suitable overseas assignment location can be found and there is no **adverse** impact on the military mission or on the active duty Service member's career .

In defining "adverse" or whatever eventual language is used, I would recommend ensuring the language in 10 U.S.C 1781c is incorporated,

"(3) In addressing the assignment of members of the armed forces under paragraph (2)(A), the policy developed under this subsection shall, in a

manner consistent with the needs of the armed forces and responsive to the career development of members of the armed forces on active duty",

2. I would recommend including definition of a person with a disability as well as clarifying that a "person with special needs" does not necessarily have a disability.
3. For the definition of "Non-clinical case management", I would recommend striking "coordination and" from this sentence, "This does not involve coordination and follow-up of medical treatments." Coordination of medical treatments should be included in non-clinical case management and does not require medical decision making skills. This section is also confusing as the other part of the definition provided seems to indicate that coordination of medical is part of non-clinical case management: "assist them in making informed decisions and navigating resources to improve their quality of life such as medical". The System Navigators associated with the Military 360 programs, an evidence-based military special needs program which is unfortunately no longer funded, are an excellent example of what an EFMP Coordinator should be allowed to do on behalf of his or her military EFMP families.
4. Under DoDEA responsibilities, "(2) Makes recommendations to the Military Services and Defense Agencies on the availability of special education services." I would recommend clarifying whether "availability of special education services" includes public and charter schools in the immediate area or just DoDEA schools and is the question for both CONUS and OCONUS. For CONUS public schools and DoDEA schools OCONUS, given the Free, Appropriate, Public, Education {FAPE} requirement of the Individuals with Disabilities Education Act {IDEA}, what exactly will DoDEA be making a recommendation regarding as it relates to military children? If DoDEA, or DoD in any other capacity, states that services are unavailable or inappropriate for a DoDEA school or any public or public charter school, isn't that a violation of FAPE under IDEA? My experience is that because of the requirements of FAPE, this educational determination conducted under EFMP isn't worth much. No public school will ever admit they can't service a military child because they are required to do so under IDEA. Yet, once the family arrives and educational services are not appropriate for a military child, there is little the family can realistically accomplish without hiring high priced lawyers and expert witnesses, expenses most military families cannot afford.
5. Findings in DoD's Report to Congress related to Sec 735 of the 2013 NDAA states "Data collection systems do not have a standardized definition of what identifies a child with special needs throughout DoD, the Military Departments, regional contractors, and pediatric specialty groups. DoD should adopt an enterprise- wide definition of "child with special medical needs" or adopt the National Institute of Child Health and Human Development definition of child and youth with special health care needs **(CYSHCN).**"

Consistent with DoD's own recommendations, I suggest DoD create a standardized definition related to children with special health needs, medical needs, and educational needs. I recommend a civilian definition like the one NICHD uses be strongly considered

as it will be important to be able to compare the short and long term outcomes of military children with their civilian counterparts (and vice versa).

6. In the same DoD Sec 735 study, one of the outcomes stated
"Develop common data evaluation systems or metrics within the DoD or the Military Departments to evaluate the multidimensional programs that support the physical and behavioral health care needs of children. Further study would be to define the overarching goals and corresponding metrics that best evaluate outcomes of wellness and resilience programs within TRICARE and DoD."

I would recommend this be incorporated into these regulations to ensure a common set of data evaluation systems and metrics are used across DoD. I recommend specifying a specific entity or organization in charge of data evaluation systems to accomplish this goal. Without specifying who is in charge of a data evaluation system, it is unlikely to be accomplished. I recommend DoD look to civilian standards to ensure that reasonable apple to apple comparisons can be made between military and civilian children.

7. According to 10 USC 1781c, The Office of Community Supports for Families with Special Needs (Section (d), Subsection Responsibilities, Bullets (5), (6), and (7)) states,

"The Office shall have the responsibilities as follows:

- (5) To monitor the programs of the military departments for the assignment of members of the armed forces who are members of military families with special needs, and the programs for the support of such military families, and to advise the Secretary of Defense on the adequacy of such programs in conjunction with the preparation of future- years defense programs and other budgeting and planning activities of the Department of Defense.
- (6) To monitor the availability and accessibility of programs provided by other Federal, State, local, and non-governmental agencies to military families with special needs.
- (7) To conduct periodic reviews of best practices in the United States in the provision of medical and educational services for children with special needs."

These responsibilities are not reflected appropriately under the specific subsection ("75.10 Office of Community Support for Military Families with Special Needs (OSN)) or elsewhere in the proposed regulations. There is some indication that these responsibilities are being transferred to the USD(P&R), the Assistant Secretary of Defense for Manpower and Reserve Affairs (ASD(M&RA)) under § 75.5 Responsibilities. The following subsections,

"(1) Consults with the Secretaries of the Military Departments, as appropriate, to ensure the development, implementation, and monitoring of an effective EFMP across DoD, in accordance with this part.

(2) Resolves disputes among the DoD Components regarding the implementation of procedures in § 75.6 through § 75.10 of this part.",

do not comply with the requirements of 10 U.S.C. 1781c. "Consults with" and "Resolves disputes" is significantly weaker language than that required by the statute, in which the Office of Community Supports for Families with Special Needs has the "responsibilities as follows" listed above. This language is also contrary to the GAO recommendation in GAO Report titled "MILITARY DEPENDENT STUDENTS Better Oversight Needed to Improve Services for Children with Special Needs" (GAO-12-680):

"To improve oversight of the military branches' programs for families with special needs, we recommend that the Secretary of Defense direct OSN to establish uniform benchmarks and performance goals for the identification/enrollment and assignment coordination components of the military branches' EFM programs. These goals can be used to determine whether EFM programs are achieving desired outcomes across DOD and identify areas for improvement. For example, such performance goals could include specific targets and benchmarks for reducing screening failures over time and reassigning families who have been sent to locations that are unable to meet their children's educational or medical needs.

To strengthen OSN's oversight over the military branches' EFM programs, we recommend that the Secretary of Defense direct OSN to develop and implement a process to assess the branches' compliance with DOD-level EFM program policies and requirements, and to identify and report any issues related to noncompliance to senior leadership for corrective action. For example, OSN could consider conducting periodic, unannounced site visits to select military installations on a periodic basis to monitor implementation of their EFM programs."

To illustrate the importance of benchmarking EFM programs, I looked at the accreditation checklist for Army Community Service programs, accessible here: [Army Community Service \(ACS\) Accreditation Checklist](#). In Appendix B (page 41), there is an EFMP Checklist that spans 10 pages of items to ensure that an Army base has a functioning EFMP system. There is nothing even remotely equivalent Air Force wide except a half page discussion of EFMP responsibilities in Air Force Instruction (AFI) 36-3009. The AFI for the Air Force EFMP system (40-701) has one paragraph (1.2.4. Research and Evaluation) that discusses the issue.

In 2009, I filed a [DoD complaint](#) on behalf of 16 Air Force families against the Air Force EFMP program. The IG found in our favor on three of the four allegations. Allegation #4, the only one in which the IG didn't find in our favor stated,

"Allegation #4

Currently the Air Force Exceptional Family Member Program lacks the independent oversight to ensure AFI 40-701 is being followed across the service and that special needs families are getting the continuous support they require. **NOT-SUBSTANTIATED.**

Recommendation:

Keep inspection oversight of the SNIAC program within the Health Services Inspection Process (HSI) process. HSIs are independent inspections conducted every three (3) years for MTFs across the Air Force (25-30 installations inspected per year) by the Air Force Inspection Agency. However, the current inspection criteria do not evaluate if adequate support and services are being provided to families. However, the HIS inspection checklist should be reevaluated as it hasn't captured the program shortfalls that have led to the above substantiated allegations during previous inspections. The checklist should include the responsibilities that evolved from the recommendation to integrate a community support services type of function into the Air Force EFMP (similarly to the Army's program) to fully capture if program is in compliance."

While the IG did not technically find in our favor, it is clear from the recommendation that the Air Force needed to revamp its inspection and oversight system (along with its entire EFMP program), an action item that has yet to be accomplished in a way that would meet the IG's criteria.

It is this level of discrepancy across the services for which the DoD Office of Special Needs was created. And, without uniform benchmarks and performance goals and DoD-level EFM oversight, many of the same problems for which 10 U.S.C. 1781c was created will continue.

8. According to the "ANNUAL REPORT TO THE CONGRESSIONAL DEFENSE COMMITTEES on Support for Military Families with Special Needs", dated April 2015, and written by the DoD Office of Special Needs,

"Combined two committees, one required by Department of Defense Instruction (DoDI) 1342.12, "Provision of Early Intervention and Special Education Services to Eligible DoD Dependents," April 11, 2005, and another required by DoDI 1315.19, "Authorizing Special Needs Family Members Travel Overseas at Government Expense," February 16, 2011, into one. The newly established Overarching Coordinating Committee for Military Families with Special Needs oversees policies and programs for military families with special needs. The two subcommittees required by Department of Defense (DoD) policy will report their activities to the Overarching Coordinating Committee."

This "newly established Overarching Coordinating Committee for Military Families with Special Needs" who "oversees policies and programs for military families with special needs." is not addressed in these proposed regulations, even though this committee appears to have many of the responsibilities as those listed in these regulations. The regulations should address what this committee's purpose and responsibilities are, including who shall serve on this committee and how often they will be required to meet, at a minimum. The regulations should also specify the Overarching Coordinating Committee's relationship with the Under Secretary of Defense for Personnel and Readiness (USO (P&R)), the Assistant Secretary of Defense for Manpower and Reserve Affairs (ASD(M&RA)), the DoD Office of Special Needs, and the Advisory Panel on Community Support for Military Families With Special Needs

9. The 2011 NDAA provided for an Advisory Panel on Community Support for Military Families With Special Needs with the following requirement:

{1} Establishment. -Not later than 90 days after the date of the enactment of this subsection [Jan. 7, 2011], the Secretary of Defense shall establish an advisory panel on community support for military families with special needs.

{2} Members. -The advisory panel shall consist of seven individuals who are a member of a military family with special needs. The Secretary of Defense shall appoint the members of the advisory panel.

(3) Duties. -The advisory panel shall-

(A) provide informed advice to the Director of the Office of Community Support for Military Families With Special Needs on the implementation of the policy required by subsection (e) of section 1781c of title 10, United States Code, and on the discharge of the programs required by subsection (f) of such section;

(B) assess and provide information to the Director on services and support for children with special needs that is available from other departments and agencies of the Federal Government and from State and local governments; and

(C) otherwise advise and assist the Director in the discharge of the duties of the Office of Community Support for Military Families With Special Needs in such manner as the Secretary of Defense and the Director jointly determine appropriate.

(4) Meetings. -The Director shall meet with the advisory panel at such times, and with such frequency, as the Director considers appropriate. The Director shall meet with the panel at least once each year. The Director may meet with the panel through teleconferencing or by other electronic means."

This legislative requirement was also discussed in the "ANNUAL REPORT TO THE CONGRESSIONAL DEFENSE COMMITTEES on Support for Military Families with Special Needs" from April 2015 mentioned previously,

"Initiated required actions to formally establish the Advisory Panel on Community Support for Military Families with Special Needs and is working with the military Departments to identify candidates who are members of a military family with special needs for the Secretary's consideration."

However, these requirements of 10 USC §1781c. are not discussed at all in these proposed regulations. I recommend that a section be created to ensure the creation of this advisory board per above Public Law cited.

10. 10 USC §1781c. Section {c)states

"Director. -(1) The head of the Office shall be the Director of the Office of Community Support for Military Families with Special Needs, who shall be a member of the Senior Executive Service or a general officer or flag officer."

However, this requirement of 10 USC §1781c. is not discussed in these proposed regulations. I recommend this requirement of law be added to these proposed regulations.

11. The 2011 NDAA provided for "Military Department Support for Local Centers To Assist Military Children With Special Needs",

"The Secretary of a military department may establish or support centers on or in the vicinity of military installations under the jurisdiction of such Secretary to coordinate and provide medical and educational services for children with special needs of members of the Armed Forces who are assigned to such installations."

However, this part of 10 USC §1781c. is not discussed at all in these proposed regulations. I recommend that a section be created to ensure this capability is available. While a current "Secretary of a military department" may not currently want to accomplish this provision of the law, having this capability created in regulation will make the process much smoother if future secretaries understand how that might be accomplished and who would be responsible for coordinating such an activity.

12. The 2010 NDAA provided for a "Foundation for Support of Military Families With Special Needs":

"{1) Establishment authorized. -The Secretary of Defense may establish a foundation for the provision of assistance to the Department of Defense in providing support to military families with special needs.

{2) Purposes. -The purposes of the foundation shall be to assist the Department of Defense as follows:

{A) In conducting outreach to identify military families with special needs.

{B) In developing programs to support and provide services to military families with special needs.

{C) In developing educational curricula for the training of professional and paraprofessional personnel providing support and services on special needs to military families with special needs.

{D) In conducting research on the following:

(i) The unique factors associated with a military career (including deployments of members of the Armed Forces) and their effects on families and individuals with special needs.

(ii) Evidence-based therapeutic and medical services for members of military families with special needs, including research in conjunction with non-Department of Defense entities such as the National Institutes of Health.

(E) In providing vocational education and training for adolescent and adult members of military families with special needs.

(F) In carrying out other initiatives to contribute to improved support for military families with special needs.

(3) Department of defense funding. -The Secretary may provide the foundation such financial support as the Secretary considers appropriate, including the provision to the foundation of appropriated funds and non-appropriated funds available to the Department of Defense.

(4) Annual report. -The foundation shall submit to the Secretary, and to the congressional defense committees [Committees on Armed Services and Appropriations of the Senate and the House of Representatives], each year a report on its activities under this subsection during the preceding year. Each report shall include, for the year covered by such report, the following:

(A) A description of the programs and activities of the foundation.

(B) The budget of the foundation, including the sources of any funds provided to the foundation.

(S) Military family with special needs defined. -In this subsection, the term 'military family with special needs' has the meaning given such term in section 1781c(i) of title 10, United States Code (as added by subsection (a))."

The above reference from Public Law regarding the "Foundation for Support of Military Families with Special Needs" was not included in the proposed regulations and should be included, even if the current Secretary of Defense does not intend to establish such a foundation. Perhaps a Secretary of Defense in the future would see the value in such a foundation.

Thank you for your consideration of my comments.

TRICARE for Kids, www.tricareforkids.org

Comment

February 9, 2016 - via www.Regulations.gov

Re: RIN 0790-A182 -- Comments submitted by Family Voices on Proposed Regulations on the

Exceptional Family Member Program (Federal Register, December 11, 2015)

Family Voices is a national, family-led organization that promotes quality health care for all children and youth, especially those with special health care needs. Our comments are based on our extensive work with the network of Family Voices State Affiliate Organizations (SAOs) and the federally funded Family-to-Family Health Information Centers (F2F HICs) in 50 states and the District of Columbia. F2F HICs are family staffed organizations provide support, information, resources and training to families of children and youth with special health care needs (CYSHCN) and the professionals who serve them. (See http://www.fv-ncfpp.org/f2fhic/about_f2fhi.c/.)

We appreciate the effort and time that went into the proposed regulations as well as this opportunity to comment on them. We hope that our comments lead to strengthening and formalizing practices across the Branches of Service in order to more effectively assist military families without regard to duty assignment or what Branch of Service they support .

Family Voices Recommendations

1. Since almost all of the F2F HICs assist military families in their states, we strongly recommend that the regulations facilitate collaboration between the F2F HICs and the EFMP and that families be given information on the F2F-HIC in their state.

2. We also strongly recommend that the Department adopt the definition of "Children and Youth with Special Health Care Needs" (CYSHCN) used by the Health Resources and Services Administration and the American Academy of Pediatrics:

Children and youth with special healthcare needs are defined as "those who have or are at risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."

The final regulations should clarify any distinctions between CYSHCN, "person with special needs," and "person with disabilities," or use consistent terminology if there is no distinction among the meanings of these terms.

3. We also recommend that the final regulations require the establishment of an Advisory Panel on Community Support for Military Families with Special Needs. We believe that policies affecting families must be developed with meaningful family involvement.

In addition, Family Voices agrees with many of the comments submitted by others regarding the need to -

Establish greater uniformity in the implementation of the EFMP across the Branches of Service, particularly with regard to the provision of Family Support Services;

Clarify definitions of and distinctions between terms used in the proposed regulations, including "Individualized Education Program," Individual Family Services Plan," "Services Plan," "Family Care Plan," and the too-vague "adverse" and "adversely";

Broaden definitions of some of the benefits, including "Non-Clinical Case Management" {to include coordination of medical services}; "Assistive Technology Services" (to include evaluation, coordination, or training of family and other professionals in the use of the assistive technology); "Related Service" (to include a broad range of interpretation services); and "Special Education" (to include Specially Designed Instruction);
Identify DOD enforcement authority consistent with 10 USC 1781c to create oversight and "agency wide benchmarks and performance goals for all components of the EFM program."

Thank you again for the opportunity to comment on these regulations. If you have any questions about Family Voices' recommendations or should need additional information about Family-to-Family Health Information Centers, please feel free to contact

Comment

PAVE is a non-profit organization funded to assist families who have children with disabilities access services, support and information that will enable them to work effectively with systems in gaining needed services for their child. In that capacity PAVE established the Specialized Training Of Military Parents (STOMP) program in 1985. This program was funded through the U.S. Department of Education from 1985 through September 2014. This program is now supported through contracts to include one from the Army and the Navy, to provide training to military families with regard to their rights and responsibilities in gaining access to educational services. In addition, this contract provides for families to learn more about future planning, communication and advocacy, and TRICARE to include the Extended Care Health Option (ECHO). PAVE also houses the Military Parent Technical Assistance Center (MPTAC) known as The Branch which provides information and support to Parent Centers throughout the United States that will enable them to more effectively reach into military communities within their States and give support to these families. It is in our capacity of knowledge and experience that spans over 30 years that we provide these comments regarding the proposed EFMP Regulations.

In preparing for this review of the Exceptional Family Member Program (EFMP) proposed Regulations, we utilized the existing EFMP regulations, the Individuals with Disabilities Education Act (IDEA 2004) Regulations, Section 504 of the Rehabilitation Act, and DODI 1020.1 as well as the findings of the GAO Report to Congress of 2015 and the Tricare for Kids Briefing Paper developed to address unmet needs of EFMP family members. We appreciate the effort and time that went into the proposed regulations as well as this opportunity to comment on them. We hope that our comments lead to strengthening and formalizing practices across the Branches of Service in order to more effectively assist military families without regard to duty assignment or what Branch of Service they support.

Subpart A- General

In our review, we found that the Purpose and the Applicability sections of the proposed rules reflect the current language in the EFMP Regulations. While this is good and gives a continuity in purpose and applicability across this process, we would suggest that within the purpose language it include a statement that states, at least in part,

"All Branches of Service must build supports and programs that are seamless and can be utilized by any member whether assigned to an installation run by their Branch of Service, or another Branch of Service, and which, when needed provides appropriate advocacy training and support consistent with this part."

Current regulations expect all Branches to develop implementing Instruction and Procedures to enact these overriding regulations. This has led to varying service delivery systems, interpretations of how the regulations apply to those identified and what supports are available to families. While all Branches use the same forms for determining eligibility, the way these forms are adapted and/or used will vary greatly across services, making it difficult for a family who is stationed at a Sister Branch Installation to have paperwork completed and determinations made. By requiring in the purpose that all Branches adhere to these regulations and provide services within their Branch consistent with these regulations and universal in implementation requirements and expectations, families will have far greater ability to understand and trust the purpose of these regulations.

Within the definitions is where new language is quickly identified. Additionally, there is language that is consistent with current DOD Regulations regarding the implementation of the EFMP Program. Of note when comparing the proposed DOD EFMP Regulations, current DOD EFMP Regulations, and the IDEA, some terms within the existing EFMP Regulations and the proposed regulations are different or not as specific as they are in the IDEA. This may be in part, due to the fact that these proposed regulations give oversight direction while the DODI 1342.12 and 1342.16 and their required actions within the DOD schools for children with disabilities provide more explicit language regarding these subcomponents. For example, the Assistive Technology Service definition is consistent with the IDEA regulations in the first paragraph regarding how this is a service used to assist the individual in the acquisition, selection, or use of a device. However, the remaining components regarding the Assistive Technology Service is not included. While this is consistent with current EFMP Regulations it does not include the information regarding evaluation, selection, coordination, or training of family and other professionals in the use of such assistive technology. As stated earlier, this may be in part, due to the fact that such language can be found elsewhere. However, when looking at the issues of assignment acquisition of such technology and coordination of therapies, interventions or services consistent with educational or rehabilitative plans and programs may have implications as it can limit, or in some cases, deny the family member with the needed technology and the training and support to understand and utilize that technology. Since Assistive Technology spans beyond K-12 education such access may only be available through the use of outside vendors or military medical personnel. Therefore, we would recommend that these additional components be inserted here within the definitions of Assistive Technology Service.

With regard to other definitions in this section:

We support including the definition of CONUS into these proposed regulations. While the term has been around for many years, incorporation of it into these proposed regulations is a way of assuring that appropriate screening and supports are made available to the installations responsible for such screening as they look at medical vs educational support.

Within the definition of "Non-clinical case management", we would recommend that the coordination of medical treatments should be included in non-clinical case management. With this recommendation in mind, we would strike the sentence stating that it does not include coordination of medical treatments. If this is not in keeping with the intent of the regulation as the statement regarding coordination would seem to indicate, then the sentence stating, "assist them in making informed

decisions and navigating resources to improve their quality of life such as medical" needs to be removed.

While both the definition of an Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) are consistent between the current EFMP Regulations and the proposed Regulations there is inconsistency with the IDEA. These inconsistencies go beyond the fact that only the first part of the definition for both of these are given, there is potential for misconceptions regarding these documents. We would therefore recommend that the definitions be changed as follows:

"Individualized Education Program (IEP) is a written document including statements of present levels of achievement, measurable goals and related services required to implement such document and the specially designed instruction (SDI) to be used (to include amount of time and type of placement when not in the general education setting)".

Since the IEP is based on the identified need for specially designed instruction (SDI) for a student to be successful and the document also includes the amount of time a student is outside of the general education environment, the definition must assure that such information is included for purposes of review in making pinpoint assignments and should therefore be part of the initial definition of an IEP. With regard to Individualized Family Service Plan, we would recommend that the definition read as follows:

"Individualized Family Service Plan (IFSP) is a written document that includes the specific early intervention services necessary to meet the unique needs of the infant or toddler and the family, including the frequency, intensity, and method of delivering services, and where appropriate transition planning."

The way that the current definition and the proposed definition of an IFSP are written it appears as though there is reference to the use of Specially Designed Instruction (SDI). While this is needed in the IEP the IFSP identifies "outcomes" expected for the child, and family, to enable the infant or toddler to navigate through natural environments and become more independent and gain age level appropriate in skills. This may include the use of therapies or only Early Intervention educators. It may be done in the home or community and it is based on input from the family on what the family needs might be.

The definition for related services does not include interpreter services. The need for interpreters for those who are deaf or hard of hearing is indicated on a student's IEP or IFSP and therefore needs to be included as a related service. Additionally, the term should make clear that interpreters are not only those who provide support for students who are deaf or hard of hearing, but also as the conduit for communicating with the student, or his/her parents, when it comes to development and review of the IEP or IFSP. This should be included as there are many bi-lingual families in the military as well as mono-lingual Non-English speaking families where the military member is the only one who reads and writes in English. Without appropriate interpreter services as a related service, the family arguably could be required to provide their own interpreter, try to understand the complexities associated with developing and implementing a family support plan as well as an IEP or IFSP without an interpreter, or have their child act as an interpreter. All of these possible strategies are directly in violation of both Section 504 of the Rehabilitation Act, and DODI 1020.1 as well as other laws addressing access to federal services by eligible Non-English speaking individuals.

We would suggest clarification regarding the term and definition for "Services Plan (SP)" as it reads as though it is referring to what is interchangeably known as a Family Care Plan. While we agree that a family support plan may be appropriate, it is critical to point out that such a plan must look at those

issues that might impact mission. This may be different than what is typically identified in the Family Care Plan that is looking at who takes care of the child or children in the event the single service member is unable to do so because of deployment, temporary duty, etc.. We would recommend that the term identify who will work with the family or family member in developing the plan and the purpose of this plan beyond family needs and steps to achieve their desired outcome. Is this as it relates to duty assignments, education, housing, deployments, Command Sponsorship, etc.? Since it has been so loosely described it has been difficult to determine how it has been used and to what end.

The definition of Special Education is inconsistent with the IDEA in that it does not address that special education includes instruction even when a student has been suspended or expelled. Without such language the use of discipline as a means of removing a student from the school environment and no longer assuring the student is getting necessary services can and does occur. It is important to have information regarding school discipline that has occurred, what positive behavioral strategies had been attempted and the result of those attempts to reduce or ameliorate the behaviors.

The definitions do not include SDI which is an essential part of a student's outcomes. This needs to be considered for insertion into the regulations to assure that all personnel required or invited to assist the family are aware of what types of supports are needed for the student/child to be successful.

We recommend a specific definition of "adverse" or "adversely". The term is too vague as to be meaningful. This term is used three times within the area for stabilization, a critical component for military families in the EFMP. Without a clearly defined definition, it is left to the Branches to determine "if" it is apt to adversely affect the service member's career development or the mission requirements of the Military Department.

The current definition commonly used by most Federal entities with regard to a person with disabilities is the one established within Section 504 of the Rehabilitation Act. We would recommend this definition be inserted into the regulations to assure consistency across Military Departments and consistent with other Federal programs.

When using the term "person with special needs" it is unclear if this is to be considered interchangeably with a person with disabilities or if it is more in reference to a person with "special health care" needs as it is defined by the U.S. Health and Human Services. A finding in DoD's Report to Congress related to Sec 735 of the 2013 NDAA states:

"Data collection systems do not have a standardized definition of what identifies a child with special needs throughout DoD, the Military Departments, regional contractors, and pediatric specialty groups. DoD should adopt an enterprise-wide definition of "child with special medical needs" or adopt either the definition used by HHS or the National Institute of Child Health and Human Development definition of child and youth with special health care needs (CYSHCN)."

If it is to be used interchangeably this must be explained. If it is a different definition, such as the one used by HHS the definition needs to be included. This is critical since by nature a "person with special needs" does not necessarily require them to have a disability.

Subpart B - Policy

Policy- While the language in the proposed regulations is consistent with current regulations, we would recommend that reference in subpart 75.4 (d) (2) be revised to state that "The family member has a documented need for stabilization." And remove the segment stating "as determined by Service-specific guidance". If the intent is for the EFMP regulations to provide a seamless system of support and guidance reverting to Military Branch guidance with regard to this issue negates the ability to have one system of support and guidance. All decisions, even those of Navy personnel, are based on the needs of the military first. While the Navy allows Homesteading, it doesn't guarantee this in all cases, just as with other Branches, who, while they can transfer a family every two to three years, are not required to do so. Having a system of uniform guidance (whether it allows for Homesteading or not, is critical to assuring that equity exists across Branches when it comes to support of military families.

In addition, while this may not be covered within the regulation, there needs to be marketing with regard to the fact that the service member must initiate the request for stabilization. This is not well known by members and when they are informed that they can request such stabilization they are also informed that it can cause them to no longer be able to reenlist if they make such a request. This misinformation has made families choose to separate to assure the service member's career is not harmed. The separation of the family can be devastating to a marriage as well as parental relationships. In addition, since the regulation identifies the ability to request stabilization due to an EFMP family member's needs, there needs to be consistent language across the Branches of Service regarding the right to appeal assignment decisions based on EFMP status. As the EFMP case management source may be the first, or only, contact the member and family may have the need to be fully informed on what is possible for the service member is critical.

75.5 Responsibilities

In 75.5 (c) (3) we would recommend, consistent with the 2013 NDAA Sec 735 study, the inclusion of the language from one of the outcomes which states,

"Develop common data evaluation systems or metrics within the DoD or the Military Departments to evaluate the multidimensional programs that support the physical and behavioral health care needs of children...Further study would be to define the overarching goals and corresponding metrics that best evaluate outcomes of wellness and resilience programs within TRICARE and DoD."

We recommend this be incorporated into these regulations to ensure a common set of data evaluation systems and metrics are used across DoD and overseen by USO (P&R). Further, it is our opinion that such metrics and analytics/measures should align with existing and evolving standards in the civilian community, so that we can have a fuller understanding of how military children are doing compared to their civilian peers.

With regard to Subsection 75.5 (d) (4) (iii), regarding the ability of DODEA to request reimbursement for expenses beyond normal operations to provide special education pursuant to the child's IEP. The DODEA is required to provide a Free and Appropriate Public Education (FAPE) to all children who are Command Sponsored to a DODEA location. Further, just as in the States, a child cannot be denied Command Sponsored travel based on the lack of educational services. In the language of the injunctive relief ruling on the Cox v. Brown (1979) it was stated,

"There is no argument that the EHA applies in full force to the DODDS as of July 1, 1979, see 20 U.S.C. S 927 (c) (Supp. 111978), lucidly demonstrating Congress's intent that DODDS participates fully in programs to educate the handicapped."

While the DODEA can assist with pinpoint assignments, the current language, as with the proposed language doesn't acknowledge this and in fact it could be interpreted that a family member could and should be denied Command Sponsorship if there aren't educational services available. While we strongly support the use of pinpoint assignments to assure the availability of services and costs associated with such pinpoint assignments, it is critical that family member travel not be denied based on the lack of educational services. One challenge associated with the current system within DODEA is that there is no identifiable way to determine actual costs associated with special education services since these costs are not delineated, according to DODEA, but are part of the overall costs of educating all DODEA eligible children. We therefore, would recommend that language be incorporated into the regulation making clear that such reimbursement can only occur when the service member's MOS cannot be supported in a pinpoint assignment and the family is sent where there are no services available of a medical nature in addition to the lack of educational services, and that the DODEA had no fore-knowledge of the decision to send the family to the location.

Additionally, under DODEA responsibilities, "(2) Makes recommendations to the Military Services and Defense Agencies on the availability of special education services." It is recommended that there be clarification of whether "availability of special education services" within CONUS, include public and charter schools in the immediate area and not only DODEA schools.

As stated above, we find it difficult to see how DODEA can effectively determine estimated costs to provide the required special services 75.5 (d) (5) (ii) when all costs are determined to be part of the general operating costs for providing educational services for DODEA eligible students.

75.5 (e) identifies that each Military Department must establish guidance, develop programs, and establish an EFMP within their department that includes not only enrollment and assignment coordination, but also provides family support components and promotes collaboration between the three components. This is the most problematic aspect of the regulations. While there is a system that could provide equity across the Branches, this does not occur. It is further emphasized when a hospital identifies a child or adult who meets the criteria for enrollment, and then refers the service member to a "Branch Specific" entity for enrollment. When a military member is assigned to a location where there is not someone from their Branch of service to assist in the enrollment into EFMP or where the family support component is not there, it leaves a family with the challenge of "figuring it out on their own". Such challenges have led families to identify repeatedly that access to EFMP is inequitable based on location or Branch of Service. The need to have a system that can be used by a family without regard to duty assignment is essential to assure that the EFMP family member has access to needed support.

In subsection 75.5 (e) (18) The annual report to ASD(M&RA) needs to have language in the regulation requiring the report be made public. While the personally identifiable information specific to a military member must be protected the data across locations, branch or service, and resource allocations need to be accessible to allow transparency with regard to numbers of EFMP family members, service members enrolled in the program, and location are consistently sought for by Legislators, families, and other interested parties. The information is useful in planning by Commands, school districts, and others and should be readily accessible.

Subpart C - Procedures

As stated earlier, it is critical that common definitions of "Person with a Disability" and "Person with Special Needs" have common definitions across the various Military Departments. This is especially critical in light of 75.6 which addresses the criteria for identifying a family member with special needs. When reviewing the descriptions in subpart (a) special needs could easily be interchanged with the term "person with disabilities". However, as stated earlier, having special needs is not synonymous with having a disability. Additionally, when looking at special education needs, (75.6 (b) the use of assistive technology should also be included. There are students who have no medical needs but who do have need for AT and as such, this should be considered educational. Since a family member can be denied Command Sponsorship based on the lack of medically related services, but cannot be denied based on the lack of educational services, Assistive Technology needs to be identified as either an educational need or a medical need. However, a "student with a disability or special need" where the AT is needed for educational purposes must not be denied Command Sponsorship based on that need.

Within Section 75.7, (c) (1) (iii) needs to be clear that this is only with regard to medical services. While it is stated earlier, it needs to be clear that assignments overseas need to be coordinated with DODEA so that appropriate pinpoint assignments can be made. It is critical that when considering an overseas assignment, the family member may need to be transported to the appropriate setting, if the sponsor can't be assigned to a pinpoint assignment. Further, DODEA must have prior knowledge documented that such assignment will not allow for a pinpoint location so that they can plan accordingly.

With regard to subsection 75.7 (e), it is critical that the sponsor be aware that removing their child from special education services, in order to get a targeted assignment and then identifying the child once they have arrived, while allowable and consistent with the IDEA 2004 amendment regarding parent rights, may also result in punishment under the UCMJ. While a parent can remove their child from special education at any time, and when such action occurs emphasize to the district, "...that they must act as if they have no prior knowledge of the need for such services", it is not in the best interest of the child and is therefore not in the best interest of the military.

Subsection 75.9 Provision of family support services has caused great angst among military families. The level of family support services varies greatly from Branch to Branch and location to location. Uniformity of services is critical. While the regulations have identified that a family member is to be supported by the "family support service" without regard to their affiliation with the Branch of Service, family members have reported being told they cannot be helped, been referred to entities that were regional and not local to get assistance, been told there are no services available to them or that they would not qualify even if services were available. The inequity has caused significant morale issues. While this section has undergone no changes from the current to the proposed regulations. We would strongly recommend that the proposed regulations include language that supports the availability of support (to include respite care services) for an active duty military member and his/her family member without regard to Branch of Service and that further, if Respite Care services are determined to be needed by the family, assure that the respite care services are provided and that the entity providing the Respite Care can and will, require payment from the Branch responsible for the care of a military member, even if such member is not assigned to an installation.

In Sept 2012, the GAO stated the following: "GAO-12-680, Better Oversight Needed to Improve Services for Children with Special Needs" that,

"DOD's recently established Office of Special Needs (OSN) is responsible for enhancing and monitoring support for military families with special needs. OSN and the military branches have initiated efforts to improve screening and overseas assignment of military families with special needs. However, it is unclear when some of these efforts will be completed. Moreover, while OSN was established in part to enhance and monitor the military branches' support for families with special needs, it has limited enforcement authority and oversight over the branches' EFM programs. Specifically, it is limited in the extent to which it can compel the branches to comply with DOD or service-level program requirements, and it has no direct means by which to hold them accountable if they fail to do so. In addition, DOD currently lacks agency wide benchmarks and performance goals for all components of the EFM program. As a result, it cannot assess the effectiveness of the branches' EFM programs and ensure that improvements are made when needed. Without overall performance information to proactively identify emerging problem areas, some of the branches have had to conduct investigations to address problems after they have arisen."

Without clear identification of an entity who will be responsible to assure that enforcement of the required activities occur, there will continue to be fragmented services and oversight thus limiting the ability to impact needed positive changes. We strongly endorse language from the GAO report that will identify DOD enforcement authority consistent with 10 USC §1781c and that will create oversight and "agency wide benchmarks and performance goals for all components of the EFM program."

The specific portion of 10 USC §1781c that we are asking be incorporated into Subsection 75.10 of the federal regulations is Section (d) Subsection Responsibilities, Bullets (5), (6), and (7) which states, "The Office shall have the responsibilities as follows:

(5) To monitor the programs of the military departments for the assignment of members of the armed forces who are members of military families with special needs, and the programs for the support of such military families, and to advise the Secretary of Defense on the adequacy of such programs in conjunction with the preparation of future-years defense programs and other budgeting and planning activities of the Department of Defense.

(6) To monitor the availability and accessibility of programs provided by other Federal, State, local, and non-governmental agencies to military families with special needs.

(7) To conduct periodic reviews of best practices in the United States in the provision of medical and educational services for children with special needs." These responsibilities are not reflected appropriately under the proposed regulations§ 75.10 Office of Community Support for Military Families with Special Needs (OSN) or elsewhere in the proposed regulations.

This additional language should be included in the final regulations to assure that the role of the OSN is not only to develop policy but to also evaluate systems of care whether educational or medical, and provide oversight and enforcement of these regulations with equity across all Branches of the Military.

The "ANNUAL REPORT TO THE CONGRESSIONAL DEFENSE COMMITTEES on Support for Military Families with Special Needs pursuant to Section 1781c (h) of Title 10, United States Code", dated April 2015, written by the DoD Office of Special Needs (page 2) states the following

"Combine two committees, one required by Department of Defense Instruction (DoDI) 1342.12, "Provision of Early Intervention and Special Education Services to Eligible DoD Dependents," April 11, 2005, and another required by DoDI 1315.19, "Authorizing Special Needs Family Members Travel Overseas at Government Expense," February 16, 2011, into one. The newly established Overarching Coordinating Committee for Military Families with Special Needs oversees policies and programs for military families with special needs. The two subcommittees required by Department of Defense (DoD) policy will report their activities to the Overarching Coordinating Committee."

The differences in the responsibilities of these two committees is clear, as is the required make-up of the DODEA Committee. The language in the IDEA provides clear direction regarding responsibilities of the Advisory Committee as well as the required make-up of the committee. This would need to be incorporated into any proposed combining of the committees. The SEAC is to have the majority on the committee be parents of persons with disabilities or persons with disabilities whose disability would have warranted SDI if the student were to attend schools now. This is consistent with the IDEA in Part B and C of the ACT. We support the joining of the ICC and the SEAC as the DODEA has done. However, it is unclear what recommendations this committee has made. Further, it has never had a majority parent or persons with a disability. So improvement might be accomplished by combining it with the Travel Committee.

While we can see advantages to combining the committees, as proposed in the Report on Supports for Military Families with Special Needs, we cannot completely endorse moving the SEAC under the oversight of the OSN as this would allow for the abdication of responsibility of DODEA to implement change and to act in coordination with the SEAC. This is a potential outcome if the GAO study recommendation is implemented without clear alignment with the expectation of DODEA to consider any recommendations made by the committee as they relate to Early Intervention and/or special education services for student within DODEA. We see the value of combining these two committees, as well as the benefit of continuing to have them act independently and report to different leadership. To support combining the two committees, as identified, would be a cost saving measure and could help those involved who might be on both Boards. We would recommend that if these two committees combine that the recommendation of representation meet DODEA requirements under the IDEA. Further, we are of the opinion that it must have representation from advocacy organizations knowledgeable about the needs of military families with special education or early intervention needs and that they report to the public regarding recommendations set forward for consideration and the committee's response to such concerns.

We recognize that the "newly established Overarching Coordinating Committee for Military Families with Special Needs" who "oversee policies and programs for military families with special needs." is not addressed in these proposed regulations though this committee appears to have many of the responsibilities listed in the OSN regulations. Will this all fall on the OSN, or what other entities will be required to address the needed and identified components? The regulations should address what this

committee's purpose and responsibilities include, who will serve on this committee, how they will be identified, and how often they will be required to meet.

Another legislative requirement also discussed in the "ANNUAL REPORT TO THE CONGRESSIONAL DEFENSE COMMITTEES on Support for Military Families with Special Needs Pursuant to Section 1781c (h) of Title 10"" written by the DoD Office of Special Needs, on page 2 states that the OSN:

"Initiated required actions to formally establish the Advisory Panel on Community Support for Military Families with Special Needs and is working with the military Departments to identify candidates who are members of a military family with special needs for the Secretary's consideration."

However, the requirement is not discussed in these proposed regulations, nor how they will work with the OSN on behalf of military families who have special needs. We recommend a section be added to the regulations to ensure the creation of this advisory panel as cited in the above Report to Congress and as required by 1781c of Title 10.

Pub. L. 111-84, div. A, title V, §563(c), as added Pub. L. 111-383, div. A, title V, §582(c)(2), Jan. 7, 2011, 124 Stat. 4227, provided for "Military Department Support for Local Centers To Assist Military Children With Special Needs" which "The Secretary of a military department may establish or support centers on or in the vicinity of military installations under the jurisdiction of such Secretary to coordinate and provide medical and educational services for children with special needs of members of the Armed Forces who are assigned to such installations." However, the requirements of 10 USC §1781c are not discussed in the proposed regulations. This proposed "Foundation for Support of Military Families with Special Needs" would provide for the:

"(1) Establishment authorized. -The Secretary of Defense may establish a foundation for the provision of assistance to the Department of Defense in providing support to military families with special needs.

(2) Purposes. -The purposes of the foundation shall be to assist the Department of Defense as follows:

(A) In conducting outreach to identify military families with special needs.

(B) In developing programs to support and provide services to military families with special needs.

(C) In developing educational curricula for the training of professional and paraprofessional personnel providing support and services on special needs to military families with special needs.

(D) In conducting research on the following:

(i) The unique factors associated with a military career (including deployments of members of the Armed Forces) and their effects on families and individuals with special needs.

(ii) Evidence-based therapeutic and medical services for members of military families with special needs, including research in conjunction with non-Department of Defense entities such as the National Institutes of Health.

(E) In providing vocational education and training for adolescent and adult members of military families with special needs.

(F) In carrying out other initiatives to contribute to improved support for military families with special needs.

(3) Department of defense funding. -The Secretary may provide the foundation such financial support as the Secretary considers appropriate, including the provision to the foundation of appropriated funds and non-appropriated funds available to the Department of Defense.

(4) Annual report. -The foundation shall submit to the Secretary, and to the congressional defense committees [Committees on Armed Services and Appropriations of the Senate and the House of Representatives], each year a report on its activities under this subsection during the preceding year. Each report shall include, for the year covered by such report, the following:

(A) A description of the programs and activities of the foundation.

(B) The budget of the foundation, including the sources of any funds provided to the foundation.

(5) Military family with special needs defined. -In this subsection, the term 'military family with special needs' has the meaning given such term in section 1781c(i) of title 10, United States Code (as added by subsection (a))."

The *above* reference from Public Law regarding the "Foundation for Support of Military Families with Special Needs" was not included in the proposed regulations and should be included, as it is one means of assuring that information and support is maintained for our service members who have an EFMP family member. We recognize, again, the difficult work that went into the completion of these draft regulations and feel that these combined recommendations would enhance the final EFMP regulations.

Military 360 Comments

The Statewide Parent Advocacy Network (SPAN) has been New Jersey's Parent Training and Information Center funded by the U.S. Department of Education, Office of Special Education Programs under the Individuals with Disabilities Education Act (IDEA), for over 25 years. We have also served as the state's US Department of Health and Human Services Maternal and Child Health Bureau-funded Family to Family Health Information Center for over a decade. Presently we are supporting the Military Family Support 360 (MFS 360) Project, a one-stop center supporting all military-connected children and youth with disabilities and special healthcare needs. The MFS360 Project came on-line in 2009 at the same time Fort Dix, Lakehurst NAS and McGuire AFB became a joint base (JBMDL). Prior to that SPAN had a rich history of working with the Fort Dix EFMP program. We conducted joint training activities, community programs, and advocacy. In fact, SPAN had a parent resource center on the base for several years run by volunteer parents, both civilian and military.

We do not want to repeat some of the very thoughtful comments that you have already received but do want to reinforce them. In that light we point you to the comments of Mr. Jeremy Hilton and also the PAVE organization to express our agreement and shared concerns as we try to keep to a minimum any duplicative statements. We will focus our comments on a few highlights and what we feel is still missing in the proposed regulations.

The privilege and challenge of working on a joint-base - actually a tri-base - is the same that you are faced with now: equity across the branches. It remains a huge challenge in service delivery. From discussions of assignments or homesteading, which we appreciate but still do not believe are clearly defined across the branches (for example, what is the definition of adverse?) to expectations of clinical and non-clinical case management, equitable access to services and supports is not available. Information and referral is always mentioned but the knowledge of community and state resources is not there. What families have to face with PCS moves and having to navigate both military and civilian systems each time with no confidence in the resources or support they will find at their next duty station requires guaranteed access to information and supports familiar with both military and civilian services and systems. Splintered supports, different knowledge bases, lack of communication and collaboration across EFMP programs and no real interface with community supports and agencies is too often a reality. There must be higher expectations and more clearly defined supports for exceptional family members. When you PCS, your uniform should never be the decider on what kind of support you get from enrollment to assignments and even respite.

We must find a way to create equal access for all service members to EFMP supports no matter what branch they serve in. It is time to equal the playing field. Our biggest concern with streamlining EFMP programming is that we keep a critical eye to raising all boats and not lowering our standards. We were very disappointed to see the word advocacy only once in the proposed regulations as it pertains to family supports. We have served over 1,000 family members in our time at JBMDL. Not all families need direct one-to-one advocacy; but many of them do. We have supported E-2's all the way up to O-S's. It is not just the young soldier, airman or sailor who needs the additional advocacy support at times. That has got to be an allowable, even encouraged, family support. As a parent advocacy organization we are committed to parent leadership and training, whether desk side, workshop or webinar; all go hand in hand with advocacy. It has been our experience that the best peer mentors for our new families are the ones we were able to support with advocacy, training and parent leadership development. We owe it to the families whose resiliency we are charged with building to get this one right.

Respectfully submitted by

Comment

February 9, 2016

Office of the Deputy Chief Management Officer
Directorate of Oversight and Compliance
Regulatory and Audit Matters Office
U.S. Department of Defense
9010 Defense Pentagon
Washington, DC 20301-9010

Thank you for the opportunity to comment on the "Exceptional Family Member Program" (EFMP) proposed regulations. On behalf of more than 390,000 members of the Military Officers Association of America (MOAA), we offer the following comments to RIN 0709-A182, "Exceptional Family Member Program."

Our comments echo those submitted by the National Military Family Association, a co-member with MOAA on The Military Coalition and the Tricare for Kids Coalition.

In recent years we have been gratified to see the Department of Defense (DoD) make the care of special needs military family members a priority. The establishment of the Office of Community Support for Military Families with Special Needs (OSN) represented a significant step forward in addressing the challenges of special needs family members. However, the promise of an effective EFMP that fully meets families' needs has fallen short. OSN and the Services' EFMP programs must act to regain the trust of military families and prove they can provide resources and services families can rely on.

OSN was created in the Fiscal Year 2010 National Defense Authorization Act (FY10 NOAA) (Public Law 111-84) to enhance and improve DoD support around the world for military families with special needs, whether medical or educational. Despite the establishment of the OSN, gaps in support to special needs military families still exist, due in part to differences among the various Services' EFM programs.

The EFMP is intended to perform three interrelated functions:

- (1) identify and enroll eligible family members;
- (2) coordinate the assignment process to ensure special needs families are not sent to locations that lack adequate resources;
- (3) and provide families with information about and referral to local resources.

While some Services take a centralized approach to EFMP, with enrollment, assignments, and case management services all housed in a single office, other Services' programs are more "stove piped." When a breakdown in communication occurs, families may find themselves assigned to locations without appropriate medical or educational services for their special needs family member or unaware of resources available to them through their communities. We often hear from families who experience a long wait before receiving services at their new installations because of a lack of communication between EFMP Coordinators at the old and new installations. Families need the reassurance they will have continuity of care and a warm hand-off as they move from installation to installation.

A 2012 GAO report, *Better Oversight Needed to Improve Services for Children with Special Needs*, (GAO-12-680, September 10, 2012) noted there are no Department wide benchmarks to set standards for the Services' EFM programs. As a result, the Department is unable to assess the effectiveness of the branches' EFM programs and ensure improvements are made when needed. In addition, although OSN was created to enhance and monitor the military branches' support for families with special needs, it has no authority to compel the branches to comply with DoD or Service-level program requirements and it has no direct means by which to hold them accountable if they fail to do so.

DoD needs to comply with the GAO report and establish benchmarks and performance metrics for the EFM program. We further ask OSN develop and implement a process for ensuring the branches' compliance with EFM program requirements.

We ask DoD and the Services to set a common standard of support families can expect to receive through the EFMP. Families have the right to expect a level of service for their special needs family members regardless of the color of the uniform they wear. This is especially important as joint basing becomes more common and when families from one Service live and work on installations operated by another.

The FY10 NOAA included specific directives for providing family support and case management services to better serve military families with special needs family members. Despite the intent of the legislation, those services have not yet been fully implemented, leaving families struggling to locate resources in their communities and manage their complex medical and non-medical needs.

The FY10 NOAA directed installation EFM programs include a "Special Needs Navigators" to help families find programs and resources available in their civilian communities. In locations where Special Need Navigators are part of the EFMP, families report a high level of satisfaction with the service and support they receive. However, few installation EFMPs include a Special Needs Navigator. We are disappointed the proposed regulation does not address Special Needs Navigators and provides little detail on the most basic level of family support and coordination of resources. We urge DoD to meet the minimum level of family support coordination outlined in Section 563 of the FY10 NOAA.

Section 563 of the FYIO NOAA also emphasizes the need for enhanced case management support. Case management is specifically mentioned three times in the legislation:

- DoD requirements for resources (including staffing) to ensure the availability of appropriate numbers of case managers to provide individualized support for military families with special needs (563(e)(4)(E)).
- The program shall provide for timely access to individual case managers and counselors on matters relating to special needs (563(f)).
- Each program shall provide for appropriate numbers of case managers for the development and oversight of individualized services plans for educational and medical support for military families with special needs (563(f)(3)(B)).

Additionally, the FYIO NOAA Conference Report language makes clear the importance of case management support for special needs military families:

"The conferees expect that implementation of this section will result in substantial improvements in identification and outreach to larger numbers of individuals who need support and coordination of available services, expansion of case management services, more direct training and counseling for parents and families, and timely access to information and referral to both Department of Defense and other federal, State, and local special needs resources and services. The conferees direct the Secretary to examine ways to mitigate the challenges for families who may be disadvantaged by relocation during their military service, and to ensure that enrollment in the Exceptional Family Member Program, or any successor to that program, is perceived as a positive and necessary family readiness resource."

The EFMP proposed regulations provide few details on case management services. There are no specifics regarding case manager resource requirements, acceptable case management access standards, or requirements for the development and updating of individualized service plans (medical and educational) for military families with special needs. Given the critical role case managers play in the support of special needs military families, we believe the regulation should include more detail on case management resource requirements and responsibilities.

Section 582 of the FY11 NDAA, Enhancement of Community Support for Military

Families with Special Needs, included two provisions that are missing from the EFMP proposed regulations:

- Periodic reviews of the best practices in the United States in the provision of medical and educational services to children with special needs (582(b)(2)), and
- Establishment of an advisory panel on community support for military families with special needs (582(d)).

Both of these provisions should be added to the proposed rule.

For many years, the Department of Defense Education Activity (DoDEA) has asked for guidance regarding special education services for children of DoD civilians stationed overseas. We are pleased the proposed regulation includes details on this important topic.

MOAA is the nation's largest and most influential association of military officers. We are a powerful force

speaking for a strong national defense and representing the interests of military officers and their families at every stage of their careers. We applaud the ongoing efforts of the Department of Defense to streamline services and predictability for Exceptional Family Members. For further inquiries, contact Brooke Goldberg, Government Relations Deputy
Director for Military Family Issues at I

Sincerely,

0049 2017 Mtg R

Submission from: **January 11, 2017**

To Whom it May Concern,

My husband and I have two special needs boys, both with severe/non-verbal Autism, and two younger completely healthy children. He is a Major and I am a retired officer. I retired at only 20 years due to my boys' needs. My primary concerns lately in the realm of special needs are twofold: 1) ABA needs to continue to be covered by TRICARE and 2) EFMP Respite care program is terribly flawed.

Regarding ABA - this therapy is the only one with proven positive results for children with Autism. If it is not continually provided to children when they are children, the results will be much greater cost in a social consciousness way, because these Autistic adults will not be self-supporting. That lack of self-support will lead to greater quantitative, economic costs for society. My boys have been authorized ABA since the age of 39 months. Initially, we had a 7 month wait, then had to drive 94 miles one way twice a week to the only center providing it. Then, we finally got in-home care and it was sub-par and I had to terminate it. We then had a 5 month gap, found a new in-home care provider who was so unprofessional I had to submit a formal complaint. We had a 3 month gap after that, and again went to a center, but it was 40 miles away one-way. This little four year experience is a snippet of what it is like already, and we hear rumors of reimbursement cuts to providers, re-evaluations of our children every two years, setting a cap on hours authorized, etc. All of these will contribute to our children growing into adults who cannot function independently. Serving Soldiers are our nation's treasure and their kids deserve better.

Regarding respite care - when we started getting respite care in 2010, it was locally managed. Parents hired a provider whom they trusted and that provider was paid by the local garrison. Each year since then, the hurdles have gotten more frequent and higher. The contractor that was awarded the contract to manage recruitment and hiring of providers is completely inept. They are ineffective in their methods, extremely disorganized and robbing the taxpayers of money. We worn-out parents need respite. Not only are we not getting it, the contractor is being paid for nothing. When we last PCS'd, I went to the new location ahead of time and interviewed some prospective providers in order to "grow my own" provider, have them communicate with the contractor and become our provider. I chose a 22 year old mature college graduate with not a blemish on any record of hers, and the process took 8 months. It's glacial, and we are not the people who ought to deal with more extended waits for any

tyi:te_oLca_re_Q_ur bo_ys_a[eJevL1_and .Le\leL2,_and therefore beginning on June-1r2011rtheir.----- authorization will go away (we do not have a provider now, it's too hard to meet the requirements!). Only level 3s and 4s will get care, and it doesn't matter that our family has TWO special needs kids.

I will wrap my comments up here; I feel that I have a lot to add and certainly have a discerning character, and could provide wonderful input toward fixing many of our EFMP / Special Needs families' challenges. I am rather unable to contribute locally on a regular basis due to my four children. That is exactly the type of negative result the two problems I highlighted above raise. I am a retired officer, previously enlisted and have a breadth of knowledge and experience that could help this community, but I'm just too flat-out exhausted to help much more than this email.

Thank you for your attention in this matter.
Sincerely,

Major (R), u:::, Army

0050 Feb 2017 mtg R

Submission from alilllllllll February 3, 2017

3rd February 2017

DOD Military Family Readiness Council and Special Needs Military Families:

I am writing you today on behalf of my son who is an EFMP family member that suffers from Apraxia, Autism and Sensory Processing Disorder. Autism is a chronic condition that can be improved with therapy. Autism is a complex disorder of brain development. This disorder is characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. ASD can be associated with intellectual disability, difficulties in motor coordination and attention and physical health issues such as sleep and gastrointestinal disturbances. Childhood Apraxia is a motor speech disorder that first becomes apparent as a young child is learning speech. For reasons not yet fully understood, children with apraxia of speech have great difficulty planning and producing the precise, highly refined and specific series of movements of the tongue, lips, jaw and palate that are necessary for intelligible speech. Apraxia of speech is sometimes called verbal apraxia, developmental apraxia of speech, or verbal dyspraxia. No matter what name is used, the most important concept is the root word "praxis." Praxis means planned movement. Sensory Processing Disorder refers to the way the nervous system receives messages from the senses and turns them into appropriate motor and behavioral responses. A person with SPD finds it difficult to process and act upon information received through the senses, which creates challenges in performing countless everyday tasks. Motor clumsiness, behavioral problems, anxiety, depression, school failure, and many other problems may impact those who do not have effective treatment. My son who is just about to turn six faces these challenges 24 hours a day. It is exhausting for him to live in our world. As his parents we are dedicated to helping him adapt and overcome this horrible disorder that has stolen his childhood. Treatment includes, but is not limited to Applied Behavior Analysis (ABA), Occupational Therapy, Speech Therapy and Physical Therapy. He also attends the Pearl Harbor Kai Special Education

Preschool Program full time in a fully self-contained classroom. Our family has spent countless hours and resources in order to set up and maintain ABA, Occupational Therapy, Speech Therapy and Physical Therapy for our son to improve his condition. He has also participated in feeding therapy, Hippotherapy, music therapy and sensory movement therapy. He is a very busy boy who is nonverbal as well as does not eat or sleep consistently. Often he will wake up in the middle of the night between 12:30-1:00am until 5:00-6:00am. That is very little sleep for a growing boy especially with one whose needs are so great. He will scream, hit turn lights on and off which lasts for hours on end. It is a huge stress on an already strained situation. My husband who the military service member with 5 deployments that include Somalia, Iraq and Afghanistan can find these nights (that has lasted up to a month straight before) very challenging to handle. I cannot stress enough the strain that our Special Needs Families are under and yet we are faced with more hoops, stress and demands with the new EFMP policies in place. On top of that services are being cut. We are no longer able to receive respite care. Our family is far away from our support network. Respite

Care is a great program when handled correctly by a company. It can provide parents with a much needed reset to face the next day. I must share that there is NO CURE, NO GUIDELINES, and ONLY TRAIL AND ERROR for helping our child. We are not guaranteed a future. When our child was diagnosed we not only faced a new way of life but we also had to mourn the loss of our child and the dreams we originally had for their life. We have to put all our dreams on hold to pour all our energy, focus, money and hope into helping our son survive a world that is a constant state of attack on his senses. My son has a HUGE sensory diet that has to be fulfilled or he stays in a constant fight or flight mode. This diet needs to be implemented 24 hours a day. One program that helps us is the ECHO Durable Medical Equipment that allots \$36,000 a year for our child's needs. We were not even aware of this program when

he was first diagnosed. When I found out what is offered I was so surprised, elated and had a new surge of hope. This means a LOT to our families that we can request equipment that will provide everyday help for our child. I have been able to request a handful of items but

recently my son has been denied left and right for items that can greatly impact his life. We had all the information needed, requests were supported by his OT/PT therapist as well as BCBA and his doctor but it was denied for some reason that cannot be explained. If there is allocated money for children's needs why is it not accessible? This can CHANGE their lives. Yet we face more stress, road blocks and out right denials for PROGRAMS IN PLACE. There is no rhyme or reason for denials as we as consistency in authorizations and denials. One parent on island can receive an item and another can receive a denial in spite the same requests, diagnosis, supporting documents and needs. Why is it that EFMP families who are already facing a very dreary future have a "programs and services" in place that do not truly help the families. All we have is empty hope from the empty words listing what is offered but in actuality we have to fight tooth and nail to get what our child needs. We are already stressed out to the max and worked to the bone and we still have to fight for services that we are SUPPOSED TO receive. The DME program can be an excellent program for all families yet it is kept a secret. There is no education on how to request items and the actual process once it leaves our Doctors hands is a mystery. Please review this ECHO care benefits and make it accessible to families so that we can help our children. If the request is supported by our therapist who seen our children daily as well as BCBA's why is that

.. _no_t_goo.d enough_wHhihe_parents_request.andltheir_doctors'?-Wbyofferfalse-hope?- ----

Another issue is our EFMP office. We receive little to no help from them. This program needs to be updated and held accountable for their services.

Thank you for your time and consideration on these topics.

0051 Feb 2017 Mtg R

Submission from:

Friday, December 30, 2016

My family is an EFMP family. Both of our children, as well as myself are enrolled in the program. I have suggestions on ways to improve it, so that we may be more supported, therefore making my active duty husband more prepared to do his job.

1. Respite care: The recent reductions in respite reimbursements have severely impacted our ability to get qualified care for our LON3 child. The reimbursement setup means funds must come out of our pockets first, and that is a heavy financial burden when we have so many other out of pocket expenses from commuting to so many therapies and appointments on an often daily basis.

2. ABA- It would be beneficial if Tricare/ECHO offered choices for Autism therapies. ABA therapy is generally considered very abusive and harmful within the Autistic community due to forced compliance despite how much it may injure the Autistic person. (Caution- <http://autismwomensnetwork.org/my-thoughts-on-aba/> < Caution- <http://autismwomensnetwork.org/my-thoughts-on-aba/> >). Please consider covering RDI therapy as an alternative.

3. School. We are stationed aboard Camp Pendleton, and the schools here are painfully overcrowded. Not only that, but children who have special needs are being shuffled around to other school/school districts, which requires at least two hours a day on a bus, on top of their school, and therapies. We have been forced to homeschool through a charter school to have an even somewhat appropriate schooling environment for our 2E, or twice exceptional child, which means he has a disability (in his case Autism, and Dysgraphia, as well as being diagnosed as gifted). The resources for gifted children are sorely lacking.

4. Adults in the EFMP program. I am an adult in the EFMP program, who has recently been diagnosed with several chronic illnesses and new physical disabilities, and the lack of resources for me out here are astounding. I have my EFMP case manager, hospital case manager, and Tricare case manager trying to help track down resources for me to help with things like grocery shopping, which I cannot physically do, housekeeping (which I cannot physically do), running errands, etc, and the resources just don't exist (If I was a Wounded Warrior, I'd have too many resources available to me to count). This glaring gap in resources is a huge hindrance for my husband for his own readiness. There are no adult support groups for myself, or my family members, there is no child care assistance for disabled adults, there is no housekeeper." With what funds? I cannot work due to my chronic illnesses and disabilities, as well as having two special needs children. This is an area which needs to be addressed in a major way.

Thank you for your time, and I look forward to many improvements for the EFMP population in the future.

Sincerely,

Submission from: [REDACTED] **January 9, 2017**

0052 Feb 2017 Mtg R

9 January 2017

To Whom It May Concern:

My name is [REDACTED] and I am the spouse of an active duty army soldier. I am writing in reference to the expected drop in respite care hours for the Exceptional Family Member Program (EFMP). Over two years ago, my husband and I chose to move a thousand miles away from our family support system so that our son, who was born with a disability, would have access to the best medical care in the country. This decision has proven to be highly beneficial to his rehabilitative therapies.

[REDACTED] was born with Thoracic Spina Bifida and attends regular private therapies on a weekly basis. Every year, for the past three years, he has participated in an intensive therapy program in order for him to reach his maximum physical potential. This may seem advantageous for a four-year-old child but I am of the belief that he will conquer any goal put before him. The amount of dedication our family has for

[REDACTED] also requires a great deal of personal sacrifice. Over the summer (2016) and I lived at an inpatient facility for eight weeks where he received intensive feeding therapy three times a day, seven days a week for the entire stay. This amounted to one hundred and sixty eight feeding sessions, thirty-two sessions in speech therapy, and another thirty-two session with an occupational therapist.

When you add his physical therapy as well, he received two hundred and fifty therapy sessions in that eight weeks. The result of this program is that Jack no

onger lives on liquid"nt91 1 e comes home from school and has a grilled cheese sandwich and a glass of milk, just like any other child. We worked incredibly hard for that grilled cheese! While [REDACTED] and I were at the hospital, our five-year-old daughter was in Florida with my parents. I am telling you all of this so that you are able to gage the amount of time, effort, and emotional energy it takes to keep our son moving forward.

The thought that our respite care hours will be cut, possibly in half, concerns me a great deal. I will be in

attendance at the open forum concerning families with special needs to discuss the matter further. This "snapshot" of our life only encompasses a two month period. I ask you to consider the fact that we have been on this road with our son for nearly five years and need this respite care a great deal. Thank you for your consideration on this matter.

Cordially,



Military Family

t. Advisory Network

0055 Feb 2017 Mtg R

Sept. 25, 2014

Under Secretary of Defense
Personnel and Readiness
4000 Washington, DC 20301-4000

Dear Members of the Department of Defense Military Family Readiness Council:

On behalf of the Military Family Advisory Network (MFAN), we request your consideration of five recommendations at your next scheduled meeting and ask that you include the contents of this letter in the minutes of that meeting. We want the best for our military community, because when we're strong, our country is strong.

MFAN, a 501(c)(3), represents our Nation's community of military and veterans families—including more than 2.2 million Active Duty and Reserve Component members, over 3 million military family members, and over 22 million veterans and their families. Our goal is simple: to build a community of military and veteran families at home and abroad who understand and use resources designed to serve them; have the tools they need for success; are connected to leaders serving the military family community; and are embraced by the general public.

We greatly appreciate the hard work of the MFRC, your efforts to build a strong and ready military through critical support programs and policies, and your recognition that our military families are directly linked to military readiness. MFAN has been especially encouraged to see the continuity of Council membership and an increase in the number of MFRC meetings over the last year. As you are so acutely aware, there is still more work to be done to address the challenges facing our military families, particularly in these very difficult fiscal times.

MFAN provides the following recommendations for Council consideration. We believe these recommendations will not only advance your goal this year and in the coming years but also result in more effective and efficient policy and program formulation and implementation, as outlined in the 2011 and 2012 National Defense Authorization Acts (NDAA's).

1. Hold at least one meeting of the MFRC outside of the National Capital Region to provide an "outside the beltway" perspective on the issues.
2. Increase the transparency of the selection process, including soliciting input from military and veteran service organizations and nongovernmental organizations (NGOs) in identifying prospective candidates to fill the military spouse slots.
3. Create a campaign to increase awareness of the MFRC and its work, publishing and disseminating meeting minutes, annual reports and other meeting materials via newsletters, social media, and other military media outlets, while encouraging Council members to actively promote these materials as well. Although the Council website (<http://www.militaryonesource.mil/those-who-support-mfrc>) is accessible to the public,

MFAN believes military families would be better served by making more information available not only on the Council website but through links to other widely distributed military and veteran information sources, as was intended in the 2011 NDAA.

4. Add two or three more military-veteran organizations or other NGO representatives to the Council membership

5. Record and either televise or live stream all Council meetings and publish their minutes along with the meeting materials.

Thank you for your consideration. We look forward to hearing your response to these important recommendations as well as seeing this letter included in the next Council meeting minutes. Please feel free to contact

Sincerely,

,r



2057 Feb 2017 mtg R

Department of Defense
Office of Family Readiness Policy 4800
Mark Center Drive Alexandria, VA
22350-2300

Attn: Military Family Readiness Council Re:
Meeting of February 15, 2017

February 3, 2017

Members of the Military Family Readiness Council,

Thank you for your time, serving military families, and for your interest in Department of Defense (DoD) Family Members with Special Needs, including healthcare and the Exceptional Family Member Program (EFMP).

We are gratified that this meeting identifies healthcare for families with special needs as a topic of study, alongside EFMP. Healthcare access and EFMPs must coexist, be evaluated in parallel, collaborate, remain transparent and consistent for families with special needs to facilitate continued readiness. Yet, healthcare lives in an entirely different administrative and functional area than the Exceptional Family Member Programs which are managed and executed by the individual military services.

Families, naturally, consider healthcare and the EFMP intrinsically connected since most often healthcare needs are what drive mandatory enrollment into EFMP. Additionally, the Extended Care Health Option (ECHO), a healthcare benefit that augments what is covered through Tricare, requires enrollment in the EFMP for eligibility. These requirements tie EFMP together with healthcare, but don't adequately explain where the benefits provided by EFMP end, and access to healthcare begins.

So, when a service EFMP has said it is okay for them to be assigned where there is a shortage of providers, families don't know where to turn or how to get access to the healthcare they need and are left to believe that the service does not have their welfare or readiness in mind.

Families also become exposed, over time to the disparities in the support programs provided by each of the services. It diminishes morale when airmen and soldiers assigned to a joint base cannot receive the same kind of support for their families.

Consistency and continuity of care are challenges for many military families, and those with special needs have increased difficulty because their health and support needs may be numerous, complex and chronic. These families must be able to rely on consistent quality and access to care and services, and sufficient resourcing of benefits delivered by the DoD and the military services.

Military families move at the direction of the government. As such, they are less likely to have a personal network to assist them when there are gaps in the services they need, and they may not be in one place long enough to develop that effective network. In those cases, they rely on local and state resources to help them get by, despite their unique challenges - meeting the needs of their special family member and serving their country simultaneously. Unfortunately, not every locality is resourced to help these families. In those circumstances, we believe the Services and DoD should be able to bridge the gap or change the assignment process that precedes these location-based challenges.

When families are assigned somewhere without local and state resources to bridge the gaps in health and education, in too many cases, the special needs family member simply goes without. They may go without critical physical or behavioral health support; a child may fail to stay on grade level in school or meet developmental milestones. The lack of access to support may be a direct result of the service member's commitment to our Nation and the requirement to relocate to a duty station where support is slim. This puts retention and military readiness at risk.

Ultimately, we think this body is in a good position to ask questions about these inequities and gaps. There are studies identifying gaps that the Office of Special Needs in DoD is trying to rectify. However, the Services and the Defense Health Agency are not accountable to the Office of Special Needs, under the law. This complicates streamlining processes. Additionally, the coordination between the authorities that manage access to healthcare, and the EFMP is slow, lacks transparency to family members and advocates,

confuses families (and advocates) and is most likely under resourced given the challenges repeatedly told by military families with special needs.

We hope that you will make recommendations to the Secretary of Defense which would enforce accountability and transparency in these program and policy areas to facilitate military readiness. We also hope you will request more information, from families, military and civilian healthcare and education support providers, and advocates about what they experience, see and hear, and get their thoughts on ways to improve programs and policies.

One recommendation you could make immediately is that the ECHO program increase services covered to more closely align with state Medicaid waiver programs. This recommendation was made in 2015 by the Military Compensation Retirement Modernization Commission because mobile military families often cannot qualify for Medicaid due to long waiting lists. This leaves a gap between what is covered by the military and what is accessible in the community.

Additionally, we hope you will consider the very different needs of children with special needs, versus adults with special needs. The healthcare and educational requirements of our military children are unique to their age population, and cannot be grouped in with adult healthcare and educational support. Adults in EFMP have often gained a sense of independence in their healthcare requirements and may require less engagement or oversight. Children's needs; however, are continually evolving, and the support systems must be robust enough to support those changing requirements. As healthcare reform continues, we hope the

~~different needs of military children will not be lost in the shuffle~~
toward broad solutions.

From the Military Officers Association of America's (MOAA) perspective, this issue is frustratingly complex and deserves to be a priority, both in healthcare reforms and in DoD oversight. Taking care of military families' most basic needs is essential to mission readiness. When families go without necessary support, they may fail to thrive, or they are forced to choose substantial hardship to get their needs met. Families may choose to live apart to maintain support networks or access to providers at their own expense. Families may also leave the service altogether to avoid these painful choices. In an era where recruitment of high quality candidates

becomes more and more difficult, we think keeping our best and brightest means also supporting their families through the rigors of what is required, and regardless of their exceptional needs.

Thank you for your consideration and MOAA looks forward to working with the Council to continue to make progress on these very important issues. If you have any questions or we can be of further assistance, please contact

Sincerely,

January 12, 2017

Dr . Randy Eltringham
Office of the Deputy Assistant Secretary of Defense (Military Community & Family Policy)
4800 Mark Center Drive
Alexandria, Virginia 22350

Sent via email: osd.pentagon.ousd-p-r.mbx.family-readiness-council@mail.mil

Re: Written Statement for the January 26, 2017 Military Family Readiness Council (MFRC) Meeting
Regarding Pediatric Health Care Services

Thank you for the opportunity to provide feedback on programs and services for military families with special needs. The National Military Family Association (NMFA) has long been an advocate for improving the quality of life of our military family members who have sacrificed greatly in support of our Nation.

Among our highest priorities is ensuring military family members have access to high quality medical care and related services.

As follow up to the June, 2016 MFRC discussion on TRICARE's Extended Care Health Option (ECHO) program, we would like to submit the attached document outlining our perspectives regarding ECHO. Specifically, we believe it is important to understand the legislative intent behind the creation of the ECHO program. ECHO is intended as an alternative for state Medicaid waiver benefits for special needs military families who cannot access Medicaid waiver services due to long waitlists and frequent geographic moves across state lines .

Given the legislative intent, we believe it is critical that ECHO benefits are comparable to those offered by state Medicaid waivers. The Military Compensation and Retirement Modernization Commission (MCRMC) conducted a state-by-state analysis of Medicaid waiver benefits and found ECHO lacking, particularly in terms of respite care. Our Association supports the MCRMC's recommendation to increase services covered by ECHO to more closely align with state Medicaid waiver programs.

Should you have any questions regarding our response, please contact Karen Ruedisueli in our Government Relations Department at 703-931-6632 or by e-mail at kruedisueli@militaryfamily.org.

The National Military Family Association is the leading nonprofit dedicated to serving the families who stand behind the uniform. Since 1969, NMFA has worked to strengthen and protect millions of families through its advocacy and programs. We provide spouse scholarships, camps for military kids, and retreats for families reconnecting after deployment and for the families of the wounded, ill, or injured. NMFA serves the families of the currently serving, retired, wounded or fallen members of the Army, Navy, Marine Corps, Air Force, Coast Guard, and Commissioned Corps of the USPHS and NOAA.

3601 Eisenhower Avenue, Suite, 425 . Alexandria, Virginia 22304 t 703 931 6632 f 703 931 4600 www.MilitaryFamily.org

060 Feb 2017 Mtg R

Submission from: , January 12, 2017

Hello again,

I wanted to send you a link to an article my family and I were featured in and which was on the front page of the Boston Globe back in July (Living in a Box-stories of chronic pain). You will see several pictures of me and my family if you scroll through images.

<https://www.bostonglobe.com/ metro/2016/07/30/can-chronic-pain - prevented/hu93w9Q8NSoVEVtdbvfsMI/story.html>

Hopefully this helps to paint a clearer picture of the severity of some of the rarer disorders and can show you a glimpse of my life living with chronic pain and an invisible, yet debilitating illness. This is not something I suffer from, but is also something my son is thought to have. I, as mentioned, am also a cancer survivor.

I hope it also helps demonstrate the importance of keeping some EFMP families together and will sway you to consider the less traditional approach of making family more important than military needs in some cases, especially for families with a long service record .

I mentioned in my earlier email that health is not a choice in any instance and I don't believe EFMP families deserve more undue burden put on them than military life already puts there.

I am hopeful that there can be improvements made to this program which will help families like mine limit the burden that an extended separation might cause particularly when no war going on in which the US is involved. And that there might be more resources available to help families when one parent, often the only parent around to care for children left behind, is incapacitation by illness or disease .

Some days I cannot walk and I am unable to tell of and when that will occur from one day the other. am not allowed to lift anything over 10 lbs and it looks like I might need a very serious back surgery. Moving my husband away or deploying him will leave out family with a major burden. At the same time it is unfair to ask my husband to leave his job-especially this close to retirement and after years of faithful military service.

In addition, my health issues and a difficult pregnancy has not helped my husband's military record. If you look into it you will see he was in favor and doing very well until I became more ill and he fell out of favor with his commanding officer-that is discrimination . He was scapegoated and lied about because he was unliked and he was told he couldn't have any "issues" outside of work. Again, discrimination. The way the military works-there was no recourse or action my husband could take at the time to remedy the situation.

I feel, in general that this program is used to check off a box, but in some branches the reality is it does little to help military families. At the very least it should be the goal of the program to keep severely compromised families together and provide much needed services instead of merely functioning as a ranking system that holds little to no importance and provides no real relief.

I hope that you will read the article and see that there are real families behind the names and numbers.

Families you have the opportunity to help greatly if this program is executed well.

I have outreached as well to my local representatives and have been in touch with them regarding the issues I have outlined above,including my husband's mistreatment by his past commanding officer. This program is broken in a lot of ways-I'm not a stranger to the military or the government and while I hope these messages will bring about much needed help and change I am worried what I am saying will fall on deaf ears.

Thank you again for this opportunity to speak.

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Thank you again for this opportunity to speak.

0062Feb2 17mtzR

3 February 2017

Dear Members of the Department of Defense Military Family Readiness Council:

I am the spouse of an active duty soldier and the mother of two boys. My oldest is 4 and he has autism. We're honored to serve and feel blessed the military offers coverage for Applied Behavior Analysis (ABA). However, accessing those benefits and continuing to access them has proven to be a major challenge. Below are suggestions as to how to make this an easier process so our soldiers can focus on work - not on whether their children will receive adequate services and healthcare.

STOP THE BURDENSOME NEW TESTING REQUIREMENTS FOR ABA BENEFITS

Beginning in 2017, DoD instituted a new set of policies requiring all children diagnosed before October 2014 to obtain a new autism diagnosis and IQ evaluations. Not only is this expensive, time-consuming and burdensome for families, but it is not the standard of care. Any medical professional will tell you autism is a lifelong diagnosis. By DoD implementing this policy, it appears it wants to deny families access to ABA benefits.

In addition, wait lists to get into specialists to diagnose autism are about a year long (in the DC area). No doctor wants to waste their time re-diagnosing a child who has already been diagnosed when there are other children out there waiting for a diagnosis so they can get help.

I have inquired about these tests to a psychiatrist and was told all these tests would be at least \$2,000 and take 8-10 hours over 3-4 appointments. So instead of taking my son to school or ABA, I will have to pull him 3-4 times and waste valuable learning and therapy time to get him tested for what we already know - he has autism. Not only does he suffer, but so does my 15 month old son who I have to take to all these appointments as well.

Please stop these unnecessary and wasteful testing requirements so we can have some stability in our lives. The point of these programs were to ensure exceptional family members are being taken care of so our soldiers could focus on their mission. This is not happening right now and DoD needs to change this policy.

ENSURE ALL MTF PROVIDERS ARE PROFICIENT IN IDENTIFYING THE SIGNS OF AUTISM AND PROVIDE YEARLY TRAINING AS A REMINDER

My son saw doctors at 4 different MTF (Ft. Belvoir, Ft. Myer, Ft. Lee, White Sands Missile Range) and I kept telling the doctors something was wrong with my son. Even when he had no words or sounds at 18 months I was told he was just a boy and would eventually talk. I finally was able to take him to see a civilian provider when we

-PCS'd to a remote location and his pediatrician suspected autism at his first visit and suggested we get him

tested. The warning signs from no eye contact, no language, not wanting to socialize, no smile were all there.

How could so many doctors miss this?

ALLOW THE USE OF CLOSEST SYSTEMS NAVIGATOR AND EFMP OFFICE

When we arrived in the DC area I contacted the systems navigator at Ft. Belvoir. I was told despite us living just outside Ft. Belvoir, because my husband was stationed at the Pentagon we would have to use Ft. Myer's system navigator and EFMP office. EFMP families should be able to utilize all the systems navigators.

Thank you for your time. Please feel free to contact me if you have any further questions.

063 Feb 2017 Mtg R

Submission from , **February 3, 2017**

Good afternoon,

My name is. and we are an Active Duty Air Force family stationed at Fort Hood, Texas with three kids on the Autism Spectrum who are all enrolled in the EFMP.

We currently have all three of our children enrolled in the Autism Care Demonstration program and they are all receiving ABA therapy services.

Tricare has recently decided to add new requirements for those families enrolled in this program including having three different tests done for each child in order to receive a "rediagnosis" of their Autism to coincide with a "two-year review" to determine whether the child should still continue receiving ABA therapy services for the next two years.

Tricare has failed to properly communicate these new testing requirements along with when our upcoming review deadlines would be in order to obtain these test results in a timely manner. We have been informed that without these new test results by said deadline for each family, our child can lose their ABA therapy services immediately.

We had to track down our own Two-Year Review deadline for our kids (all set for May 8 2017) because the Tricare South Region failed to provide any notification.

We have been unsuccessful in trying to schedule appointments with any provider specialists in this area who can provide the three testings (the ADOS-2, Vineland 3 and Wechsler Intelligence Scale) prior to the May 8 deadline. Most are booked at least 6 months- 1 year out in advance with regular appointments alone.

We are also PCSing in June and therefore would not be able to set up any appointments after our deadline until we had reached our next duty station location.

We were told to express our concerns to you regarding the impossibility of having these required tests performed on our kids within such a short time frame, especially living at a duty station that is heavily saturated with many families with Autism; Fort Hoed is among a handful of posts that EFMP will send military families with Autism in order to have their medical and therapy needs met.

I can speak on behalf of many families who are experiencing the exact same difficulties in obtaining appointments with providers who can and are even willing to perform these tests within a specified time frame. Many providers in the various TRICARE regions have expressed great concerns over these new guidelines and do not see these as appropriate or ethical for them to perform these tests on children who already have a diagnosis of Autism.

So with providers unable to, or even unwilling to perform these tests, it leaves us families without any means of achieving these parameters in order to ensure the continuation of ABA therapy services.

My twin daughters are on the severe end of the Autism Spectrum and they require 35 hours per week of intensive 1:1 ABA therapy. A break in or end of services would be detrimental to their health and well being and their ability to progress would be abruptly halted.

As these new Tricare testing requirements and two-year reviews pertain to all EFMP families who have a dependent with Autism receiving ABA therapy services, this will adversely affect every one of these families.

We ask that you please reconsider these new testing guidelines for the Autism Care Demonstration Program and allow exceptions and continuation of ABA therapy services for those EFMP families who are unable to meet these deadlines and requirements due to situations that are out of their control.

I greatly appreciate your time in addressing these concerns. Thank you so

much!

· · (Air Force Spouse)

0064 Feb 2017 mtg R



11 January 2017

To Whom It May Concern.

**Re: Website using publicly available information a potential OPSEC and
PERSEC risk to military personnel and families.**

I am writing as a concerned military spouse.

An article titled "Opt out of FamilyTreeNow", dated 11 January 2017, by Amy Bushatz and published by Military.com (available at <http://pouschun.c1111/hlog/2017/01/opt-out-of-familytracenm.html>) details a new website called <http://H\H\H.famih trcernm.enml> that is sharing publicly obtained information including familial relationships and addresses - including on base addresses.

I consider *this* to be an OPSEC and PERSEC issue. While I understand that the website and the company are within their constitutional rights to publish this information, I do believe that personnel and their families need to be made aware of this and other websites like it and be given the information they need to be able to opt out or have their information removed. I also believe that OSI and its equivalents should be made aware to ensure that on base addresses are not being illegally published.

Not only does this make the work of those engaged in identity theft easier, *it* is also making the work of those who seek to do us harm much easier, as the base addresses often identify the installation name making *it* easier for those with even the smallest web savvy to identify military personnel and their families.

The article (written by military spouse Amy Bushatz) provides a link to how to opt out of this website and others like it. Here is a link to the opt out feature: <http://v...\\..family:tn:cno\\..com/npllllt/bcgim1pinut>. The opt out process wasn't easy to find/navigate without it (especially trying to get rid of more than one profile).

Personally, they only had one of my addresses, but they had me connected to my husband and his whole family and more than 10 of their base housing addresses. Given that both my husband and his hrnthcr are active duty and my father-in-law served is retired US Navy, this is personally

of concern. But, after having made the Sq1:1.adr.m1 Fii:st Sevgeant aware

an issue of family readiness that would be best shared with your council.

Yours Faithfully,

0065 Feb

17 MTR

Submission from February 2, 2017

Topic: Military Family Readiness Council meeting January 26

BLUF: Tricare's hospice offering is not sufficient and/or does not align with pediatric best practices in a critical care environment. Readiness of active duty families are impacted as a result. Request meeting location and time in order to attend.

Story:

My daughter was diagnosed with ATRT brain cancer in 2011. Most children do not live a year past diagnosis but my daughter has defied these odds. In the past five years she has been in critical condition on multiple occasions and has almost died numerous times. At other points within the past 5 years she has done well and started to develop and push past the disease. These changes are a direct result to the size and location of her tumors (both have changed pending treatment methods) and complications from the treatment. Due to the ups and downs she has required different levels of medical assistance. Currently she requires critical care/in home nursing. In order to make this happen we were set up with hospice care although we are not at the "end of life". Since being on hospice, Tricare has denied different things that my daughter requires to include physical therapy and occupational therapy. We have decided to remain within the hospice program until she is in a position that is more stable (in home nursing is a big help) but we extend her recovery time by doing so. We have been working with Virginia medicade to supplement Tricare.

Overall Tricare has been easy to work with but since my daughters requirements change often it is not flexible enough to accommodate the pediatric requirements. Currently Tricare is a roadblock to her recovery process.

My ability to devote myself to work has suffered. My section has worked diligently so my absence has a limited effect on overall readiness but it has required significant workload increases throughout. It also impacts my ability to be an impact player in the operational environment as my family requires me at home.

--Very-Respectfully --

0066 Feb 2017 mtzR

Submission from: I

. -, January 11, 2017

To Whom it May Concern,

My daughter is almost 13 years old. She has been diagnosed with severe autism accompanied by a diagnosis of mental retardation. She is mostly non verbal.

We have made great progress using ABA, and other integrated treatments through the Autism Demonstration Program. My concern is that with the drop in the reimbursement rate we will see a great reduction in experienced, qualified, caring, individuals and agencies that are willing to work with our children. In many areas there are already long wait times for care. This pay rate drop could greatly increase this likelihood. I also believe that re-evaluating every six months is an immense waste of time for everyone involved. Parents of EFMP children already deal with extra paperwork, IEP meetings, doctor's appointments, etc... on top of the additional time it takes to supervise, and tend to the every day needs of our special needs child. Doctors and medical facilities struggle with getting patients in for appointments in a timely manner, and the ensuing paperwork that each patient requires. We are adding unnecessarily to that workload. Our children's progress is often slow but steady, and more accurately measured on a yearly basis.

My other major concern at this time is the Respite system. It used to be that I could choose a trusted family friend or relative to do my respite work. For years I had someone that knew my daughter, loved her, and cared for her in a conscientious manner in our home. Now I have to choose a random stranger off a list (if there is anyone available). I am supposed to leave my non verbal child with that person.

That is not going to happen. I always had to make sure my fourteen year old daughter was home, or use respite while I was home (think date night in the den), to ensure my daughter was being carefully cared for. She was repeatedly left in messy diapers, and when we weren't in the room the respite person would switch the movie to her movies, and not what my daughter was watching. She never emotionally connected with my daughter in any way. The qualified RN Respite Provider told me she really couldn't communicate with my daughter because my daughter couldn't have a conversation. My daughter has bonded and loved every Respite Care provider I have ever hired myself. I tried to retrain, and finally had to stop using the Respite provider I had been referred to, only to find there was no one else available. Trusting parents to know what is best for their children when it comes to care is imperative. In six months there have not been any additional Respite providers added to the list. When one of my

-- daughter previous paras-attempted to get hired and one returned her calls and the wait-time for --

the background check was over six months. This is unacceptable. As military spouses we are often parenting alone while our soldier is TDY or deployed. There needs to be adequate Respite options available. We need to be able to hire someone we know and trust.

Thank you,