

Prepared Statement

Of

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and

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Before the

**Senate Armed Services Committee Subcommittee
on Military Personnel**

June 20, 2012

Mr. Chairman, Members of the Committee, it is a privilege for both of us to appear before you today, and we appreciate the opportunity to testify on our efforts to support military families that include a member with special medical or educational needs.

The Department of Defense is proud of the programs and services we provide to military families with special needs. We have been providing specialized services to families for decades. In response to the landmark legislation for military families with special needs (Sec. 563 of the National Defense Authorization Act, Pub. L. No. 111-84), the Secretary of Defense established the Office of Community Support for Military Families with Special Needs (OSN) in October 2010. This office is leading efforts to streamline processes that can be improved, to develop policies that guide the provision of support by the Military Departments, and to generally help families identify, understand and navigate the systems they will encounter. This office is closely linked with our colleagues in the Office of the Assistant Secretary of Defense (Health Affairs) and the TRICARE Management Activity (TMA) within the Office of the Under Secretary of Defense (Personnel & Readiness).

Support to military families with special needs is an especially important task for the Department. Military families with special needs are first *military* families. They have the same challenges any other military family may encounter in the face of periodic moves, deployments, and separation from family. Further, they face additional challenges, navigating often complex systems to obtain the services and benefits their families need to help their loved one function to their maximum potential. Each time a military family moves the process starts over, and they face questions such as: Who provides early intervention services in this state? Am I going to the local school system, public health or a regional board to get help? What do they call their programs here? Is there a waiting list for Medicaid, or perhaps, how long is the waiting list? Where do I sign up for the women, infants, and children program, and will they accept the certification from my current state? What will we do when we can no longer take our non-verbal child to the dentist who has finally achieved his trust? Will there be anyone at the new location who will understand what we need? What school district can best meet the needs of my child?

We recognize that these military families need assistance with these questions, and we have worked to make this process less challenging wherever possible.

The Current State of the Exceptional Family Member Program

For over 30 years, the Military Services have administered the Exceptional Family Member Program (EFMP), which identifies family members who have special medical or educational needs, documents their needs and ensures they are considered when the Servicemember is being considered for the next assignment. Since the FY 2010 NDAA, the EFMP has been expanded to include a requirement for family support and to extend the coordination of assignments based on the family member's special needs to permanent change of station (PCS) moves within the United States as well as overseas.

Currently, over 400 EFMP family support personnel serve military families with special needs. All installations have either a full- or part-time staff person, or (in smaller locations) a point of contact for military families with special needs. Installations with greater numbers of families with special needs may have multiple EFMP family support personnel. All providers have been trained in their roles, the agencies with which they will work, and the requirements of supporting military families with special needs.

The OSN developed an *EFMP Family Support Reference Guide* and disseminated it to all EFMP family support providers (to include Reserve and Guard Components) as a guide to providing family support and networking with community support systems. Through a Memorandum of Understanding with the U.S. Department of Agriculture (USDA), the OSN partnered with Cornell University and the University of Kansas to conduct a benchmark study identifying the concerns of military families with special needs, the support they require, and the systems that have been effective in providing services. The research team conducted focus groups with military families from all branches of Service and with civilian populations. This study will generate recommendations for the military in refining our support programs including staffing models, metrics, evaluation standards, and a family satisfaction scale.

The OSN is working closely with the Military Services to standardize the EFMP across Services. Military families want consistency, and we are improving their ability to navigate internal processes more easily by having standard forms, terms, and procedures. The OSN embarked on a multi-year project to analyze current systems (medical, personnel and family support) that make up the EFMP (identification/enrollment, assignment coordination and family support) to even more closely integrate service delivery. We have concluded the first year of the functional analysis. Over the longer term, we will create an integrated, longitudinal electronic

record that works across all Military Departments. This system will prevent families from reinventing paperwork with every PCS, allow the medical command to alert the personnel command about availability of medical services, and regardless of Service affiliation the family will receive a warm handoff to the receiving location. This is a detailed, iterative process involving multiple data and case management systems. The end result, however, will offer an important enhancement to the families we serve.

Listening to our Military Families

In the last two years, we have held two EFMP family panels representing military families of all ranks, Service affiliation, active duty and reserve components, and ages and disabilities of the family member with special needs. We have conducted three studies on access to special education in the public schools, access to Medicaid, and a benchmark study on what makes a support system work. The lack of state and local data identifying military-connected families who use public sector programs, including special education, remains a gap.

We have also consulted with non-governmental agencies on their knowledge of the relevant issues regarding special needs families, and participated in several of the Military Family Caucus sessions. These Caucus sessions pertained to special needs, and military family members who advocate for families with special needs were invited to discuss issues in our office. We have read the National Council on Disability's report, *How to Improve Access to Health Care, Special Education, and Long-Term Support and Services for Family Members with Disabilities*, and met with the researchers who developed the report. The same issues for our families emerge in each forum: access to special education, access to Medicaid, transition problems with access to TRICARE when families change locations, and a request for inclusion of applied behavior analysis as a medical benefit within TRICARE rather than through the Extended Care Health Option.

We have focused on providing the information military families with special needs members need, particularly during critical transition moments; we work to educate them about what is available to them and assist them with obtaining resources and benefits within the scope of the law. Our efforts have been directed at identifying the problems families encounter, addressing those we have the authority to address (such as consistency across the Military

Departments) and collaborating with the agencies/programs responsible for services not within our control.

Educating Our Families

While the Department does not have authority over programs in other governmental agencies or programs administered by the States, we have the responsibility to educate our families on how to identify resources available to any American citizen and obtain benefits. We can provide information about special education and the Individuals with Disabilities Education Act (IDEA) and all its requirements and protections. Many military family children benefit from special education and the families must know how these systems work. Our military families need and benefit from programs such as Medicaid, Supplemental Security Income, and early intervention, too.

The OSN has created a wealth of information for military families available on line at the *MilitaryOneSource.mil* website or by calling Military OneSource. These include written guides for families whose children have disabilities and a new guide for families where there is an adult family member with special needs. Both guides will be accompanied by a facilitator's manual, which can be used by EFMP staff (or families) to conduct training sessions on special education, early intervention, TRICARE, and much more. We conduct monthly webinars utilizing the talents of leaders in our field on such subjects as care giving, assistive technology, guardianship and estate planning, and advocacy. We have produced a series of podcasts available on smart phones and a mobile website that allows families to access EFMP providers, EFMP enrollment forms, and all of our online content. Several e-learning modules have been developed to increase parents' knowledge about special education and how to collaborate with school personnel, about the EFMP and about other Federal and State programs.

We are in the process of revising the content and presentation on the Military OneSource website and anticipate completion of this revision by September 1. From one landing page families with special needs will be able to learn about military and community programs, access an EFMP provider, sign up for a webinar or view archived webinars, request materials, or make an appointment for a specialty consultation with a Military OneSource consultant who is a professional in special needs.

Supporting DoD Programs to Serve Family Members with Special Needs

OSN has created an internal coalition of Defense organizations to address issues of access for our military families with special needs. Through effective collaboration with the Military Departments, the EFMP and Morale, Welfare and Recreation, we have built over 200 accessible playgrounds for children with disabilities and installed pool lifts in all military swimming pools. We have developed on line tools for families who are moving with a special needs family member to help them plan their move. For the past two years in cooperation with the military children and youth programs, we have funded on-going training and support to enable those programs to integrate children and youth with disabilities. The OSN purchased and distributed books and electronic subscriptions to all Military Departments' installation libraries and family centers to create an EFMP library. The set of references is intended to assist professionals and family members in accessing materials on disability-related topics. In addition, special education law resources were provided to Military Department legal offices and selected medical offices. We work closely with the DoD Education Activity to ensure the 9,700 children with special needs attending a DoD schools receive appropriate special education services.

Access to Special Education

Military families are concerned about access to special education services. Obtaining comparable services from one assignment to the next is the most consistently reported obstacle for military families and often reflects differences in eligibility and services between States. For example, the American Association for Employment in Education (AAEE) has reported shortages of special education teachers, speech-language pathologists, school psychologists, vision and hearing specialists, school nurses, physical therapists and occupational therapists, with many regions of the country reporting considerable shortages for several years in a row (AAEE, 1996-2010). There are wide disparities in school nurse staffing ratios; some exceed 1: 4,000. Only seventy-five percent of schools have a full or part time nurse; 25% have no registered nurse. Seventeen percent of schools with more than 750 students have no registered nurse on duty (National Association of School Nurses (NASN)). Forty-eight states and the District of Columbia identified special education teaching and/or at least one of the related service provider categories as an official "shortage area" for the 2011-2012 school year (Teacher Shortage Areas

Nationwide Listing, U.S. Department of Education, Office of Postsecondary Education, March 2011). Given well-documented fiscal pressures on State budgets, it is likely that discrepancies in which resources are available between school districts and among States will persist.

To address family member information needs in this area, OSN has initiated multiple efforts including establishing a resource clearinghouse to help families with relocation; identifying and promulgating effective support practices among service branches; and sponsoring research studies on evidenced-based educational practices. OSN developed an online Education Directory to inform families of points of contact, resources, and procedures in public school districts in the States with the highest number of military assignments. The project continues and by the end of FY 2014, we will publish a directory that includes all 50 States and the District of Columbia.

Through the USDA MOU previously mentioned, we are partnering with Ohio State University and Pennsylvania State University to collect more detailed data about the extent and types of issues impacting families as they attempt to access comparable special education services in their new duty station. This project will support the identification of special education issues for which parents and family support providers need additional training and assist in determining if a formal military complaint documentation system should be explored in collaboration with the U.S. Department of Education.

Access to Medical Services – TRICARE, Extended Health Care Option (ECHO) and Medicaid

In managing health and health benefit issues, we first ensure we are faithfully following public law regarding what is a covered medical benefit. We also seek to align our initiatives to the Military Health System (MHS) strategic plan, the Quadruple Aim, which is comprised of four interrelated missions -- Assure Readiness; Improve Population Health; Enhance the Patient Experience of Care; and Responsibly Manage the Cost of Care. We consider “family readiness” as an essential element of our Readiness strategy.

The MHS has long been a leader in offering benefits and services to military families with special needs. We have directed considerable effort in formulating policy for coverage of effective therapies under the TRICARE Basic Program and the Extended Care Health Option program. (ECHO).

TRICARE Basic Program. The TRICARE Basic Program – whether TRICARE Prime, TRICARE Extra or TRICARE Standard – offers a comprehensive health benefit that covers any medically or psychologically necessary care for special needs beneficiaries, to include physician visits, immunizations, psychological testing and medical interventions such as speech therapy, physical therapy and occupational therapy. TRICARE offers exceptionally comprehensive coverage with very low out of pocket costs to our beneficiaries. For active duty families enrolled in TRICARE Prime, the out of pocket costs are almost non-existent, and families are further protected by a \$1,000 out of pocket catastrophic cap, after which DoD pays 100% of allowable costs. By law, the TRICARE Basic Program may not cover non-medical services such as Applied Behavior Analysis (ABA).

ECHO. The ECHO program, established under Title 10 USC Code 1079, provides additional benefits not otherwise available under the TRICARE Basic Program to certain eligible active duty family members with special needs. As established by law (National Defense Authorization Act for Fiscal Year 2009, Public Law 110-417), the government will cover up to \$36,000 per beneficiary per year in ECHO benefits.

As we noted at the beginning of our testimony, similar to other military families, our active duty families with special needs members must move frequently from one location to another. To ensure continuity of care for ECHO participants when they move, our TRICARE contractors have established case management hand-off processes so that the receiving contractor will be prepared to maintain for a family the set of ECHO services it had been receiving before moving. Because of the complexity and diversity of the services required to effectively address the special needs of many participants in ECHO, TRICARE requires its regional managed care support contractors to provide case management services to ECHO participants. Applied case management ensures access to a comprehensive, coordinated set of required treatments and services.

Each of the three TRICARE contractors is required to deliver a uniform TRICARE benefit. Consequently, a family can expect to receive the same ECHO services upon arrival at the new duty station. However, families may notice some differences in the administration of these services by our regional contractors. The Department does permit some variation in administrative practices in order to permit the use of contractor best practices. In the unlikely event a family should be denied coverage under either TRICARE Basic or ECHO it had been

receiving in another TRICARE region, there is a well-designed appeal process beneficiaries may use, and the contractors are required to assist them in understanding and exercising their appeal rights.

Examples of benefits not available through the TRICARE Basic Program, but available through ECHO include: assistive services, expanded in-home medical services, institutional care when a residential environment is required, and other services that the Director of TMA determines are capable of reducing the disabling effects of a qualifying condition. These “qualifying conditions” include Autism Spectrum Disorders (ASD). At the end of FY 2011, DoD had over 10,000 TRICARE beneficiaries registered in the ECHO program.

The Department has worked to ensure our special needs families with ASD have access to the most widely-accepted educational intervention, known as ABA. Since 2001, the Department of Defense has covered ABA services for eligible active duty family members under the ECHO program (and its predecessor, the Program for Persons with Disabilities (PFPWD)). Originally, we covered ABA services only if provided by a Board Certified Behavior Analyst (BCBA). We found there were not enough of them available to satisfy the demand from active duty family members for services. So, in 2008 we constructed a demonstration to increase access to ABA services by permitting tutors, under the supervision of BCBAs, to provide the services. Even today, ECHO enrollees with an autism spectrum disorder who want ABA services but who do not want to participate in the demonstration may obtain the services directly from a BCBA, if available from that source.

This demonstration has succeeded in expanding access to services – and we continue to witness increased participation by ABA supervisors, tutors and TRICARE beneficiaries. As of March 31, 2012, there were 3,783 beneficiaries enrolled in the demonstration – a number that has grown by 3-5% annually, on average, since the program was first introduced in 2008. Just as importantly, a recent DoD survey of military parents of dependent children with autism reported that the improved access to ABA services contributed to improved military family readiness and retention.

The Department is now moving beyond a demonstration program and seeking to embed the supervisor-tutor model of ABA provision as a permanent element of the ECHO program. We published a proposed rule in the Federal Register on December 29, 2011 to establish coverage of this ABA provision under ECHO for eligible beneficiaries with ASD. Upon final

implementation of this rule, we intend to categorize ABA as an “Other Service” under the ECHO statute and permanently adopt a more robust ABA services delivery and reimbursement methodology.

While we are pleased that we have been able to broaden access to these services, we do recognize that some families experience additional out-of-pocket costs when needed services exceed the government’s statutory limit of \$36,000. Based on our own claims data from 2011, 207 beneficiaries using the ECHO program had expenditures above \$35,000 per year. Another 489 beneficiaries had expenditures between \$30,000 and \$35,000. Thus, in 2012, we estimate that approximately 86% of TRICARE beneficiaries with an ASD diagnosis and using the ECHO program have had 100% of their expenses covered within the \$36,000 government maximum.

Several Members of Congress have inquired about the feasibility of categorizing ABA services as a medical benefit covered under the TRICARE Basic Program. The Department conducted a thorough technical assessment of ABA in 2010 to determine whether ABA met the requirements for inclusion as a TRICARE covered service.

Our technical assessment looked at the following: Does the reliable evidence, as that standard is defined in law and regulations for TRICARE Basic Program coverage determinations, support a conclusion that ABA is medically or psychologically necessary and that it is appropriate medical care for Autism Spectrum Disorders (ASD)? (2) Does the reliable evidence support a conclusion that ABA is proven as medically or psychologically necessary and that it is appropriate medical care for ASD in accordance with the requirements of 32 Code of Federal Regulations Sec. 199.4. Can ABA be covered as a TRICARE benefit under Chapter 55 of Title 10, United States Code if it is concluded that ABA is not medically or psychologically necessary and that it is not appropriate medical care for ASD, or that it is not proven as medically or psychologically necessary or that it is not appropriate medical care for ASD?

We found that ABA is an “educational intervention” and does not meet the TRICARE definition of medically or psychologically necessary care. The majority of the reliable evidence characterizes ABA as not being a medical treatment, as that standard is defined in law and regulations for TRICARE Basic Program coverage determinations, but instead as involving non-medical, behavioral intervention services.

Consequently, the Director, TRICARE Management Activity has concluded that ABA is not medically or psychologically necessary or appropriate medical care within the meaning of

the law and regulations governing coverage of medical benefits under the TRICARE Basic Program. However, the assessment indicates that TRICARE has authority to pay for ABA to reduce the disabling effects of ASD for ECHO-registered dependents with an ASD diagnosis, and this assessment helped guide our decision to make ABA services a permanent part of the ECHO program. The assessment and Director's conclusion serve as the administrative record of the agency's decision and is reflected in the proposed rule. The TMA's Medical Benefit & Reimbursement Branch reviews information about Medicare's and other payers' coverage, regular medical technology updates available through a subscription to Hayes, Inc. reports (a medical technology assessment firm), data/evidence submitted by beneficiaries and providers on appeal, evolving practice information from the Office of the Chief Medical Officer, and TRICARE Managed Care Support Contractors' evolving practice reports. TMA decides on the basis of these information sources whether it is warranted to conduct a formal review to determine if a medical technology can be confirmed by the hierarchy of evidence specified in 32 CFR 199.2 to be considered medically safe and efficacious.

Medicaid. Some military families with special needs beneficiaries also qualify for Medicaid. There are select services that TRICARE does not cover that are available through this federal-state medical program. Example of items and services that TRICARE (and most civilian health insurance) does not cover includes long-term care, custodial care (assistance with daily living), adult day services, or expendable items such as diapers.

Because Medicaid is state-administered, military families that include member(s) with special needs face difficulties each time they move and they are required to reapply for Medicaid eligibility. In some cases, this includes placement on waiting lists. Because of the frequency of military rotations, some families do not move off the waiting list before they once again relocate. The Department has contracted with West Virginia University to study the problems military families face with accessing Medicaid. Preliminary findings of the West Virginia study indicate that families and EFMP providers need more training on how to access Medicaid. The final report from this study will be available in Fall 2012.

The DoD State Liaison Office held an open meeting recently to discuss adopting this as one of the issues to address with States much as they have addressed the transition of school-aged children. We will provide an update on the outcome of this recommendation in the near future.

The Department recognizes the enormous challenges that military families with special needs beneficiaries experience, and we have aggressively sought to meet their needs with targeted programs and services. As we stated earlier – family readiness is a military readiness issue. We have made tremendous progress over the past several years, consistent with the law that Congress has established.

In the case of military children with special needs, we have crafted programs that have only been enhanced and improved over the last 10 years – in the areas of education, special education, community wide information and education. In the medical arena, we have successfully expanded programs that allow for the delivery of services beyond the traditional medical services authorized under TRICARE. We have continuously worked to expand both service delivery and reduce their out of pocket expenses. Congress has also expanded the government’s maximum cost-share for the ECHO program from \$2,500 monthly maximum to \$36,000 annually.

We are committed to maintaining our passion for excellence and service to these very special families. We are proud of what we have accomplished to date, and we are optimistic about our ability to continue to meet family member needs for the long-term.

Again, we thank you for inviting us to be here today, and we look forward to your questions.

Executive Summary

The Department is proud of the programs and services we provide to military families with special needs. We provide educational, administrative, medical and other services to these families that meet or exceed the services offered by most employers in the country.

The frequent reassignments and relocations that are a part of life in the military are a challenge for even the healthiest families. For those who have children with special needs, the challenges are even greater. Together with Congressional support and direction, we have taken a number of steps to ameliorate these challenges. These steps include: the establishment of the Office of Community Support for Military Families with Special Needs (OSN); efforts to standardize Exceptional Family Member (EFMP) programs across the Services; investments in focus groups and academic research that inform policy makers about what is working, and what needs greater attention; enhanced infrastructure on military installations in support of children with special needs; assistance with Medicaid rules and eligibility in the States; and a robust education and outreach effort to inform military families about services both within DoD, and those available in the States and local communities.

The Military Health System (MHS) also provides critical services and benefits to military families comprised of children with special needs. The TRICARE Program offers a comprehensive benefit for all military beneficiaries through its Basic Medical Program - particularly to active duty service members and their families - who have very low out-of-pocket costs for covered medical services, and protection against family medical costs that exceed \$1,000 on an annual basis.

The TRICARE Program also includes the Extended Health Care Option (ECHO) which provides additional benefits not otherwise available under the TRICARE Basic Program to eligible active duty family members with special needs, covering up to \$36,000 per year for certain conditions. About 10,000 TRICARE beneficiaries are registered in the ECHO program.

One of the services covered under ECHO for special needs families with Autism Spectrum Disorder (ASD) is access to the most widely-accepted educational intervention for ASD -- Applied Behavior Analysis (ABA). Since 2001, the ECHO program has covered ABA services. In 2008, we expanded the number of providers who could provide ABA services under a demonstration program. This demonstration has succeeded in expanding access to services, and users of the service have grown by 3-5%, on average, each month since 2008. A DoD survey of military parents of dependent children with autism reported that the increased access to ABA services contributed to improved military family readiness and retention. We are in the process of making this ECHO benefit a permanent part of the ECHO program.

A number of military families wish to see the ABA benefit covered under the TRICARE Basic Program rather than ECHO (and thus removed from the \$36,000 annual ECHO cap). The Department commissioned an independent technical assessment of whether this service qualified as medically necessary and appropriate. Consistent with the law and regulations for the TRICARE Basic program, this assessment was deemed an "educational intervention" and does not meet the criteria for coverage under TRICARE Basic.

The Department is committed to providing a comprehensive set of services for military families who have children with special needs. We have strengthened our program in a number of ways over the last several years, and are confident of our ability to continue to meet the needs of these military families for the long-term.