

HEARING TO RECEIVE TESTIMONY ON DEPARTMENT OF DEFENSE PROGRAMS AND POLICIES TO SUPPORT MILITARY FAMILIES WITH SPECIAL NEEDS IN REVIEW OF THE DEFENSE AUTHORIZATION ACT FOR FISCAL YEAR 2013 AND THE FUTURE YEARS' DEFENSE PROGRAM

THURSDAY, JUNE 21, 2012

U.S. SENATE,
SUBCOMMITTEE ON PERSONNEL,
COMMITTEE ON ARMED SERVICES,
Washington, DC.

The subcommittee met, pursuant to notice, at 2:35 p.m. in room SD-106, Dirksen Senate Office Building, Senator Jim Webb (chairman of the subcommittee) presiding.

Committee members present: Senators Webb, Begich, Gillibrand, and Blumenthal.

Committee staff member present: Leah C. Brewer, nominations and hearings clerk.

Majority staff members present: Jonathan D. Clark, counsel; Gabriella E. Fahrer, counsel; and Gerald J. Leeling, counsel.

Minority staff member present: Diana G. Tabler, professional staff member.

Staff assistants present: Jennifer R. Knowles and Brian F. Sebold.

Committee members' assistants present: Brian Burton, assistant to Senator Lieberman; Lindsay Kavanaugh, assistant to Senator Begich; Elana Broitman, assistant to Senator Gillibrand; Ethan Saxon, assistant to Senator Blumenthal; and Lenwood Landrum, assistant to Senator Sessions.

OPENING STATEMENT OF SENATOR JIM WEBB, CHAIRMAN

Senator WEBB. The subcommittee will come to order. The subcommittee meets today to receive testimony on the Department of Defense programs, and policies to support military families with special needs and a review of the National Defense Authorization Act for Fiscal Year 2013 and for Future Year Defense Programs.

At the outset, let me say a few things. First, I know that this is a hearing that was supposed to have been held yesterday. And some of you have been required to stay over a day in order to testimony. I want you to know I appreciate that, and I think everybody here is aware of what we have been doing on the Senate floor for

the past three days. We have had the Farm Bill up, and we entertained more than 70 amendments in three days.

Having spent 4 years as a committee counsel on the House side, I can tell you it is a lot different on the Senate side in terms of how we address amendments because each of these amendments is debated. There is a time for a vote, and each senator has to personally present themselves when they vote. So it is a very time consuming process. And I think there is actually a pretty good bipartisan feeling right now that we were able to get through such a complex piece of legislation, nearly a trillion dollar piece of legislation during that time period.

But I do apologize for not having been able to have held this hearing yesterday. We thought about trying it, but quite frankly we would have been in and out of here constantly, and I do not think it would have been the best use of the time of the people who have come here to testify.

I would also like to acknowledge Senator Gillibrand, who is, I have heard, on her way, for having expressed an interest in a couple of these issues, which resulted in Senator Levin and Senator McCain suggesting that we do go ahead and hold a hearing on these issues. And so this is what we are doing. And this was the recent markup of the Defense Authorization bill. She held or she requested that some specific special needs programs be examined in an open subcommittee hearing. So we are doing that today and very pleased to be doing that today.

We are fortunate to have with us today a diverse panel. Our witnesses are Dr. Karen Guice, Principal Deputy Assistant Secretary of Defense for Health Affairs, the Principal Deputy Director of TRICARE Management Activity; Dr. Rebecca Posante, Deputy Director of the Department of Defense's Office of Community Support for Military Families with Special Needs; Dr. Vera Tait, Associate Executive Director and Director of the Department of Community and Specialty Pediatrics of the American Academy of Pediatrics; Mr. Jeremy Hilton, a military spouse, a veteran, and military family advocate, as well as the 2012 Armed Services Insurance military spouse of the year as voted by his fellow military spouses; Dr. Geraldine Dawson, Chief Science Officer of Autism Speaks, and Professor of Psychiatry at the University of North Carolina at Chapel Hill; and Mr. John O'Brien, Director of Healthcare and Insurance for the Office of Personnel Management.

This panel represents a variety of interests and viewpoints: the Federal Government, clinicians, the military family community, non-profit organizations, and academia. We look forward to hearing from each of you today.

I have said in many previous hearings that ensuring that our uniform personnel and their families receive first rate healthcare is one of the critical elements in what I view as the military's moral contract with those who volunteer to serve our Nation. I say that as someone who grew up in the military, who had the honor of serving as a Marine rifle platoon and company commander during Vietnam, whose son served as a Marine infantryman in Iraq, and a brother served, and both my sisters married military professionals. I care deeply about this, as I am sure everybody on this panel does also.

Families play a significant role in maintaining our volunteer force, and this is true now more than ever. Our servicemembers must know that their families are receiving timely and professional medical care, especially when they are so frequently deployed. This can be even more imperative in cases where military family members have special needs.

We are mindful that the term “special needs” is very broad. For some families, “special needs” may mean obtaining necessary care and treatment for complex medical issues. For others, it means gaining access to resources necessary to accomplish goals set out in a child’s individual education program at school. And for many, it can mean a combination of medical treatment, educational services, and systems of support for caregivers.

Given the unique challenges inherent to military life, including frequent relocations to new homes and schools, and having a new team of medical providers with each permanent change of station, not to mention deployments, it is no wonder that the Department felt it necessary to establish the Exceptional Family Member program. This program provides support to our military families with special medical and educational needs through identification and enrollment, assignment coordination, and family support. Currently more than 120,000 servicemembers are enrolled in this program.

Beyond support, through EFMP, DOD reports that in fiscal year 2011, more than 10,000 beneficiaries were enrolled in the extended care health option, or ECHO program, which supplements basic TRICARE coverage. This program provides eligible active duty families with up to \$36,000 a year to help cover the costs of services and supplies necessary for qualifying medical and physical conditions.

Data for the ECHO program provides us with a sense of the scope of conditions that some military families face today. For example, DOD tells us that more than 6,000 dependents have been diagnosed with autism. More than 1,000 have infantile cerebral palsy. Another 2,700 have disorders including epilepsy, hearing loss, digestive disorders, spina bifida, or muscular dystrophy. These are just the major categories of medical conditions military families with special needs must address.

Today we aim to increase our awareness of the challenges facing our military special needs families. Some examples: we recently heard of the need for better outreach to military families with special needs, some of whom may be unaware of resources that are available to them, continued effort to provide more uniform support through the Exceptional Family Member program from installation to installation, and assisting our servicemembers and their families to navigate the various medical and educational services available from State to State.

We have also been informed that the Office of Personnel Management recently determined that applied behavior analysis, or ABA, therapy for autism spectrum disorders is considered medical therapy for purposes of offering it to beneficiaries under the Federal Employees Health Benefits program. DOD has been offering ABA therapy for several years, but not under its basic TRICARE program as it has determined that ABA is an educational intervention

and not a medical therapy. And we are interested in hearing the thoughts of today's witnesses about this distinction.

So we appreciate the breadth of knowledge the panel before us today possesses. I hope that our witnesses can help us to identify the key issues and concerns facing military families with special needs, the steps the Department has taken to address those concerns, and where the Department of Defense and the Congress can do a better job.

We look forward to your testimony. I encourage all of you to express your views candidly, to tell us what is working and what is not, and to raise any concerns and issues you may want to bring to this subcommittee's attention.

I would also point out at this time that we have received written statements from the National Military Family Association, the National Council on Disability, and they will be included in the record at the end of the written testimony of the witnesses that we have today.

[The information referred to follows:]

[SUBCOMMITTEE INSERT]

Senator WEBB. We will now hear brief opening statements from each of our witnesses. I would like to say to each of our witnesses that your full prepared statements will be entered into their record in their entirety at the end of your opening statement. I would ask that you look to keeping your opening statements to about 5 minutes.

We have one, two, three, four, five, six—that is going to take us probably a little more than a half hour to do that. But, Dr. Guice, welcome. We will start with you.

[The prepared statement of Senator Webb follows:]

[SUBCOMMITTEE INSERT]

STATEMENT OF DR. KAREN S. GUICE, PRINCIPAL DEPUTY ASSISTANT SECRETARY OF DEFENSE FOR HEALTH AFFAIRS AND PRINCIPAL DEPUTY DIRECTOR, TRICARE MANAGEMENT ACTIVITY

Dr. GUICE. Mr. Chairman, members of the committee, as you can tell, I have laryngitis. I would like to beg your indulgence in letting me talk a little over the 5 minutes if I have to.

Thank you for the invitation to discuss the military health system—

Senator WEBB. Very convenient, Dr. Guice, that you would have—

Dr. GUICE. Oh, sorry.

Senator WEBB.—laryngitis when we have called you to this hearing.

Dr. GUICE. You know, if it had been held yesterday—

Senator WEBB. You are getting a lot of empathy right now, so if you want to make your statement briefer, that is fine. We can do it any way possible to accommodate you.

Dr. GUICE. Thank you. Military service brings unique challenges to anyone who wears the uniform. Those servicemembers who have special needs children have additional challenges.

The Department is proud of the programs and services we offer to these families in conjunction with other support services pro-

vided by State and local governments and the private sector. Dr. Rebecca Posante will talk about those services provided by the Office of Community Support for Families with Special Needs. I will briefly touch on the health benefits and supplemental services we provide through our basic medical plan and the extended healthcare option, or ECHO program.

The Department of Defense offers a comprehensive and uniform medical benefit for military beneficiaries delivered worldwide through our military treatment facilities or purchased care. For our beneficiaries, these medical benefits include access to a variety of providers, including specialists, inpatient and outpatient care, as well also prescription medication.

In addition to the basic health plan, the military health system offers the ECHO program. This program provides additional beneficiaries not otherwise available under the basic health plan to eligible active duty servicemembers with special needs. By ensuring our active members have access to these services, we support military retention and readiness for the Department.

One example of the services covered under the ECHO program is applied behavioral analysis for patients with autism spectrum disorders or ASD. Since 2001, the Department has covered ABA services for qualifying members. Because many of our active duty families found it difficult to access certified ABA providers under the traditional ECHO program's criteria, we implemented a demonstration project in 2008 to determine if we could expand the availability of providers.

Under the demonstration program, we cover ABA services when provided by tutors who are under the direct supervision of certified ABA therapists. This demonstration project has succeeded in expanding access to services, and participation in the demonstration project has grown by average of 3 to 5 percent per year—per month per year. We are now in the process of converting the demonstration project into a permanent part of the ECHO program.

Military families also asked us to help sustain continuity of care and service during reassignments and relocations. We work closely with our TRICARE regional offices and TRICARE contractors to ensure that there is a smooth transition for families with children who have special needs when they relocate.

I understand that one of the primary purposes of this hearing is to address medical coverage decisions by the Office of Personnel Management for the Federal Employee Health Benefit Plan and TRICARE relative to ABA for patients with ASD. In 2010, the Department of Defense conducted an assessment to determine if ABA qualified as medically necessary and appropriate under existing TRICARE law and regulation. Through robust analysis, peer review literature, and independent technical analyses, ABA was determined to be an educational intervention, and as such, did not meet the criteria for coverage under the basic medical program.

Our determination is consistent with the 2011 Agency for Healthcare Research and Quality's comparative effectiveness review of therapies with children who have ASD. In this review, the investigators found the literature to be highly variable in quality, limited in those specific areas, and inconclusive. They identified the

need for more research to determine which children benefit from a particular intervention or combination of interventions.

In the same report, the investigators clearly separated education and behavioral interventions for medical interventions. They did not consider ABA to be a medical intervention, which is consistent with the Department's 20101 review. However, we also understand that OPM has recently reviewed evidence that they believe now meets their threshold for determining ABA as a covered medical service. We have formally requested that OPM provide us this evidence so we can evaluate it against our coverage criteria.

Medical care evolves over time, and we continuously evaluate new medical interventions or treatments for effectiveness and safety prior to a coverage determination. Our coverage determinations are strictly governed by statute and regulations, and require an extensive assessment of reliable medical evidence. Our determinations are also based on what is medically or psychologically necessary to diagnose and treat disease or injury.

The Department is committed to providing comprehensive services for military families who have children with special needs. By providing robust medical care for our active duty members and their families, along with supplemental services to further support those with special needs, we contribute to a stronger war fighter.

I am proud to be here with you today to represent the military health system and our exceptional health providers who provide exceptional service to exceptional people. I look forward to answering your questions.

[The prepared statement of Dr. Guice follows:]

Senator WEBB. Thank you very much, Dr. Guice.

Dr. Posante, welcome.

STATEMENT OF DR. REBECCA L. POSANTE, DEPUTY DIRECTOR, OFFICE OF COMMUNITY SUPPORT FOR MILITARY FAMILIES WITH SPECIAL NEEDS, DEPARTMENT OF DEFENSE

Dr. POSANTE. Thank you. Thank you, Senator Webb, for inviting me to testify today. Supporting individuals and families with special needs has been a passion of mine for over 30 years, and I really appreciate the attention being paid to this topic today.

When I brief the fiscal year 2010 National Defense Authorization Act to military audiences, I always refer to it as landmark legislation. It established the Office of Community Support for Military Families, with Special Needs, for which it has been my pleasure to serve as the deputy director for nearly 2 years. It served as a catalyst for our efforts to streamline processes that can be improved, to raise issues that need to be raised, to develop policies that guide the provision of support by the military departments, and to generally help families identify, understand, and navigate the systems they will encounter.

Military families with special needs are military families first. They face the same challenges that other military families face due to periodic moves, deployments, and separation from their extended families. But in addition, our families with special needs face the challenge of navigating often complex, stove piped, and confusing educational, medical, and community support systems. Our families have children with intellectual, physical, communication, and

emotional disabilities. In about a third of our families, it is the adult member that has a special need.

The good news is that there are a myriad of systems, military, state, and local community systems, available to support them. The bad news is there are a myriad of systems. Our office has been charged with bringing order to this chaos and helping our families access the support they need.

Currently, over 400 family support personnel serve military families with special needs. All of our installations, depending on their sizes, have a full or part-time staff person or, in some very small locations, a point of contact for military families with special needs. Over the last two years, all of our providers have been trained on their roles, on the agencies with which they should be working, and on the requirements of supporting military families with special needs.

Communicating with our families is important. Educating them on programs, benefits, and resources is crucial. Working jointly with the military departments, we have provided a wealth of information to military families with special needs, including materials available online and through Military OneSource.

My written testimony outlines our ongoing work in greater detail, where we are succeeding, and where we have more work to do. Thank you so much for your support.

[The prepared statement of Dr. Posante follows:]

Senator WEBB. Thank you, Dr. Posante. And, again, I would remind the witnesses that your full written statement will be entered into the record at the end of your opening statements. And also just for the subcommittee, that the hearing record will remain open until close of business tomorrow in case there were written questions that anyone would like to present to you.

[The information referred to follows:]

[SUBCOMMITTEE INSERT]

Senator WEBB. Dr. Tait, welcome.

STATEMENT OF DR. VERA F. TAIT, ASSOCIATE EXECUTIVE DIRECTOR, DEPARTMENT OF COMMUNITY AND SPECIALTY PEDIATRICS, AMERICAN ACADEMY OF PEDIATRICS

Dr. TAIT. Thank you. Chairman Webb and members of the subcommittee, thank you for holding today's hearing on such an important topic: military families who have children with special healthcare needs. I am Dr. Fan Tait, and I represent the American Academy of Pediatrics, a professional organization of more than 60,000 primary care pediatricians and pediatric sub specialists. I am honored to join this panel, which includes such extraordinary advocates and experts.

I am a pediatric neurologist and an associate executive director at the AAP. Prior to joining the AAP, I was in practice for more than 25 years with my major areas of expertise including children and youth with special healthcare needs, traumatic brain injury, neurodevelopmental disabilities, and neurologic rehabilitation. Caring for our Nation's military families and their children has always been of paramount importance for the Academy. And I am proud to say that one of the oldest sections in our academy is the section on uniform services.

The impacts of long or multiple deployments on all military families can be significant. And for families with children who have neurodevelopmental disabilities or disorders, these impacts are often significantly exacerbated. The AAP believes that the optimal health and well-being of all infants, children, adolescents, and young adults, including those in military families, is best achieved with access to appropriate and comprehensive health insurance benefits. These benefits must be available through public health insurance plans, like Medicaid, the Children's Health Insurance Program, and TRICARE, as well as the private health insurance plans.

AAP policy recommends that minimum health benefits for infants, children, and youth should provide all medically necessary care within the medical home. So we believe that medical and other services must be delivered and coordinated, as you said, Senator Webb, in a comprehensive patient- and family-centered medical home, which is the quality setting where physicians who are known to the family and to the child have developed a partnership of mutual responsibility and mutual trust.

As you know, the health insurance plan that most military families use is TRICARE, and services, as we have heard, covered by TRICARE provided by pediatricians who are active duty military, but also community pediatricians and pediatric sub specialists, who provide care near military facilities. Military families often face challenges navigating the TRICARE program, many times struggling to find the appropriate pediatric providers or have certain pediatric services covered.

One area of particular concern among military families, and the reason we are here today, is to look at children with special healthcare needs and the coverage of services for children with neurologic disorders, especially the autism spectrum disorders, or ASDs. Unfortunately, there is often no simple solution for families whose children must receive care often from numerous providers. A coordinated approach to intervention and treatment among the medical home, the educational institutions, and the family is really critical for success.

One demonstrated effective treatment for autism is applied behavior analysis, or ABA. The symptoms associated with autism are directly addressed by ABA methods, which have proven effective in addressing the core symptoms of autism, as well as helping children develop skills and improve and enhance functioning in other areas that affect health and well-being.

The effectiveness of ABA-based interventions and autism has been well documented through a long history of research. Children who receive early intensive treatment have been shown to make substantial gains in cognition, language, academic performance, and adaptive behavior, as well as social behavior. And their outcomes have been significantly better than those of children who have not access to these interventions. Though more research and ongoing research is needed, ABA has both long-term empirical and research data to demonstrate its effectiveness in helping children who are diagnosed with ASDs.

The AAP has endorsed the use of ABA treatments when determined appropriate by physicians within a medical home in close consultation with families.

Thank you for allowing me to testify before the subcommittee today. We must do all that we can to support our military families, but especially those who have the added challenge of raising children with special healthcare needs. Thank you, and I look forward to the questions.

[The prepared statement of Dr. Tait follows:]

Senator WEBB. Thank you very much, Dr. Tait.

Mr. Hilton, welcome.

**STATEMENT OF JEREMY L. HILTON, MILITARY SPOUSE,
VETERAN, AND VETERAN FAMILY ADVOCATE**

Mr. HILTON. Mr. Chairman and distinguished subcommittee members. Thank you for allowing me to discuss our military families impacted by disabilities.

I am a Navy veteran. My wife is active duty Air Force. When our daughter, Kate, was born in 2002 with significant disabilities, I resigned my commission to take care of her. This year I was honored as military spouse of the year by my peers in Military Spouse magazine. It is an amazing privilege to be able to represent a million plus military spouses and their families.

A recent National Council on Disability Military Families study concluded, "Far reaching systemic changes are needed in our Nation's health, education, and long-term service systems to address the significant barriers faced by exceptional family members." This hearing is a critical step in addressing and acting on these extraordinarily important issues to our military families.

Caring for a child with a disability can be exceptionally expensive and remarkably stressful. We have higher medical bills, therapy bills, home modification and equipment bills, and other large expenses. Many families will need Medicaid waiver assistance for their children, but State Medicaid waiver wait lists are very long, lasting for years. Every time a military family moves, they go to the bottom of the next State's wait list. They rarely reach the top before moving again. Those that do lose their Medicaid when the military moves them.

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 servicemembers to maintain wait list eligibility based on their home of record, or extending the ECHO benefit into retirement. In the end, we ask that our children are not penalized for the service their mother or father renders to the Nation.

The extended care health option, otherwise known as ECHO, was created to bridge the needs of families unable to access the State Medicaid waiver programs. But experience shows it fails to come close to replacing Medicaid waiver benefits. We are grateful for this benefit, but we would like to see it updated and made more flexible so it better fulfills its purpose.

We support the Senate report language directing DOD to explore more flexible ECHO options. We respectfully ask that EFMP families are included on any working groups considering this and other issues that impact our families.

While we look forward to enhanced functionality and flexibility of the ECHO 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, the standard of care, and the treatment of autism into ECHO as a non-medical educational service. TRICARE's classification of ABA as non-medical allows TRICARE to limit care to dependents of active duty servicemembers, and places a financial cap on treatment services which fall far below recommended standards. There is no other disease, disability, or chronic health condition which is treated similarly as autism and its segregation of treatment outside the basic TRICARE benefit.

Because the ECHO benefit is only available for dependents of active servicemembers, dependents of our retirees are not able to access ABA treatments under TRICARE. Prior to the hearing, we supplied 80 plus stories to the subcommittee. Many are heart-breaking, but inspiring at the same time. I am going to read from a letter written by Lance Corporal Hardy Mills, United States Marine Corps, Retired.

"In 2004 while serving with the 1st Marine Expeditionary Force in Fallujah, Iraq, I was wounded severely by a rocket propelled grenade. Because of my injuries, I retired medically from the Marine Corps in 2006 with full disability benefits. I am blessed with a supportive wife, and we have two beautiful children.

Our son, Shane, has autism. As a retired Marine and disabled veteran, my family depends on the military healthcare system, TRICARE, for coverage of medical services and interventions. Unfortunately because of my retired status, Shane's medically recommended autism treatment, ABA, is not covered by TRICARE. My family faces out-of-pocket costs of \$4,600 a month associated with this vital service because of current TRICARE policy deficits. We have sold our home to provide Shane the care he requires, but we are running out of funding and ask for your intervention."

The other letters are no less important and show the struggles our military families have gone through to be able to provide therapy to their children. In the end, many of these families are still coming up significantly short, particularly those with younger children and our retirees.

You will hear Dr. Tait and Dr. Dawson testify on the scientific evidence that proves ABA is effective. Many other reputable organizations and members of the medical community have endorsed ABA therapy as the standard of care for autism. I sincerely hope that the Armed Services Committee will take this into consideration and support an amendment to the 2013 NDA to help our military kids impacted by autism.

These military families are remarkable Americans who endure exceptionally trying circumstances in addition to their service in an already stressful military lifestyle. I would encourage you to take a moment and get to know each of them. As I am certain you realize after reading these stories, we have much work left to do in order to provide the appropriate level of medical care, services, and support these military families deserve.

I would like to personally thank the committee members and the professional staff for their leadership in providing much-needed oversight to these issues. Thank you to this committee for not forgetting our military families. I look forward to your questions.

[The prepared statement of Mr. Hilton follows:]
 Senator WEBB. Thank you very much, Mr. Hilton.
 Dr. Dawson, welcome.

STATEMENT OF DR. GERALDINE DAWSON, CHIEF SCIENCE OFFICER, AUTISM SPEAKS, AND PROFESSOR OF PSYCHIATRY, UNIVERSITY OF NORTH CAROLINA AT CHAPEL HILL

Dr. DAWSON. Good afternoon, Chairman Webb, and members of the subcommittee. I am Dr. Geraldine Dawson. I am the chief science officer at Autism Speaks, and I serve as professor of psychiatry at the University of North Carolina at Chapel Hill. Prior to joining Autism Speaks, I directed the University of Washington Autism Treatment and Research Center for close to two decades.

Autism Speaks is the world's leading autism science and advocacy organization. We are dedicated to funding research into the causes, prevention, treatments, and cure of autism, and to increasing awareness and advocating for individuals with autism and their families.

I am honored to appear before the Senate Armed Services Subcommittee on Personnel, and to participate in this hearing on issues facing military families who have dependents with special needs.

Like their counterparts in civilian life, many military families face challenges in providing proper treatment for their child with autism. I am here today to talk about those challenges and how the military healthcare system can lessen their effect on families.

But first some information about autism. Autism is a developmental disorder that affects a person's ability to form social relationships and communicate with others. People with autism also exhibit repetitive behaviors, some of which can interfere with their ability to learn and function. Autism is caused by a combination of genetic and environmental risk factors.

But autism is no longer considered a rare condition. It affects 1 in 88 children in the United States, 1 in 54 boys. This year, more children will be diagnosed with an autism spectrum disorder than AIDS, diabetes, and cancer combined. The prevalence of autism has risen dramatically over the last several decades. In fact, statistics show a tenfold increase in the past 40 years. Many in the autism community use the word "epidemic" when describing autism.

Fortunately there are effective treatments for autism that can change a person's course and outcome. Numerous controlled clinical trials have shown that early intensive behavioral treatment significantly increases IQ, language abilities, daily living skills, while reducing the symptoms of autism.

In fact, a 2010 randomized controlled trial, funded by the National Institutes of Health and published in the prestigious *Journal of Pediatrics*, found that 50 percent of children with autism who received early intensive behavioral treatment for two years had a 15-point increase in IQ. One-third of the children showed an increase in IQ of greater than 30 points. This means that early treatment changed these children's life trajectories, setting them on a course that increases their chance of living productive and satisfying lives.

These children will likely attend a regular classroom, develop spoken language, and make friendships. This is not only good for

these individuals, it results in significant cost savings as fewer services will be needed in the long run, and these individuals now can become more productive members of our society.

Behavioral health treatments that are based on applied behavior analysis, or ABA, have become widely accepted among healthcare professionals as an effective treatment for autism. These treatments are provided by highly-trained licensed and certified professionals. Early in life treatment involves working one-on-one with a child typically for 25 to 40 hours per week.

Thirty States now require coverage of ABA treatment as part of medical care. Employers, such as Microsoft and Home Depot, universities, such as Ohio State, Harvard, Princeton, and healthcare facilities, such as the Mayo Clinic, do so as well.

Earlier this year, the U.S. Office of Personnel Management concluded that there is enough evidence to classify ABA as a medical therapy. In contrast to the benefits covering ABA treatment that now will be made available to the Federal civilian workforce, the healthcare program for uniform servicemember and their families, TRICARE, provides only limited coverage for ABA treatment.

TRICARE classifies ABA treatment as an educational intervention, and makes it available only through the extended care health options, and caps coverage at \$36,000 a year.

Furthermore, ABA treatment is restricted to dependents of active duty servicemembers, dependents of retirees, including dependents of wounded warriors who were retired due to their injuries sustained in combat, are unable to access ABA treatment for their child with autism. Guard Reserve families receive intermittent care as they move between active and non-active duty status.

Thirty-six thousand dollars a year pays for about 11 hours of ABA treatment per week. Many children with autism, particularly early in life, and some who face severe challenges, need more treatment hours in order to fully benefit from the treatment.

Given all that our military families have shouldered for the past decade, they deserve better. On behalf of thousands of military families affected by autism, I strongly urge Congress to require TRICARE to provide behavior health treatment, including ABA, to military families regardless of duty status, and at the level of care prescribed.

Thank you, Chairman Webb, and members of the subcommittee for this opportunity to speak about this important issue affecting military families. And I look forward to your questions.

[The prepared statement of Dr. Dawson follows:]

Senator WEBB. Thank you very much, Dr. Dawson.

Mr. O'Brien, welcome.

STATEMENT OF JOHN O'BRIEN, DIRECTOR OF HEALTHCARE AND INSURANCE, U.S. OFFICE OF PERSONNEL MANAGEMENT

Mr. O'BRIEN. Chairman Webb, thank you very much, members of the subcommittee. Thank you for the opportunity to make a statement on behalf of the Federal Employees Health Benefit program, the FEHB, administered by the U.S. Office of Personnel Management. We appreciate the subcommittee's interest in our program and its support of families whose children have special needs, specifically those with autism spectrum disorders.

We understand that the subcommittee seeks information on our recent reclassification of applied behavioral analysis, ABA, as a medical therapy. In contrast to the single provider model of TRICARE, the FEHB program contracts with 91 separate insurance carriers to offer health plans to over 8 million Federal employees, annuitants, and families. All plans are required to provide basic services, and may propose and negotiate to offer a range of additional benefits. All FEHB plans are required to provide children with autism access to pediatric care, physical therapy, occupational therapy, speech therapy, mental health treatment, and medications.

However, during the current 2012 contract year, the FEHB benefit—the ABA is not an FEHB benefit because it is classified for the FEHB as an investigational or educational intervention, and, therefore, is subject to a blanket exclusion. That means that children of a Federal employee cannot access ABA services through their health insurance regardless of whether the plan they have selected would have normally considered such a treatment as medically necessary and provide it to its non-Federal subscribers.

Beginning in 2010, members of Congress, families, and other stakeholders asked OPM to reexamine this blanket exclusion. The OPM Benefit Review Panel evaluated the status of ABA for children with autism. Previously ABA was considered to be an educational intervention and not covered under the FEHB program. The Benefit Review Panel concluded that it is now sufficient evident to categorize ABA as a medical therapy. Accordingly, plans may propose a benefit package that include ABA.

The insurance marketplace in which the FEHB operates is changing rapidly with regard to ABA therapy. At present, 30 States require some health insurance coverage of ABA. In a week, that number will be 31. Had I been before this committee in June 2010, the number of States requiring ABA would have been 14. In June 2008, just 4 years ago, the number would have been two.

OPM has made the decision to reclassify ABA as a medical therapy rather than as an educational service based on the evolving body of clinical research and the maturing provider infrastructure to deliver this modality under a medical model. This reclassification does not presume medical necessity, and does not specifically require FEHB plans to add ABA service to their basic benefits package. Rather it allows plans to propose ABA as an additional benefit under conditions where medical necessity is satisfied and appropriate and qualified providers are available.

Medical necessity criteria are evaluated by each health plan in FEHB, not by OPM. Plans assess whether a proposed treatment is safe, supported by sound medical evidence, effective for an individual, more effective than alternative treatments, and conforms to relevant standards of medical practice. Our decision only applies to the FEHB and not to TRICARE programs, and accordingly, was published as technical guidance to our carriers.

The evidence is not yet sufficient to support an official OPM position requiring coverage by all FEHB carriers. In the interval, our administrative change will allow FEHB plans that choose to to make ABA services available as the research and provider base

matures. OPM will periodically re-review ABA as the research develops.

We are grateful for the subcommittee's support of Federal employees and their families. Thank you for this opportunity, and I am happy to answer any questions you may have.

[The prepared statement of Mr. O'Brien follows:]

Senator WEBB. Thank you very much, Mr. O'Brien. And let me just begin by thanking all of you for really your extraordinary breadth of experience that has been reflected in your testimony today, both written and oral.

And just as an immediate reaction, before we get into some of these more complex issues that are being addressed with respect to ABA therapy, I think that, Mr. Hilton and some of the others, you raised some very valid points about inconsistencies in the ability to get treatment, the eligibility requirements when people move. And I think that is something I am going to right now encourage staff to pursue further. These are things that could, I think, be handled administratively perhaps working with the Pentagon on these sorts of issues.

And, boy, do I remember what it was like to move around when I was a kid. I remember at one point I went to nine different schools in 5 years between the fifth and the 10th grade. We were in England, Missouri, Texas, Alabama, California, Nebraska. And I remember what it was like to be at the bottom of the pile in these types of things. We did not have Medicaid waiver programs when I was a kid. I do not think we had Medicaid when I was a kid. I do not remember any of it.

But certainly there are issues that have been raised that could be dealt with in a more immediate sense just by working with DOD to see if we cannot iron out some of those matters that have been raised.

As I mentioned in my opening statement, let me begin with this. There is a lot of debate with respect to the OPM determination that, Mr. O'Brien, you discussed. I would like to start by getting a better understanding of the factual nature, the specific nature of the treatments. And maybe the best place to start would be with Dr. Tait and Dr. Dawson. If you could help us understand the difference in current practices that are regarded as medical therapy in these cases as opposed to what have been educational interventions. Just in basic terms, what are the differences? Dr. Tait, maybe we will start with you.

Dr. TAIT. Thank you. When I am thinking about and when we are talking in terms of whether this is medical versus educational, unfortunately when we are looking at any therapy, whether it is OT, PT, speech, ABA, it has both educational and medical effects. So I think maybe the best way that I could maybe give some examples of that.

So if you are looking at ABA, as I mentioned in the testimony, it certainly affects cognition or thinking. It affects language. It affects academics. That is the school piece of it. But if you look at children who have autism spectrum disorders, many of them have specific medical issues that have to be dealt with through a behavioral approach. Examples of that would be self-injury. So many of the children actually are involved in self-injurious behaviors.

Another example would be eating. One of the things that we look at, some children at the extreme of autism spectrum disorder really have such very specific eating habits that unless you look at it behaviorally, they can be malnourished. So that is the medical piece of it. They can have what we call PICA, which is eating other objects that you should not be eating, and then you go to the doctor's for that.

Another piece of that is they can be—behavior can be such a part of what we are talking about that they cannot get the basic needs they need, like going to a dentist, or getting the medical needs that they have addressed unless they are sedated.

So all of those are kind of—they are behavioral in one sense, Senator, but they are also educational. When I am thinking in terms of ABA, I think that it certainly is medically based. It is also educationally based.

Senator WEBB. But in terms of—just for clarification here, in terms of programmatically what is now funded and what is considered educational intervention, what type of program is now funded that does not reach the ABA area? What are they—

Dr. TAIT. Are you asking—

Senator WEBB. Programmatically, when we say there are certain practices that are acceptable, and at the same time we are saying that the ABA is educational intervention and, as a result, not funded, what are we treating and what are we not?

Dr. TAIT. So the way that I look at this is if you look at therapies that are funded—maybe that is the best way to approach it. So the therapies that we know that are funded are things like occupational therapy, physical therapy, speech language pathology. So if you look at those therapies, they are very specific and individualized with respect to the children that need them.

Those therapies are not as behaviorally based where you set up a specific behavior program that has to be carried through at home, at school, by the family. So you are looking at different, what we call, trials where you look at behavior changes and trials. So I think that is why when we are looking at this, you are saying it is educational because it is looking at the cognition, language, academic performance, and adaptive behavior. But all of that rolls into the medical piece of it, too.

Not all children need 40 hours of ABA per week that have autism, and that is why we were saying it has to be individualized. And you look at the therapy that is appropriate.

Senator WEBB. And, Dr. Dawson?

Dr. DAWSON. Well, so one way to look at it has to do with who delivers the treatment and the scope of the treatment. And when we think about an educational service, it is typically provided in an educational context by educators. And when we think about ABA treatment, early intensive behavioral intervention, first of all, it is often prescribed by a physician. Second, it is delivered by either a licensed clinical psychologist or a board certified behavior analyst, not necessarily a special educator. And then, third of all, it requires many hours of intensive intervention that is not accommodated within an educational program. Educational programs simply do not offer either the level of expertise in this area or the number of hours and intensity. So it really goes beyond the scope of a typ-

ical educational program that we might offer. Even a child with special needs would not be offered these kinds of services typically in an educational program. So it really goes beyond the scope of what we think of as education.

The other thing to point out is that it does—it has an impact on brain development. In fact, there is study in press right now that shows that it not only impacts things like IQ and language ability, but can change the pattern of brain activity in these children to normalize them over time. So it is much more of a whole medical intervention than we think of as restricted specifically to an educational activity.

Senator WEBB. I want to finish this thought with Mr. Hilton. In your own experience with the program, what does it cover, and what does it need to be covered, and how does the \$36,000 annual cap fit into that?

Mr. HILTON. Sir, I am just going to back up for a second and piggyback on something that the lady said and give you an example. A lot of these children, for whatever reason, are runners, meaning they run and run. Another thing, they like water for a reason I do not understand.

We lost a little girl, a little Army girl, seven years old in May who had autism. She ran and they ended up finding her in a pond not far from the family. This is documented in a variety of different circumstances. So from our perspective, for a lot of our families, this is life or death. And I do not think that qualifies educational. That qualifies as medical.

To answer your specific question, what my friends and what I have seen is that particularly when you are talking about younger children, two to five range, or the children who need much more intensive therapy, that \$36,000 simply is not enough to cover their costs. I have a friend who is a Navy commander. I served with him back a long time ago. And he has a child with autism, and this is an O5 that you would think might be able to cover this therapy. Well, he has had to take out a second mortgage on his house. That just gives you an example of what an O5 has to deal with. Imagine an E3 or E4. They are simply just going without the therapy.

Senator WEBB. Mr. O'Brien, we have been told that Department of Defense has asked OPM to see the studies and the basis for your decision, OPM's decision. Is OPM going to share that study with DOD?

Mr. O'BRIEN. Yes.

Senator WEBB. Good. Senator Begich.

Senator BEGICH. Thank you very much, Mr. Chairman.

First, Mr. Hilton, congratulations again on your award as military spouse of the year. I know you corresponded off and on with my wife by e-mail. I thank you. We really appreciate your effort and your lead and your leadership today in representing families in a very succinct way. I will have some questions for you in a second, but I just wanted to acknowledge that I really appreciate you being here today.

I am actually going to take the question that the chairman just asked. If the answer, is yes, the question is obviously how long will it take you to review it? When will you do it? That, to me, is very simple.

Dr. GUICE. When we get the information, we will put it in our normal review process and evaluate it according to our requirements by statute and by regulation as to whether or not it is a—serves as medical care according to our criteria.

It may take us very little time, six months. It just depends on all the information that we get. And we invite others to submit information as well if they have credible evidence, peer review publication of studies, that would help us, inform us about a better or a different coverage decision, we would be delighted to receive those as well, sir.

Senator BEGICH. And do you—can you do that administratively? In other words, once you review and if you determine you can move it to medical therapy, can you then do it?

Dr. GUICE. Yes, sir. If it is deemed to be appropriate according to our criteria, and statute, and regulations that we evaluate evidence by, then it can be made a coverage decision.

Senator BEGICH. Okay. And here is the question I have. I guess if we are able to—I am able to do it, right, because I am under one of your policies somewhere in the mix because I pay a bunch of money. I know that. Despite what people think, we actually lots of premiums as senators. I think I had my co-payment premiums at \$6,000 last year. So if I wanted to buy additional coverage for one of my policy holders or one of the folks I have under Federal insurance, that is covered as additional, I can get it, correct?

Mr. O'BRIEN. Assuming the plan offers service.

Senator BEGICH. Right.

Mr. O'BRIEN. But it is not a required part of our basic benefit plan. We are offering plans the opportunity to propose this benefit. So this does not guarantee anyone would get this benefit.

Senator BEGICH. I understand that. I understand, but it is now offered where several years ago we had a couple only that offered it, correct?

Mr. O'BRIEN. Right. As of today for the 2012 contract year, there is no child in the FEHB program who is receiving applied behavioral analysis. It is blanket exclusion as we have identified it as an educational service. We have removed that blanket exclusion.

Senator BEGICH. Because the evidence is telling you something, and it is worthwhile to ask the question for policyholders to consider, correct?

Mr. O'BRIEN. In our benefit review panel we went back there. We considered the evidence, and the evidence has said this is a promising therapy. There is also a wiggle around it. And additionally we looked at the costs and we looked at what the evolution of the provider infrastructure and the insurance market.

Senator BEGICH. And let me ask you. On that, what you have done there, do you do that frequently?

Mr. O'BRIEN. We will be doing it. We have other services we are going to be doing in the future. This is a relatively new process we are doing.

Senator BEGICH. Okay. So, okay. Well, that helps me because you have a standard. You are not just doing it for anything. You are reviewing it, and then you are moving it to the next stage. And then it could move to the next stage. Is that fair to say?

Mr. O'BRIEN. Yes, that is fair to say.

Senator BEGICH. Okay. So your process, once this information and other information may come in, you may have 6 months or so to review. And then at that point, you will determine if it fits your criteria. And if not, you will identify what those gaps are. Is that fair to say?

Dr. GUICE. Yes, sir.

Senator BEGICH. Okay. You will keep, I am assuming, the chairman, the committee informed on that process?

Dr. GUICE. We will be happy to.

Senator BEGICH. Great. Let me—and actually, Mr. Hilton, you brought up a lot of good questions, and I am going to take one which the chairman mentioned, but I want to follow up on, and that is the Medicaid waiver.

It is interesting. We do not what the Supreme Court is going to do in the next four or five days, but under that new program, we pay—when I say “we,” Federal Government—when it is all done and said, all new entrees in the Medicaid at a certain level, we pay 90 percent to any State. So it seems logical to me that there should be probably a veteran or an active military Medicaid program because we are going to pay 90 percent of it anyway, that is portable.

So, you know, you serve in one community, because the way it is going to work—I think this is the way it is going to work. Let us say you are in Alaska. You serve a year or two. You get transferred. You go to another State. You are going to be a new member on their Medicaid roll. You are going to be a new entry. So, therefore, we are going to pick you up at 90 percent. So do we not just figure this out now because within a two- or three-year period, every military person will be—who needs a service and a Medicaid waiver, will be actually a new entry on to every State’s roll, which we pay 90 percent of. So why not just cut through it all and create a Medicaid waiver program for military that will actually go into play anyway? Your thoughts on that?

Mr. HILTON. Sir, I think I would be obviously be supportive of that.

Senator BEGICH. Yeah, I thought that would be the case.

Mr. HILTON. You know, in my written testimony, I list the Medicaid waiver website. There are 423 different Medicaid waiver programs in the Federal Government—

Senator BEGICH. That is right.

Mr. HILTON.—at the various States. So you can see why we sometimes get confused as we move state to state. However, as I note in my testimony, there has got to be a way to figure out how to service our military families.

Senator BEGICH. Yeah. Well, just sitting here listening to you and thinking about the law by the example I just gave, every military person will become a new—who needs the Medicaid waiver will by automatic become a Medicaid new entry in the State they go to. And those are people we are going to be covering 90 percent of under the new law. So why not just do it? That is just a thought that I wanted to share.

I am giving it through the chairman and the staff, and maybe some thought there because I think you bring up—what other—if I can in my last minute here, Mr. Hilton, what other things do you think we in the Federal Government can do? You mentioned a cou-

ple in your testimony, and I appreciate that—that we can do to better really service families that have children with disabilities and special needs?

Mr. HILTON. Sure. If had to prioritize—

Senator BEGICH. Yes.

Mr. HILTON.—the variety of things I put in my written testimony—it was pretty lengthy—I would obviously put high on the top of the list is this ABA issue. We have been admiring this problem—

Senator BEGICH. To get it classified as a medical—

Mr. HILTON. Yes, sir, as medically necessary. And I will be honest with you. I hear medical therapy, but not medically necessary. I hear educational. I hear see lawyer combined with insurance adjuster, to be honest. And that is what our families hear. So that would be at the top of the priority list for me.

Obviously getting in place appropriate policy to standardize the EFMP process such that, exactly as the chairman said. You know, as we move from base to base, it is consistent, you know. From my perspective, disabilities do not care what uniform you wear, and so it is, you know, it is one of those things where we all scratch our head and wonder why are we receiving different services.

Senator BEGICH. Very good. Thank you very much. Thank you, Mr. Chairman.

Senator WEBB. Thank you, Senator Begich. And let me—before I call on Senator Gillibrand, let me just say to her that I was talking good about you before you got here. She is—was really one of the motivating forces behind—principal motivating force behind having this hearing. So we welcome her, and she is now recognized.

Senator GILLIBRAND. Thank you, Mr. Chairman, and thank you so much for holding this hearing. And thank you to each of the witnesses. This is so helpful because this is not an issue that I think gets enough sunlight, enough discussion, and one that so urgently does for families that have children that are suffering. And that is what I am really worried about.

I am worried that this would take six months. Six months is a long time. That could be a whole half year for a one-year-old or a two-year-old where those therapies are the difference between whether they will ever reach their God-given potential. So I think that is too long.

I am very concerned because, you know, the prevalence is so high. One in 54 boys today are being diagnosed with autism. And the fact that these therapies actually work is the greatest hope that we have. So we should not be denying them to any child, certainly not children of military families, certainly not children of wounded warriors or veterans. So we have to do better in my view.

Now I was very interested in both of the doctors' testimonies because what you described to me sounded a lot—very much like psychological therapies that are similar to what we do for post-traumatic stress disorder. So I want to go to our first witness. Doctor, could you tell us, when we look at PTSD, are those therapies covered as medically necessary?

Dr. GUICE. Those are covered as medically necessary, yes.

Senator GILLIBRAND. And what is the difference between the types of therapies, because as Dr. Dawson described, she described

them being administered by psychologists, by people who have specific training for these needs, very similar to PTSD.

Dr. GUICE. The difference is when we looked at providing ABA back in 2010, the evidence at that point in time convinced us it was still considered a behavioral intervention, and as such could not be covered under our statutory and regulatory requirements for determining medical care that is medically and psychologically necessary to treat a disease or an illness.

Senator GILLIBRAND. And so, even as you just described it, that perfectly describes PTSD therapy, something that is behaviorally necessary that actually is an intervention that actually does help these men and women in life and death situations.

Dr. GUICE. And the treatment actually treats the underlying condition of PTSD. It is designed to treat post-traumatic stress disorder.

Senator GILLIBRAND. Exactly. And that sounds exactly what behavioral therapies for ABA are. So I feel that if you did reexamine it, where the literature is today, and since studies are being published every month that shows that it work—it is scientifically and medically necessary, that it actually affects the brain and the development of the brain, I think every criteria that you have been using for all these other diseases and disorders and treatments, it will match up perfectly just from the testimony I have heard today.

So my question is, how can we do this more quickly? Is there a way for us as the Armed Services Committee, as we do these authorization legislation, to write something that allows you to do this immediately, and to have the resources put in place to understand the literature immediately, to be able to say this is a psychologist offering medical treatment so children can develop their brains, their behavior, their abilities properly?

Dr. GUICE. We have it separate. We have a very defined process through which we look at these potential coverage decisions, and we use that routinely and standardly. I do not think—it is about getting information and assessing it according to our criteria. And we will do it as expeditiously as we possibly can.

Senator GILLIBRAND. I would like to turn my attention now to Mr. Hilton. I want to thank you, sir, for your service. The men and women who serve and their families are the greatest Americans we have. They are some of our best and brightest, and certainly sacrifice more than anyone else. And so I want to thank you for coming to this panel to tell us about what the lives of these families are actually like.

So can you describe to me, to the extent you know, and if Dr. Dawson or Dr. Tait can amplify this, I would be grateful. Explain what happens when a child is newly diagnosed? And how do they navigate the current system? And please tell me how they navigate whether you are active duty, or whether you are recently separated, or whether you are injured and in wounded warrior status. What are the differences for each of those type of members of our military families, and what needs to be address for each person?

Mr. HILTON. That is a pretty big question.

Senator GILLIBRAND. Take your time.

Mr. HILTON. I will just tell you part of our experience from our daughter being in born in 2002. In 2004 to 2008, we moved roughly

five times. We moved five times. And that was due to deployments, regular PCSs. My wife was in training. During that period of time, every time you move, it took—I mean, I would start preparing for the next move six months prior to. And I can consider myself a pretty decent advocate for my daughter, and we only had one daughter at the time. As you are going through the normal PCS process and you are dealing with the deployment, it takes probably six months from getting to the next duty station for you to get all the pieces of the puzzle back in play.

Reading through some of the testimony or some of the notes from the parents, and you are talking about the retirees, or the veterans, or the wounded warriors particularly, I cannot even imagine frankly dealing with those situations and having a child with autism or another developmental disorder.

Senator GILLIBRAND. Because they are not eligible at all.

Mr. HILTON. Correct. And if you think about that, going from something to nothing is like hitting a brick wall for these families. And for that child, and, again, I would really encourage everyone to read their stories. And you read it again and again how devastating that is for the family and the child.

Senator GILLIBRAND. Dr. Dawson, could you speak a little bit to what is the difference for a child that you are treating that they have now 11 hours covered a week. And imagine it is a child that you have actually prescribed 40 hours a week. What is the difference for that child's future to the extent you can describe it?

Dr. DAWSON. Well, first of all, it is important to keep in mind that the National Academy of Sciences did convene a group. It has been a while now, but they convened a group to look at how many hours should be standard of care. And at that point, and this was actually a number of years ago, 2001, so it could have even changed now. But standard of care was a minimum of 25 hours a week for a child during the pre-school period.

Senator GILLIBRAND. And that was a decade ago.

Dr. DAWSON. And that was a decade ago. And the difference is really in IQ points, and language ability, and adaptive behavior. And so even in the last few years, there have been studies that have examined the difference in IQ and language and adapted behavior of a child who gets fewer hours versus more, and it does make a difference.

So if we want children to have the best possible outcome, then they need to have access to the number of prescribed hours. And it is important to keep in mind that that can vary, and it should be looked at by each physician working with a family, as Dr. Tait has said. And for some children, it is going to be 40 hours, particularly early on. Other children may only need 10, and that needs to be an individual decision so that that child has the best outcome.

Senator GILLIBRAND. Thank you, Mr. Chairman. And just for the record, may I submit a statement that Senator Lieberman asked me to submit his testimony?

Senator WEBB. That will be entered into the record at this point.

[The information referred to follows:]

[SUBCOMMITTEE INSERT]

Senator GILLIBRAND. Thank you, Mr. Chairman. Thank you, witnesses.

Senator WEBB. And thank you, Senator Gillibrand.

Let me make one point if I may just as a follow-on to Senator Gillibrand's comments about PTSD. I was committee counsel on the House Veterans Committee many years ago when we did the initial studies on PTSD. And if I were to see a parallel here—first of all, let me be careful. I know there is a lot of frustrated people out here, but I do not think this is a see layer syndrome. I do not think that is fair to the people who have the burden of having to make these determinations.

I think it is more that the process of trying to figure out how to take care of people is an evolutionary process. We went through this back in the late 1970s and early 1980s with respect to PTSD. And I think the question is a legitimate one in terms of evaluating the methodology in order to determine whether a particular therapy is medically effective. And that is what our challenge is here. And I think Senator Gillibrand has given our committee, you know, a great shot in the arm in terms of putting this issue in front of the committee.

And with that, Senator Blumenthal.

Senator BLUMENTHAL. Thank you, Mr. Chairman. And thank you for having this hearing, and to all our witnesses for being here, and all who have been such effective advocates for families in this situation.

Dr. Dawson, I have read a lot of materials and witness testimony regarding applied behavior analysis. And my impression is that ABA is a widely accepted, successful set of tools that can be used in assisting people who are facing the challenges of being diagnosed with autism and other developmental disorders. And you have the immensely impressive background experience, as do all of our witnesses here today. But I would like to ask you to describe how applied behavioral analysis is being used to assist in the treatment and the effectiveness of this treatment in relation to autism. And if you could highlight the differences between the TRICARE coverage of ABA and the coverage in the civilian sector.

Dr. DAWSON. So let us first look at the evidence in terms of what is the impact of ABA on children's outcomes. And there have been numerous clinical trials that have been conducted and published. There was a study that was funded by the National Institutes of Health. It was published in the Journal of Pediatrics. This is the flagship journal of the American Academy of Pediatrics, and it was published in 2010, that showed that the impact of the early intervention was to—for 50 percent of the children, they had a 15-point IQ gain, and for 30 percent of the children, they had a 30-point IQ gain. That is to standard deviation.

So the majority of children who received this treatment actually moved from a status of intellectual disability into the normal range of cognitive functioning. And we know that in terms of predicting long-term outcome, that IQ is the strongest predictor. Also let us think about the cost to society.

The current estimates, based on an analysis that was conducted this year, are that the costs are \$137 billion annually to care for people with autism in the United States. Most of that cost is based on adult care. And the average cost per individual is reduced by about half if they do not have intellectual disability.

So imagine now that we provide this early intervention. You change the life course. This individual has either less severe intellectual disability or none at all, and they have a chance now to go to a regular classroom, form friendships, have language, go on to have a job, and be productive members of society. From a cost benefit analysis, it saves taxpayers a tremendous amount of money.

So in terms of TRICARE, the issues are several. One is the fact that they limit the amount of coverage to cover about 11 hours of ABA. And for some children, particularly in that early period, they need more than that in order to get the kind of gains that I am talking about. So the parents are not getting adequate medically prescribed treatment, what the physician would recommend.

The second has to do with the status, and this has to do with when you retire, you no longer have access to treatment. Or if you are, say, in the National Guard, you are going to have intermittent access to treatment. So if you can imagine your child is doing well and they are in intervention, and then you change your status, and suddenly the treatment program is gone.

And what happens is that families will do anything. They will mortgage their home. They will give up their other children's college savings in order to get treatment because they know that these are effective. They are aware of the literature. And the idea of a parent, after learning about a diagnosis and then raising to the challenge, and then finding that the treatments that we know are effective and that can make a difference for their child are not available to them, it is just not something that we should be doing. We really need to do better by these families.

Senator BLUMENTHAL. You know, it strikes me as I listen to you and Mr. Dawson—Dr. Dawson, and I want to thank you for your service, this hearing room is a very colorless, antiseptic, majestic, but still very abstract setting to talk about what a parent faces in this situation. And since many of us—I have four children—are parents, if we were called in the middle of a family emergency out of the most important hearing in this room or the most important vote ever, we would all be gone in a flash.

And the instinctive reaction that you have described to disregard cost and to sacrifice almost anything to mortgage homes, to, in effect, put a family's future under a severe financial cloud is one that I think we need to understand. We as a Nation, we as a Congress need to understand.

And the hopes offered by ABA, I think, are very impressive. And maybe I can ask others who are on this panel whether they have any comments on what we have just heard.

Dr. TAIT. If I may comment for just a moment, thank you so much. I was just keying off of some of the things that have been said thus far, and I think whether you are looking at PTSD or whatever we are talking about here. We spend a lot of time not separating our head from our body. So when we are talking about health of children, that includes the behavioral health. That includes the physical health.

So for a child to be healthy and learn and grow, we have to look at all of those issues, and that is exactly what parents want. They just want their kids to have the services that they need to be able

to have them fulfill their potential. And I know that is what you all want, too.

I just wanted to comment on the navigation of families within systems. I can remember when I have talked to families, and one mother said to me, I want you to know that I spend all my day trying to navigate the payment system and nine care coordinators. I coordinate the care coordinators. And they do that willingly, and day in and day out so that their children can receive the services that they need.

And so from the perspective of this hearing, what we want is to make that as successful and easy to the families as we can make it. If they have to worry about what is getting paid or what is not getting paid and not concentrate on the children and the families, then that just puts extra stress on a family that is already stressed for a number of reasons. Thank you.

Mr. HILTON. Sir, if I could offer one other thought. Looking through these 80 plus testimonies of individual military families, I realize it is not a scientific study, so you cannot rely on it exactly. But there is no one in here in this enormous, you know, population this says, oh, we tried ABA and it did not work out. You know, consistently, I mean, literally in every story, they say ABA—and it has been beneficial through the ECHO program, and we are thankful. I will admit. It is an amazing program, and it has been helpful to a lot of families.

And every one of them then says, what we are worried about retirement, and retirement is one of the stories. It is literally a week away for this family, and they are looking forward to retirement after multiple deployments, after many, many years. I know families that have put off retirement for a variety of reasons when they would like to, and they simply cannot.

Senator BLUMENTHAL. Thank you. Again, thank you, Mr. Chairman. My time has expired, but I am going to continue my interest. And I would like to, again, thank the chairman for being very much attuned to this issue, and my colleagues, especially Senator Gillibrand, for being so active and attentive to it. Thank you.

Senator WEBB. Thank you, Senator Blumenthal. And, again, let me emphasize that I do not think there is any disagreement in this room about wanting to help the people who are in need, and particularly for us at this moment, family members and people who are serving and who have served.

Our question, our burden, is evaluating the methodology in order to determine whether this therapy is medically effective. And if it is, in those cases where it should be applied, there should not be any question about what we do. But that is the question that is before us.

And I understand there are people who would like a second round. Senator Begich, are you—

Senator BEGICH. No, I am good.

Senator WEBB. Okay. Senator Gillibrand, I know you want to ask or have other comments.

Senator GILLIBRAND. So I would like to go back to the conversation about specifically what we can do to hasten the re-review process. I would like guidance to this committee about how we can help you legislatively.

Dr. GUICE. I do not believe at this point that we would require additional legislation to do it. I think it is just getting the evidence and having the time to sift through it.

I would like to add, though, I think one of the witnesses said that TRICARE limits the ECHO or the payment available for ABA therapy to the \$36,000 per year. That limit is set by Congress.

Senator GILLIBRAND. So we could change that. What would the limit have to be to cover the prescribed ABA therapies, Dr. Dawson or Dr. Tait?

Dr. TAIT. So we have looked at some of those costs, and they run anywhere from \$30 to \$50,000 depending on where you are and whether you need the 40 hours versus the 20 hours. So I believe that it is in that range, and that is generally what we are asking at the State level per child, of course. Gerry?

Dr. DAWSON. Yes, I think that is the way to look at it. So think about it from the point of view of a physician making a prescription, and I do not think many children would go above 40 hours. So one would look at the range that would cap at 40 hours a week and what that would cost, particularly during that early intensive period. Obviously when children are entered into school and they are spending the majority of their time in school, they are not going to require 40 hours. So it would, over time that amount would be lessened. But to have that option during the early period is what is critical.

Senator GILLIBRAND. And is there a way to facilitate, both Dr. Dawson and Dr. Tait, getting the studies that you mentioned today to DOD so that you can have immediate answers on trying to prove the case to the DOD so when they do their re-review, they have those studies on hand and those peer review studies?

Dr. DAWSON. Absolutely. And, in fact, just to point out, since the evaluation was done, which I think was based on 2010, you know, there have been over—well over a dozen studies that have been published since then. And so I can certainly provide that literature. And even the AHRQ report, which I think was referred to in the testimony, is historically already out of date, and also very limited in its scope. It only looked at 10 years' of literature, and it is—the literature now that actually began in 1987 was the first clinical trial that was published. None of those studies were included in that particular report.

So I think we really need to include the breadth of knowledge in the review that is available today.

Senator GILLIBRAND. And although this is—

Senator WEBB. And if I may, as chairman, if there are studies that have not been provided to our staff along those lines, I think we would appreciate being able to look at them as well.

Senator GILLIBRAND. So I have at least an informal commitment of this group of people to be a working group to coordinate data, coordinate studies, get it done. And to the extent this committee asks for a recommendation in the near future from the DOD, that might be a way to formally at least request that this process continue as quickly as possible. And we could either do that by letter or put something as an amendment into the authorization bill. And I would like to work with you on how that should be requested in

the way most effective to help your team apply the proper resources to do it now.

Dr. GUICE. We would appreciate that. Thank you.

Senator GILLIBRAND. Thank you very much. Thank you. Thank you, Mr. Chairman.

Senator WEBB. Thank you, Senator Gillibrand. And, again, I appreciate all of the testimony from a very wide breadth of knowledge and experience, and it has been extremely useful to us.

Your written testimony will be gone over in very thorough detail as well. And thank you, Senator Gillibrand, for being the motivating factor in having this hearing. I think it has been very useful for us.

This hearing is now closed.

[Whereupon, at 3:55 p.m., the subcommittee adjourned.]