

Prepared Statement
of
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2012 Military Spouse of the Year
Regarding
Military Families Impacted by Disabilities
Before the
Senate Armed Services
Personnel Subcommittee

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Mr. Chairman, Senator Graham, and distinguished members of the Subcommittee, thank you for the opportunity to discuss the issues facing our military families impacted by disabilities and your consideration of actions and initiatives that I submit need to be accomplished to ensure our nation honors its obligations to our military families. By doing so, I believe we enhance the readiness of our all-volunteer force and improve the lives of our military children.

Introduction

I am a 1995 United States Air Force Academy graduate that cross-commissioned into the Navy and served eight years in the submarine force. In 2002, while on shore duty at the Washington Navy Yard, our daughter, Kate, was born with a number of significant disabilities. Seven months later, I resigned my commission and have been taking care of our children ever since. Since Kate's birth we have moved six times, five of those within a five year time frame due to deployments, training, and military Permanent Changes of Station (PCS). Kate has undergone nine surgeries and received thousands of hours of therapy, provided by our family and outside therapists. Our primary goal is to ensure she lives life to her fullest and is educated and lives in the community to the greatest degree possible. My wife remains active duty Air Force, and we are currently stationed at Andrews AFB where she is the commander of an AFOSI squadron. We have a two-year-old son, Jackson.

In May 2012, I had the distinct honor of being selected as the Military Spouse of the Year, based on my advocacy for military families. I started as an advocate for our daughter. That advocacy expanded within the Air Force, then the DoD, and then to the larger disability population. I quickly discovered there are so many unmet needs in the disability world. Our families are overwhelmed. There is little to no time to be advocates because many families are simply surviving. We don't have the defense industry or unions to ensure our programs receive the funding they require. We have a very small group of volunteer parents that do their best to raise these tough issues when they happen to be stationed in the DC Metro area. What I have learned from being part of this process is that our families do have a voice, but many times it is very quiet, at least relative to

the normal buzz in DC. However, what we lack in volume, we make up for with passion. In the short amount of time we've had since the hearing was announced, these amazing families have provided me the most astonishing and personal insights into their lives and the hope they have for their children. I hope the Committee finds their stories instructive (see attachments after written testimony).

This Committee plays an integral role in both legislation and oversight on the issues that enable our families to support our service members while they protect our country. Your support continues to be instrumental in making needed changes to the DoD infrastructure, policy, and procedures which will allow our special needs military families to deal with the significant stresses associated with service; Permanent Changes of Station (PCS), multiple deployments, and the high operational tempo that has marked these past ten years of war.

There are a number of areas that I will be discussing today: Medicaid Waivers, the Extended Care Health Option (ECHO), TRICARE, Autism, Education, the Exceptional Family Member Program (EFMP), Survivor Benefits, and Legal Issues. Each of these programs and issues has a substantial impact on the health and well-being of our military families with disabilities and it is critical that the Committee understand what areas require improvement.

Many of these areas were considered in a recent National Council on Disability (NCD) study on Marine Corps EFMP families (transmittal letter included as Attachment A). In the preamble to the study, the NCD Chairman, Jonathan Young stated:

“However, many of the changes necessary to improve the supports available to military families with [Exceptional Family Members] are beyond the control of the Marine Corps and may require statutory and regulatory changes to meet these needs.

NCD has concluded that far-reaching systemic changes are needed in our nation’s health, education, and long-term service systems to address the significant barriers faced by EFMs. NCD thus seeks support from Congress, the military, and the Administration to build the critical federal partnerships necessary to effect systemic change and ensure that the men and women serving our country can do so knowing their Family Members with disabilities will have the supports and services they need.”

This hearing is the first step in addressing these extraordinarily important issues to our military families.

Medicaid Waivers

Caring for a child with a disability can be exceptionally expensive and remarkably stressful. We have higher medical bills, therapy bills, home modification, equipment and supply bills, and other large expenses. Many, if not most, families impacted by disabilities will come to rely on public assistance programs in some fashion for our children who are disabled. The majority of such programs relate to state-run Medicaid waiver programs which provide short and long term benefits that TRICARE does not. Examples of such supports include incontinence supplies, respite, employment supports, housing, and more flexible medical coverage. Most of the Medicaid waiver programs run by the states have significant waiting lists for citizens to access these benefits because the need is simply much greater than the available benefits. It is not uncommon for a family to place a one-year-old on the state Medicaid waiver waitlist with the hope the child will receive benefits by the time they are a teenager or an adult, depending on the type of waiver and the state in which they reside. For our highly mobile military families, that means our children constantly remain at the bottom of any given state's waitlist. If by chance they get off the waitlist and receive services in one state, they will lose their eligibility once they PCS, and they will find themselves back on the bottom of the next state's waitlist. Upon retirement after a career of service, our children, yet again, find themselves on the bottom of waitlist at their new and final home.

There are a variety of ways in which this problem could be rectified, including a military Medicaid waiver, an Interstate Compact addressing Medicaid portability, allowing service members to maintain list-eligibility based on their home of record, or extending the ECHO benefit into retirement. Given the cross-committee jurisdictional nature of this issue, Medicaid reform may seem like a bridge too far, but it is one that will have a significant impact on our families.

Parent advocates are currently working with a variety of partners on finding a fix that addresses the problem.

The DoD has funded a grant for West Virginia University to study this issue and we expect findings this

summer. We would ask that this Committee remain engaged on this issue moving forward to ensure state Medicaid services for our military children are provided for equally in comparison to their civilian counterparts.

ECHO Program

The Extended Care Health Option (ECHO), created in 2005, was originally designed to bridge the needs of families due to the inability to access state-run Medicaid programs. Our experience has been that it does not replicate those benefits because of the lack of flexibility in the ECHO program. Military families strongly support the Senate report language that directs the DoD:

“to assess participation in the ECHO program by eligible dependents with special needs, and to explore options to provide more flexible benefits.” [sec 703]

Our families are grateful for the ECHO benefit. However, it is time to reassess its effectiveness to meet the requirements for which it was created. As one is considering the benefits typical families might need, it is imperative that DoD consider best practices as applied by the states. Please understand that while these studies are taking place, children may be very well going without necessary items or therapy. We would hope for an aggressive timeline for dissemination and prompt action on the basis of the results from the study.

There are two helpful resources when considering both Medicaid and ECHO issues:

- United Cerebral Palsy’s annual “Case for Inclusion” which ranks the 50 states and DC on its Medicaid waiver programs: <http://www.ucp.org/the-case-for-inclusion/2011/>
- Medicaid’s Web based resources: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Waivers/Waivers.html?filterBy=1915%28c%29#wavers>

One striking item included in the Medicaid website highlights that there are 423 different Medicaid waiver programs and demonstration projects throughout all 50 states and the District of Columbia. There must be a way we can find to serve the military family appropriately.

TRICARE

As most parents are quite aware, children are not simply little adults. It is why the children's hospital model exists, to provide for a child's unique health care needs. This is why TRICARE, being based on Medicare, sometimes doesn't provide the best possible care for our military children, particularly those who have special health care needs. It is also why military families support the TRICARE for Kids Amendment (Attachment B) included in FY 2013 NDAA recently passed by the House. This bi-partisan amendment was co-sponsored by Representative Steve Stivers (R-OH15), Representative Susan Davis (D-CA53), and Representative Bobby Schilling (R-IL17) and has been endorsed by the Military Officers Association of America (MOAA), the National Association of Children's Hospitals (NACH), the National Military Family Association (NMFA), and the March of Dimes.

From a recent endorsement letter by the March of Dimes (Attachment C), they noted:

“Unfortunately, because TRICARE utilizes a reimbursement structure based on Medicare, it often adopts policies and practices from Medicare that do not address the unique health care needs of children. Moreover, despite the best efforts of the Department of Defense, military families with children with special health care needs and chronic conditions often have difficulty accessing resources and services from local or regionally specialized providers. This problem is further exacerbated by the mobility of military families, who must repeatedly locate and obtain specialized health care service in unfamiliar geographic regions as their assignments change or they are deployed.

The *TRICARE for Kids Act* seeks to better shape the policies and practices of TRICARE to meet the needs of children, including those with special health care needs or chronic illnesses.”

Our hope is to ensure that the final NDAA includes the Tricare for Kids amendment, section 723 in the House bill, and that the conference committee report will mirror the Section 703 report language provided by the Senate, thus providing a specific panel to address children's health needs, and adding ECHO to DoD's ongoing evaluation and reporting of cost, access, and quality.

Autism

While we look forward to enhanced functionality of the TRICARE program, the treatment of autism for our military children is one area that I do not believe requires further study; it requires action.

TRICARE currently segregates ABA (Applied Behavioral Analysis), the standard of care in the treatment of autism, into ECHO, which is an entirely separate arm of TRICARE, as a “non-medical educational” service. TRICARE’s classification of ABA as “non-medical” allows TRICARE to limit care to dependents of active duty service members and places a financial cap on treatment services which falls far below recommended standards. There is no other disease, disability or chronic health condition which is treated similarly as autism in its segregation of treatment outside the basic TRICARE benefit. Families are forced to make the difficult decision of paying thousands of dollars out of pocket to address these deficits or forgo medically recommended care. Because the ECHO benefit is only available for dependents of active-duty service members, dependents of our retirees (including Wounded Warriors retired due to injuries sustained in combat) are not able to access ABA treatments under TRICARE and Guard/Reserve families receive intermittent care.

Contrary to DoD’s stated position, in April of this year, the U.S. Office of Personnel Management (OPM) concluded that ABA treatment for autism is a "medical therapy." In a letter dated 19 April 2012 (Attachment D), OPM stated [bottom of page 5]

“The OPM Benefit Review Panel recently evaluated the status of Applied Behavior Analysis (ABA) for children with autism. Previously, ABA was considered to be an educational intervention and not covered under the FEHB Program. The Panel concluded that there is now sufficient evidence to categorize ABA as medical therapy.”

The previous findings are instructive as well as they point to what level of evidence was required to overcome OPM’s original objection. In a 2006 letter to Representative Christopher Smith (R-NJ4) (Attachment E), the Director of OPM, Linda Springer, stated

“It is OPM’s most sincere hope that one day randomized trials will demonstrate ABA to be an effective course of treatment for autism and no longer be considered investigational. OPM has

great empathy for the families affected by this tragic disorder, and regret our decision could not be more favorable”.

Coverage of ABA care in the civilian sector also exceeds that of TRICARE. Currently, 30 states have laws requiring private insurers to cover autism-related therapies, including Applied Behavior Analysis (ABA), as a medically necessary service. TRICARE’s position that ABA therapy is “non-medical” is now contrary to the federal government and laws in 30 states.

We now stand at a point where, without action by the Congress, we will soon see federal workers provided medically prescribed autism therapy for their children while military families receive either an inferior level of care or, as in the case of the retired veteran’s child, receive no care. Our families simply cannot imagine that Congress would find that appropriate.

With strong bipartisan leadership, the House’s 2013 version of the NDAA includes important language clarifying that military dependents with autism, regardless of duty status, have access to medically necessary behavioral health treatments including ABA through the TRICARE basic program. Our military families ask that you work to ensure comparable language is included with the Senate version of the NDAA.

Education

Special education as a career is truly a calling and the vast majority of teachers who instruct our children are competent professionals whose greatest desire is to see our children succeed. However, with the pace, length, and number of deployments over the past ten years, as well as the normal structure of the military lifestyle, military families whose children require special education have struggled to receive a free appropriate public education.

According to the Military Child Education Coalition, the average military child will transfer schools 6 to 9 times between grades K to 12. For the special needs military family, the frequent moves present additional challenges: reestablishment of medical care, educational services, and necessary therapies each time they move

to a new location. For many of our families, this means the primary caretaker parent will devote countless hours ensuring their child's needs are met. In the event the spouse is employed outside the home, or in the case of a dual active duty couple, there is little time to digest the changing special education laws and regulations required to ensure a child receives a free, appropriate public education. In many situations, military families either go into debt to hire advocates or lawyers to ensure their child is receiving an appropriate education or they go without and watch their child regress in an inappropriate placement without proper supports.

In the event that a school district does not provide appropriate services for a military child, the family must weigh the following before attempting to hold a school district accountable under the Individuals with Disabilities Education Act (IDEA):

1. Legal fees, many lawyers no longer will take a case on contingency
2. Expert witness fees (not reimbursable even if you win your case)
3. Length of time left in the current assignment
4. Family and life considerations (financial and medical stress, spouse deployed, wounded, or otherwise unavailable).

Military families have little control over where they will be stationed, sometimes as part of a normal base reassignment, and sometimes when a spouse and child(ren) have to live close to family when a member deploys for a year or more.

Some school districts take advantage of military families, calculating how long they will likely spend at a current base, and the families' emotional, physical, and financial abilities to utilize their procedural safeguards under IDEA.

The average due process case to hold a school district accountable lasts a number of years, making IDEA's procedural safeguards essentially meaningless for the large majority of military families, particularly when confronted with an aggressive, cost-cutting school administration. Most school districts have law firms retained from taxpayer funds with unlimited time to run out the clock against a military family. Military families have

few resources to hire lawyers or retain experts to ensure our children receive an appropriate education.

Included in the 2011 NDAA was a directive to DoD to consider these issues for study (sec 583). The DoD's response was that the evidence was anecdotal therefore they could not make any conclusions without appropriate data. This lack of data has been a consistent issue for all military connected children as evidenced by the DoD report as well as two GAO reports spanning over the last five years (GAO study entitled "Military Personnel: Medical, Family Support, and Educational Services Are Available for Exceptional Family Members" (2007) and GAO study entitled "Education of Military Dependent Students, Better Information Needed to Assess Student Performance" (2011)). Over the last five years, we could have been collecting data to take action, but for some reason, we haven't. It seems clear to me that a data element is needed to identify our military connected students so we can access and evaluate their needs.

In August of 2011, four service representatives wrote a letter to the Assistant Secretary for Special Education and Rehabilitative Services, Ms. Alexa Posny, for clarification and guidance on issues specifically related to military families (Attachment F). To date, no response has been provided. While many of the educational challenges facing our military connected special needs students involve cross jurisdictional issues, we desperately need this committee's strong leadership to ensure our children are appropriately taken care of.

Finally, the new Post 9/11 GI Bill offers a terrific option to transfer educational benefits to dependents; expanding these benefits to cover more options beyond traditional degree-granting education would be a welcome improvement for our special needs dependents.

Exceptional Family Member Program

DoD support for families with special needs has been a work in progress for many years. The 2010 NDAA included the creation of the Office of Special Needs (OSN) within the Military Community and Family Policy

Office. The next year's NDAA provided for the creation of the Military Exceptional Family Member Panel, which includes military family members and adults impacted by disability. The goal of the panel is to provide specific real world input to the OSN on issues facing our families. Each of these has been a forward step in improving our family member's ability to access a life that any parent would want for their child. We thank the committee for taking legislative action to improve DoD support for military families with special needs. However, the proof is in the implementation of these directives.

The specific mandate provided to the OSN included "The development and implementation of a comprehensive policy on support for military families with special needs". Two years later, this hasn't been completed. Without appropriate policy to review, it is not clear where we stand with many of the other mandates assigned to the OSN.

Our families ask that appropriate oversight be provided to ensure that the Office of Special Needs has the funding and personnel to carry out its mandates and then ensure that they are completed in a reasonable amount of time.

To consider best practices within DoD, one need look no further than the Marine Corps, which is universally lauded as providing the best care for its exceptional family members. Attached you will find a recent brief provided by the head of the USMC Family Programs branch, Rhonda LaPorte, which provides an immediate overview of the current EFM Program as well as future direction. (Attachment G). We believe the other services should follow the lead of the Marine Corps as they review their EFMP programs.

Survivor Benefits

Today, service members with permanently disabled children face an unfortunate dilemma. Under current law, the service member can only direct survivor benefits to that child, and not a trust of any sort. Because the SBP

annuity cannot be placed into a special needs trust this survivor benefit ironically will make the beneficiary ineligible to receive the Medicaid waiver which allows many individuals with a disability to survive. One example of a consequence includes a disabled adult being removed from a group home or other long term care facility provided by Medicaid because the SBP amount exceeds state income thresholds for Medicaid waiver programs and disqualifies the individual from that program. Please see Attachment H for a more detailed analysis of this issue by a lawyer who specializes in special needs trusts.

Civilian families are able to create special needs trusts for their permanently disabled children that preserve their access to Medicaid while providing them additional supports that enable them to live in their communities. We believe that members of the military should have the assurance that their surviving family members with disabilities will have the same opportunities after they are gone.

The Disabled Military Child Protection Act, HR 4329, was introduced in this Congress to correct this disparity. Unfortunately, because of a very modest cost and lack of a means to pay for it, the measure was not included in the House version of the NDAA. We request the Committee to file an amendment to be added to the Senate NDAA in order to resolve this issue.

Legal Issues

There are a whole host of issues our military families face when trying to access the legal system. For military families with special needs, these primarily include issues related to guardianship, wills, trusts, and special education. Each one of these issues create significant out of pocket expenses above and beyond that of a typical military family. The issues are not ones that the on-base JAG officers are qualified to provide counsel on, and most JAG officers do not have the connections required to even provide a referral.

Our families are encouraged by the Senate language regarding its support for the American Bar Association's Military Pro Bono Project. We would encourage the Secretary of Defense and the DoD's General Counsel to consider the unique issues of our military families impacted by special needs as they are investigating the report request by the Senate (detailed in Senate Report 112-173).

Disability Issues

There are a variety of issues which impact the disability community as a whole, including our active duty military families, our veterans and retirees, and particularly our Wounded Warrior community. The Senate will soon consider the Convention on the Rights of Persons with Disabilities (CRPD). The Senate HELP Committee will hold a hearing on restraint and seclusion in our public schools on the 30th of June. While the Senate Armed Services Committee does not specifically play a role in these issues, please appreciate the fact that these issues are ones that our families care about and your support in ensuring these issues are resolved significantly impacts our military community.

Conclusion

“Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society.”

These are the Congressional findings from the Individuals with Disabilities Education Act (IDEA), the federal law that ensures children with disabilities are provided a public education. If the concept that having a disability is a natural part of our world is foreign to you, you are not alone. But like so many things in our world, your perception can change in a millisecond. For some of us, this will happen in a split second, whether that is an IED explosion or from the doctor telling you something is wrong with your baby. For others, it will be the shocking realization of the road you are about to travel as you deal with your MS, cancer, or Alzheimer's. Smart disability policy is the right thing to do, both for our military families and for its positive impacts on our force's readiness. Short term thinking and budgeting will in fact have significant long term cost, whether we are talking about the rehabilitation of a young airmen with TBI or a child with cerebral palsy or autism. Our

entire society as a whole has made significant strides in the last four decades in supporting people with disabilities. The strides our society as a whole has made have been mirrored in many of the programs within the Department of Defense and the VA. However, there continue to be significant stovepipes within DoD, the VA, Tricare, the individual services as well as individual states as opposed to an appropriate sharing of best practices and implementing changes needed. What we need is leadership at all levels of the chain of command, within the Congress, and within our local communities to make change reality.

I've attached a number of stories of individual military families immediately after this written testimony. These are amazing Americans, who endure exceptionally trying circumstances and somehow find ways to serve their nation and many times try to help others. I would encourage you to take a moment and get to know each of them. If you look "hero" up in the dictionary, you'd see the faces of these moms, dads, and their children.

We don't pretend to think that there are any easy tasks in front of us as a nation. How we deal with these tough issues will define us as a nation. Our families appreciate the opportunity and leadership demonstrated by holding this hearing. Thank you to this Committee for not forgetting our military families.

List of Attachments

Attachment A	NCD Transmittal Letter on USMC EFMP Study
Attachment B	TRICARE for Kids Amendment
Attachment C	March of Dimes Endorsement Letter
Attachment D	OPM FEHB Program Carrier Letter
Attachment E	2006 OPM Ltr to Rep Christopher Smith
Attachment F	2011 Ltr to Assistant Secretary Posny
Attachment G	USMC Family Programs Briefing
Attachment H	SBP Legal Analysis