



**NATIONAL
MILITARY FAMILY
ASSOCIATION**

Together we're stronger

Statement for the Record

of the

NATIONAL MILITARY FAMILY ASSOCIATION

Before the

**Subcommittee on
Personnel**

of the

**UNITED STATES SENATE
ARMED SERVICES COMMITTEE**

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The National Military Family Association is the leading nonprofit organization committed to strengthening and protecting military families. Our over 40 years of accomplishments have made us a trusted resource for families and the Nation's leaders. We have been at the vanguard of promoting an appropriate quality of life for active duty, National Guard, Reserve, retired service members, their families and survivors from the seven uniformed services: Army, Navy, Air Force, Marine Corps, Coast Guard, and the Commissioned Corps of the Public Health Service and the National Oceanic and Atmospheric Administration.

Association Volunteers in military communities worldwide provide a direct link between military families and the Association staff in the Nation's capital. These volunteers are our "eyes and ears," bringing shared local concerns to national attention.

The Association does not have or receive federal grants or contracts.

Our website is: www.MilitaryFamily.org.

Chairman Webb, Ranking Member Graham, and Distinguished Members of the Subcommittee, the National Military Family Association thanks you for the opportunity to present testimony for the record concerning the quality of life of military special needs families. After 11 years of war, we continue to see the impact of repeated deployments and separations on our service members and their families. We appreciate your recognition of the service and sacrifice of these families, as well as the unique challenges facing families who have a child or other family member with special needs. Your response through legislation to the increased and ever-changing need for support has resulted in programs and policies that have helped sustain these families through difficult times.

Support for Special Needs Families

Military families tell our Association the issues they face in caring for a special needs family member while simultaneously supporting the service of the military member are complex. Most often, meeting these needs requires the coordination of many distinct military and community entities, with the responsibility for that coordination too often falling to the already-burdened family. Military families caring for a special needs family member need not just medical and educational support. They also need assistance from state and local agencies, relocation help, respite, and family support, especially if they are also dealing with the deployment of their service members.

True support for these families must be designed and delivered holistically, but with the understanding that diagnoses and the severity of conditions vary from one special needs family member to another. No “one-size-fits-all” solution exists to solve the problems these families face. The military support systems guided through Department of Defense (DoD) offices, such as Health Affairs and Military Community and Family Policy, and the programs implemented by the individual Services and installations must be coordinated and flexible enough to meet the variety of needs in the military community. The military must lead an outreach to schools; other federal, state, and local government agencies; and charitable service-delivery organizations to ensure families know about and have access to the full range of support for which they are eligible.

To engage in this outreach and to support these families, and thus the service member, DoD must have the resources. We encourage you, in this time of scarce resources, to direct the Services to maintain robust Exceptional Family Member Programs and to provide enough School Liaison Officers to assist ALL families with issues they experience transitioning from school to school. While installation School Liaison Officers are available to assist all transitioning military families, special needs families especially benefit from their assistance as part of the installation support team in ensuring proper, timely placement, and delivery of educational services. Respite and family support programs provided by the Services for special needs families pay off in greater family capacity to meet the challenges of military life and deployment. Unfortunately, funding and availability for these programs has varied among the Services and among installations. We believe the support for the family and assistance with their special needs family member make these programs crucial in enabling the service member to focus on the mission.

While many issues remain for families caring for their special needs member, we are encouraged by the progress made at the installation, Service, and Department levels when adequate resources and the proper focus are provided. Your creation of the Office of Community Support for Military Families with Special Needs (OSN) in the National Defense Authorization Act for Fiscal Year 2010 (NDAA FY10) is one sign of progress. OSN's mission is to enhance and improve DoD support around the world for military families with special needs, whether medical, educational, relocation, or family support. Last year when discussing the OSN in testimony, our Association expressed concern about a lack of coordination on these issues between the various DoD program and agency stovepipes. Our Association is pleased OSN now regularly meets with the Department of Defense Office of Health Affairs to address the medical resources our special needs families require. We are also pleased the OSN has twice convened the Advisory Panel on Community Support for Military Families with Special Needs created in the NDAA FY 11 to get input from families on medical, educational, relocation, and family support resources our special needs families require.

Despite the progress, a holistic approach to supporting these families still remains the goal and not the reality for many. Case management for military beneficiaries with special needs is not consistent across the Services or the TRICARE Regions because the coordination of care for the military family is being done by a health care system whose individual elements do not always work in synergy. Beneficiaries try to obtain an appointment and then find themselves getting partial health care within the Military Treatment Facility (MTF), while other health care is referred out into the purchased care network. Thus, military families end up managing their own care. Incongruence in the case management process becomes more apparent when military family members move, not just from one TRICARE Region to another, but often even when transferring within the same TRICARE Region. This incongruence is further exacerbated when a special needs family member requires not only medical intervention, but non-medical care as well. Each TRICARE Managed Care Support Contractor (MCSC) has created different case management processes.

Families need a seamless transition and a warm hand-off between and within TRICARE Regions and a universal case management process across the Military Health System. We believe TRICARE leaders must be more engaged with their family support counterparts both through the Office of Community Support for Military Families with Special Needs and at the local level to develop a coordinated case management system that takes into account other military and community resources, as well as health care. We recommend a Government Accountability Office (GAO) report to examine the case management process for special needs families.

ECHO

The Extended Health Care Option (ECHO) program, the primary benefit enhancement for special needs military families, has been the topic of a great deal of debate among military families and by Congress. Congress created the ECHO program to allow active duty families with special needs to receive additional services to offset their lack of eligibility for state or federally provided services due to frequent moves. We assert that this focus on supporting currently-serving families is appropriate and should remain the priority for DoD. We suggest that, before making any more

adjustments to the ECHO program or to other benefits, Congress should request a GAO report to determine if the ECHO program has been effective in addressing the needs of the population it was intended to serve in the way it was intended. The report should also address ECHO coordination with other benefits, both the regular TRICARE benefit and state and local resources.

Special needs families come in all demographics and diagnoses. It is important to note that the TRICARE ECHO program provides services for all types of diagnoses. A military spouse eligible for ECHO can be diagnosed with multiple sclerosis, an adolescent with psychosis, or a child with Down's Syndrome. Recent focus on TRICARE ECHO has been on supporting military children diagnosed with autism spectrum disorder. However, family members with other diagnoses are also enrolled in the ECHO program and benefit from its services. As the conversation on changing ECHO or TRICARE benefits continues, we ask Congress to recognize that special needs family members enrolled in ECHO with diagnoses other than autism spectrum are also benefiting from Applied Behavior Analysis (ABA) therapy. These diagnoses include, but are not limited to, Down's Syndrome, Mental Retardation, Angelman Syndrome, Cerebral Palsy, developmental delays, and Fragile X.

Under the ECHO benefit, the TRICARE Management Activity established an Autism Demonstration, known to beneficiaries as the "Demo." The Demo provides beneficiaries with an autism spectrum diagnosis the ability to purchase more ABA therapy through the use of tutors. ECHO-enrollees who cannot qualify for the demo based on diagnosis, but who would benefit from ABA, cannot use the tutors and thus their benefit would not cover as many hours. Our Association recommends any changes made to the TRICARE ECHO benefit or related demonstration programs need to incorporate the needs of ALL diagnoses among program-eligible family members.

We also hear from our ECHO-eligible families that they could benefit from additional programs and health care services to address their special needs. We request a DoD pilot study to identify what additional services, if any, our special needs families need to improve their quality of life, such as cooling vests, cranial helmets, diapers, or nutritional supplements. We recommend families in the pilot have access to \$3,000 annually above what is provided by ECHO to purchase self-selected items, programs, and/or services not already covered by ECHO. DoD would be required to authorize each type of purchase to verify the requested item, program, or service is appropriate. This pilot study could identify gaps in coverage and provide DoD and Congress with a list of possible extra ECHO benefits for special needs families.

The Reserve Component (RC) has unique challenges with their special needs family members. They only qualify for ECHO when they are on active duty status. The population is relatively small, but our Association is concerned with the coordination of care and seamless transition of services as the special needs family member becomes eligible to receive ECHO benefits and then loses them when the member is deactivated. We request that Congress direct GAO to examine ECHO benefits during the activation and deactivation cycle, and the impact on the RC family and the special needs family member.

Transitions

We applaud the attention Congress and DoD have given to our special needs family members in recent years and the desire to create robust health care, educational, and family support services for special needs family members. However, these robust services do not follow the family members when the service member retires from the military. When ECHO was created as an active duty support program, its creators believed families in retirement would be able to access similar services through other federal, state, or community programs.

We know the transition to retirement can be difficult for many families, however, because of the immediate loss of ECHO benefits upon retirement. Both TRICARE and civilian insurers face growing pressure to incorporate coverage of services currently available for military families only through ECHO into their basic benefit package, even though only certain special needs family members may benefit. As you review possible TRICARE changes, we ask you to ensure that benefits changes balance the needs of all members of our community

We remain concerned about the transition of wounded, injured, or ill service members and their families from active duty status to that of medically-retired, especially when the family includes a special needs family member. We support DoD's proposal to exempt medically-retired service members, survivors of active duty service members, and their families from the TRICARE Prime enrollment fee increases. However, we believe wounded, ill, or injured service members need even more assistance in their transition. We continue to recommend that a legislative change be made to create a three-year transition period in which medically-retired service members and their families would be treated as active duty family members in terms of TRICARE fees, benefits, and MTF access. This transition period would mirror that currently offered to surviving spouses and would allow the medically-retired time to adjust to their new status without having to adjust to a different level of TRICARE support, increased costs, and the immediate loss of ECHO benefits for their special needs family member.

Our Association has always recommended that special needs families be allowed to pick their last duty station, preferably in the state where they will reside after they retire from the military. This additional time would give them a head start on establishing themselves in their communities, enrolling in state Medicaid Waiver programs, and receiving local services. As our military downsizes, the preparation for transition and establishing eligibility for needed services before entering civilian status could become more difficult. We recommend the Services allow special needs families enrolled in EFMP the opportunity to choose their final duty station before retirement. Because such a move is not always possible, we recommend legislation be passed to extend ECHO eligibility for one year after retirement for enrolled family members to provide more time for families to transition to state and local services or employer-sponsored insurance.

We also encourage you to use your Congressional bully pulpit to stimulate more awareness in the states about the needs of military families. We believe one of the most critical issues at the state level for our special needs families is the availability of and military family eligibility for Medicaid waivers. The Office of Community Support is studying Medicaid availability for special needs military family members. Our Association is anxiously awaiting this study's findings. We will

be especially interested in the types of value-added services individual State Medicaid waivers offer their enrollees and whether state budget difficulties are making it harder for military families to qualify for and participate in waiver programs. This information will provide yet another avenue to identify additional services ECHO may include in order to help address our families' frequent moves and their corresponding inability to qualify for these additional value-added benefits in a timely manner.

We have also asked the DoD State Liaison Office to consider exploring ways to stimulate state discussions on how to provide portability for military family members' enrollment in Medicaid waivers. Too often, military families arrive in at a new duty station, put their special needs family member on a waiting list for a waiver, and finally start receiving services under the waiver not long before it is time for another military move to a different state, where they must start the process to obtain a waiver all over again. We know achieving portability may be difficult because each waiver program has its own set of eligibility requirements, services determined, and funding provided by the states, but believe it is important to raise awareness about the issue and stimulate discussions at the state level.

Recommendations

To meet the needs of all our special needs military families, we need a coordinated approach to both service-delivery and information gathering. We encourage Congress and DoD to seek more information from a variety of sources:

- military families representing the full range of diagnoses and conditions
- DoD service providers in the Service and Installation Exceptional Family Member Programs
- civilian and military health care providers and case managers, including those working for the TRICARE contractors
- educators in DoD and civilian school districts
- state and local agencies, such as Medicaid
- representatives of the national disability organizations

Only with the right information can DoD apply correct solutions to meet the needs of these families. Our Association believes the Medicaid waiver report, a GAO report on the ECHO program, along with our recommended pilot study will provide DoD and Congress with necessary information to determine if the ECHO program needs to be modified in order to provide the right level of extra coverage for our special needs families. We also recommend a report examining the impact of wartime deployments on special needs military families.

In conclusion, we ask Congress to:

- *Ensure any changes made to the ECHO benefit incorporate the needs of families with ALL diagnoses.*
- *Direct DoD to expand the Autism Demo 's coverage of Applied Behavioral Analysis therapy to all eligible ECHO-enrolled beneficiaries when therapy is deemed necessary by their physicians.*

- *Create a DoD pilot study to identify what additional service(s) special needs families need to improve their quality of life.*
- *Allow medically-retired service members and their families to maintain the active duty family TRICARE benefit for a transition period of three years following the date of medical retirement, comparable to the benefit for surviving spouses.*
- *Allow already-enrolled family members in ECHO to remain eligible for one year following the service member's retirement from the military.*
- *Require GAO reports*
 - *to evaluate DoD's existing case management programs and program coordination for special needs family members*
 - *to evaluate how well ECHO coordinates with other benefits: with the regular TRICARE benefit and those offered by other federal, state, and local government agencies and community resources.*
 - *to examine the impact of almost 11 years of war on our special needs families.*
 - *to examine the impact of ECHO benefits during the activation and deactivation cycle on the RC family and the special needs family member and if the program has been effective in addressing the needs of this population.*
- *Direct the Services to maintain robust Exceptional Family Member Programs*

Military Families – Our Nation's Families

Bringing the troops home does not end our military's mission or the necessity to support military families, especially their children, dealing with the long-term effects of more than a decade at war. Downsizing and budget cuts will present new challenges. The government should ensure military families have the tools to remain ready. Effective support for military families with special needs must involve a broad network of government agencies, community groups, businesses, and concerned citizens. Our Nation must continue to fund what works to support military families, protect the most vulnerable, and, above all, value their service.