TESTIMONY OF

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and

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BEFORE THE

United States House of Representatives

Armed Services Committee

Subcommittee on Personnel

ON

"Exceptional Family Member Program- Are the Military Services Really Taking Care of Family Members?"

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I would like to thank Chairman Speier, Ranking Member Kelly, and members of the Subcommittee for this opportunity to speak before you and share my family's as well as other families' experiences with the Exceptional Family Member Program (EFMP). I want to be honest and upfront that every single one of these experiences could have been prevented, the services have had years[1] to fix this program and they have failed us at every level and at every step along the way.

My family is probably the typical enlisted success story. My husband and I were high school sweethearts. We married young and had children young. My husband has been active duty for 17 years and is now a 1SG (E8) in The Old Guard at Fort Myer. During this time we've been through five military moves and my husband has deployed and gone to training away from our family more times than I can count, with many of these absences happening while our children were in crisis or in the hospital often times.

Child 1

Despite our challenges, we managed to keep our heads above water, so to speak until 2006 when our youngest son was diagnosed with a rare, life-threatening medical condition while my husband was deployed to Iraq. A year later, the same child was diagnosed with autism and from that moment our lives would never be the same, and we would struggle to find the care and support necessary. We spent many months flying our son back and forth from my husband's current duty station to Boston, Massachusetts so that our son could receive appropriate medical care by one of the only physicians in the country that treated children with his rare medical

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[1] https://fas.org/sgp/crs/natsec/IF11049.pdf

condition. By 2011, after ten ER visits within a fourteen day period it became clear that our son needed medical care that could not be provided at our current installation and these expensive trips to Boston were taking their toll on our whole family with little relief for him between visits. So we started the long process of a Compassionate Reassignment to be near his medical provider. Compassionate reassignments happen quickly, which is appropriate, but there is no one to help families like ours navigate through the process. We arrived in Boston to learn that no one had been notified of our family's arrival. The local Military Treatment Facility (MTF) couldn't provide medical care for our children and advised us that they never would have approved our transfer to Boston had somebody from the Army done their due diligence and contacted the Air Force EFMP office. This didn't occur in our case because my husband is Active Duty Army and the services do not communicate with each other.

On top of this, we also had to work with the school to try and establish appropriate accommodations for our son. Like many families who have children on an Individualized Education Program (IEP), we struggled to come to an agreement with the school on his special education goals, and proper care for his life threatening medical condition while at school. My husband was stationed in Boston for 18 months, and during that time we filed a complaint with the Department of Education based on their refusal to properly manage his healthcare. When it became clear to us that the school would simply rather pay the fine imposed by the government rather than modify their programming to meet our child's needs, we made the difficult decision to break our lease, and move to another school district within the local economy.

Child 2

It was during our time at this duty station that we brought our daughter home. What should have been the most exciting time of our lives turned into a bureaucratic nightmare. Our daughter was born with Down syndrome and a congenital heart defect (CHD) that would land her in the hospital just three days after she joined our family. We soon learned that, in order to survive, she would need open heart surgery at 8 weeks old. Yet, we also discovered that, because we were an Army family stationed at an Air Force base, the process to get her covered by Tricare would be long and protracted. To do so, we'd be forced to drive to the nearest Army National Guard Base to complete the paperwork, then wait for it to be processed. This process could not be expedited, and our daughter's surgery could not be delayed. As we met with the hospital's finance department, they explained that we needed to put down a ten-percent deposit – and that deposit was $100,000. Over the course of the next thirty minutes, we were inundated with forms outlining expected costs: ultimately, the cost of saving my daughter's life was one million dollars - and time was not on our side. Then someone suggested we explore Medicaid as an option. Because of the Medicaid expansion adopted in our state after the passage of the Affordable Care Act, Melanie qualified for Medicaid. I'm thrilled to share with you that thanks to Medicaid coverage this million dollar hospital bill, she had her open heart surgery and at 8 weeks old and not only was it successful but it appears that she will not likely need a second.

For any family, this alone would likely be the most stressful event of their lives. However, it was while our daughter was in the hospital that we were told that my husband had two options:

move our family for his upcoming Permanent Change of Station (PCS) to Joint Base Lewis-McChord or voluntarily separate from the Army. My husband begged for an alternative, explaining that he deeply valued his military career and most certainly did not want to separate, but that our daughter simply could not be discharged so quickly from the hospital following open heart surgery. The response he received is seared into our memories. While sitting at our infant daughter's bedside, waiting for recovery from open heart surgery, he received a phone call from someone at Army Branch. The room was full of doctors on their morning rounds and my husband was told "**maybe you can just return that one and get a different one once you're there**" in regards to our newly adopted daughter. The conversation happened on speaker phone and the entire room went silent upon hearing those words. Neither one of us remembers his specific response, but we do know that is the moment we realized that our family meant nothing to the military.

Our daughter's care team banded together, intervening to see if anything could be done to keep her in the hospital until she was fully recovered. Sadly, they received the same response as my husband and subsequently our daughter was stabilized to the best of their ability and, despite her fragility, was discharged for our upcoming move to Washington state. Just 12 hours later she quit breathing and was readmitted and placed on a ventilator, a difficult situation for any family who thought their child had fought a battle and came out the other side relatively unscathed. For our family, yet again the stress of the upcoming move loomed heavy. We were scheduled to move in less than a month, and she was not stable enough for transport. We reached out to the gaining station's EFMP office only to be told there was nothing they could do. All of our children's needed services were available in the local area. Three weeks later, I was forced to discharge my daughter against medical advice and take Amtrak with my two youngest children for 5 days across the country to my husband's new duty station in Washington State since neither could be cleared to fly, and we didn't have the finances to support two households and the childcare that would be needed due to the separation.

Once we arrived in Washington, it became clear that although services were available in the area, the waitlists were over a year long for some specialties. Our first stop at the MTF was the EFMP office, where we begged them for help. I remember explicitly asking "you said there was care, you know there is a 28-day standard where did you find the providers you did to approve our move?" The EFMP provider replied "It's not our job to check or tack waitlists we just look at the Tricare website to see if a provider is listed and taking new patients". We then explained that my husband had not checked in with the base yet and we had not secured housing. We asked her to tell the Army Branch that medical and educational services were not available so that we could be moved to a duty station where they were. She told us that if she did that it would affect the hospital's status as an EFMP hub and they were not willing to jeopardize that status, but that we should submit paperwork for another compassionate reassignment. It took us two and a half years of fighting to finally get a compassionate reassignment out of Joint Base Lewis-McChord, Two years of heartache, two years of constant stress, two years of delayed and inefficient care for our children. We know that the military is in the process of setting up Centers Of Excellence. It is my fear and the fear of the families I'm working with that this will set up a system similar or worse to what had occured for us and all of the other families who are also waiting for services at Joint Base Lewis-McChord, Fort Bragg, Fort Carson and several others. A system in which families are sent to installations with such a high concentration of medical, education and mental health needs that not only have we pushed the MTF providers past sustainable capacity but we've done the same to their civilian counterparts. These decisions are affecting not just military children but civilian children as well.

After two years, struggling to get our children appropriate education services and medical care, we had high hopes for a compassionate reassignment to the Metro DC region. I will say that we have unequivocally received the best medical care that my children have ever received in the military at this Duty station. But that has meant that we have care spread across three states and the District of Columbia. And it is only because we have the option to have multiple medical providers at different MTFs across the region that this has occurred. We finally have the flexibility to choose who we want our children to see for the most part and that choice is what I think all families like ours desire. That being said the move from an education standpoint has not been great, you could actually describe it as flat out dismal. In the five years since we arrived here, we have had to sue the local school district three times on behalf of our sons and we are currently in the middle of a due process complaint on behalf of our daughter as well as a federal ADA complaint and a DC human rights complaint[2] because she has been excluded from school for nearly two years and because of their treatment of her when she has been allowed in school. This is a place where all of you could help families like mine because too often school districts

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[2] https://www.courtlistener.com/docket/16065310/1/carrigg-v-gallaudet-university/

feel like they do not have to provide military families and their children with the necessary services because they can wait them out and the families will eventually move. Can you imagine what it is like for a child with a disability if this is how every school district in their entire educational history has treated them?

Earlier I mentioned that my daughter had to be placed on Medicaid in order to get her open heart surgery covered, but that's not where her need for Medicaid ended. Despite having the Extend Health Care Option (ECHO), which was supposed to be the military's answer to families like mine needing Medicaid we still rely heavily on it. A recent report released by the Tricare For Kids Coalition[3] states:

> ***"200,000 military kids — roughly 10 percent of children of active service military families who are covered by TRICARE — also rely on Medicaid for health care coverage, many due to serious medical conditions requiring specialized pediatric "wraparound" programs provided in the Medicaid program. As many as 500,000 children of TRICARE-covered families qualify for Medicaid coverage on the basis of income, which may cover needed pediatric services when TRICARE does not."***

Examples of these needs are the fact that DHA recently updated their coverage for Continuous Glucose Monitors but children like mine with a rare metabolic condition are not covered. Nursing although covered is so restrictive that without Medicaid I wouldn't be able to care for

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[3] http://www.tricareforkids.org/wp-content/uploads/2018/11/11152018-TFK-Military-Report.pdf

my other children and we are not alone in this. Dual military families who are forced to have one chaptered because the "primary" parent is not allowed to work or go to school while their children are receiving nursing care.

> ***"EHHC services and EHHC respite care services are not available for the purpose of covering primary caregiver(s) absences due to deployment, employment, seeking employment, or to pursue education. Except for those excluded activities, this exclusion does not otherwise restrict or prohibit the primary caregiver(s) from engaging in other activities they choose, including those outside the beneficiary's primary residence."***[4]

Children who need slide in orthotics and babies that need cranial reshaping helmets.

- ***"Arch supports and shoe inserts designed to change the foot's shape or alignment.***
- ***Orthopedic shoes, unless one or both shoes are necessary to a covered brace.***
- ***Over-the-counter custom made or built-up shoes or other supportive devices of the feet, except where otherwise covered.***
- ***Cranial orthosis and cranial molding helmets for: Flat spots on your baby's head from your baby lying on its back too frequently*** *or* ***Sole treatment for craniosynostosis, a condition where joints in your baby's skull fuse together before they should"***[5]

Conversions on vehicles so that the child can be safely transported to medical appointments in their wheelchair.

> ***"Vehicle conversions are excluded. That is conversions such as but not limited to, raising the roof, widening the door, or permanent attachments installed (e.g., items that are non-transferable to another vehicle). Purchases and (or) conversions of personal vehicles for a wheelchair bound beneficiary fall outside the scope of the TRICARE medical benefits and, therefore, are excluded."***[6]

- Additional exclusions that we believe should be covered but are not can be found at:

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[4] 7.3- https://manuals.health.mil/pages/DisplayManualHtmlFile/TO15/42/AsOf/tp15/c9s15_1.html
[5] https://tricare.mil/CoveredServices/IsItCovered/ShoeInserts
[6] 3.8.2.3-- https://manuals.health.mil/pages/DisplayManualHtmlFile/TP15/45/AsOf/TP15/c8s2_1.html

http://www.tricareforkids.org/wp-content/uploads/2020/02/Examples-in-support-of-Pediatric-Med-Nec-definition.docx

Addressing the obviously needed ECHO reform, I offer this background. Home and Community Based Services (HCBS) waiver programs (known as Medicaid waiver programs or Katie Beckett waivers) are state run and as such, are nearly impossible for military families to access due to frequent moves between states. Each state has its own waiver program, requirements, and enrollment caps. We must re enroll our dependents in our new state's HCBS waiver program, and existing enrollment caps create lengthy waiting lists, which average 30 months, and make the services offered by these programs inaccessible to active-duty families.

While Congress created the TRICARE Extended Care Health Option (ECHO) program to serve as an alternative to HCBS waivers for families of active-duty service members, ECHO currently fails to provide comparable services. Indeed, the Military Compensation and Retirement Modernization Commission (MCRMC) concluded "ECHO benefits, as currently implemented, are not robust enough to replace state waiver programs when those programs are inaccessible."

The MCRMC provided specific legislative language to fix this issue:

"SEC. ___. EXTENDED CARE HEALTH OPTION (ECHO).

Section 1079 of title 10, United States Code, is amended by adding at the end the following: "(q) In carrying out the Extended Care Health Option (ECHO) the Secretary of Defense, after consultation with the other administering Secretaries, shall ensure that the services provided under such option are an alternative to, and are comparable to, the services provided under the applicable (as determined by the Secretary of Defense) State plans for medical assistance under title XIX of the Social Security Act (42 U.S.C. 1396 et seq.).".

To ensure specific items are enacted immediately as part of this reform, request the following be included in any legislative changes to the ECHO program.

1) Increase hours of covered respite care to 60 hours per month. Respite care is short-term care for a patient to provide rest for the patient's primary caregiver. ECHO currently covers only 16 hours per month while states, on average, cover 60 hours.

2) Codify new regulations on respite care eligibility. Under recently revised regulations, respite care may be offered regardless of whether the eligible dependent receives another ECHO benefit. We request legislative language to codify this policy change.

3) Request codification of currently existing regulations allowing ECHO to cover service and modification of durable equipment and assistive technology devices, as well as training in use, to ensure equipment is fully functional and matches the physical needs of the user.

4) Provide coverage of residence and vehicle adaptations. Most states with HCBS waivers cover medically necessary alterations to residences and vehicles to reduce the disabling effects of a person's qualifying medical condition.

5.) Mandate annual assessment of utilization rates for ECHO services, gaps in covered services, and the barriers military families encounter to program access.

6.) Mirror skilled home nursing care to that of the HSBC Waivers allowing parents to work, and subsequently maintaining a skilled military force.

I wish I could say that my family is alone in the things that we've been through and the experiences that we've had but we aren't. I’ve spent the last seven years advocating for families like mine being there to help families find resources when their local military services wouldn't or couldn't help them. I'm the person they call at 2 a.m. when they're in the hospital and Neurology won't come in despite their child actively seizing. I'm the one they call when they've arrived in a new Duty station only to learn that it's an 18-month wait for services, and they know that their children are going to regress and nobody will help them. I'm the one they call when the school district is refusing to follow their child's IEP, or writing an IEP that they don't agree with and telling them that they've been outvoted. I shouldn't have to be doing these things, I'm doing them because no one else will. These families, our families should not have to live this way.

Caring for children like ours is overwhelming, we learn to live with a higher threshold of stress than our peers who do not have children with disabilities. Secretary of Defense Esper recently said, **“Having previously served in the Regular Army, National Guard, and Reserve, I understand well the sacrifices our Service Members, Civilians, and their Families make to**

protect this great country. This is why I am committed to taking care of Families and ensuring they have the resources they need to thrive."[7] One thing I know beyond a shadow of a doubt is that your military members living with children on EFMP are far more resilient than those that are not. The skill set to remain calm under constant pressure, while juggling life or death decisions is a skill we know the military needs and our families practice daily. Yet the military services continue to fail us at every level. We've learned the hard way that the more assistance you need the less you get. Why does DoD continue to fail on issues like this? Whether it's housing, child care, healthcare or special needs families? There is a consistent theme that DoD isn't serious about taking care of its military families.

The rest of my testimony will consist of stories from families like mine who have been let down by the military EFM Program. Our hope is that our stories prove to you that this is a system that doesn't just need overhauled but needs to be done with input from families at the lowest levels of your military branches. Our EFMs will continue to be on the frontline of denials, non coverage, and harmful delays in care if Congress does not act specifically to protect them, especially in these times of transition. We collectively ask that you:

1. Enact a pediatric medical necessity standard.
2. Adopt the protections provided by Medicaid's Early Periodic Screening Diagnosis and Testing (EPSDT) standard.
3. Create a stand-alone contract that can provide care management by families for families in all aspects of their lives. We picture a single care manager who can assist and will be knowledgeable about all aspects of our family's lives. The care managers will assist with the handoff of care from one installation to the next assisting with getting the required referrals generated in advance of a PCS. With the next installation care management team

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[7] https://news.usni.org/2019/06/24/acting-secdef-espers-first-message-to-pentagon

picking up the care management and families apply for community resources, locate appropriate medical providers and advocate on their behalf if they can not be found. Assist with educational concerns and partner as advocates in education along with educational attorney from the Judge Advocate General that have been suggested by other witnesses. It can be done as Children's hospitals recently completed a federal grant (the CARE Award) in which such care coordination was implemented, studied, and improved upon via a national effort. It was of course, in the civilian environment, but would form a strong basis on which to build a model for our EFMP families"

4. Require that the Office of Special needs makes public the "quarterly advisory panels with military families to assess program satisfaction"[8] and opens this panel up to families from all branches, ranks, and backgrounds.

Dr. Kristi Cabiao, Fort Bragg, NC

"*My family pcs'd from Macdill AFB to Bragg in July 2019. Thankfully we had a smooth transition but I had to push our provider very hard and use my knowledge as a family medicine physician. Our son was diagnosed with ASD level 3 and global developmental delay at age 2 while at macdill AFB. We received 24 hours applied behavioral analysis per week, ST and OT weekly. A few weeks prior to our move to Bragg, I asked our pcm to place referrals for ABA, ST, OT. The request was declined stating the policy for Macdill clinic is to not give referrals for out of state providers. I called back and explained that I already had an appointment with our new civilian pcm, and evaluation appointments scheduled by the new therapy companies a few weeks after our move. The request was again declined stating the clinic policy. I called a third time and spoke with a nurse. I explained that tricare allows referrals to be placed by a pcm for out of state referrals and that as a family medicine physician, I have personally placed those referrals for my patients. I explained that I was prepared to speak with the colonel of the medical group as a peer physician and explain how this denial would interrupt care for my child with a significant disability. The referrals for authorization and one treatment were placed that afternoon. I received a call from a clinic nurse later that afternoon "scolding" me that I called so many times, and that I had better see our new PCM ASAP to have a new referral placed in order to continue care.*"

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[8] https://fas.org/sgp/crs/natsec/IF11049.pdf

CPT Jennie A. Olson and SFC Maggie E. Delaune-Olson (Jaxon and Jonah Olson)
Schofield Barracks, HI and Joint Base Lewis McChord, WA

"Before joining the Army I had to be sure I was okay with putting myself in a position to lose my life, I'm well aware of the organization I work for and have made peace with that possibility, but I have also made a deal that my family will be taken care of now and if/when I do give my life. The situation seems absurd and impossible but if you listen to my story you will see how real the circumstances are for me and my family. My family is an afterthought at best.

We were nearing our DEROS, the date we are required to leave our overseas duty station, and my wife and I were in contact with our branch managers regarding our next assignment. We wanted to stay in Hawaii because having twin boys with special needs, one is on the Autism spectrum and the other has a rare growth disorder called Russell-Silver Syndrome (RSS), is a lot to manage as an active duty couple. We had been receiving great care starting during my pregnancy with the twins and couldn't imagine starting the treatment process over. Initial establishment of care for both boys can be nightmarish at best, particularly for Jaxon, diagnosed with RSS, because many providers have never treated a patient with his condition. Couple the rarity of the condition with the number of specialists he is required to see (ophthalmologist, nutritionist, endocrinologist, orthopedist, speech therapist, geneticist, developmental pediatrician, physical therapist, and early intervention) and it is easy to understand how we spent a great amount of time with providers establishing a treatment plan. The fight for diagnosis for Jonah, ASD, was just that…a fight. We spent months having to circumvent his pediatrician and going outside our military treatment facility. Once we received the diagnosis the wait for care began. Because applied behavioral analysis (ABA) therapy, the only scientifically proven treatment for Autism recognized by Tricare, is ongoing and often life long treatment, there is no way to predict when treatment/providers will become available. Fortunately for us we found a great company that could start treatment for Jonah five months after diagnosis. Jonah was doing well in therapy and making strides toward speech, overall communication, eye contact, less elopement, more awareness of danger, and appropriate social interaction.

Before we were officially placed on assignment I requested a tour extension based on Jaxon's treatment requirements. The G1 personnel office in Ft. Shafter, United States Army Pacific (USARPAC), denied the request and refused to send it to the Army Human Resources Command (HRC), because I was stationed in Hawaii for too long and because Jaxon can be treated by specialists in other duty stations for his condition. I started researching ABA companies in the Joint Base Lewis-McChord (JBLM) area with the knowledge that we would likely be placed on assignment there only to find that there were plenty of ABA providers in the area but none of them had openings for treatment. Although there is no way to know when treatment could become available, one of the companies said their waitlist has been a year long for some patients. One year waiting for treatment could mean that our son would never speak to us, have a job, live on his own, get married, or any of the expectations that parents have for their kids. Once again, I tried to apply for an extension in Hawaii. This time I went through the compassionate actions branch. Again, I was told care was available. Not long after receiving the news I heard from other moms/parents that the JBLM EFMP office is not allowed to say no to treatment availability for assignment purposes. Given all the information we had my wife and I were faced with the toughest decision we had to make to date. My wife decided to sacrifice her career and retire so she could stay in Hawaii with Jonah. She ended the life that she knew for the last 20+ years before she was ready to stop serving so our son could maintain the care he needs. Jonah may not ever hold down a job or live on his own, it's far too early to tell, but my wife, without hesitation, chose Jonah and his well-being over her desire to continue to serve her country. Jaxon and I left Jonah and Jen in Hawaii and moved to JBLM in August 2019. We have been separated for five months. Being separated and maintaining two households is expensive. Being separated has been torture on our relationship. I know I would choose to be separated again if it were my only option but it shouldn't have to be the only option. Either one or both of us would have gladly sacrificed promotion potential for our children and their continuity of care. We would have paid any price to ensure the twins were healthy and happy. Please make adjustments to the broken EFMP system. Our children's lives and development depend on it."

Ivy Dailey and Willow Dailey, Fort Bliss, TX
"Hello my name is Ivy Dailey and this is about my daughter Willow Dailey. We are currently in a place where all her needs are met, but it hasn't always been so. Willow was diagnosed with hydrocephalus at 4 months old. When she was 4 turning 5 we received orders to Fort Bliss in El Paso, Texas. Her EFMP packet was sent and subsequently approved we were told that her needs will be met.

Shortly after we arrived at Fort Bliss my daughter developed 6th nerve palsy, I rushed her to the post ER, where they told me they were not comfortable dealing with her and sent us to the local hospital called Providence Hospital. That is where we were informed that while we were enroute to Bliss that the Pediatric Neurosurgeon had left and there was only 1 Adult Neurosurgeon in the city and he covered 2 different hospitals. We sat in the hospital for 10 days getting pushed for test after test. They were claiming all her tests were fine even though she still had an eye that was stuck in place (which she has never had).

They released us after those 10 day. We got an appointment with a pediatrician at the post hospital and 2 days later he sent us 7 hours away to Phoenix Arizona to see a pediatric neurosurgeon and 3 days later my daughter is having brain surgery that resulted in a stroke from too much pressure build up and also the loss of vision in her right eye from going to long with the amount of pressure that built up. We spent 2 weeks in ICU and 2 months in the rehab there in Phoenix, our dogs were left with a family my husband knew but we also had at the time a 2 year old to figure out what to do with 7 hours away from anything or anyone that we knew."

Brenda Evans, Fort Meade, MD
"Our case I think is very extreme. To the point that care is being denied on base due to doctors not being comfortable with care. The education system can not fulfill our daughters needs. We moved from JBLM to VA March 2019, after our daughter did a month in residential in Texas. Care was not able to be obtained. We were told to file a compassionate when we found an accepting behavioral health facility. We found one in VA at Belvoir. The day before we were set

to arrive we were told she would not get care. They denied her admittance into their program on base. It then took 2 months to find a facility, we did but that was over 2 hours away. She was hospitalized from May2 too June 24. When she came home we had already been advised care could not be maintained at Belvoir not in the entire NCR. We have the written statement from her doctor to MEDCOM and our EFMP I would be happy to turn over.

My husband works for Usasa and thankfully they were a great unit. We paid out of pocket for all expenses for our daughter to include our travel back and forth every weekend for therapy sessions with her.

Upon her return, there was not any ABA nor a group therapy placement due to her IQ. Our Nurse case manager and doctors tried hard to find a location to accept her. I also have this documentation. They told us to look for family support. Do a compassionate because that's all we will get for her and our family. The level of care she needs is not out there that Tricare can find. Nowhere!!! Not north south or overseas.

In April after we arrived, we submitted for Kennedy Kreiger. Aubrey was accepted. We lived in Belvoir at the time. The travel alone was killing us. My husband asked for a change in location for his job as Meade had an opening. We were allowed to move as a no pay for our daughters care. No the Army did not pay for us to move.

After arrival, 3 visits, it became apparent that she could not fit in their program due to cognitive functions. So we are here at Meade. The therapist on base and the first PCM said her care was above their level. So here we travel to Walter Reed for a majority of her care.

The education system is something else. In Maryland there is not a placement for her in any school program. She attends a special school with non verbal peers. She is in a classroom of lower level students. She will not be allowed to continue this program. We meet again in May to discuss another placement.

She is Autism level 2, CP, Holoprocscenpaly brain malformation. She can not control her behaviors. She only gets ABA when therapists are available. The recommendation is a full day program with ABA. We have not had it and she's almost 16.

On top of that, my husband is not stabilized. So we are due to PCS again in the near future. Our compassionate became invalid when we moved to Meade on our own.

She is not our only Special Need child. We have one more. We have moved so many times for care since 2004. I think this was our right wrong. They failed us. The military system is what failed us."

Jackie N, Fort Bragg, NC

"Avery was born with a rare genetic disorder called Hemihypertrophy. It causes the left side of her body to grow faster than the right, resulting in a leg length discrepancy. Since it's an overgrowth syndrome it also puts her at risk for certain childhood cancers and tumors. Avery is 600 times more likely to develop cancer than her peers. She has to get routine cancer screenings which consist of blood work and abdominal ultrasounds. The worst form of Avery's genetic disorder is called Beckwith-wiedemann syndrome (BWS). Having BWS puts her at a much higher risk for developing cancer requiring 4 week lab draws instead of having her blood drawn every six weeks. TRICARE does NOT pay for the genetic testing required to determine if Avery has BWS. They said since it's such a rare genetic disorder there isn't as high of a demand compared to the amount of children needing more common genetic testing. We appealed the case and TRICARE still said no, that the protocol for her having BWS compared to just having hemihypertrophy is only a difference of 2 weeks. I get it, just two weeks. That's a difference of 13 blood draws a year on an infant and child compared to 9. When you're the mother having to hold down your little girl as she screams in fear as the phlebotomist comes near her, that difference of two weeks means a little bit more to you. My daughter turned 5 in December and has had well over 30 blood draws in her short life. I can't even tell you how many ultrasounds she's had to date but it's roughly 45. She's had 3 MRI's and countless x-rays. Tricare did not care. My

husband and I had to pay for the genetic testing out of pocket. We were expecting a $3500 bill but by the grace of God the hospital at Children's Mercy Children's Hospital in Kansas City covered all but $200. Besides not providing Avery with the genetic testing she deserves, Tricare also does not pay for her modified shoe lifts. Her leg length discrepancy is over a 1/2 inch so we have to have her shoes specially made to make up the difference for her right foot. Otherwise she develops back pain. It cost us $85 per shoe lift. Don't get me wrong Tricare pays for a lot. She was born 6 weeks premature and was in the NICU for 16 days, we did not have to pay a dime of her $100,000 NICU bill. But since her diagnosis of Hemihypertrophy, I realized how much Tricare doesn't help when you have a child with a rare disorder."

Anonymous Quaintico, VA
This family has asked to stay anonymous for fear of recurrent reprisal.
"*Our family is an EFMP family stationed aboard Marine Corps Base Quantico. Our children have a progressive, life threatening disease that gradually causes respiratory illnesses in their lungs, causing them to sit hours on vest treatments, nebulizer medication, and oral medication. Throughout our time living on base, we had issues with mold growing in our medically fragile children's bathroom shower. Work order after work order was created and we were constantly told it was "just mildew" or "soap scum". It wasn't until my sons' medical tests came back that a rare fungal bacteria was growing in his lungs that his doctors had never seen before, that we needed more help to get rid of the mold in the shower.*

My husband approached his command for help, as well as us reaching out to Military Safe Housing Initiative who subsequently reached out to housing and within a couple days, representatives from housing, maintenance and our advocate was in our home for a walk through. I showed them all my children's medical records showing the fungus he was growing, the deleted work orders that were no longer on my account but I took screenshots of when I made them, and a list of concerns I had. Over a course of two weeks, my house became a construction zone and mold was found in spots where we didn't even know was there. Housing asked if we wanted to be removed for our home during this time, but we decided it was in our Autistic child's best interest to not mess up his routine. They tried to put new flooring over old, *moldy flooring, which my husband had to tell the manager. When they were here working, as their mother I would drive around with them, take them on outings for therapy and tried to keep them far away from the work being done. Housing took our concerns seriously, but we had to stay on top and watch them while they were working to ensure they were doing as promised.*"

M.Mathews, Joint Base Lewis-McChord, WA

"My son is a sped kiddo who sees Psychiatry, Psychology, and specialty pediatrics At JBLM the wait times were ridiculous on post Specialty peds was always a month booked out Psychiatry and psychology was worse There were times you'd wait 6 weeks for an appointment and psychiatry was ALWAYS running half hour at least behind in appts But at least you could get in Of course trying to get anybody on the phone at JBLM was a fun game and most usually you would have to just go into the clinic itself The OBGYN clinic was not using the appt line that Madigan automatically kicks you to when you call to schedule an appt They would say call the clinic itself But no one ever answered the phone at the clinic and it was sometimes a week before you would get called back.

We were denied orders for Riley because we would have to drive for certain services They gave us Hood instead because all of our services were already being offered on post at Hood

Upon getting to Hood, we had to wait over a month for our first psychology appt only to be told Darnall wont do continuous care and will only see us a max of 6 times So we had to wait over a month for an appt to be told that at our first appt But she would not give us a referral for outside care for TWO more visits So we left WA in Sept and Just Now got a referral for off post services to continue counseling for our son Our wait for Psychiatry was closer to 7 weeks for our first appt Specialty Peds can't even see us on post because they are so overbooked We were instantly referred off post to Scott and White in Temple (which is a bit of a drive from our place in Kempner) But they have a MINIMUM of a one YEAR wait for appts So my son cannot see anyone for a year WITH a drive

There is no continuous care in a PCS And trying to get meds refilled means waiting for a PCM appt (which we were referred off post to a pcm bc of the amount of people being seen on post) His meds needed adjusted before we left but our leaving psych wouldn't adjust them because he was leaving Then we had to wait a month for a PCM appt She wouldn't adjust them because she's not psych. Our first psych appt he wouldn't adjust them bc we just met and he wanted labs So we had to wait another month for the adjustment And then he gave us a lecture on families using Tricare costing the military money And how meds adjustments cost money bc we need a diff dosage and sometimes the better dosage is more so he gave us a smaller dosage (5 instead of 10) and told us to double up bc it was more cost effective than him prescribing the 10
Thanks for the lecture. You know what would help? Being able yo see a provider when needed There has to be a better way for military families, especially those of us enrolled in the EFMP program.
Why is everyone sent to the same post because that's where services are offered Only to get there and find out there are no services because there are so many families already being seen Meanwhile you only have 30 days to switch tricare So you switch to on post and then find out the services are terrible you have to wait until open enrollment comes back around before you can switch to choose providers off post."

Deshawn and Christina Perkins, Kings Bay, G
"*December 2016 our family applied for housing in Kings Bay, GA. With Balfour Beatty. While talking with the leasing agents, and on our application we stated we were an EFMP Category 5. We inquired about EFMP housing, that is when we were told, special housing was for E-6 and above.*

Our first home, we lived in for exactly one year, all of which had standing work orders, finally after getting my husbands command involved, we were to be moved. We have four children. My husband was about to be deployed. Our only respite provider lived in our same cul-de-sac, with there being multiple empty units. We begged and pleaded to be moved to a nearby one, as my son *would have an easier adjustment, and him being a flight risk it would be nice to remain close to our respite provider. To no avail, we were told all of the empty units at that time had already been rented out. However it was 2 1/2 months before the unit directly next to our respite provider, became occupied. We had to move to the other side of Housing. We later learned they did not want our respite provider and our family near each other, for the facts of we turned in a family that we're running loose breaking windows, They were tired of the complaints etc*

That following year of being moved my son was admitted to residential long-term facilities, became more aggressive, jumping out of the second-story window, our duplex was not safe for us. They agreed then to give us the ADA home."

Stephanie Waterhouse, Fort Bragg, NC

"Our problem with EFMP was that they were preventing us from going to Bragg over a blood draw. Our EFMP paperwork said that my son needed weekly blood draws and Bragg said they couldn't support it. My son also needs to see a Hematologist which will almost always be too far away (over 50 minutes) because there aren't any Army Hematologists. This was all so frustrating because we were never going to live on post and could prove that the necessary services would be available through UNC. We were not allowed to waive any of these restrictions so that my husband could get to the huge Army base that is Bragg. It makes us fear for the future of his career because under these restrictions, we don't think we would be able to ever find another assignment that will work through EFMP (even when we are willing to take the costs on our own)."