

Prepared Statement  
of  
Jeremy Hilton  
Navy Veteran, Air Force Spouse  
2012 Military Spouse of the Year  
Regarding  
Military Families Impacted by Disabilities  
Before the  
Senate Armed Services  
Personnel Subcommittee

20 June 2012

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 our appropriately take 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 30<sup>th</sup> 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

Attachment A

NCD Transmittal Letter on USMC EFMP Study





## National Council on Disability

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An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

### Letter of Transmittal

November 28, 2011

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit the enclosed report, "United States Marine Corps Exceptional Family Members: How to Improve Access to Health Care, Special Education, and Long-Term Supports and Services for Family Members with Disabilities." NCD conducted this study at the request of the Marine Corps, which has a longstanding commitment to providing support for its Families with disabilities. This report is based on a study conducted within the Marine Corps interviewing Marines and Families that have dependents that meet the requirements to qualify for the Exceptional Family Member Program (EFMP).

The lifestyle of the Marine Corps Family is challenging under the best of circumstances. Among the challenges that military Families face are separation from their extended families, Service Member absences, permanent changes of station moves, and the stresses of combat and noncombat deployments. These challenges are compounded for Families with disabilities, referred to in the Marine Corps as "Exceptional Family Members" (EFMs).

The Services have recently passed the marker of 10 plus years of armed conflict across the world, but most specifically in Afghanistan and Iraq. Multiple deployments to these theaters have increased stress on all military Families, but even more on those with EFMs.

The objectives for this study were to:

- 1) Document the experiences of USMC EFMP participants in accessing appropriate and effective services in health care, special education, related services, long-term supports, and services;
- 2) Identify barriers impeding access to appropriate resources and services; and
- 3) Develop recommendations to improve access.

NCD conducted focus groups and interviews of Caregivers, Family Members with disabilities, and service providers between January 2010 and March 2010 at Marine Corps Base Quantico, Camp Lejeune, and Camp Pendleton.

NCD findings indicate that EFMs and their Families face barriers that span the domains of health care, education, and long-term supports and services. Key findings include:

- For Caregivers, navigating the health, education, long-term services systems, and obtaining and maintaining disability-related services require

relentless hard work—a process they have to start over every time the Family moves. For some—particularly young parents, Families with more than one EFM, Families with a dependent with significant disabilities, parents who are themselves EFMs, and Families with a deployed sponsor—it can be an overwhelming prospect and can be so time-consuming that it becomes impossible for the spouse of an active-duty Marine to work outside the home.

- Many Families lamented the lack of qualified health care specialists near their installations, and they struggle to obtain timely referrals and appointments and make long trips to medical specialists.
- For Family Members in need of special education services, having to make frequent moves to a new school system results in substantial gaps in critical education and therapeutic services.
- The lack of Medicaid portability across states is a significant barrier to obtaining necessary long-term supports and services for Families with EFM dependents. Each time the Family moves, they have to start over on a Medicaid waiver waiting list and often do not live in one place long enough to qualify. Tricare does not cover the same services provided under a Medicaid waiver.
- Many families are dependent on the disability-related services typically covered by ECHO, a Tricare supplemental insurance, and they worry about how they will pay for these services when they retire and ECHO is no longer available to them.

These findings reveal that prompt action must be taken to improve health, education, and long-term services for Marine Corps Families with EFMs. NCD commends the Marine Corps for making significant improvements to their EFM program during the time this study was being conducted (many of which are highlighted in this report). However, many of the changes necessary to improve the supports available to military Families with EFMs 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.

NCD commends your Administration for focusing on the needs of military Families, particularly the launch of Joining Forces, and would welcome the opportunity to work with you on behalf of military Families with EFMs.

Sincerely,

  
Jonathan M. Young, J.D., Ph.D.  
Chairman, National Council on Disability

Attachment B

TRICARE for Kids Amendment

112TH CONGRESS  
2D SESSION

# H. R. 4341

To direct the Secretary of Defense to establish a working group to review TRICARE policy with respect to providing health care to children and determine how to improve such policy, and for other purposes.

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## IN THE HOUSE OF REPRESENTATIVES

MARCH 29, 2012

Mr. STIVERS (for himself, Mr. SCHILLING, and Mrs. DAVIS of California) introduced the following bill; which was referred to the Committee on Armed Services

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## A BILL

To direct the Secretary of Defense to establish a working group to review TRICARE policy with respect to providing health care to children and determine how to improve such policy, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*  
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SENSE OF CONGRESS.**

4 It is the sense of Congress that—

5 (1) children of members of the Armed Forces  
6 deserve health-care practices and policies that—

7 (A) are designed to meet their pediatric-  
8 specific needs;

1 (B) are developed and determined  
2 proactively and comprehensively; and

3 (C) ensure and maintain their access to pe-  
4 diatric-specific treatments, providers, and facili-  
5 ties;

6 (2) children's health-care needs and standards  
7 of care are different and distinct from those of  
8 adults, therefore the TRICARE program should un-  
9 dertake a proactive, comprehensive approach to re-  
10 view and analyze its policies and practices to meet  
11 the needs of children to ensure that children and  
12 their families receive appropriate care in proper set-  
13 tings and avoid unnecessary challenges in seeking or  
14 obtaining proper health care;

15 (3) a proactive and comprehensive review is  
16 necessary because the reimbursement structure of  
17 the TRICARE program is patterned upon Medicare  
18 and the resulting policies and practices of the  
19 TRICARE program do not always properly reflect  
20 appropriate standards for pediatric care;

21 (4) one distinct aspect of children's health care  
22 is the need for specialty care and services for chil-  
23 dren with special-health-care needs and chronic-  
24 health conditions;

1 (5) the requirement for specialized health care  
2 and developmental support is an ongoing and serious  
3 matter of day-to-day life for families with children  
4 with special or chronic-health-care needs;

5 (6) the Department of Defense and the  
6 TRICARE program, recognizing the special needs of  
7 certain children, have instituted special-needs pro-  
8 grams, including the ECHO program, but there are  
9 collateral needs that are not being met, generally be-  
10 cause the services are provided in the local commu-  
11 nity rather than by the Department of Defense, who  
12 may not always have the best tools or knowledge to  
13 access these State and local resources;

14 (7) despite wholehearted efforts by the Depart-  
15 ment of Defense, a gap exists between linking mili-  
16 tary families with children with special-health-care  
17 needs and chronic conditions with the resources and  
18 services available from local or regional highly spe-  
19 cialized providers and the communities and States in  
20 which they reside;

21 (8) the gap is especially exacerbated by the mo-  
22 bility of military families, who often move from  
23 State to State, because special-needs health care,  
24 educational, and social services are very specific to

1 each local community and State and such services  
2 often have lengthy waiting lists; and

3 (9) the Department of Defense will be better  
4 able to assist military families with children with  
5 special-health-care needs fill the gap by collaborating  
6 with special-health-care needs providers and those  
7 knowledgeable about the opportunities for such chil-  
8 dren that are provided by States and local commu-  
9 nities.

10 **SEC. 2. ESTABLISHMENT OF TRICARE WORKING GROUP.**

11 (a) ESTABLISHMENT.—

12 (1) IN GENERAL.—The Secretary of Defense  
13 shall establish a working group to carry out a review  
14 of the TRICARE program with respect to—

15 (A) pediatric health care needs under para-  
16 graph (2); and

17 (B) pediatric special and chronic health  
18 care needs under paragraph (3).

19 (2) PEDIATRIC HEALTH CARE NEEDS.—

20 (A) DUTIES.—The working group shall—

21 (i) comprehensively review the policy  
22 and practices of the TRICARE program  
23 with respect to providing pediatric health  
24 care;

1 (ii) recommend changes to such poli-  
2 cies and practices to ensure that—

3 (I) children receive appropriate  
4 care in an appropriate manner, at the  
5 appropriate time, and in an appro-  
6 priate setting; and

7 (II) access to care and treatment  
8 provided by pediatric providers and  
9 children's hospitals remains available  
10 for families with children; and

11 (iii) develop a plan to implement such  
12 changes.

13 (B) REVIEW.—In carrying out the duties  
14 under subparagraph (A), the working group  
15 shall—

16 (i) identify improvements in policies,  
17 practices, and administration of the  
18 TRICARE program with respect to pedi-  
19 atric-specific health care and pediatric-spe-  
20 cific healthcare settings;

21 (ii) analyze the direct and indirect ef-  
22 fects of the reimbursement policies and  
23 practices of the TRICARE program with  
24 respect to pediatric care and care provided  
25 in pediatric settings;



1 (iii) consider case management pro-  
2 grams with respect to pediatric complex  
3 and chronic care, including whether pedi-  
4 atric specific programs are necessary;

5 (iv) develop a plan to ensure that the  
6 TRICARE program addresses pediatric-  
7 specific health care needs on an on-going  
8 basis beyond the life of the working group;

9 (v) consider how the TRICARE pro-  
10 gram can work with the pediatric provider  
11 community to ensure access, promote com-  
12 munication and collaboration, and optimize  
13 experiences of military families seeking and  
14 receiving health care services for children;  
15 and

16 (vi) review matters that further the  
17 mission of the working group.

18 (3) PEDIATRIC SPECIAL AND CHRONIC HEALTH  
19 CARE NEEDS.—

20 (A) DUTIES.—The working group shall—

21 (i) review the methods in which fami-  
22 lies in the TRICARE program who have  
23 children with special-health-care needs ac-  
24 cess community resources and health-care  
25 resources;

1 (ii) review how having access to, and  
2 a better understanding of, community re-  
3 sources may improve access to health care  
4 and support services;

5 (iii) recommend methods to accom-  
6 plish improved access by such children and  
7 families to community resources and  
8 health-care resources, including through  
9 collaboration with children's hospitals and  
10 other providers of pediatric specialty care,  
11 local agencies, local communities, and  
12 States;

13 (iv) consider approaches and make  
14 recommendations for the improved integra-  
15 tion of individualized or compartmentalized  
16 medical and family support resources for  
17 military families;

18 (v) work closely with the Office of  
19 Community Support for Military Families  
20 with Special Needs of the Department of  
21 Defense and other relevant offices to avoid  
22 redundancies and target shared areas of  
23 concern for children with special or chron-  
24 ic-health-care needs; and

1 (vi) review any relevant information  
2 learned and findings made by the working  
3 group under this paragraph that may be  
4 considered or adopted in a consistent man-  
5 ner with respect to improving access, re-  
6 sources, and services for adults with spe-  
7 cial needs.

8 (B) REVIEW.—In carrying out the duties  
9 under subparagraph (A), the working group  
10 shall—

11 (i) discuss improvements to special  
12 needs health care policies and practices;

13 (ii) determine how to support and pro-  
14 tect families of members of the National  
15 Guard or Reserve Components as the  
16 members transition into and out of the rel-  
17 evant Exceptional Family Member Pro-  
18 gram or the ECHO program;

19 (iii) analyze case management services  
20 to improve consistency, communication,  
21 knowledge, and understanding of resources  
22 and community contacts;

23 (iv) identify areas in which a State  
24 may offer services that are not covered by

1 the TRICARE program or the ECHO pro-  
2 gram and how to coordinate such services;

3 (v) identify steps that States and  
4 communities can take to improve support  
5 for military families of children with spe-  
6 cial health care needs;

7 (vi) consider how the TRICARE pro-  
8 gram and other programs of the Depart-  
9 ment of Defense can work with specialty  
10 pediatric providers and resource commu-  
11 nities to ensure access, promote commu-  
12 nication and collaboration, and optimize  
13 experiences of military families seeking and  
14 receiving health care services for their chil-  
15 dren with special or chronic health care  
16 needs;

17 (vii) consider special and chronic  
18 health care in a comprehensive manner  
19 without focus on one or more conditions or  
20 diagnoses to the exclusion of others;

21 (viii) focus on ways to create innova-  
22 tive partnerships, linkages, and access to  
23 information and resources for military  
24 families across the spectrum of the special-  
25 needs community and between the medical

1 community and the family support commu-  
2 nity; and

3 (ix) review matters that further the  
4 mission of the working group.

5 (b) MEMBERSHIP.—

6 (1) APPOINTMENTS.—The working group shall  
7 be composed of not less than 14 members as follows:

8 (A) The Chief Medical Officer of the  
9 TRICARE program, who shall serve as chair-  
10 person.

11 (B) The Chief Medical Officers of the  
12 North, South, and West regional offices of the  
13 TRICARE program.

14 (C) One individual representing the Army  
15 appointed by the Surgeon General of the Army.

16 (D) One individual representing the Navy  
17 appointed by the Surgeon General of the Navy.

18 (E) One individual representing the Air  
19 Force appointed by the Surgeon General of the  
20 Air Force.

21 (F) One individual representing the re-  
22 gional managed care support contractor of the  
23 North region of the TRICARE program ap-  
24 pointed by such contractor.

1 (G) One individual representing the re-  
2 gional managed care support contractor of the  
3 South region of the TRICARE program ap-  
4 pointed by such contractor.

5 (H) One individual representing the re-  
6 gional managed care support contractor of the  
7 West region of the TRICARE program ap-  
8 pointed by such contractor.

9 (I) Not more than three individuals rep-  
10 resenting the non-profit organization the Mili-  
11 tary Coalition appointed by such organization.

12 (J) One individual representing the Amer-  
13 ican Academy of Pediatrics appointed by such  
14 organization.

15 (K) One individual representing the Na-  
16 tional Association of Children's Hospitals ap-  
17 pointed by such organization.

18 (L) One individual representing military  
19 families who is not an employee of an organiza-  
20 tion representing such families.

21 (M) Any other individual as determined by  
22 the Chief Medical Officer of the TRICARE pro-  
23 gram.

24 (2) TERMS.—Each member shall be appointed  
25 for the life of the working group. A vacancy in the

1 working group shall be filled in the manner in which  
2 the original appointment was made.

3 (3) TRAVEL EXPENSES.—Each member shall  
4 receive travel expenses, including per diem in lieu of  
5 subsistence, in accordance with applicable provisions  
6 under subchapter I of chapter 57 of title 5, United  
7 States Code.

8 (4) STAFF.—The Secretary of Defense shall en-  
9 sure that employees of the TRICARE program pro-  
10 vide the working group with the necessary support  
11 to carry out this section.

12 (c) MEETINGS.—

13 (1) SCHEDULE.—The working group shall—

14 (A) convene its first meeting not later than  
15 60 days after the date of the enactment of this  
16 Act; and

17 (B) convene not less than four other times.

18 (2) FORM.—Any meeting of the working group  
19 may be conducted in-person or through the use of  
20 video conferencing.

21 (3) QUORUM.—Seven members of the working  
22 group shall constitute a quorum but a lesser number  
23 may hold hearings.

24 (d) POWERS.—

1           (1) HEARINGS AND TESTIMONY.—The working  
2 group may, for the purpose of carrying out this Act,  
3 hold public or private hearings, sit and act at times  
4 and places, take written or oral comments or testi-  
5 mony, and receive evidence as the working group  
6 considers appropriate.

7           (2) OFFICIAL INFORMATION.—The working  
8 group may secure directly from any department or  
9 agency of the United States information necessary  
10 to enable it to carry out this Act.

11          (3) MAILS.—The working group may use the  
12 United States mails in the same manner and under  
13 the same conditions as other departments and agen-  
14 cies of the United States.

15          (e) CONSULTATION.—

16           (1) ADVICE.—With respect to carrying out the  
17 review of the TRICARE program and pediatric spe-  
18 cial and chronic health care needs under subsection  
19 (a)(3), the working group shall seek counsel from  
20 the following individuals acting as an expert advisory  
21 group:

22                   (A) One individual representing the Excep-  
23 tional Family Member Program of the Army.

24                   (B) One individual representing the Excep-  
25 tional Family Member Program of the Navy.



1 (C) One individual representing the Excep-  
2 tional Family Member Program of the Air  
3 Force.

4 (D) One individual representing the Excep-  
5 tional Family Member Program of the Marine  
6 Corps.

7 (E) One individual representing the Office  
8 of Community Support for Military Families  
9 with Special Needs.

10 (F) One individual who is not an employee  
11 of an organization representing military families  
12 shall represent a military family with a child  
13 with special health care needs.

14 (G) Not more than three individuals rep-  
15 resenting organizations that—

16 (i) are not otherwise represented in  
17 this paragraph or in the working group;  
18 and

19 (ii) possess expertise needed to carry  
20 out the goals of the working group.

21 (2) COMMENTS.—With respect to carrying out  
22 the review of the TRICARE program and pediatric  
23 special and chronic health care needs under sub-  
24 section (a)(3), the working group shall invite and ac-  
25 cept comments and testimony from States, local

1 communities, national special needs advocacy  
2 groups, educators, pediatric-health-care providers,  
3 and military family advocates.

4 (f) REPORTS REQUIRED.—

5 (1) REPORT.—Not later than 12 months after  
6 the date on which the working group convenes its  
7 first meeting, the working group shall submit to the  
8 congressional defense committees a report includ-  
9 ing—

10 (A) any changes described in subsection  
11 (a)(2)(A)(ii) identified by the working group  
12 that—

13 (i) require legislation to carry out, in-  
14 cluding proposed legislative language for  
15 such changes;

16 (ii) require regulations to carry out,  
17 including proposed regulatory language for  
18 such changes; and

19 (iii) may be carried out without legis-  
20 lation or regulations, including a time line  
21 for such changes; and

22 (B) steps that States and local commu-  
23 nities may take to improve the experiences of  
24 military families with special-needs children in

1           interacting with and accessing State and local  
2           community resources.

3           (2) FINAL REPORT.—Not later than 18 months  
4           after the date on which the report is submitted  
5           under paragraph (1), the working group shall sub-  
6           mit to the congressional defense committees a final  
7           report including—

8                   (A) any additional information and up-  
9                   dates to the report submitted under paragraph  
10                  (1);

11                  (B) information with respect to how the  
12                  Secretary of Defense is implementing the  
13                  changes identified in the report submitted  
14                  under paragraph (1); and

15                  (C) information with respect to any steps  
16                  described in subparagraph (B) of such para-  
17                  graph that were taken by States and local com-  
18                  munities after the date on which such report  
19                  was submitted.

20           (g) TERMINATION.—The working group shall termi-  
21           nate on the date that is 30 days after the date on which  
22           the working group submits the final report pursuant to  
23           subsection (f)(2).

24           (h) DEFINITIONS.—In this Act:

1           (1) The term “children” means dependents of a  
2 member of the Armed Forces who are—

3                   (A) individuals who have not yet attained  
4 the age of 21; or

5                   (B) individuals who have not yet attained  
6 the age of 27 if the inclusion of such depend-  
7 ents is applicable and relevant to a program or  
8 policy being reviewed under this Act.

9           (2) The term “congressional defense commit-  
10 tees” has the meaning given that term in section  
11 101(a)(16) of title 10, United States Code.

12           (3) The term “ECHO program” means the pro-  
13 gram established pursuant to subsections (d)  
14 through (e) of section 1079 of title 10, United  
15 States Code (commonly referred to as the “Extended  
16 Care Health Option program”).

17           (4) The term “TRICARE program” means the  
18 managed health care program that is established by  
19 the Department of Defense under chapter 55 of title  
20 10, United States Code.

○

Attachment C

March of Dimes Endorsement Letter

March of Dimes Foundation

Office of Government Affairs  
1401 K Street, NW, Suite 900A  
Washington, DC 20005  
Telephone (202) 659-1800  
Fax (202) 296-2964

marchofdimes.com  
nacersano.org

June 13, 2012

The Honorable Steve Stivers  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Susan Davis  
U.S. House of Representatives  
Washington, DC 20515

The Honorable Bobby Schilling  
U.S. House of Representatives  
Washington, DC 20515

Dear Representatives Stivers, Davis, and Schilling:

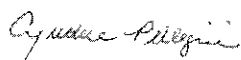
The March of Dimes, a unique collaboration of scientists, clinicians, parents, members of the business community, and other volunteers affiliated with 51 chapters representing every state, the District of Columbia and Puerto Rico, is pleased to endorse H.R. 4341, *the TRICARE for Kids Act*, a bill to ensure that all military families and children receive the essential health care services they need.

The TRICARE program covers 9.6 million lives, including children and families of active duty soldiers. 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. If enacted, the bill would convene a working group with a wide range of expertise in children's health and health care to systematically review TRICARE's policies and practices and make recommendations for improvements. The working group would also work with specialty providers of children's health care and support services to better connect military families to state resources for children with special and chronic health care needs.

Our nation's soldiers and their families have made tremendous sacrifices for the sake of our country. It is our duty to ensure that these families receive the health care that best meets their needs. The *TRICARE for Kids Act* will help make this possible. We look forward to passage of this important bill.

Sincerely,



Cynthia Pellegrini  
Senior Vice President, Public Policy & Government Affairs

marchofdimes



Attachment D

OPM FEHB Program Carrier Letter

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# FEHB Program Carrier Letter

## All Fee For Service Carriers

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U.S. Office of Personnel Management  
Healthcare and Insurance

Letter No. 2012-12(c)

Date: April 19, 2012

Fee-for-service [11]    Experience-rated HMO [n/a]    Community-rated HMO [n/a]

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### Subject: 2013 Technical Guidance and Instructions for Preparing Proposals for Fee-For-Service Carriers

Enclosed are the technical guidance and instructions for preparing your benefit proposals for the contract term January 1, 2013 through December 31, 2013. Please refer to our annual Call Letter (Carrier Letter 2012- 09) dated March 29, 2012 for policy guidance. Benefit policies from prior years remain in effect unless otherwise noted.

This year's deadlines are as follows:

- **No later than May 31, 2012:** Please send your complete proposal for benefit changes and clarifications to your contract specialist on a CD-ROM (or other electronic means) in addition to a hard copy. Your proposal should include corresponding language describing all proposed brochure changes. Your OPM contract specialist will discuss your proposed benefits and finalize negotiations in a close-out letter.
- **Within five business days following receipt of close-out letter or by date set by your contract specialist:** Please send him/her an electronic version of your fully revised 2013 brochure. See Attachment VI: Preparing Your 2013 Brochure.

Carriers are strongly encouraged, as always, to follow our guiding principles of affordability and value based benefit design when preparing proposals. This year you will see an increased focus on quantitative data which we need to measure each plan's overall performance. For some items, we ask for historical data to establish a baseline for performance reviews. In addition, we appreciate your continued timely efforts to submit benefit and rate proposals and to produce and distribute brochures.

Enclosed is a checklist (Attachment XVI) showing all the information to include with your benefit and rate proposals. Please return a completed checklist with your submission.

We look forward to working closely with you on these essential activities to ensure a successful Open Season again this year.

Sincerely,

John O'Brien  
Director  
Healthcare and Insurance



## Preparing Your 2013 Benefit Proposal

Your benefit proposal must be complete. Timeframes to conclude benefit negotiations are firm and we cannot consider late proposals. Your benefit proposal should include:

- A signed contracting official's form (Attachment I);
- A plain language description of each proposed change (Attachment II) and revised language for your 2013 brochure; and
- A plain language description of each proposed clarification (Attachment III) and revised language for your 2013 brochure.

If you anticipate significant changes to your benefit package, please discuss them with your OPM Contract Specialist before preparing your submission.

As stated in the 2013 Call Letter, our three primary initiatives this year are:

- Implementing additional requirements under the Affordable Care Act;
- Improving the delivery and cost efficiency of prescription drugs; and
- Advancing quality of care principles.

### **I. CALL LETTER INITIATIVES**

#### **A. Implementing the Affordable Care Act**

##### **1. Lifetime and Annual Limits on Essential Health Benefits**

FEHB plans have historically not imposed lifetime limits and we will continue to enforce this requirement.

In addition, FEHB plans are expected to eliminate annual limits on essential health benefits (EHB), regardless of grandfathered plan status.

On December 16, 2011, the Department of Health and Human Services (HHS) released a Bulletin ([http://cciio.cms.gov/resources/files/Files2/12162011/essential\\_health\\_benefits\\_bulletin.pdf](http://cciio.cms.gov/resources/files/Files2/12162011/essential_health_benefits_bulletin.pdf)) describing its approach to define EHB under the Affordable Care Act. On February 17, 2012, HHS issued a FAQ (<http://cciio.cms.gov/resources/files/Files2/02172012/ehb-faq-508.pdf>) to provide additional guidance on the subject.

Information Required for Proposal: Attachment IV- Lifetime and Annual Limits on Essential Health Benefits

##### **2. Clinical Trial Coverage**

FEHB plans are expected to comply with certain coverage requirements for clinical trials next year, in advance of required implementation for 2014, regardless of grandfathered status. The requirements are described in detail in Attachment V.

Information Required for Proposal: Attachment V- Clinical Trial Coverage

**3. Preventive Services**

Last year, we requested FEHB plans to eliminate cost-sharing for all recommended in-network preventive services, immunizations, screenings, tobacco cessation services and medications. Please check the latest posting by the Advisory Committee on Immunization Practices (ACIP) at <http://www.cdc.gov/vaccines/pubs/ACIP-list-by-date.htm> for the full list of required vaccinations as some have changed. Note that, unless otherwise specified, plans must cover these requirements no later than the start of the plan year which follows the year in which the recommendation becomes effective.

Plans must submit proposals that cover preventive services, including birth control, with no cost-sharing, regardless of grandfathered status. The Affordable Care Act adds new preventive services requirements for 2013 that go beyond recommendations of the United States Preventive Services Task Force. See <http://www.hrsa.gov/womensguidelines/>.

Information Required for Proposal: Attachment VI- Preventive Services

**4. 2013 Brochure**

FEHB plans are required to provide a "Summary of Benefits" for 2013, in advance of required implementation for 2014, regardless of grandfathered status. To evaluate our "Going Green" goals to help reduce FEHB administrative costs, please provide your cost savings information on the worksheet provided. You will receive additional guidance in a forthcoming carrier letter.

Information Required for Proposal: Attachment VII-Preparing Your 2013 Brochure

**5. Grandfathered Plans**

You only need to complete the certification for options that you anticipate will remain grandfathered for plan year 2013, based on benefit changes. Please read the certification carefully as it lists specific regulatory requirements that allow a plan to remain grandfathered under the Affordable Care Act. We will confirm requested grandfather status once final benefits and rates are negotiated.

**Note: If one or more of your plan options was grandfathered in 2012, but will no longer meet regulatory requirements for 2013 then all Affordable Care Act requirements for non-grandfathered plans must be met in 2013.**

Information Required for Proposal: Attachment VIII-Grandfathered Status Certification

## **B. Improving the Delivery & Cost Efficiency of Prescription Medications**

OPM continues to explore innovative methods to reduce pharmacy spending and to develop effective prescription drug management without cost shifting or burdening members. The rate proposal, which you will receive separately, has our pharmacy data request.

Information Required for Proposal:

- Describe effective prescription drug management without cost shifting or burdening enrollees;
- Describe proposals to implement specialty drug programs that manage these costs;
- Describe how you are managing the control of drug administrative costs such as dispensing fees; and
- Complete Attachment IX for four issues below.

### **(1) Generic Medications**

OPM's target for 2013 is to achieve an overall FEHB average generic dispensing rate of at least 75 percent. The Generic Dispensing Rate (GDR) is defined as the percentage of total prescriptions filled with generic drugs.

### **(2) Specialty Pharmacy**

OPM's target is to stabilize the growth and cost of specialty drugs by keeping cost trends below the industry average of 14 to 20 percent.

### **(3) Pharmacy Benefit Managers Accreditation**

FEHB plans should provide the highest quality pharmacy services to Federal employees, retirees and their families as demonstrated by the accreditation status of their pharmacy benefit managers (PBMs) or pharmacy components.

### **(4) Control of Dispensing Fees**

Carriers will provide OPM with baseline data on the administrative fees in their current PBM contracts and describe how they intend to mitigate inflation in those fees. Examples are dispensing fees for generic drugs, brand name drugs, and for specialty drugs.

## **C. Advancing Quality of Care**

### **1. Quality**

OPM supports enhanced care coordination and the principles underlying patient centered medical homes (PCMH). To the greatest extent possible, we encourage participation in pilots offered by states or other Federal agencies, including the Comprehensive Primary Care (CPC) initiative sponsored by the Centers for Medicare and Medicaid Innovation Center. Read about this important initiative at

<http://www.innovations.cms.gov/initiatives/Comprehensive-Primary-Care-Initiative/index.html>  
We invite you to propose arrangements through which your FEHB members can participate in the new CPC activities.

Information Required for Proposal: Attachment X-Quality of Care: PCMH

Additionally, we support the goals of the HHS' *Partnership for Patients, Better Care, Lower Costs* to reduce hospital readmissions by 20 percent and decrease preventable hospital acquired conditions by 40 percent when compared with 2010. We expect that you will make concerted efforts to improve the quality and safety of health care by addressing both those concerns.

Note: Plans will receive separate guidance in a forthcoming Carrier Letter describing how to measure applicable rates for FEHB populations.

We seek to eliminate elective deliveries before 39 weeks' gestation to reduce prematurity and adverse neonatal outcomes. We encourage you to describe initiatives supporting this goal in your benefit proposal, including those in place through your plan, participating hospitals or network providers.

Note: The forthcoming Carrier Letter regarding readmission and preventable conditions will include data requests reflecting maternity care and prematurity.

## 2. Wellness

In your proposal, please describe all wellness programs you intend to offer - including any quantitative data or other measures of their effectiveness - that can improve employee productivity, enhance healthy lifestyles and lower long-term healthcare costs.

FEHB plans are expected to continue programs to manage obesity as part of their focus on members' health and wellness. Your 2013 benefit proposal should update weight management coverage to ensure that enrollees receive all appropriate support to achieve and sustain a healthier weight.

Information Required for Proposal: Narrative information on all wellness programs with outcome data and Attachment XI-Weight Management

## II. **BENEFITS & SERVICES**

### A. **New Guidance: Coverage of Applied Behavior Analysis (ABA)**

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. Accordingly, plans may propose benefit packages which include ABA.

Information Required for Proposal: Describe what benefit package you intend to offer and describe how you will deliver these services through appropriate providers.

## B. Benefit Changes

Your proposal must include a narrative description of each proposed benefit change. Please use Attachment II as the template to submit benefit changes. You must show all changes, however small, that result in an increase or decrease in benefits, even if there is no rate change.

We expect you to answer each of the following questions in worksheet format for each proposed benefit change. Indicate if a particular question does not apply and use a separate page for each change you propose. We will return any incorrectly formatted submissions.

### Information Required for Proposal:

- Describe the benefit change completely. Show the proposed brochure language, including the “How we change for 2013” section in “plain language” using the active voice and written from the member’s perspective. Show clearly how the change will affect members and the complete range of the change. For instance, if you propose to add inpatient hospital copays, indicate whether the change will also apply to inpatient hospitalizations under the emergency benefit. **If there are two or more changes to the same benefit, please show each change clearly.**
- Describe the rationale or reasoning for the proposed benefit change.
- State the actuarial value of the change and if it change represents an increase or decrease in (a) the existing benefit and (b) your overall benefit package. If an increase, describe whether any other benefit offsets your proposal. Include the cost impact of the change as a biweekly amount for the Self Only and Self and Family rates. If there is “no cost impact” or if the proposal involves a “cost trade-off” with another benefit, indicate which result is applicable, i.e. no cost or trade-off.

## C. Benefit Clarifications

**Clarifications are not benefit changes.** Please use Attachment III as the template to submit all clarifications that better explain to members how a benefit is covered.

### Information Required for Proposal:

- Show the current and proposed language for each proposed clarification and reference all portions of the brochure it affects. **Prepare a separate worksheet for each proposed clarification.** You may combine more than one clarification for the same benefit, but you must present each one clearly on the worksheet. Remember to use plain language.
- Explain the reason for the proposed clarification.

## D. Continued Focus from Previous Years

### 1. Health & Wellness

We continue to encourage you to offer financial incentives to enrollees who (a) complete a health risk assessment or biometric assessment or (b) participate in wellness activities or treatment plans to improve their health status.

Information Required for Proposal: Attachment XII-Health & Wellness

**2. Increase FEHB providers**

We continue to encourage you to increase the number of health care providers in FEHB plan networks who are board certified or have training in geriatrics.

Information Required for Proposal: Attachment XIII-Geriatric Providers

**3. Affinity Products**

We encourage you to add products on the “non-FEHB” page of your plan brochure that may be of interest to members and ineligible family members, especially individual policies for domestic partners as well as for members who may seek additional insurance products, such as short-term disability.

Information Required for Proposal: Attachment XIV-Affinity Products

**4. Organ/Tissue Transplants**

We have updated the guidance on organ/tissue transplants which we provided in last year’s technical guidance. When a carrier determines that a transplant service is no longer experimental, but is medically accepted, you may begin providing benefits coverage at that time. Carriers are not obligated to wait for the next contract year before they begin providing such benefits. We have updated the following table in Attachment XV:

- Table 1-- OPM’s required list of covered organ/tissue transplants. Although we no longer require coverage for autologous transplants for breast cancer, plans may continue to offer it.

Information Required for Proposal: Attachment XV: 2013 Organ/Tissue Transplants and Diagnoses

**5. Describing Prescription Drug Co-Pays in the Guide to Federal Benefits**

Plans that use levels or tiers to denote different prescription drug co-pays must clearly describe the coverage and difference between each level or tier in the 2013 brochure. The *2013 Guide to Federal Benefits* will illustrate the prescription drug co-pays at the following levels.

- Level I – generally includes generic drugs, but may include some brand formulary or preferred brands. Usually represents the lowest co-pays.
- Level II – generally includes brand formulary and preferred brands, but may include some generics and brands not included in Level I. Usually represents brand or middle-range co-pays.

- Level III – may include all other covered drugs not on Levels I and II, i.e. non-formulary or non-preferred and some specialty drugs.

If your plan has more than three co-pay levels for prescription drug coverage, please work with your OPM Contract Specialist to ensure that we accurately reflect your coverage in the *2013 Guide to Federal Benefits*.

Attachment E

2006 OPM Ltr to Rep Christopher Smith





UNITED STATES  
OFFICE OF PERSONNEL MANAGEMENT  
WASHINGTON, DC 20415-0001

OFFICE OF THE DIRECTOR

JAN 27 2006

The Honorable Christopher Smith  
U.S. House of Representatives  
Washington, DC 20515

Dear Representative Smith:

Thank you for your recent communication concerning applied behavior analysis (ABA) for autism. You asked that the Office of Personnel Management (OPM) direct the Federal Employees Health Benefits (FEHB) Program carriers to provide information on the extent of their coverage for therapies such as ABA.

OPM has conducted an extensive literature review on ABA and consulted with medical experts in this field. While it appears that ABA is considered a promising behavioral intervention therapy for autism, there is no strong scientific evidence of its benefit. A National Library of Medicine "Medline" search of the scientific literature from 1966 to present revealed no evidenced-based articles on behavioral therapy of autism. The current evidence rests on small numbers of children with autism treated over several years. ABA has not yet been proven in randomized experimental trials and is considered to be experimental or investigational. Therefore, benefits coverage under the FEHB Program is not available.

The American Academy of Pediatrics and the National Research Council indicate that more replicative studies with improved methodology are needed before ABA can be recommended for all autistic children. The National Institute of Mental Health reported in April 2004, "Research is beginning to show that specific medical and behavioral treatments, and combinations of these treatments, are effective in ameliorating various problems that are often associated with autism. Further research is needed to fully evaluate the efficacy and effectiveness of such treatments."<sup>1</sup> In May 2004, the National Institutes of Health's Interagency Autism Coordinating Committee reported that "Randomized controlled trials of behavioral interventions are also needed, as well as outcome measures for behavioral treatment studies."<sup>2</sup>

Under its mental health coverage, the Federal Employees Health Benefits (FEHB) Program provides benefits for services related to autism as it does for medical conditions. For example, if a specific service (e.g., speech therapy) is covered by a FEHB Plan, the service cannot be excluded if it is prescribed to treat autism. These mental health benefits, along with pre-authorization requirements, limitations, and exclusions of services considered experimental or investigational are described in each carrier's plan brochure available during open season. As with any type of service (medical or mental), regardless of the condition, OPM cannot authorize benefits for services that are considered to be experimental or investigational.


The Honorable Christopher Smith

2

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.

I appreciate the opportunity to respond to your interest in this matter.

Sincerely,



Linda M. Springer  
Director

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<sup>1</sup> Department of Health and Human Service, National Institutes of Health, National Institute of Mental Health, Congressional Appropriations Committee Report on the State of Autism Research, April 2004, Pg. 16.

<sup>2</sup> Department of Health and Human Services, Interagency Autism Coordinating Committee, Meeting Highlights, May 11, 2004, National Institute of Health, Pg. 3.

Attachment F

2011 Ltr to Assistant Secretary Posny

Dr. Alexa Posny  
Assistant Secretary for Special Education and Rehabilitative Services  
United States Department of Education  
400 Maryland Avenue, S.W.  
Washington, D.C. 20202

Dear Assistant Secretary Posny:

We are active duty members and/or their spouses who have a child with a disability who receives special education services under the Individuals with Disabilities Education Act (IDEA). We request that the Department of Education via your office investigate a number of serious issues related to the ability of military children to receive appropriate services in our nation's public schools.

There are over 150,000 military children impacted by a disability (many more if you count Reserves and Guard families). The root of our problem is that military orders and requirements cause military families to move more often than the general public. We move both due to short term training and deployments (6 months to 1 year) and normal military transfers (every three years on average). It is not uncommon for military families to relocate 15 or more times in a 20 year career, generally across state lines. When we move, our children with disabilities are impacted and they often fall behind at school. Families and children must adjust to new IEPs, new staff and new programs. At a time when they need more services due to the transition, a number of families find that the new school district significantly cuts their child's services or alters them to the child's detriment. Some districts deny the child accommodations they had through their previous school district. Some of these districts seem to be aware that families will move soon again, and have little ability to protect themselves (once a family moves, it may be difficult to bring due process). We wish to recognize that there are school districts that provide excellent services to military children with disabilities and many individual teachers and staff who go above and beyond in providing effective educations to military children. These staff and schools are heroes to the families they serve. But still these problems persist with a number of school districts.

There are five significant issues for your consideration.

**First, contrary to IDEA 2004, children who move into new school districts do not necessarily receive services comparable to those in their prior IEP.** 20 U.S.C. 1414 (d)(2)(C)(i)(II) of IDEA states "the local educational agency shall provide such child with a free appropriate public education, including services comparable to those described in the previously held IEP." Regulatory Commentary states that "comparable" was intended to mean "similar or equivalent" to the old IEP [71 Fed Reg. 46681 (2006)]. But, it has been our

experience that some school districts ignore the commentary. This is because the commentary is not legally binding, and school districts have told parents this when they cite it. But regulations are binding and making the commentary part of the regulation would be a significant step toward solving the problem. A number of families find that their child's services are cut significantly and accommodations and modifications are not provided. Assistive technology needs may not be recognized across districts, forcing students to learn new programs and computerized devices with each move. As one example, military parents of a child with hydrocephalus and associated issues moved from Texas to Alabama for a required 10 month military training program. The new Alabama district reduced the child's services by half, effectively ignoring the Department of Education's commentary. Since the family was in Alabama for such a short period, they had little recourse. Their story is included from the September 2009 edition of Exceptional Parent Magazine. We ask for three things with regard to this section of IDEA 2004.

We ask that the regulatory commentary should be made part of the regulations. There are school districts that ignore the commentary because it is not binding. Regulations are legally binding and everyone must follow them. Most families do not even know about the Commentary or that they need to go find an August 2006 Federal Register notice to access it. Most schools and families simply focus on the regulations. Military families, often with a family member deployed or otherwise serving their country, often find it difficult to take on advocacy for their child on top of everything else. Consequently, we would be grateful for clearer regulations.

Pending this regulatory reform, we would request focused, clear guidance be issued to school districts and State Educational Agencies. It would be most helpful if the new school district fully understood the requirement to provide similar or equivalent services, per the previously agreed to IEP from the losing school district.

Third, we hope that guidance can be developed around evaluation needs related to this part of IDEA. IDEA 2004 appears to suggest that an LEA needs to conduct an evaluation before writing an IEP. 20 U.S.C. §1414 (d)(2)(C)(i)(II). This further delays services, as states go through the evaluation period. Districts get 60 days to write IEPs unless states set their own deadlines, and some deadlines exceed 60 days. After this, there is a delay before the IEP is written, and then a slight delay again for implementation. It seems that districts should be urged to adopt assessments that have already been conducted, which would save LEAs money. It wastes resources to conduct the same assessment twice in a year, merely because a child moves.

**Second, military families moving school districts face difficulty with evaluations.** As mentioned previously, state evaluation periods can vary from 60 days to much longer. For military children who move in the middle of the evaluation, the delay in services can become appalling. One military family noted that they notified Child Find in late March in one state, only to eventually be provided a IEP and services in another state in late October. We would ask that you clarify in regulations and in guidance that 20 U.S.C. 1414(a)(1)(C) requires the evaluation timeline to begin from when the child is first evaluated in the old district. Some districts take the position that it does not.

**Third, the protections in IDEA for moving families are limited to moves during the “school year.”** Because military families move during the summer, LEAs refuse to implement their old IEP or provide similar or equivalent services. They simply read IDEA 2004’s protections for families which move as inapplicable, since the family moved in the summer. We urge you to clarify that the intent of IDEA, even with summer moves, is for school districts to implement comparable, meaning similar or equivalent, IEPs.

**Fourth, we’d request that coordination be conducted between the Department of Education and the Department of Defense regarding the above investigation.** Many times, a military child who needs to access special education will transition from a public school to a DoDEA school or vice versa. Our families need both entities to be on the same page to ensure our children receive an appropriate education.

**Fifth, school districts know that military families are a transient population and that the large majority are unable to effectively access IDEA’s procedural safeguards (most notably the due hearing process), due to cost and timeliness issues. This creates incentives for some school districts to deny services and refuse to negotiate.** Many times, families who move give up certain due process rights, except those related to compensatory education. Moreover, military families, with one spouse deployed or otherwise serving the country, are already stretched to the breaking point without considering the extensive time and energy required to advocate for our children who access special education. We would request that the Department of Education, in accordance with Presidential Directive No.9 “Strengthening our Military Families”, consider regulations and guidance on ways to help military families impacted by their child’s disability, particularly related to transitions and procedural safeguards. It is directly in line with the Directive’s “Priority #2: Ensure excellence in military children’s education and their development” that clear guidance should be provided on the requirements that schools must implement for military families and their children who access special education.

We would request you consider the following documents as supportive of our comments:

- **GAO Study: Education of Military Dependent Students: Better Information Needed to Assess Student Performance**  
(<http://www.gao.gov/products/GAO-11-231>)
- **RAND Study on Effects of Deployments on Military Child's Education**  
(<http://www.rand.org/pubs/monographs/MG1095.html>)

An upcoming study provided by the National Council on Disability is expected to also validate our complaints above.

Thank you very much for considering our concerns. We are providing our names and contact information below, if you need further information or to follow up.

Sincerely,

Mike Barrett  
US Army  
[barrettfamily@hotmail.com](mailto:barrettfamily@hotmail.com)

Laura Blair  
US Navy  
[laura.blair@navy.mil](mailto:laura.blair@navy.mil)

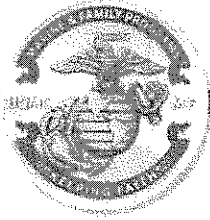
Karen Driscoll  
USMC Spouse  
[Karen0622@aol.com](mailto:Karen0622@aol.com)

Jeremy Hilton  
USAF Spouse  
[ktp1995@gmail.com](mailto:ktp1995@gmail.com)

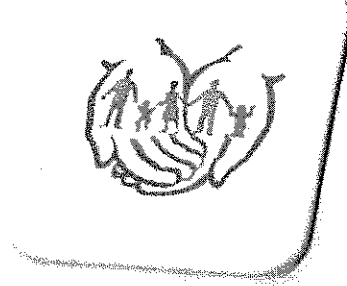
Please note that our signatures in no way imply endorsements by the Department of Defense or our individual branches of services. The views expressed are our own.

Attachment G  
USMC Family Programs Briefing





# FAMILY CARE BRANCH



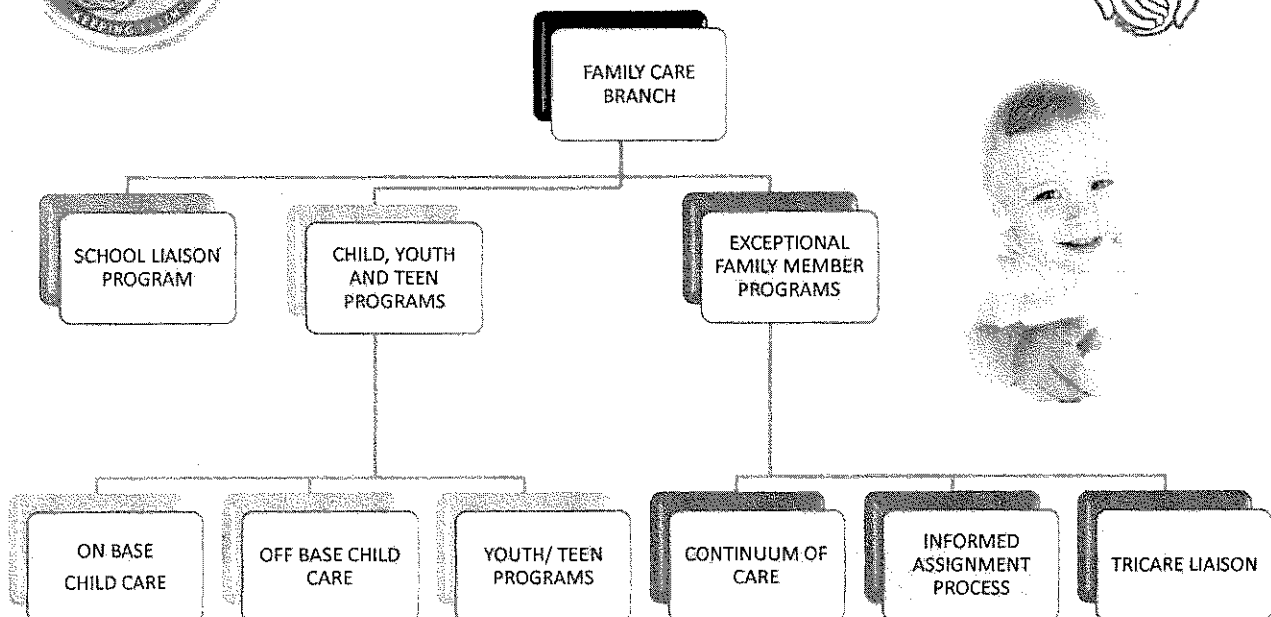
For HQMC Contact Information

[https://www.manpower.usmc.mil/portal/page/portal/M\\_RA\\_HOME/MF/F\\_Family%20Care](https://www.manpower.usmc.mil/portal/page/portal/M_RA_HOME/MF/F_Family%20Care)

*"Keeping Faith"*



# FAMILY CARE BRANCH



*"Keeping Faith"*

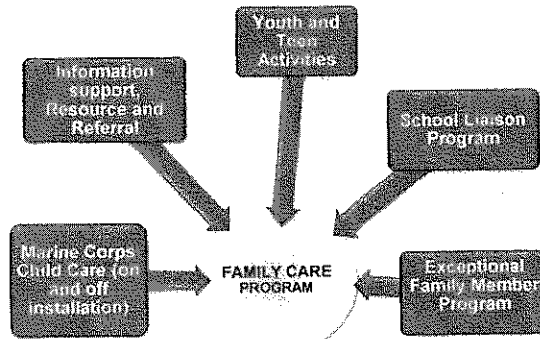


## FAMILY CARE PROGRAMS (MFY) Strategic Concepts

*Enhancing Marines and their families' quality of life through programs that provide, support, or facilitate, care and services for children, youth and teens and exceptional family members*

### STRATEGIC ENGAGEMENT

- FULL INCLUSION IN CHILDREN, YOUTH AND TEEN PROGRAM
- INCREASE CHILD CARE CAPABILITIES
- REVIEW AND IMPROVE CAPABILITIES OF SCHOOL LIAISON PROGRAM
- INCREASE CAPABILITIES OF EXCEPTIONAL FAMILY MEMBER PROGRAM



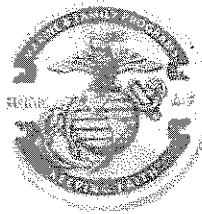
### STRATEGIC PRIORITIES

- KEEP FAITH WITH MARINE CORPS FAMILIES
- BRANCH AND DIVISION INTEGRATION
- TRANSPARENCY
- INCREASE EFFICIENCIES
- DO THE RIGHT THING

*The Family Care Branch was established to align natural working groups. Family Care is integrating and reorganizing to exploit all capabilities and eliminate redundancies.*

43% INCREASE IN EPMP ENROLLMENT 28% INCREASE IN CHILD CARE CAPABILITIES \$10.5M IN K-12 PARTNERSHIP GRANTS

**"Keeping Faith"**

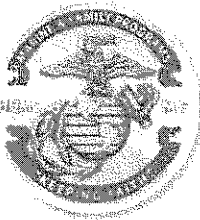


## CYTP – Inclusion Services

### A Primary Focus for MC CYTP

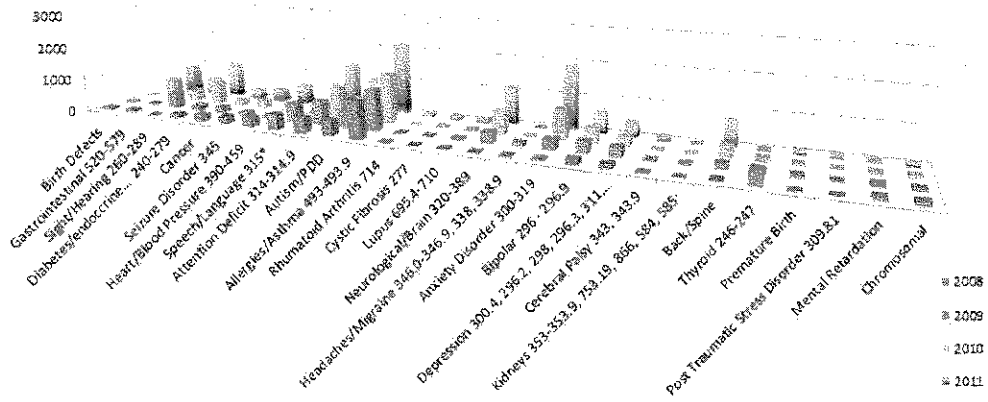
- **CDC Nurses** hired to serve CYTP at over 70% of MC installations with 100% goal. The Marine Corps CYTP benefitted from training and technical assistance offered through a *Kids Included Together (KIT)* program, contracted by DoD to provide installation staff with professional technical assistance and partnership with the Exceptional Family Member Program and the School Liaison Program to meet the individual needs of children with specific disabilities and challenging behaviors.
- **A Diabetes Management Pilot Program** was also successfully implemented at three pilot sites to promote and ensure safety and support for children with diabetes in CYTP. CYTP nurses were hired to support the special medical needs of children enrolled in and to provide increased awareness and training for CYTP staff.
- **Behavior Specialists.** During 2012, the Marine Corps is adding another critical capability to support the inclusion of all children. Behavior Specialists will be added at each installation to support service to children with social, emotional or behavioral concerns.

**"Keeping Faith"**

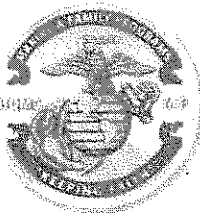


# EFMP Enrollment

Enrollment. EFMP support to enrolled families is provided by both HQMC and installation EFMP personnel. Since FY08, EFMP has experienced a steady increase in enrollment from 4,500 Marines to 8,404 Marines to over 11,000 EFM's. EFMP enrolled Marines account for 4.1 % of the Marine Corps population. A myriad of diagnoses may lead to EFMP enrollment.

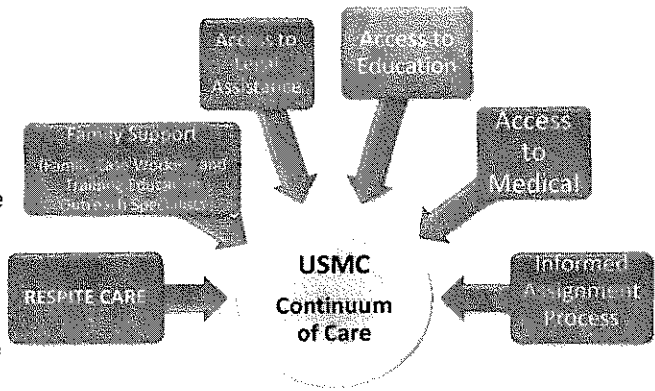


*"Keeping Faith"*



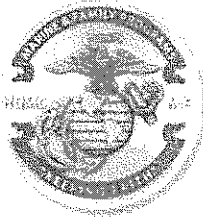
# THE USMC EFMP CONTINUUM OF CARE

Assignment Coordination. HQMC EFMP Assignment Coordinators reviewed 3,125 orders to ensure availability, accessibility and reasonable travel time to TRICARE-approved medical providers. Family Case Workers (FCW) at the installation has provided over 80,000 hours of direct and indirect support to enrolled families. An improved assignment process and investigative protocols, results in HQMC EFMP endorsement of 90% of first identified assignments for enrolled Marines, allowing Marines to remain competitive for promotion while ensuring the continuum of care for EFM's. On-going analyses of declines have resulted in conversations with OSD Office of Special Needs and Navy Medical which could result in gap resolution.

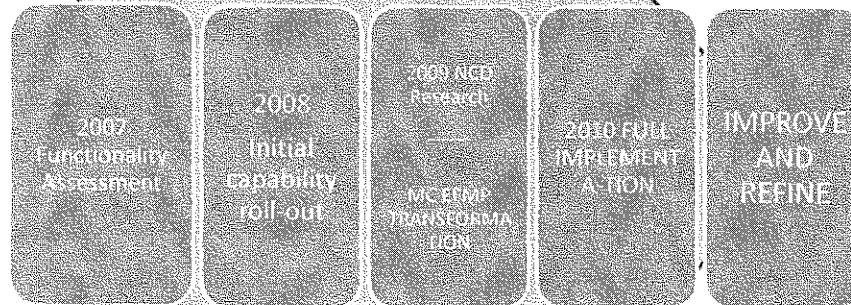


*"Keeping Faith"*

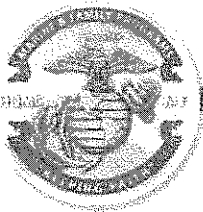
Increased enrollments by 43% (reduced stigma); DOD Premier Program



## NCD Research



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## NCD Research

- A joint undertaking of the USMC and the National Council on Disability (NCD)
- NCD is an independent federal agency "...to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities, and that empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society." ([www.ncd.gov](http://www.ncd.gov))
- NCD contracted ICF International, a professional research firm with extensive background in military community research, to conduct the Research.
- The Research took place fall 2009 through fall 2010.

*"Keeping Faith"*



## Research Purpose

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### **How to Improve Access to Healthcare, Special Education, and Long-Term Supports and Services to Family Members with Disabilities**

- **Document the experiences** of USMC families with members with disabilities in accessing appropriate and effective healthcare, special education and related services, and long-term supports and services in the U.S.
- **Identify barriers** impeding access to appropriate supports and services
- **Develop recommendations** to improve access to healthcare, special education and related services, and long-term supports and services for Marine Corps family members with disabilities.

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***“Keeping Faith”***



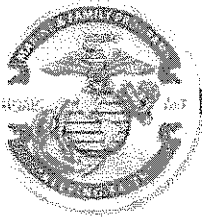
## Research Approach

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- Data collection period/sites:
  - MCB Quantico (January 2010)
  - Camp Lejeune (February 2010)
  - Camp Pendleton (March 2010)
- Data collection methods: Focus groups and interviews
- Instrumentation: Discussion guides and demographic sheets
- Research participants: EFM, their caretakers, and service providers
- Research outputs: Aggregated findings, NCD recommendations, final report.

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***“Keeping Faith”***



## EFMP—Strengths

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- USMC relies on EFMP as the primary USMC resource for families with special needs
- Participants almost unanimously recognized that EFMP is a program in transition that has grown significantly in recent years
- Many families and providers affiliated with other base and off-base programs praised EFMP and described a number of EFMP providers as exceptional.

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### *"Keeping Faith"*

Findings



## EFMP—Areas for Improvement

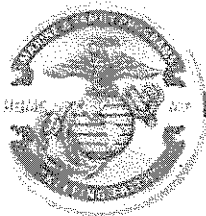
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- Barriers to EFMP program entry:
  - Lack of awareness among potential enrollees about EFMP
  - Misinformation regarding who is eligible to enroll and benefits of enrollment
  - Lingering stigma associated with EFMP and its impact on a Marine's career
  - Inconsistent referral of appropriate candidates by providers (incl. physicians)
- Communications barriers:
  - Inconsistent communication between losing and gaining EFMP offices about PCSing families .

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### *"Keeping Faith"*

Findings



## EFMP—Areas for Improvement

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- Barriers to delivery of quality service:
  - Absence of outreach contact from EFMP (reported by many families)
  - Large caseloads
  - Under-qualified caseworkers
  - Perception of limited services (assignment coordination, information & referral)
- Distrust of assignment process:
  - Skepticism about the capabilities of assignment monitors to make appropriate assignment decisions on behalf of Marines and their EFM's
  - Concern about impact of enrollment on the Marine's assignment options, deployability, and advancement.

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***"Keeping Faith"***

Findings



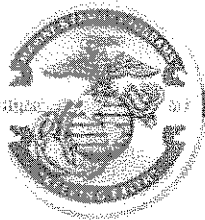
## Key Recommendations—Short-Term

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- Conduct accessibility review of human service programs and facilities on USMC bases (incl. base housing). Develop plans for each base to make programs and facilities accessible, as necessary, i.e., ADA compliant. Execute plans. (USMC)
- Increase accuracy and timeliness of information EFMP families receive from Tricare by instructing Tricare case managers to assist families in accessing services, assigning Tricare case managers to a larger proportion of the EFMP population, and establishing multiple communication mechanisms (incl. a 24/7 Tricare telephone hotline for EFMP families, similar to the Medicare hotline. (Tricare)
- Disseminate to Local Education Agencies (LEAs) and EFM families detailed guidance for implementing initiatives included in the Interstate Compact on Educational Opportunity for Military Children. (Interstate Commission, Federal and State DoEs, LEAs, DoDEA)

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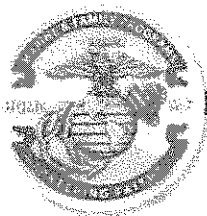
***"Keeping Faith"***



## Key Recommendations—Long-Term

- Implement mechanisms to enable military EFM's to maintain Medicaid waiver services when they move from state to state, rather than requiring them to go to the bottom of the waitlists each time they PCS:
  - Place incoming EFM's on the new state's waitlist based on their position on the previous state's waitlist (i.e., based on "time served"). If individuals have a Medicaid waiver in the previous state, they should automatically receive one in the new state. (Congress and state agencies)
  - For EFM's who lose Medicaid waiver services as a result of a PCS, provide the same benefits the EFM received in the previous state until eligibility can be established in the new state. (Congress and state agencies, DoD, Tricare)
- Increase the flexibility of services covered by ECHO to closely mirror the services available through a Medicaid waiver. (Congress, DoD, Tricare).

### "Keeping Faith"

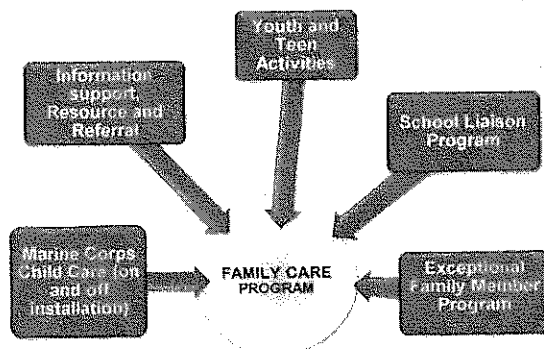


## FAMILY CARE PROGRAMS (MFY) Strategic Concepts

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### STRATEGIC ENGAGEMENT

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### STRATEGIC PRIORITIES

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- TRANSPARENCY
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- DO THE RIGHT THING

*The Family Care Branch was established to align natural working groups. Family Care is integrating and reorganizing to exploit all capabilities and eliminate redundancies.*

43% INCREASE IN EFMP ENROLLMENT • 28% INCREASE IN CHILD CARE CAPABILITIES • \$10.5M IN K-12 PARTNERSHIP GRANTS

### "Keeping Faith"



Attachment H  
SBP Legal Analysis



# The Dilemma for Military Parents of Children with Disabilities

BY KELLY A. THOMPSON

**M**ilitary parents of children with disabilities face a serious dilemma at retirement—whether or not to choose the military Survivor Benefits Plans (SBP) retirement option for their children. Saying “yes” to a monthly income for your child seems the obvious choice, BUT it may well be the wrong one under current law!

Let’s explore the differences between military SBP and Medicaid benefits, the usefulness of combining eligibility for both programs, and the unfair dilemma that military families now face when planning for the future of their special children.

## SBP BENEFITS & SSI/MEDICAID BENEFITS COMPARED

The SBP will pay up to 55% of the military member’s retirement pay to a spouse and/or dependent child when the retiree dies. The member can also select a lesser benefit at a lesser cost. The military member can select coverage for a spouse only, a spouse and children, or children only. The member takes a reduction of about 6.5% in retirement pay for SBP for a spouse and only about \$20/month for dependent children.

In addition to (or in place of) the survivor benefit, a military member can provide an array of benefits for a child with a disability. In most cases, a disabled child over age 18 can be designated as an Incapacitated Dependent (DD Form 137-5) and be permanently eligible for military post privileges as well as TRICARE health benefits. However, these military benefits do not include supportive living programs or vocational opportunities. Unfortunately, the SBP and TRICARE benefits are often not enough to pay privately for all the help that may be needed by an adult child with a disability. So, the military family must often look to other programs to provide for a child’s needs.

If the child with a disability who has reached age 18 has assets less than \$2,000 and minimal income, he or she will usually be eligible for Supplemental Security Income

(SSI) and Medicaid. Although SSI pays only \$674 monthly (2011 maximum benefit) and Medicaid may seem to duplicate TRICARE’s health benefits, Medicaid “waiver” programs pay for a wide variety of programs and services that TRICARE does not. If the child with a disability is living independently, SSI is intended to pay for the child’s food and shelter, while Medicaid may pay for supported living programs, day programs, job coaching and other services. Thus, TRICARE and Medicaid provide a complementary mix of health care benefits and support services needed by many adults with disabilities.

## THE DILEMMA

The dilemma is that the SBP income payments after a military parent’s death paid to a child with a disability may cause the loss of the child’s SSI and essential Medicaid benefits. SSI payments are offset by other income received (including SBP payments) by the recipient. ANY unearned income over \$20 offsets SSI income, dollar-for-dollar. Once SSI income reaches zero, SSI is lost and, in the majority of cases, Medicaid is lost also. If the military member dies having chosen SBP for his or her child with a disability, that child will receive as much as 55% of the retiree’s income. If that SBP payment to the child amounts to more than \$674 monthly, the child with a disability will lose SSI and Medicaid health care and community support benefits. In my home state of Virginia and in many states, if the SBP exceeds \$2,022 per month, then all supported living assistance, job coaching, respite care and other services provided under Medicaid “waiver” programs are lost.

A recent example concerns a 52-year-old man with an intellectual disability who had lived in a group home for 18 years and attended a day program for individuals with disabilities. His only income was SSI of \$674 per month. His SSI benefits and Medicaid paid for his programs and services. However, when his father, a retired

House Resolutions 2059 and 3324 were introduced in 2009, allowing assignment of the SBP to a special needs trust that provides for payback to Medicaid at the death of the SBP recipient.



Special needs require special attorneys.

Navy officer, died, his adult son began to receive military SBP in the amount of \$2,030 per month. This SBP payment made him ineligible for Medicaid waiver services. The private pay cost of the programs and services he was receiving prior to his father's death is \$8,600 per month, more than four times his SBP payment. He lost his group home placement, as well as his day program, and was transferred to a state "training center"—a large institutional setting isolated from the community.

**PLANNING OPTIONS?**

What about just canceling the SBP beneficiary payments? If the military retiree has already made an SBP election that includes a benefit for children, and he or she has a child with a disability, then the retiree can apply to the Board for Correction of Military Records to modify the SBP election. This option must be completed while the retiree is still alive, since SBP beneficiary payments to the disabled child start upon death. The member must complete DD Form 149, justifying why the SBP selection option must not include children (i.e. spouse only). For example, the retiree might tell the Board that he or she did not understand when the retiree originally made the election including children how the SBP benefit would negatively impact the disabled child's other benefits. The individual services have separate Boards for the Correction of Military Records that will consider such requests.

Unfortunately, once the retiree has died and payments begin, there is no way to stop them. Medicaid will not allow the renunciation of the SBP payment and will continue to count it as income even if not collected, and the child with a disability will lose Medicaid. The only true option under current law is NOT to elect the SBP benefit when the military member retires.

**PLANNING OPTIONS UNFAIRLY LIMITED FOR MILITARY FAMILIES**

Most of my military clients feel that this SBP issue as it effects their children with disabilities is blatantly discriminatory and unfair. Non-military parents can easily assign their pension and life insurance benefits to a special needs trust for their child with a disability. This allows the child to receive SSI and Medicaid and to supplement those benefits with distributions from a special needs trust containing the parents other assets. The rules for military families are different, however. Defense Finance and Accounting regulations (based on a provision of the United States Code) provide that the SBP

A military family may spend years on a waiting list for Medicaid waiver services in one state and finally receive benefits, only to be transferred to another state and start the waiting list process all over again.

payment may only be paid to a "person." When interpreted literally by the military, this means that SBP payments cannot be assigned to a trust for the benefit of that "person."

Support is growing for a legislative fix to this problem, by allowing the SBP payment for a child with a disability to be assigned to a special needs trust. House Resolutions 2059 and 3324 were introduced in 2009, allowing assignment of the SBP to a special needs trust that provides for payback to Medicaid at the death of the SBP recipient. Identical provisions were introduced by Senator James Webb (D-VA) as amendments to the National Defense Authorization Act. Unfortunately, the 2009-2010 initiatives were unsuccessful and, in the recent political climate, it is difficult to get attention focused on this issue.

**YOU CAN HELP**

The Military Coalition has placed this SBP issue on its legislative agenda and has actively sought an amendment to the United States

Code to allow assignment of SBP payments to a special needs trust. The American Bar Association and The Arc of the United States have also endorsed such an amendment. As of August 1, 2011, Senator Webb has agreed to introduce the measure again. Meanwhile, the Coalition continues to look for a sponsor on the House side.

Military families who have a member with a disability face numerous challenges not faced by most families. Frequent transfers make meeting the educational needs of their children a moving target. Those same transfers mean that applying for Medicaid and other benefits for their children is repeated often as the families move from state to state. A military family may spend years on a waiting list for Medicaid waiver services in one state and finally receive benefits, only to be transferred to another state and start the waiting list process all over again. The inability to assign SBP payments to a special needs trust is one challenge facing military families that can and should be fixed. Add your voice to this effort. •

Kelly A. Thompson has been a lawyer for 32 years, practicing law in Arlington, Virginia for the last 16 years. Her clients include many military families and her practice focuses on planning for individuals with disabilities and the elderly, special needs trusts, trust administration and estate planning. She has been honored as a Super Lawyer, and is listed as one of Americas' Best Lawyers and as a Washingtonian Magazine Top Lawyer. Ms. Thompson is a member of the Special Needs Alliance, a national, non-profit organization committed to helping individuals with disabilities, their families, and the professionals who represent them. Contact information for a member in your state can be obtained by calling toll-free 1-877-572-8472, or by visiting: [www.specialneedsalliance.org](http://www.specialneedsalliance.org)