

STATEMENT FOR THE RECORD

THE TRICARE FOR KIDS COALITION

before the

House Armed Services Committee Subcommittee on Military Personnel

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

February 5, 2020

CHAIRMAN SPEIER AND RANKING MEMBER KELLY. The Tricare for Kids Coalition is a stakeholder group of children's health care advocacy and professional organizations, disability advocacy groups, military and veterans' service organizations and military families committed to ensuring that the children of military families receive the unique care, supports and services they need.

We appreciate the opportunity to submit testimony regarding issues and challenges facing families enrolled in the Exceptional Family Member Program.

These families are often the ones bearing the brunt of the many transitions of military life, including almost twenty years of high operational tempo moves and deployments, and almost constant change in Family Programs, Tricare and even military health system restructuring.

Frankly, these most vulnerable military children are the ones disproportionately affected by these transitions. As transitions continue and even escalate in to 2020, if the needs of these EFM children are not specifically addressed, they are the ones most likely to fall between the cracks, and suffer harm.

1. The Coalition respectfully requests the provide specific direction to DHA regarding pediatric care

Tricare is based generally on Medicare, which is formulated and maintained for older adults; and regularly results in "square peg, round hole" situations for children and their families, particularly those children with rare, chronic and complex conditions, disabilities and special needs – namely, EFMP children.

Our Coalition was created around passage of legislation known as "Tricare for Kids", passed in the 2013 NDAA requiring the Secretary of Defense to complete a comprehensive review of all pediatric policies and practices, and report on plans and progress to address those gaps and barriers to care. Subsequent NDAAs have required additional information and alignment with nationally recognized pediatric standards.

We are concerned about lack of progress, and request that the Committee direct the DHA to specifically protect our most vulnerable military children by instituting the referenced alignments:

- A pediatric medical necessity standard, specifically the model language authored and recommended by the American Academy of Pediatrics.
- Adopt the Medicaid standard for pediatric care of "Early Periodic Screening Diagnosis and Testing"

2. Impact of PCS and other service-related relocations on continuity of care for children who have special medical or behavioral health needs

The Defense Health Board in 2018 noted two recommendations for improving transitions, and we concur: "[r]equire inclusion of parents in working and policy groups at all levels" and the absolute need for better care coordination especially during PCSs. Again, aligning with best practices and working with organizations specializing in pediatrics (and not just pediatrics, but even the much smaller category of complex pediatrics) who have made headway in this space of complex care coordination, such as children's hospitals "CARE Award" project, make much more sense than reinventing the wheel.

Our Coalition respectfully requests the Committee direct DHA to:

- create more opportunities for family inclusion in policy groups, more regular stakeholder advocacy interaction on pediatric issues as the stakeholders bring necessary perspective from families and providers, and
- to work with stakeholders such as children's hospitals to improve care coordination for EFMP families.

3. Emerging and high cost treatments in pediatrics

Children with rare and/or significant medical conditions are most likely to rely on high cost, emerging treatments that are often the target for formulary changes, cost cutting and utilization measures.

TFK is very concerned that Tricare must be nimble in order to ensure that children receive the care they need in a timely manner, which often differs greatly from timeliness for adults. There is a waterfall of emerging and promising treatments for rare and serious childhood conditions, which are almost all very expensive and have specific procedures for use in children, and don't fit neatly in Tricare payment methodologies. This reality which is already challenging, coupled with the new pharmacy tier benefit changes could spell disaster for EFMP.

Our Coalition has expressed to DHA that we would appreciate an ongoing stakeholder presence in a concerted DHA effort to discuss and prepare for access, coverage, and payment for emerging pharmaceutical, genetic, and advancing technology treatments as they apply to children and pediatric care.

• Direction to DHA from the Committee in support of this request would be appreciated.

4. Extended Health Care Option (ECHO)

ECHO is uniquely an EFMP issue as it is only available to EFMP enrollees. In 2015 the Military Compensation Retirement Modernization Commission (MCRMC), in alignment with our Coalition's concerns, found that access to Medicaid home and community-based services

(HCBS) waiver benefits provided at the state level is a ongoing issue for military families with EFMs; that many Service members encounter HCBS waiting lists that exceed their time assigned to a location, and referenced 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

The MCRMC recommended that DHA increase services covered through the ECHO to more closely align with state Medicaid waiver programs, including custodial care and respite care hours that match state offerings, more flexible expanded services subject to existing ECHO benefit caps, and modernizing the program to better serve current demographics of the Force.

The Defense Health Board referenced the MCRMC findings as examples of the challenges facing Tricare covered families, and the fact that ECHO is only available to active duty members as an example of military health system lack of standardization and implementation of best practices enterprise-wide.

Other than recent modest changes to the respite care benefit, there has been no further movement on ECHO modernization or improvement.

The Coalition would like to see the Committee:

- Align ECHO with Medicaid based waiver services per the MCRMC recommendations
- implement a grace period for eligibility upon separation from active status to cover an average Medicaid waiting list timeframe, and
- revisit program assumptions, as some of the care that is provided only pursuant to ECHO is medically necessary care and therefore should be available to all beneficiaries under the basic TRICARE program.

5. The Exceptional Family Member Program (EFMP)

Continuing with EFMP challenges, again full generations of children with special, often complex needs, have been left without the services and supports needed, while their families are dealing with high op tempos, PCSing, a managed care transition that has been nothing short of disastrous in many quarters, and in some cases such as the subcommittee members heard in a recent hearing, the already serious issues have been compounded by hazardous living conditions on base.

The situation has deteriorated to the point that families had to band together and request an Inspector General investigation, after years of failure by DoD to implement recommendations made by the Government Accountability Office and the Military Family Readiness Council. Why does a Congressionally mandated council on military family readiness, staffed with our most senior leaders, have problems helping military families? Much like the current housing crisis, these problems have been identified and recommendations made over the years, but with no sense of urgency or accountability by the implementers, have been left to fester. At times it appears that it takes Congressional intervention to prod accountability. Given the egregious and longstanding problems, the Coalition respectfully requests the Committee to

• support the families' request to the DoD IG to investigate the Exceptional Family Member Program's compliance with applicable statutes and instructions. This would put DoD on notice that the Committee is serious about this issue and give these families confidence that Congress is in their corner.

6. Health and Safety Hazards in Base Housing

Military families depend on base housing for many reasons, including when housing on local economy is not affordable or in less appropriate neighborhoods. Furthermore, families who have children with special needs have even more limited housing options when moving to a new duty station. Sometimes, the only affordable housing that is ADA compliant is on-post housing. We are concerned health of those with special needs may be further compromised in housing with these hazards.

The conditions of critical concern around base housing range from mold to vermin to lead and toxic waste. There is no easy answer to this; the problem needs leadership and ownership. A major concern is the apparent lack of ownership of the known health problems arising from these conditions, which prevents them from being addressed promptly and appropriately while the big picture of liability or responsibility is being sorted out.

Meanwhile, however, DHA, the MHS, and TRICARE own the prevention, treatment and promotion of health and wellbeing of its beneficiaries many of whom are especially vulnerable children who live on base and have been and are exposed to these safety and health risks regularly, often with dire consequences. DHA must step up and figure out how to address screening, testing and treatment needs, as well as families' concerns, at the very least.

Toward finding solutions, the Coalition respectfully requests that the Committee

• ensure DoD addresses the health impacts to children, immediate and long term, that are linked to housing hazards.

The Tricare for Kids Coalition appreciates the opportunity to submit testimony for the record toward improving family readiness.