



Tricare For Kids Coalition
Briefing Book

Presented to the Defense Health Board (DHB)
For Consideration in its Review and Recommendations regarding
Pediatric Health Care Tasking by the Defense Health Agency (DHA)

May 5, 2017

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Introduction

The TRICARE for Kids Coalition is a stakeholder group of children's health care advocacy, provider and professional organizations, disability advocacy groups, military and veterans' service organizations and military families committed to ensuring that the Department of Defense meets the unique needs of children of military families.

Every day military families face challenges in receiving the right care for their kids at the right time, in the right setting and from the right provider. Families are often forced to navigate a complex health care system that is based on the needs of adults. While all children have unique needs as compared to adults, military children - particularly those with special, complex or chronic needs - face additional challenges due to the nature of their parents' service. Military kids deserve a health care system that is tailored for their unique health needs, which entails appropriate *coverage, access* to services, and a system that is *accountable* to its stakeholders.

The Coalition was formed around supporting and implementing legislation passed as Section 735 of the 2013 National Defense Authorization Act (NDAA), which directed the Secretary of Defense to study the health care and related services for children of military families and make necessary improvements. The Department of Defense (DoD) submitted its Section 735 pediatric (Tricare for Kids/TFK) report to the Congressional Defense Committees in July 2014.

The DoD report included 31 significant findings of "gaps" and "areas for clarification" (better termed "areas in need of improvement") in the nine Congressionally-directed elements regarding children's health care supports and services (attached). While agreeing with the need to address the 31 findings, the Coalition was also troubled by numerous discrepancies and omissions in the report, including its failure "to set forth a plan to improve and continually monitor pediatric care" and to make "recommendations for legislation that the Secretary considers necessary to maintain the highest quality of health care for dependent children," both requirements of Section 735 of the 2013 NDAA.

The Coalition provided significant input to the Department following its release of the July 2014 report. The Department indicated to Congress and separately that additional follow up reporting would take place, but no further report has been issued. While some positive action has been taken, including alignment with Bright Futures guidelines, improved access to urgent care, and several pediatric stakeholder forums, to date, most of the discrepancies, gaps and need for improvement are still at issue. **Therefore, the Coalition is pleased that the DHA tasked the DHB with review and recommendation of pediatric health issues, which encompass most if not all, of the original TRICARE for Kids elements.**

The DHB review of these issues and recommendations for improvement are of such consequence. The Coalition greatly appreciates the Board's commitment to this serious undertaking.

Please find the following analyses, concerns, comments, and recommendations of the Coalition for each tasking element. Clearly, many of the issues overlap or relate to more than one tasking element, so please review in context of the whole. The TFK Coalition and its members would be pleased to provide further information or discussion at the DHB's convenience.

DHA Tasking to DHB

On July 26, 2016, the Acting Assistant Secretary of Defense for Health Affairs requested the DHB “**examine opportunities to improve the overall provision of health care and related services for children of members of the Armed Forces.**”

- I. Identify the extent to which children receive developmentally appropriate and age appropriate health care services, including clinical preventive services, in both the direct care and purchased care components.**

Appropriate Care for Children

Every day military families face challenges in receiving the right care for their kids, at the right time, in the right setting and from the right provider. Ensuring access to age and developmentally appropriate care for children should be a cornerstone of Tricare.

Most of the responses included in this document are on point to this important first task. However, in attempting to include responses under the tasking element most specifically related to the response topic, much of the relevant narrative is found throughout among more specific tasks. We recognize there is a great deal of overlap and interconnectivity, and appreciate DHB reviewing the document as a whole.

Children’s Unique Development and Growth Needs

Children grow and develop quickly and for many years, thus requiring differing treatment, equipment, frequency, and tailoring than adults in many instances. For example, diabetes counseling, a commonly covered benefit, should be tailored to ensure that parents are adequately trained when the child is young, that training and education is then available for older children and teens as they grow; hearing aids, glasses, wheelchairs and durable medical equipment need more frequent updates; therapies must begin quickly upon identification and diagnoses, and may require more frequent visits or spread over a longer period of time than for adults. While the requirements may seem more intense, early and adequate intervention will ensure better outcomes and lower costs over time and throughout the life of the child.

Tricare must review and adapt its policies to ensure that the developmental nature of childhood is appropriately reflected.

Tricare's Extended Care Health Option (ECHO)

The ECHO benefit, intended to replace state Medicaid waiver programs (which are generally inaccessible to mobile military families), falls short relative to average waiver program coverage.

ECHO Background & Legislative Intent

Medicaid Waiver programs, also called Home and Community-Based (HCBS) Waivers, provide long term care services in home and community-based settings to people who would otherwise require care in an institutional environment. Most states have lengthy waitlists for their Medicaid waiver programs, rendering them inaccessible to military families whose Permanent Change of Station (PCS) moves them from one state to another before they reach the top of the waitlist.

"I have two special needs children and have never been able to access Medicaid services till our recent assignment. When we move out of state this summer, we will again lose services. In 9 years, we have received only 9 months of Medicaid waiver services due to frequent military moves. The process takes so long each time we PCS. It is really discouraging."

Congress established ECHO to substitute for state Medicaid waiver services that are often unavailable to mobile military families. Services provided by Medicaid waiver programs should serve as the benchmark for ECHO covered services. However, ECHO currently falls short relative to Medicaid waiver services, particularly in the area of respite care.

As evidenced by the similarity in benefits authorized under the [Medicaid] Home and Community-Based Services and ECHO programs, as well as the directive to use state and local services before accessing ECHO, Congress intended ECHO as an alternative to unavailable waiver benefits.

Source: Final Report of the Military Compensation and Retirement Modernization Commission, January 2015

MCRMC ECHO Recommendations

The Military Compensation and Retirement Modernization Commission (MCRMC) recommended that services covered through ECHO should be increased to more closely align with state Medicaid waiver programs. Expanded services should be subject to the ECHO benefit cap of \$36,000 per fiscal year, per dependent. Specific examples include, but are not limited to:

- expanding respite care hours to align more closely with state offerings
 - allowing families to access respite care without receiving another ECHO benefit during the same month the respite care is received
 - providing custodial care
 - allowing for consumer-directed care
 - providing adult diapers where necessary and appropriate
- (completed/policy updated by DHA – Fall, 2015)*

ECHO Respite Gap vs. State Medicaid Waivers – Intellectual/Developmental Disabilities

ECHO's current respite care coverage falls far short of the average number of respite hours provided by State Medicaid Waiver programs:

- ECHO currently provides a maximum of 192 respite hours per year
- Average maximum number of respite hours per year in state Medicaid waiver programs: 695

Source: MCRMC state-by-state Medicaid waiver analysis – January 2015

Exceptional Family Member Program (EFMP) Respite

There are common misperceptions about the EFMP respite program; it is often confused with respite coverage under ECHO or Medicaid waiver programs. Although both EFMP and ECHO offer respite, they were created to address very different challenges.

EFMP Respite was established to address the impact of high operational tempo on families with special needs family members; it was not intended to replace ECHO or state Medicaid waiver respite care hours. EFMP Respite is subject to the budgetary needs of each individual service and could be changed/eliminated at their discretion. Even if a family maxed out use of ECHO and EFMP respite hours, they would still fall short of the Medicaid waiver average of 695 hours annually.

Improving ECHO

Congress established ECHO to substitute for state Medicaid waiver services that are often unavailable to mobile military families. Services provided by Medicaid waiver programs should serve as the benchmark for ECHO covered services. ECHO currently falls short relative to Medicaid waiver services, particularly in the area of respite care. The MCRMC highlighted and validated this issue in their January, 2015 report. ECHO services must be brought in line with Medicaid waivers to ensure military families caring for special needs family members have adequate support.

Emerging Technologies - Lab Developed Tests

Military children seen in the Tricare network do not have access to lab developed tests (LDTs) recommended by their medical providers to diagnose genetic conditions and guide treatment of certain cancers.

In January 2013, Tricare ceased coverage of over 100 LDTs without notice to health care providers or beneficiaries. These diagnostic genetic tests play a critical role in the diagnosis and treatment of disease. They include tests for genetic disorders such as Fragile X Syndrome and other tests considered the standard of care in the diagnosis and treatment of leukemia, lung and other cancers.

Due to different requirements in the direct care system, these diagnostic genetic tests are still available for families who receive their care via military treatment

facilities (MTFs.) This creates two standards of care for uniformed service members, retirees and their families and relegates Tricare beneficiaries without access to an MTF to substandard health care.

In June 2014, DHA established a demonstration project to review and approve LDTs for Tricare coverage. However, progress has been slow and nearly 3 years later TRICARE still covers only a fraction of the diagnostic genetic tests that are covered by Medicare, Medicaid and commercial health plans.

How does Tricare's lack of LDT coverage impact care for military kids?

- National Capital Region (NCR) military children are being referred to Children's National Medical Center (CNMC) for genetic counseling and testing that Tricare will not reimburse. CNMC has developed a relationship with a physician at Walter Reed and in certain instances and diagnoses sends military children to him to have genetic testing done. This work around delays diagnosis and treatment and presents significant inconvenience to both families and medical providers. Furthermore, it is a solution specific to the NCR – military families in other areas must either pay for genetic testing out of pocket or forego the tests their provider recommends. Moreover, it is confusing for families who have their CNMC appointments approved but are then informed the resulting recommended testing and treatment are not covered; Similarly, pediatric providers who see these children are frustrated to inform parents that the recommended testing, often critical to diagnosis or treatment plan, cannot be completed.
- Tricare denied coverage for a diagnostic genetic test for the infant son of an Active Guard Reserve (AGR) soldier in Indiana. The baby's doctors believe he may suffer from a rare genetic syndrome and recommended the test to inform their treatment decisions and better understand the child's prognosis. After many months, the family was eventually able to obtain the test at Walter Reed. The family traveled from Indiana to Maryland for a blood draw. The baby's blood sample was then sent to a commercial laboratory in Wisconsin for testing. Since the testing was done as a courtesy, the family doesn't have access to the genetic counseling and possible future genetic testing necessary to determine next steps.
- Tricare denied authorization for a diagnostic genetic test for the daughter of an active duty Army soldier. The child suffers from retinoblastoma and has already had one eye removed due to the disease. Her physician recommended genetic testing to determine the likelihood that the cancer would appear in her other eye. Without the genetic test, the child would require rigorous monitoring until age 6 including eye exams under anesthesia as well as sedated MRIs every 4-6 weeks. After getting the genetic

test results, her treatment plan was modified to greatly reduce the number of eye exams and MRIs. Because Tricare refused to cover the diagnostic genetic test, this Army family had to find a third party to pay for it. Without the test results, this family would have faced greater uncertainty about their daughter's condition, while the child would have been subjected to many more sedated eye exams and MRIs.

Congress, concerned about military families' lack of access to diagnostic genetic tests, gave DoD the authority to cover emerging technologies in the FY15 NDAA. However, DoD seems reluctant to exert that authority as evidenced by their lack of progress in reviewing LDTs via the demonstration project. As one physician familiar with TRICARE coverage policy said:

"If DoD wants to insert themselves in the clinical decision making process, they must do it in a clinically relevant timeframe."

In other words, taking years to review and evaluate diagnostic genetic tests that have widespread acceptance, use, and reimbursement in the medical community and commercial insurance plans is unacceptable. DHA must develop a means for efficiently modifying coverage policies to ensure military children and families have access to diagnostic genetic testing and other emerging medical technologies.

II. Identify the degree to which the MHS delivers clinical preventive services that align with standards, guidelines, and recommendations established by the Patient Protection and Affordable Care Act; the Early and Periodic Screening, Diagnosis, and Treatment program; and organizations that specialize in pediatrics, such as the American Academy of Pediatrics and the American Pediatric Surgical Association.

Align with Best Practices

Aligning with best practices is one of the most effective ways that Tricare can ensure it meets the needs of its pediatric beneficiaries and correct the inappropriate application of Medicare based standards and norms to children's services.

Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) is the means by which Medicaid ensures that all of a child's health needs are identified and treated. TRICARE does not in any way align with EPSDT's comprehensive, pediatric-specific coverage, and many health needs of military children go unmet for this reason. The Department's TFK Report identified this lack of alignment as a potential issue, but once again, no discernible action has taken place to further alignment. The report intimated that a study may be in order; we strongly reject that notion, as it is a well established and well studied pediatric care standard.

Organizations such as the American Academy of Pediatrics (AAP) provide excellent resources on best practices that should be adopted and utilized much more fully in order to ensure that Tricare is meeting the needs of children.

There are several key protections afforded by the Patient Protection and Affordable Care Act (ACA) that are not guaranteed for children covered by Tricare, concurrent curative and hospice care, coverage of habilitation as an essential health benefit, a "stay put" of services while a beneficiary exhausts the appeals process, and aspects of preventive care and mental and behavioral health services as essential health benefits.

Note, that while Tricare recently adopted Bright Futures and other preventive guidelines required by the ACA, it is unclear if the standards apply to all Tricare covered children and how implementation is going, and that comprehensive mental health regulations were recently promulgated but not yet being implemented. DHA's recently announced implementation of Bright Futures guidelines is, to date, not being consistently implemented. In addition, better messaging to providers is in order on both issues.

Collaboration is Critical

There are many situations in which collaboration with the civilian sector could help the DoD and DHA. For example, with respect to data, collaboration could help

determine what data to collect, how to meaningfully analyze for pediatrics, preferred metrics and assistance with civilian sector comparisons. Some of these areas include alignment of services available under EPSDT, the ACA and Bright Futures, assessing access to specialty care and building a complex care management and coordination system.

It is imperative that the DoD refrains from reinventing the wheel in order to address each of these areas. While some of the issues are unique to the DoD, such as the interaction of EFMP, ECHO and other support programs run by the military branches, and TRICARE and other programs run by DHA, many of the issue areas are those in which civilian organizations have expertise, interest and a commitment to serving military families. Public-private partnerships are critical to addressing and TFK Coalition partners stand ready to assist.

III. Evaluate whether children have ready access to primary and specialty pediatric care.

Access in the Direct Care System

Most military hospitals and clinics fail to meet Tricare Prime's published access standards for acute and routine primary care.

Access to care standards for Tricare Prime enrollees have been in place since the start of the Prime program in 1995. They were recently republished in the June 22, 2016 Federal Register.¹ According to Prime access standards, routine visits shall be available within one week while urgent care appointments shall be available within 24 hours.

Despite these well-documented standards, families routinely tell us about difficulties in accessing primary care at military treatment facilities (MTFs) for both urgent and routine appointments.

My 3 year old was hospitalized this year and we still couldn't get in for a follow up appointment with her PCM when she was discharged. She also had croup (she has Down Syndrome and any sickness is far worse for her) and we weren't able to get an appointment until 7 days after I called. I took her to the ER and she was sent home with no medicine or steroids. Her pediatrician was appalled when we finally saw her. This happened twice with croup this year. My husband was deployed, so I had to take all my children to the ER to have my daughter seen.

Military Health System data validates direct care access challenges. We recently analyzed MHS Transparency Data available on all MTF websites and found that from April through December, 2016, over half of MTFs failed to meet Tricare Prime's urgent care access standard while about one-third failed to meet the routine care access standard.

% of MTFs Failing to Meet Tricare Prime Access Standard:

2016	Urgent Appointments	Routine Appointments
April	51%	26%
May	63%	33%
June	53%	39%
July	68%	41%

¹ <https://www.gpo.gov/fdsys/pkg/FR-2016-06-22/html/2016-14786.htm>

August	48%	42%
September	66%	36%
October	53%	26%
November	68%	28%
December	72%	31%
<i>9 Month Average</i>	<i>60%</i>	<i>33%</i>

Source: MHS Transparency Data

There is considerable performance variation across the Services, with Navy hospitals and clinics performing significantly better against access standards versus Army and Air Force MTFs.

% of MTFs Failing to Meet Tricare Prime Access Standard:

2016	Urgent Appointments			Routine Appointments		
	Army	Air Force	Navy	Army	Air Force	Navy
April	56%	66%	7%	22%	31%	11%
May	63%	82%	11%	22%	46%	7%
June	59%	68%	7%	28%	53%	11%
July	72%	86%	15%	28%	57%	11%
August	50%	64%	4%	34%	57%	11%
September	66%	80%	26%	16%	50%	19%
October	59%	66%	11%	16%	36%	7%
November	63%	85%	30%	9%	43%	7%
December	63%	91%	33%	6%	49%	11%
<i>9 Month Avg</i>	<i>61%</i>	<i>76%</i>	<i>16%</i>	<i>20%</i>	<i>47%</i>	<i>11%</i>

Source: MHS Transparency Data

Although difficulty accessing primary care is not specific to pediatrics, we believe the issue is more pronounced for military families, given children's greater need for routine and preventative care, the frequency of childhood illnesses, and the anxiety that results when families can't access the appropriate care for an ill or injured child.

We have been pleased to learn about several initiatives within the Services to improve access to care. As this data demonstrates, however, the MHS must continue to seek ways to improve access to primary care.

Bureaucratic Barriers to Access

In pediatrics, wait time for specialty care is a reality due to shortages and volumes; wait time concerns should not be further exacerbated by inappropriate or difficult referral and authorization processes, or arbitrary limitations on distance to travel. Distance limitations that may be reasonable for adult Prime enrollees can be arbitrary and burdensome for pediatric patients.

Pediatric care is regional in nature. Children, particularly those with special needs and complex medical conditions, often must travel to another state or region of their state to receive the best care, or sometimes the only care, for their conditions, much more so than adults. Regional concentration is due in part to shortages, but also the reality that pediatric volumes are less than for adults. Pediatric specialists cannot maintain practices in every community, and need to work within the infrastructure of children's hospitals or academic medical centers in order to provide the necessary complex care.

Tricare must recognize and adapt its policies and practices accordingly, to protect against exacerbating those difficulties with barriers such as referrals and authorizations that may be difficult to obtain and process, Prime limitations such as requirements to be seen on base first without exception (may lengthen an already problematic wait time that much more), requiring children under the ongoing care of specialists to see a local PCM in a new duty station before making specialty appointments in the new location, or distance limits that may not make sense for pediatrics.

Reimbursement Impact on Access

Tricare should afford more flexibility in reimbursement for care designed for and tailored to children. Reimbursement should follow appropriate care, not form the basis for care decisions. Too often Tricare reimbursement policy is the result of Medicare policy, and does not make sense for children.

Even when coverage decisions are ostensibly made to allow certain treatments and procedures for children, the payment codes do not reflect the value of the covered services and therefore Tricare is playing both sides –announcing to providers and families that certain care is covered, but not paying or including the value of those

services in payment for the care when it is provided. Examples include melody heart valve, conscious sedation, and emerging technology.

Tricare should not ask pediatric providers to absorb the cost of medically appropriate care for children, or to choose outdated care options when the standard of practice calls for something different.

Instead, we encourage Tricare to adopt flexible payment policies that allow providers to make the best care decisions for the child. Care and clinical standards as to whether the procedure is performed on an inpatient or outpatient basis vary among children's hospitals, communities, practice models, state standards, and other meaningful elements that inform quality of care, and those standards of care and practice should be respected.

As beneficiaries are moved from direct to purchased care, problems with Tricare's reimbursement policies will become more prevalent as they impact more families. We fear this will be a particular problem for families with young children, given longtime pediatric reimbursement issues caused by an inappropriate alignment with Medicare reimbursement. Reform measures did not address the challenges faced by patients needing care involving emerging treatments and technologies. If the intent is to move a significant portion of military family care into the purchased component, Congress must soon focus on fixing Tricare reimbursement issues so they don't impede beneficiary access to appropriate care.

IV. Address any issues associated with the TRICARE definition of "medical necessity" as it might specifically pertain to children and determine if the requirement for TRICARE to comply with Medicare standards disadvantages children from receiving needed health care.

Linkage to Medicare Disadvantages Children

One of the foundational problems with the current Tricare program is its reliance on Medicare, an adult-based health care plan and payment system.

Children's health care needs and standards of care are different and distinct from those of adults. Because they continually grow and develop, early identification and intervention for all care needs, and robust specialty care and services for children with special health care needs and chronic health conditions are especially critical. Children utilize care at different rates, in different settings, and for different conditions than do adults. Additionally, reimbursement based on Medicare often leaves the family or provider subsidizing the cost of pediatric care. This occurs when policies such as Medicare's inpatient only list results in denial of care even when provided consistent with the pediatric standard of care; when services that children need but adults do not, are ostensibly "covered" but not included in the relative value of the payment code (examples of this include Melody Heart Valves, conscious sedation for an MRI or wound care); and when adherence to Medicare policy results in parents being forced to deny curative care to their children in order to access hospice services.

Instead, DoD should comprehensively address the specific needs of children, using the following framework of principles and facts that distinguish the different care needs of children versus adults.

- Children are dependent on their parents and families.
- Pediatric care is regional in nature
- Children with special health care needs and complex medical conditions require an array of primary, acute, post-acute, highly specialized, therapeutic, and continuing care, treatment, services and supports.
- Pediatric volumes are less than adult volumes.
- Children's health is influenced by many entities outside of the health care arena.
- Children require services and care in a timely manner specifically suited to their unique development and growth needs.
- Measures and methods are different when judging quality and outcomes for children as compared to adults.
- Hospitalization rates and reasons are very different than for adults.
- Children have specialized pharmaceutical needs.

- Children utilize preventive/well care much more so than adults, and care is concentrated at the beginning of life versus adults, at end of life.

If adopting the model of another national health care program is important to TRICARE, modeling on Medicaid's standard coverage and benefit package makes much more sense than modeling Medicare when it comes to children's health. Medicaid generally recognizes and ensures coverage appropriate to children's age and developmental needs, by requiring EPSDT and including the Bright Futures guidelines for preventive and well care. (Note: Tricare has recently adopted Bright Futures, very much a step in the right direction, but we have no implementation feedback yet.) Families covered by Tricare but requiring significant health care services for a child often must turn to Medicaid for wraparound coverage to Tricare. The availability of this secondary coverage is extremely valuable and in some cases an absolute necessity, but that should not be the goal. Tricare should strive to make sure it meets the needs of all children in its charge, and not rely on Medicaid to serve military children with complex conditions and significant needs. This is especially true because Medicaid is different in every state, requiring families to learn to navigate an additional complicated system with every PCS, and it continues to face its own (extremely significant) funding and infrastructure challenges.

While Medicaid coverage is comprehensive and more appropriate than Medicare's for children, we would caution against modeling on Medicaid infrastructure or reimbursement levels, as years of financial constraints (and current financing "reform" discussions that could be devastating) have resulted in payment levels that have driven away providers and made it difficult to sustain pediatric practices because of they are inextricably linked to Medicaid's less than cost reimbursement, because more than 30 million, or 1 in 3 children in the United States rely on Medicaid.

Pediatric Medical Necessity Definition

A general or adult-based medical necessity definition and the resultant hierarchy of evidence requirement leaves children's needs unmet with fragmented coverage (under ECHO) or non-coverage of medically necessary care such as ventilator support, habilitation, medical nutrition therapy, compound medication and other specialty pharmaceuticals.

DHA hierarchy of reliable evidence includes only "published research based on well controlled clinical studies, formal technology assessments, and/or published national medical organization policies/positions/reports." Evidence of effectiveness is a cornerstone of medical necessity, yet such tightly prescribed data for children is not always readily available. Due to their very nature of constant growth and development, and a societal responsibility to protect children, they are not always the subjects of such controlled and prescribed studies. Strict adherence to this adult-based hierarchy of evidence results in children not receiving the care and treatment they need, care that is widely and more quickly accepted and practiced elsewhere in the health care system.

Examples

Habilitative Services

Habilitative services, provided for a person to attain or maintain a skill for daily living, are uniquely necessary for children due to their stages of growth and development. Habilitative services are not, but should be, covered as a basic program health benefit, just as rehabilitation services are covered. If a child is in an accident and needs therapy to regain a skill, it is covered. There is no TRICARE coverage for a child who needs habilitation to learn a skill for the first time.

Habilitation services are available only for active duty family members through the ECHO program and are subject to an annual dollar limit of \$36,000. This differs from the ACA which recognizes habilitative services and devices as an essential health benefit without lifetime or annual dollar caps on care.

Medical Nutrition

The FY 2017 NDAA legislation addressed a critical gap in Tricare coverage for medically necessary food, vitamins and related supplies for certain conditions. To date, anecdotes suggest fragmented implementation. While the coverage is an improvement, TRICARE must implement it consistently. In addition, broader coverage of the spectrum of medical nutritional therapy is still needed. Tricare's current definition of medical nutrition is too narrow, and counseling and management are only covered as part of diabetic care. It is especially critical that nutritional therapy be broadly offered as covered, medically necessary care and treatment for children due to their unique growth and development needs, and an element of care in multidisciplinary specialty clinics caring for children with complex needs. Tricare is not keeping pace with national best practices for specialized pediatric care.

Narrow coverage forces pediatric providers and families to make care decisions that may be less than optimal.

Compound Medications

Compounded medications, not fully covered by Tricare, are often the only safe and effective medications for children with chronic disabilities or allergies to commercial additives, or infants and children who cannot tolerate an adult dose of commercially manufactured medications, or need a liquid form.

Conclusion

These are just several examples of TRICARE coverage policies that are not designed to address children's unique health needs. DoD should adopt the pediatric definition of medical necessity, and commensurate hierarchy of evidence standards as recommended by the AAP, found in the Pediatrics Official Journal of the American Academy of Pediatrics. Committee of Child Health Financing Pediatrics 2013.

Medically Necessary Care Available Only Pursuant to Special Programs

Children with complex needs receive medically necessary care under ECHO while their families are eligible. Skilled nursing and ventilator support, for example, for a child with spinal muscular atrophy, is medically necessary yet not covered by Tricare basic. Active duty families may avail themselves of the Extended Home Health Care (EHHC) program pursuant to ECHO, but the moment the sponsor retires, that benefit is removed – even though the retiree family is ostensibly still fully insured by Tricare. The medical necessity of a ventilator for a TRICARE beneficiary is not at all tied to the active duty or retiree status of the parent.

Specialty Pharmaceutical Needs

It is often said that children are not just little adults. This is especially true with respect to pharmaceuticals and their role in children's health care. Children require highly-specialized care and highly-customized medications to meet their unique needs, and these customized pharmaceuticals are too often unavailable on the commercial market.

Thus, there are there are many instances in which compounded medications are the only safe and effective medications for children. This can be the case for children with chronic disabilities, for those with allergies to commercial additives, or infants and children who cannot tolerate an adult dose, for lifesaving medications that must be specially formulated, and in cases of drug shortages in which medication is not otherwise available. Children's hospitals are staunch advocates for a reliable and safe pharmaceutical supply chain to provide appropriate, safe and effective medication for children, and work to ensure children's access to these medications.

It has been estimated that in a children's hospital roughly 70 percent of the medications dispensed require some type of pharmacy customization. For example, medications commercially manufactured for adults are often packaged in doses too large or too strong to be given to children and must be divided down into smaller doses or else diluted. Children's medications may need to be preservative-free and often must be converted from solid to liquid for infants who cannot yet eat—yet another example of why children's medication needs are unique.

Furthermore, children are particularly vulnerable to drug shortages because their medication is already in such short supply. During drug shortages when commercial product is unavailable, children's hospital pharmacies sometimes look to reputable compounding pharmacies with the expertise to compound medication into pediatric-appropriate pharmaceuticals. Upon orders of a prescribing physician, these compounds may be necessary for the care of children who have no other source of life-sustaining treatment or nutrition.

We have concerns about any unintended consequences of TRICARE medication coverage policy that might limit the collective ability of the pediatric health care system to respond during shortages or that might disincentivize compounding

manufacturers from responding, leaving children with no other access to medication they need to survive.

Pediatric use of pharmaceuticals that have not been specifically tested in children must also be protected. Unfortunately, although children's hospitals are adamant advocates for more pediatric specific research, and strides have been made, pediatric research is far from universal. Meanwhile, then, this type of "off-label" pediatric use must continue to ensure that children have access to best possible or only medication for their needs.

On the other side of the equation, emerging approved pharmaceuticals need to be added to the formulary with appropriate coverage and payment policies without delay. The best current example of this issue is a market entrant approved in late 2016 by the U.S. Food and Drug Administration (FDA), Spinraza (nusinersen), the first drug approved to treat children and adults with spinal muscular atrophy (SMA), a rare and often fatal genetic disease affecting muscle strength and movement. Through fast track designation and priority review, Spinraza advanced more quickly through the FDA approval process than anticipated. Tricare must be nimble and flexible so that its beneficiaries have timely access.

The unique needs of children with respect to pharmaceuticals is important to note, given the recent announcement by TRICARE that excluded some or all compound medications necessary for children's life and health. The decision was quickly delayed in order to ensure "excellent and safe care for our beneficiaries and clear communication with our providers and beneficiaries." However, it is not clear that there is a final resolution that safeguards all necessary uses of compound medication by children. To that end, it is included as an area of concern with respect to specialty pharmacy needs of children. All pharmacy policy should be reviewed in context of unintended consequences to children and tailored for pediatric usages.

In Home Care

Children with chronic and/or complex illnesses and likely to require multiple hospitalizations throughout the year, can benefit from in home health care for palliative, routine, and anticipated care needs. This can be done alone and in combination with telehealth. In home consultations and services protect against exposure for those who are vulnerable to infection, save on expensive transport in many cases, support the care giving efforts of parents, and allow for physicians to maintain regular contact with their chronic patients to monitor for potential problems without waiting for crises.

Tricare will not generally cover in home services because it does not consider a child "home bound." Children are not as a rule, "home bound" in the Medicare sense of the definition, because a parent arranges transport. This is another example of Medicare policy and lack of a pediatric medical necessity standard, preventing children's access to appropriate care.

Concurrent Care

Tricare's current pediatric hospice policy is out of step with today's standard of pediatric care as well as Medicaid and commercial coverage policies. It requires military families to forego curative care and quality of life therapies if they elect hospice services for their children. This outdated policy, based on Medicare requirements for senior adults, has a devastating impact on military kids with life threatening conditions and their families. Furthermore, while the policy itself is outdated and results in a travesty, the Coalition has now been made aware of several instances in which not only curative care is being denied once a family chooses hospice, but other quality of life and palliative care as well.

"My daughter was diagnosed with ATRT brain cancer in 2011. In the past five years, she has been in critical condition on multiple occasions and has almost died numerous times. At other points, she has done well and started to develop and push past the disease. 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 "end of life." Since being on hospice, Tricare has denied my daughter's physical and occupational therapy. We have decided to remain within the hospice program until she is in a position that is more stable but we extend her recovery time by doing so. Currently, Tricare is a roadblock to her recovery process." –Marine Corps Family

"We are a military family who has experienced pediatric hospice twice for the same dependent. The way hospice is handled with Tricare is outdated and causes an immense amount of undue 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. We had to make a very difficult choice. 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 up that 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." -Navy Family

The Coalition recently discovered that the DoD had commissioned a study and been told that military children should receive comprehensive hospice care and ignored the recommendation. A study, called the ["Children's Hospice Department of Defense Report"](#), completed in 2007 under contract with the Henry M. Jackson Foundation for the Advancement of Military Medicine, found:

Children with life-threatening conditions (LTC) who are entitled to services from the Military Health System (MHS) do not receive care in the comprehensive pediatric palliative care and hospice model called for by the Institute of Medicine, Medicaid, the Children's Hospice International, and the National Quality Forum.

Recently, when officials in the Military Health System were asked how many children were impacted, they assured advocates that the numbers amounted to perhaps a handful. However, the DoD study stated “*An estimated 4000 children with LTC [life-threatening conditions] are eligible for medical care through the MHS each year. Approximately 400 of these children die each year.*”

If DoD’s numbers are accurate, in the decade since the hospice study was published, roughly 4000 military children died without proper end-of-life care. Similarly with many other issues addressed herein, there was a known problem that has been unacted on for the better part of the last decade.

In response to advocates' request for a hospice solution in fall 2016, DHA stated:

“Please be assured we remain committed to ensuring pediatric patients who are seriously/terminally ill receive individualized attention. This individual attention provides the pediatric patient, and their families, with compassionate support, understanding of the wide variety of benefits, and access to the entire spectrum of TRICARE benefits available to meet their needs. The best way to meet those needs is to work individually with each and every family, and we are doing so.”

The DHA response is problematic for two reasons, 1) we, as advocates, have brought to DHA leadership’s attention several individual cases over the last year and none of the families were afforded any concurrent coverage, waiver, or other accommodation, and 2) one-off accommodations are appropriate in crisis situations as policies and practices are in transition, but should not be the answer for systemic problems that affect many. There is no way for us as advocates to identify every family in this situation to bring to DHA’s attention, and even if we could there has been no demonstrated authority to waive problematic constraints. The policy must be changed so that all receive the care they need.

Tricare benefits do not align with pediatric best practices recommended by the AAP² and the Institute of Medicine³. They are also out of step with other health plans. Acknowledging that the path of a child’s illness is unpredictable and parents – as well as medical providers – are reluctant to halt curative care, Medicaid and commercial plans will now cover hospice in addition to curative care, and a growing number focusing on providing broader home based care in these situations, for pediatric patients. Tricare’s policy must be modified to ensure terminally ill military kids receive appropriate care.

Furthermore, this is another example of an issue area in which DoD is well aware of its shortcomings with respect to standard of care for children, yet has failed to pursue a solution.

² <http://www2.aap.org/sections/palliative/WhatIsPalliativeCare.html>

³ <https://www.ncbi.nlm.nih.gov/books/NBK285669/>

Medicare Based Reimbursement

Too often Tricare reimbursement policy, because it is based on Medicare policy, does not make sense for children's care. DoD must ensure that reimbursement policy is based upon sound principles and demonstrated need, will create desired outcomes, and is tailored to the unique needs of the children and families served. Examples of disconnects that lead to access problems, Melody Heart valve, compound medication, emerging technology and medication, inpatient or outpatient decisions dictated by payment versus by physicians based on child's needs and pediatric community standards of care, and conscious sedation (for example, for wound care or MRIs).

V. Measure the impact of permanent changes of station and other service-related relocations on the continuity of health care services received by children who have special medical or behavioral health needs.

Permanent Change of Station (PCS) Challenges

Military families recognize they must sacrifice **a degree of continuity** of medical care as a result of the highly mobile military lifestyle. Unfortunately, Tricare policy hinders rather than facilitates the transition of care during PCS moves.

Established specialty care requires a new referral at each new duty station – even for chronic conditions where ongoing specialty care is undoubtedly required. To reestablish their specialty care, newly relocated military families must first have an appointment with a new Primary Care Manager and then get a new referral processed, resulting in delays and disruptions in care.

“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 move to an area with every specialist she needs, because we are put into a situation where we can’t have her medical specialists set up at our incoming location for IMMEDIATE care. We wait to be enrolled in our new region, we wait for an appointment to see our new PCM, and then we wait for her PCM to refer us to, more often than not, outside civilian specialists. Most of the time there’s at least a 3 to 6 month 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. Two of our last three PCSs, we ended up in the emergency room with life threatening complications/illness and no specialists who were familiar with her history and her diseases.”

Military families who require specialty care would appreciate the ability to make appointments with *providers – and to do so in consultation or with assistance of current providers – for the new location before they leave the current duty station and provider/s’ care. This would allow families to get on specialty provider schedules, and facilitate communication between old and new providers, before their PCS occurs, minimizing disruptions in care.*

The FY17 NDAA eliminates the specialty care preauthorization requirement for outpatient care. We welcome this attempt to streamline access to specialty care, but it is only a partial solution.

Removing the requirement to get a new specialty care referral following a PCS, and allowing the existing referral to transfer to the new duty station, would greatly help military families with the timely transition of specialty care. It would also eliminate unnecessary appointments to obtain new referrals and reduce the health care disruptions inherent in PCS moves.

VI. Assess certification requirements for residential treatment centers of the Department to expand the access of children of members of the Armed Forces to services at such centers.

Certification Requirements

The Tricare behavioral health final rule published last September would replace the standards and certification process that had been in place since 1995. However, despite an October 3, 2016 “effective” date, DoD has released no information on what the new certification process will be or which national accreditation standards will be approved. Currently authorized providers are operating under the outdated standards, as their contracts require. New providers who would like to participate cannot. Neither providers nor accreditors have any information that would allow them to plan to serve Tricare enrollees when the rule is eventually implemented at some uncertain future date.

VII. Evaluate the quality of and access to behavioral health care under the Tricare program for children, including intensive outpatient and partial hospitalization services.

Behavioral Health

Despite identifying behavioral health as one of the two most utilized specialty areas, the July 2014 Tricare for Kids Report to Congress did not provide clear information about the availability or delivery of behavioral health services. Covered mental health and substance use disorder treatment benefits were described in some detail, but there was no discussion of provider capacity or geographical locations relative to Tricare beneficiaries' home communities. The limited utilization data that was presented referred to visits, not admissions, apparently reflecting only outpatient services. There is not a mechanism to quantify unmet demand.

Contrary to DoD's conclusion that "the MHS is meeting the needs of the children in its care, including those with special needs," significant barriers to behavioral health care had been documented by other sources and still exist today. Among them are access issues such as inaccurate provider directories, long waiting periods for initial outpatient appointments, and the too-frequent need to send a child to another state for Tricare-certified psychiatric residential treatment or substance use disorder rehabilitation. Quality issues range from a lack of care or delayed care while conditions worsen, to treatment standards for residential settings that are decades behind best practice.

An overarching shortcoming is that the behavioral health benefits are not designed to be developmentally or age appropriate for children. Key services are not covered, such as intensive in home services or wraparound services, which have been validated in the civilian sector as producing better outcomes than higher intensity services when those are not needed, at lower cost. Telehealth is not covered in a way that makes it functional for military families dealing with behavioral health conditions, whether everyone lives in the home, or one parent is deployed, and/or a child is receiving out-of-home treatment. A family-centered philosophy has not made it to the military health system, a conspicuous shortcoming given the entire family's commitment to a service member's duty assignment.

In 2016, DoD proposed significant improvements to Tricare's mental health and substance use disorder treatment in "institutional" settings, in terms of both access and quality. At that time, institutional behavioral health providers included inpatient psychiatric hospitals, psychiatric residential treatment centers (RTCs) for children and adolescents, substance use disorder rehabilitation facilities (SUDRFs), and partial hospitalization programs (PHPs) for mental health and substance use disorders. There were – and are – inadequate numbers of institutional providers willing to participate because of a lengthy and expensive certification process with antiquated and overly-prescriptive Tricare standards.

The new regulations would improve access to services in two ways: by expanding coverage to include opioid treatment programs (OTPs) and intensive outpatient programs (IOPs) for mental health and substance use disorders, and by streamlining requirements for providers to become Tricare certified.

Quality would be improved by relying on national accreditation of providers, eliminating the existing standards in Tricare regulations. This would ensure that standards for Tricare services would keep pace with improvements in the larger health care field without requiring regulatory revision.

Largely consistent with federal laws governing other health benefits programs, the new regulations also established parity of behavioral and physical health coverage.

The proposed rule was published February 1, 2016. The final rule was published September 2 with an effective date of October 3, 2016. However, most of its provisions have not been implemented and it is unclear when they will be, leaving beneficiaries without promised services and providers unable to deliver them.

The new regulations require between 90 and 100 changes to Tricare policy and reimbursement manuals. The only changes that have been released as of May 1, 2017 are related to eliminating day limits and discriminatory copayment amounts to achieve parity with physical health benefits.

The current managed care support contractors do not have any instructions or authority to make the new treatment services available. The T-2017 contracts do not reflect the changes made by the final rule, so future provider networks are also not being developed consistent with the new behavioral health coverage. DoD's recent decision to delay the implementation of T-2017 contracts until January 1, 2018, raises concerns that the final rule which was "effective" October 3, 2016 will not actually be implemented until the larger TRICARE transition in 2018.

No information is available on what the new process will be to certify institutional behavioral health providers for Tricare participation, or which national accreditation standards will be approved. Currently certified providers are operating under the outdated standards, as their contracts require. New providers who would like to participate cannot. Neither providers nor accreditors have any information that allows them to plan to serve Tricare enrollees when the rule is eventually implemented at some uncertain future date.

This was the first update of Tricare behavioral health benefits in decades, and there does not seem to be any sense of urgency to implement changes even when DoD recognizes the need to. For example, as long ago as July 2009, DoD was reviewing the standards for psychiatric residential treatment which had been issued in 1995. Regulatory changes were not proposed until February 2016 and have still not been implemented. A child born to a military family in 1995 would have lived his entire childhood and adolescence without a single update being made to Tricare's residential treatment standards, 22 years of tremendous growth in mental health treatment philosophies and practices.

Autism and Applied Behavior Analysis (ABA)

Autism is a developmental disorder that affects a person's ability to form social relationships and communicate. Many people with autism exhibit repetitive behaviors, some of which can be harmful and interfere with their development, ability to learn, and their overall functioning. Autism is no longer considered a rare condition. It affects 1 in 68 children, including 1 in 45 boys.

There are effective treatments for autism that can change a person's course and outcome. In controlled clinical trials, applied behavior analysis (ABA) has been demonstrated to ameliorate harmful and interfering behaviors, improve language and communication, teach daily living and safety skills, and reduce the symptoms of autism. *Mental Health: A Report of the Surgeon General* states, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior." Study after study has provided evidence for the efficacy of ABA based treatments for improving outcomes of patients with autism.

ABA is widely accepted throughout the medical community as the standard of care. It has been endorsed by American Academy of Pediatrics, National Institute of Mental Health, and the federal Interagency Autism Coordinating Committee. At the time of this writing, 45 states have laws requiring private insurers to cover ABA as medical care, and ABA is required coverage for state Medicaid programs through Early Periodic Screening Diagnosis and Treatment (EPSDT).

After completing an internal review in 2012, the U.S Office of Personnel Management (OPM) concluded there is enough evidence for OPM to classify ABA as a medical therapy. In 2017, all plans under the Federal Employees Health Benefits Program (FEHBP) provide benefit packages that offer behavioral treatments based on ABA. In communicating this decision to Autism Speaks, a national autism advocacy organization, OPM stated, "This decision reflects our perspective that families covered under the FEHBP should have access to medical treatment that is safe, effective for their individual diagnosis, supported by sound medical evidence, and delivered by appropriate providers."

Current Status

Tricare currently covers ABA for beneficiaries with autism under its Autism Care Demonstration (ACD). The ACD began in 2014 and will run through December 31, 2018. We've seen several benefit improvements under the demonstration (i.e. removal of dollar caps on care, aligning cost shares with other medical services, and more), but families have also experienced ongoing policy missteps resulting in interrupted services and serious delays in care.

Context

The following outline provides an overview of some of the ACD challenges, and helps one understand why providers, families and advocates are extremely concerned about coverage and access to medically necessary ABA services in both the short and long term.

- **June 2012:** Senate Armed Services Committee hearing on a host of issues related to EFMs, with a significant focus on autism. The military family stories submitted and testimony provided a window into the daily lives of military families with special needs and the way legislators can help. Expert testimony by the American Academy of Pediatrics focused on the medical necessity of ABA.
- **August 2012:** Military families with autism win a class action lawsuit against DoD. The Court finds that the Agency's decision to deny coverage for a recommended autism therapy as a medical benefit is "***arbitrary and capricious and not in accordance with the law.***" While the class action aspect is eventually cancelled, the case is remanded to DoD for correction and implementation.
- **2013:** DoD implements a number of poorly drafted policies that would have halted therapy services for thousands of children with autism, forcing the families and advocates to fight back in an unprecedented grassroots uprising.
- **2014:** DoD decides to cut reimbursement for TRICARE autism providers in half. The ensuing wait lists and access challenges cause another uproar.
- **2016:** DoD cuts provider rates again, further exacerbating access to care, after which senior military leadership urgently calls on the Office of the Secretary of Defense to reverse the cuts highlighting "*access to care...effect[s] both family and unit readiness*" and "*capacity of ABA [therapy] services cannot meet the current demand.*" DoD fails to course correct, so Congress intervenes and orders the rate cuts reversed.
- **2017:** DoD institutes a new set of policies requiring all children undergo inappropriate testing every two years (including IQ evaluations) to assess ongoing care. Military developmental pediatricians were not given an opportunity to provide input to the policy that directly affects their patients' care and subsequently send a letter to the Defense Health Agency (DHA) stating the "*Required testing as proposed by TOM [TRICARE Operations Manual] is not standard of care, expensive and time-consuming.*" Once again, the policy was walked back within weeks, after outcry from those and other providers, families and advocates about the policy's threats to access and expensive, unnecessary testing. Yet the changing dynamic once again has led to confusion and fragmented implementation.

No Consistent Reliable Access to Care

In a 2016 survey conducted by the Behavior Analysts Advocacy Network, 66% of beneficiaries reported that they are currently waiting for services or not receiving recommended levels of care. 72% of beneficiaries report a 3 to 12 month gap or delay in services as a result of PCS'ing. Insufficient provider network, ACD policy changes, and provider credentialing delays were cited as major causes for delays.

The Tricare commissioned RAND report states "locations with a high number of potential ABA users per certified provider include several locations in the Southwest (San Diego, southern Arizona, and west Texas) and in the Southeast

(Virginia, South Carolina, Georgia, and Alabama). There are more than 100 potential Tricare users for each Board Certified Behavior Analyst.” The ABA access challenges affect military assignments. In a 2016 letter senior military leadership highlighted this issue to the Undersecretary of Defense for Personnel and Readiness stating *“Reduced access to ABA therapy will force families to prioritize healthcare options over military career options, and/or impose undue financial hardship for families...who chose ABA therapy. Quality access to care affects family and unit readiness. This reduction causes concern for our most at risk dependents and is already impacting Navy and Marine Corps’ ability to assign Sailors and Marines to specific locations.”*

Action Needed

As DHA approaches the end of the ACD, it has signaled its intent to study whether ABA is medically necessary. As described fully above, that decision has already been thoroughly vetted. This is not a matter for further study. Action is needed to bring ABA under the TRICARE basic benefit to ensure beneficiaries have access to services consistent with other medical care. Further, efforts are needed to efficiently administer the benefit and develop the provider network to ensure beneficiaries have consistent access to care in a timely manner.

VIII. Assess other issues related to the evaluation and general improvement of health care for children within the MHS including:

- Data collection, data utilization, and data analysis that could improve pediatric care and related services, including the availability and maturity of pediatric specific outcome measures.**
- Best practices for coordination of pediatric care.**

Effective Use of Data

Tricare covered children do not access care solely in the direct care system or solely in the purchased care system; the systems must be able to communicate, collect and share data along the way. Not only is it inefficient for DoD to formulate its own standards and measures, it is harmful to the advancement and understanding of children's health needs, access and utilization.

Subject matter experts that are global and national thought leaders in the field can help DoD avoid the trap of creating its own system of quality and outcome measures and data collection points, which would not be meaningful or credible due to the relatively small numbers of children covered and lack of consistency with national standards;

DoD can mitigate deficiencies in data collection, data utilization, and data analysis, in collaboration or contract with organizations specializing in data analysis and utilization specific to pediatrics, per standards in the pediatric community.

Best Practices for Coordination of Care

Tricare does not, and cannot on its own, adequately provide care management for the sickest, most vulnerable children of military families. Children with medically complex conditions require the highest level of services and support from children's hospitals due to the intensity of care and breadth of pediatric specialists required to care for their conditions. Children's hospitals offer their expertise and support in partnership with Tricare to improve children's health and advance a new care model that will not only improve care, improve coordination and transition among providers, and better support families, but will also reduce cost.

Medically complex children, with chronic conditions involving multiple illnesses and disabilities, comprise approximately 6% of children (120,000) covered by Tricare, yet account for more than an estimated 40% of the cost of providing care for pediatric beneficiaries. Care for medically complex children looks very different than it does for the typical child with an occasional injury or illness. The need for different care, specialty care outside the military health system, and ongoing care coordination by pediatric professionals is obvious for children with medically complex conditions

Current Quagmire

Coordination is more complex when the child receives segments of his or her medical care in the direct care component (MTFs), other care in the purchased care components (non-MTFs), and non-medical support services from both civilian and military professionals. Thus, one of the gaps identified by DoD in care management is that there is “no clear inter-care collaborative process for direct care, purchased care, and related supports to address medical and non-medical complex beneficiary needs.” In addition, TRICARE regional offices also reported that data is not available to review ECHO beneficiaries and case manager ratios and clinical outcomes.

These processes must work well and seamlessly in order to accomplish their mission. To date, there is no central coordination or point of accountability. Layers of case management, particularly when those points of contact do not interact with each other or have knowledge and understanding of how the various programs or services work together do little to ease the family’s burden. A family should be able to enter the system at any point on the coordination spectrum and trigger communication and cooperation up and down the line. Without this capability, military families of children with special needs end up acting as their own “case manager of their case managers,” which defeats the point of case management.

In its TFK Report DoD suggests conducting a 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. It also suggests developing 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.

Families have expressed frustration asking: “When will these processes be created? Moreover, how will they be adopted and implemented?” Advocates are asking: “Who among DoD and DHA senior leadership has responsibility for pediatric issues and action items? Similarly, who has responsibility for interactions and communication between DHA and DoD programs that intersect, such as ECHO and EFMP, Office of Special Needs, and ensuring that qualified EFMP beneficiaries have access to Medicaid including waiver services. What form are these interactions taking? We have no answer and no actual coordination across the spectrum of DoD programming and services, or meaningful interaction among DoD and community based services.

As just another example of a long known problem, in 2015 DoD reported to Congress that it was creating an Overarching Committee for Families with Special Needs. To date, there has been no information, announcements, or rollouts from this “Overarching Committee.” The Committee was referenced again, still with no detail, in a just released Instruction by the Office of Special Needs regarding EFMP regulations that were required by the 2010 NDAA and still not finalized. Military families of children with special needs deserve much more attention to and problem solving for their care coordination needs.

Meanwhile, the pediatric community and specifically children's hospitals, have been studying, conducting demonstration projects, sharing information among themselves to further quality, outcomes and understanding, and attempting to collaborate with the military health system to ensure that Tricare covered children and their families have access to these constantly improving best practices of care coordination.

Emerging Best Practices

The children's hospital innovative model ensures that care for medically complex children is coordinated by pediatric professionals with seamless spokes, hubs, and concentric circles, locally, regionally and nationally, so that care is delivered in the most effective setting with immediate access to the most complex and intensive care when necessary. These models recognize that care, as well as support and ancillary services take place across a full spectrum of providers and settings including the MHS (in the case of military families) and in the community.

The use of nationally designated children's hospital networks across the country to serve as the anchor of the care coordination model for these unique children provides a much higher quality, more effective care experience for families while lowering the costs of providing that care.

As health care plans, including TRICARE, move in the direction of accountable care and medical homes, it is imperative that models must be designed FOR children. Care for medically complex children is much different in nature than for adults; it is regional, as highly specialized providers are spread out around the country, and generally based in children's hospitals. Children with medically complex conditions, especially if the complexity involves different body systems, often must seek specialty care in different locations. Furthermore, when caring for children, time is of the essence for identification, intervention, collaboration among providers, and monitoring treatment due to their unique and constant growth and development. Similarly, military families experience frequent moves and with those comes the need to transfer among specialty providers. Collaboration with children's hospitals to implement a medically complex care model would place DoD at the forefront of innovative and effective care for the most vulnerable children in military families, and improve patient satisfaction and outcomes.

Moreover, working with a national network of children's hospitals, in conjunction with DoD's own pediatric specialty units where available and feasible, not instead of them, would ensure that TRICARE coverage policies are appropriate clinically and practically, and moves DoD toward more efficient health care financing and long term cost savings.

Conclusion

The Coalition concurs with the gaps identified, and urges DoD to refrain from reinventing the wheel in this arena and rather, encourages work with providers and groups such as children's hospitals, with expertise and experience in this arena. Children's hospitals have made great strides in creating networks of complex care coordination and management across the country that integrate clinical, non-

clinical, hospital based and community based, medical and support services to more effectively and efficiently serve families of children with complex health needs. Collaboration, contracting, and/or otherwise establishing demonstration project centers are all options for DoD in addressing this gap and achieving the goal of comprehensive, supportive networks to meet family needs.

Areas of DHB Interest:

- **Difficulties monitoring the provision of pediatric services due to data limitations and challenges tracking TRICARE Standard beneficiary care**

Data Challenges

DoD data regarding children's health are rich and robust; the only limitations seem to be bandwidth and expertise on how to use and understand it. Standard is changing into "Select" per the 2017 NDAA, which may change ease of access to data. Regardless, even with Standard, claims data is available for every encounter.

DoD data regarding children's health is readily available overall, robust and longitudinal, making it a wealth of information and positioning DoD to be a leader in research that could impact and improve children's health and well being in the short and long terms if it is researched properly. DoD should partner with pediatric experts in this arena, to tap data for useful and meaningful analysis. The PolicyLab at Children's Hospital of Philadelphia, for example has tremendous experience and depth, and has expressed interest in pursuing meaningful analysis and translation of DoD data as it relates to children's health care needs, access and outcomes.

System-wide Definition of Children and Youth with Special Health Care Needs

Because of inconsistencies within the data and programs throughout the military health system, the DoD should adopt an enterprise-wide definition of a "child (or children) with special needs," particularly we suggest the National Institute of Child Health and Human Development definition of children and youth with special health care needs (CYSHCN) for consistency among its own programs and those of other federal agencies.

- **Comparing covered services in TRICARE to national recommendations and guidelines**

National Recommendations and Guidelines

Tricare should be aligned with best practices in the pediatric community. Appropriate standards of care are not dependent on whether a child's parents are military or civilian. DoD could commission a specific study by a panel such as DHB, and include stakeholders to determine whether and how Tricare should align with known best practices and recommendations by organizations specializing in pediatric or prenatal care, such as those recommendations published by AAP, American College of Gynecology, and for children's vision and dental needs.

- **Emerging issues in pediatric medicine, such as the provision of care for transgender beneficiaries and the impact of vaccine exemptions & refusals**

Emerging Issues

One idea is to create a robust stakeholder engagement team with the pediatric health care community. With 2 million children covered by Tricare, many of whom will transition in and out of the military health system over a lifetime (about a third of military children join the Armed Forces!) regular interaction and sharing of best practices is sorely needed as a public health and readiness issue.

- **Coordination of care and the importance of the military family**

Children are dependent on their parents and families. Period.

Medical care and treatment options for the pediatric population must be structured and implemented in the context of the entire family. This is a fundamental difference from Medicare's focus on the adult individual, and should be embraced rather than addressed as afterthought only when an egregious example is highlighted.

This maxim is particularly evident when considering military families, with the unique challenges they face in the day to day support of the servicemembers' service to this nation.

Excellent examples of the need for this approach can be found in behavioral health where treatment options which encourage family participation should be not only accepted but encouraged; policies that recognize that a parent – often a single parent due to deployment – must manage the needs of multiple children; as well as policies for diabetes and other chronic conditions, e.g., a small child with diabetes will need family counseling and training as the child relies mainly on the parents during childhood, then older children and teens need differing counseling and training as they develop and take on more responsibility for their own decisions.

- **Vision of how pediatric beneficiaries should experience care in the Military Health System**

Vision of Pediatric Focused Care

The DHA must begin to proactively and comprehensively address children's unique health needs. This will mean identifying ways to remove barriers to appropriate care, rather than simply citing the current statutory, regulatory and policy explanations for less than optimal quality, access and coverage for children.

In order to contrast and compare a system where children's needs are made to fit within adult constraints, the DHB may wish to set up a site visit to one or more children's hospitals to see how the facilities, operating policies, services, supports and care plans in these institutions are completely tailored to children and their families, with everything from artwork and design, to child life services, to sleeping arrangements for parents, and so forth.

Stakeholders Must be Included

Because of continuous missteps in communication and misunderstanding of beneficiary experiences and needs, a Stakeholder Engagement Team that includes families, providers and advocates is critical to success. Families, providers and advocates must be integrated into the DoD processes for reviewing children's health benefits, coverage, access and quality, and for vetting and assisting with messaging of changes, reforms, and opportunities. Furthermore, DHB should consider recommendations for DHA officials to immerse with families in the field, experiencing from their standpoint a day in the life, or an episode of care for a child with chronic or complex needs.

Military families don't live or receive care in a vacuum and DoD should not develop or implement its programs in a vacuum. DoD must be committed to partnerships and communication with the communities in which our military families live—with their children's hospitals, their pediatricians and behavioral health providers, their service organizations, the educators and friends who form their support circles.

Leadership and Accountability

Although it is well established that Medicare policies are often inappropriate for children, and that medical care evolves rapidly, there is no indication that DHA takes responsibility for proactively identifying coverage gaps that impact military kids. Furthermore, even when alerted to problematic coverage policies, DHA seems reluctant to fix them.

When we as advocates are impatient for change, its not because we need immediate

gratification, rather because the lives of real people - real families, real children - are upended every day that policy and practice are behind the standard of care.

The Tricare for Kids Coalition has spent the last few years demonstrating examples and areas in which Tricare policy and practice gaps are leaving children without appropriate care, and offering to be a part of the solution via recommendations, and collaboration. We are pleased with the few steps forward taken to date, including stakeholder forums, but as is evident throughout this document, many identified and acknowledged problems are still churning without resolution and without any sense of urgency, merely vague reliance on further study or review. Time is of the essence when fashioning health care policy and practice for children, not just individually, but generationally. As reflected in the above discussion, many of these problems have been at issue throughout the entire childhood of an eighteen year old considering military service today. At some point action is needed to correct the deficiencies, not just further reports and plans.

Operationally DoD is known for its ability to tackle complex problems and execute solutions. Generally, a leader defines a goal, works with a team to problem solve and then implement the solution set, with benchmarks and deadlines along the way. Failure to do so triggers consequences. This does not ever seem to be the case for DHA regarding children's health benefits.

One can only assume that leadership has not made or communicated this issue area as a priority. If successfully addressing children's health needs requires a Tiger Team at the highest level of leadership, members across silos of responsibilities, a transparent mission, and a firm deadline, one must be chartered.