John P. Wilson
497 Candlebark Drive
Jacksonville, Florida 32225

June 17, 2012

Dear Sir or Ma'am,

I'm writing to you pleading to make the current TRICARE ECHO benefits a permanent benefit for all military service members who are active, retired due to disability, or retired after serving 20 plus years.

After reaching High Year Tenure, I transfer to the Fleet Reserves after 26 years of Honorable service in the Navy on 30 June 2012, and that's the day my benefits expire for my autistic 10 year old son, Adam, who will still be autistic. We were very excited when TRICARE announced ECHO and we were enrolled and receiving benefits two months after it started as well as respite care.

Due to all of his therapies, school, etc., I have to be a stay at home dad once I retire and do side jobs when I can. His mother served 10 years active duty Navy, got out while I was on active duty to raise two boys and is now a RN.

Adam was a non-verbal and totally dependent child before starting ABA therapy and now talks in four to five word sentences, can go to the bathroom, sit in his chair at school, dress himself, starting to socialize with his peers, etc. I contribute all of these milestones to ABA therapy.

Even though Florida has mandated that insurance carriers offer ABA therapy, there are loop holes that I can't seem to get through. The main loop hole is the companies insurance has to be fully funded whereas most are self funded. I have exhausted all avenues in search of insurance to cover his ABA and we have applied to many programs to assist with no avail.

With all of his medical expenses and our limited income we have to reduce his ABA in half (which was half of the recommended treatment to begin with), reduce his speech and OT therapies from four times a week each to one, and are still out $1884.00 a month with TRICARE Prime for Retirees, who doesn't cover any ABA. We are going to do everything we can to give Adam a chance in life and will do this until our savings is depleted and credit cards are maxed out, after that we are on our own...unless this bill passes.

I have read that treating autism early is much less expensive then dealing with it later in life.

Thank you for your time and consideration, and thank you so much in advance for approving this bill.

Sincerely,
John P. Wilson and Family

Bo Brown

Diagnosis:

* Severe Autism

Military Support System Struggles:

* The Browns pays $25,000 per year for ABA therapy not covered by Tricare. This comes as a huge financial burden to the family.

* Because of the funds being applied to ABA therapy, there is no money left over for normal family experiences like a simple vaccation

* The Brown family has moved seven times in the last fourteen years. They have three more moves coming up in the next four years.

The McClenney Family

Branch: US Navy Duty Station: VFC-12, Oceana Naval Air Station

Carsun McClenney, son of PO2 Cecil McClenney and Brenna McClenney of VFC-12 Oceana Naval Air Station, was born with Cerebral Palsy (CP). Now almost 5 years old, he is unable to walk independently without medical equipment. Although still very young, Carsun has already endured a bilateral femur osteotomy (surgical reshaping of the femur and pelvis) in hopes that would help make walking easier. Unfortunately the surgery was unsuccessful, and it has actually made walking harder for Carsun. He will be undergoing a second surgery July 19th to remove plates from previous surgery.

While the McClenneys feel they have been more fortunate than most in America to have health insurance, they have still faced many trials at trying to make life better for Carsun. One of the many difficulties the McClenneys have encountered is finding out what kind of medical equipment is best for their son, and then locating companies to purchase the equipment. They do extensive research, only to be faced with a brick wall when it comes to TRICARE. The McClenneys are paying extensive out of pocket expenses for the equipment, while they wait significantly long times to even be seen by specialists at their Military Treatment Facilities. It has created a financial burden on the McClenneys to have to pay for equipment upfront, when it is TRICARE that is holding up the process. For example, the family ordered Carsun a pediatric wheelchair on March 1, 2012, and to date, they are still fighting with TRICARE and the equipment has yet to be ordered.

Petty Officer McClenney decided to move his family back to their hometown so they could have a larger support network. Unfortunately, their new home could not accommodate Carsun, so they requested for a ramp through TRICARE. Unfortunately, neither TRICARE nor ECHO covers any type of ramp, even when it is a necessity. Fortunately, through the love of a close-knit community, the townsfolk built the McClenneys a ramp, at no expense to the family.

Medical and equipment needs will always be a necessity for Carsun. As he gets larger, the McClenneys will need a vehicle lift, which is also NOT covered by insurance. But the McClenneys will continue to fight and advocate for their son's needs, no matter what.

Above are some pictures of Carsun: some of Carsun in his equipment, one of him right after surgery, him in his temporary wheelchair on his new ramp, and also a picture of him participating in the Specials Olympics for Young Athletes. This will show you how happy and full of life he is, despite his disabilities.

Thanks,

PO2 Cecil McClenney and Brenna McClenney

The Adams' Family consists of John, Kathy, Brent (14) and Claire (12). John is an active duty Marine stationed at Quantico with 21 years of service. Our daughter Claire was referred to the developmental center at 15 months. She regressed in health and developmentally sometime after turning one.

She began Occupational and Speech therapy at 18 months. At that time there were no providers in the Cherry Point area accepting Tricare, and the family had to commute 45 minutes to Jacksonville, NC for 30 minutes of therapy. Claire's mother noticed that children of the same age and with less noticeable delays with Medicaid insurance were receiving 1 hour of therapy.

At 2, Claire was diagnosed with Cerebral Palsy and Physical therapy was added. At 34 months, Claire was diagnosed with Pervasive Developmental Disorder-Not Otherwise Specified by Dr. Gretchen Meyer at Portsmouth Naval Hospital.

In October 2002, Claire began ABA services after filling out extensive paperwork to get $1000 covered under the Person's with Disabilities Program under Tricare. $1000 did not cover the recommended 40 hours of intensive therapy that is recommended and the family decided to pay the overages. The family was able to hire "tutors" to work directly with Claire, while being supervised by a Board Certified Behavior Analyst.

In 2006, Claire's mother began inquiring about respite options for Claire thru the state and insurance. She was told she could only get respite thru insurance if receiving ABA services. After close to a year wait (paperwork misplaced) she started receiving respite thru North Carolina's Intellectual Disability Waiver and was allotted 9 hours a week. In 2010, the respite hours were taken away due to budgetary cuts.

In 2008, Claire's mother pursued respite thru the new Exceptional Family Program. She was told she could get reimbursed up to 10 hours per week at the rate of $18 an hour, but that she would need to find her own provider. Finding a qualified provider was difficult and they did not receive respite for some time. Then the rates dropped to $15, to $10 and after major cuts to $6.

In 2010, the family decided it was in Claire's best interests to move to Northern Virginia for better services (ABA, schools, respite). In VA, there are more ABA providers but many do not accept the new Autism Demo ECHO guidelines which reimburse up to $3000 a month; this will typically cover 10- 15 hours a week of supervised ABA programming. She is currently getting tutoring thru Cuuriculum Autism Services and is making quick progress with the communication program Proloquo to Go with the iPad.

In early 2011, Claire's mother applied for Medicaid as was told the wait in VA was 10-15 years, especially if the child was under 18 and the parents were in good health. She was referred to the ID waiver for respite. In March 2011 she was meeting with the ID respite caseworker, who told her they reimburse at a $6 an hour rate, when Claire fell out of chair into a grand mal seizure. She was hospitalized for 6 days.

After the seizure, Claire's health status made her eligible for services under the Elderly and Disabled Waiver, reimbursing at $11.37 per hour. Claire began receiving up to 30 hours per week of respite in the Spring of 2011.

Claire's father is approaching retirement and they are concerned about services for Claire. ABA has been integral for Claire and is opening a world to her, but these services will no longer be covered after retirement and few states provide coverage for older children. Please re-consider extending the services to retirees! Also consider the difficulty military families have obtaining services and have to re-start the wait in each state when they move ... this should not be the case! Furthermore, states receiving Federal bailouts should not have been allowed to make employee cuts (does not help stimulate the economy) which led to respite services being discontinued. It is disconcerting, that Tricare is not universally accepted by civilian providers; our soldiers are putting their "lives on the line" in service and their families deserve the best. Our country is not prepared for the epidemic rates in which the disabled children are approaching adulthood.

John and Kathy Adams 10800 Park Road, Lorton VA 22079 703-339-0729 jkandkb@yahoo.com

To the Senate Armed Services Subcommittee on Personnel:

My name is MSgt Melinda Burts, and I have been an active duty member of the United States Air Force for 15 years. My oldest son, Simon, was diagnosed with autism at 20 months old in 2006. My husband and I were devastated. He was completely non-verbal and behaviorally was nearly impossible to control. I cannot express how thankful my husband and I are that Simon was able to receive ABA Therapy beginning at age 2, and that this therapy was covered under my Tricare insurance. Although the road has been frustrating and challenging at times, Simon's progress has been truly astounding. He has been receiving ABA Therapy now for over 5 years. He just completed first grade in a mainstream classroom. He still has plenty of academic and behavioral issues to work on, but he was able to handle the kindergarten and first grade academic curriculum with some special education support. He was even identified by the Advanced Academics Teacher for being gifted in math, and received weekly group instruction in advanced math concepts. He is a success story (yet still a work in progress) and I truly believe he would not have made these strides without years of intensive ABA Therapy.

My husband and I watched our younger son, Alex, very closely for signs of autism throughout his infant and toddler years. His language, cognitive, and social skills seemed to be on track for a while. But at age 4, we started to notice delays in some of these areas and also a few familiar autism behaviors. Alex was diagnosed with autism in November of 2011 at age 4. His condition is milder than his older brother's, but he has issues that definitely need to be addressed. Again, my husband and I are relieved that we have access to ABA Therapy that is covered by Tricare, and Alex has already made progress in many areas in the few months he has been receiving therapy.

I cannot imagine how my family could have survived financially if I had been paying for this therapy without the help of insurance. The going rate for a BCBA (Board Certified Behavior Analyst) is $150 per hour, and the going rate for an ABA Tutor is $50 per hour. If I add up the services that my children currently receive in a typical month, at these rates it comes to $3800 for Simon and $2400 for Alex, for a total of $6200 per month. But because each child with autism is different, the services that each child needs can vary. Also, the services that a child needs can vary at different times in his life. For example, Simon was having some behavioral difficulties at school this year, and our BCBA spent a lot of time at his school working with his teachers to create a behavior plan for him. It was extremely successful and all of his teachers agree that his behaviors improved drastically after the plan was put in place. But this required our BCBA to spend as much as 15 hours a week at his school for several weeks. This comes to an extra $2250 per week (or an extra $9000 per month) for a temporary period of time. I am an enlisted member of the U.S. military and my husband is a public school teacher. There is just no way that our family would have been able to afford this level of ABA services without help.

I strongly believe that all medical insurance plans should cover ABA Therapy. I have seen with my own eyes how incredibly beneficial ABA Therapy is for all children with autism, both the mildly impaired children and the severely impaired children, and all of those in between. And as I approach 20 years of service in the military, I must admit that I am nervous about how I will pay for ABA Therapy for 2 children after I retire. I cannot impress enough how important I believe it is for ABA Therapy to be covered for Active Duty Members, Federal Employees, and Retired Military Members alike. Please consider taking the action necessary to make this happen for your service members.

Sincerely,

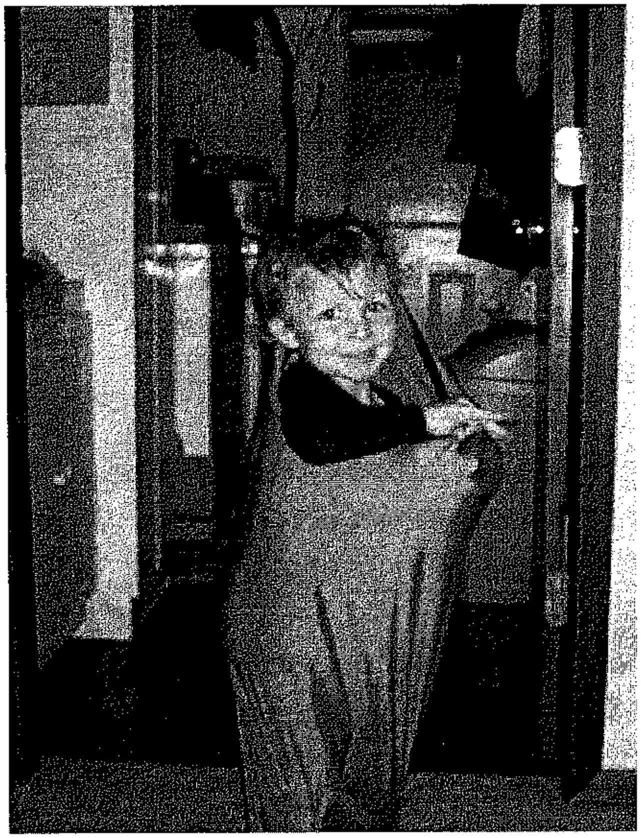
Melinda M. Burts

Autism Blog: www.placesonthespectrum.wordpress.com

Drake Andrews

Diagnosis:

*** PDD-NOS**



Military Support System Struggles:

*** System is hard to navigate, easy to get lost in the shuffle**

*** Lack of coverage of sensory equipment and communication devices like iPads.**

*** Tricare continuing to refer patients to companies that have histories of fraud and neglect.**

*** Financial burden of paying for durable equipment that TRICARE does not cover for disabilities, such as SPIO vests, lycra swings.**

14 June 2012

Senate Armed Services Subcommittee on Personnel
Russell Senate Office Building
Washington, DC 20510

Dear Ladies and Gentlemen,

I am an active-duty Army officer who has served for thirty years and am currently undergoing a Medical Evaluation Board for my injuries and illnesses incurred during that time. I also have a fourteen year-old son with profound autism. He has never said a single word in his life, has to use diapers, has had his own struggle with many medical issues; but I consider him one of the happiest kids that I have ever met. A large part of that happiness can be attributed to the Applied Behavior Analysis (ABA) therapy that he has received through the TRICARE Extended Care Health Option (ECHO) Program. His increasing ability to understand his environment and the verbal commands of others can be directly related to this therapy. In one instance, his ability to understand my verbal command of STOP prevented him from walking in front of a car which he was unaware of. When he stopped, the car was literally inches from his nose and the front of his shoe was actually touching the tire of the car, but he was completely unaware that there was even a car in front of him due to his autism and his fixation on the object that he was running towards. Unfortunately, his ABA therapy is due to end when I retire after thirty years and with my own set of significant medical issues.

The TRICARE ECHO Program and its predecessor programs have provided ABA therapy to a very small percentage of affected dependents of active-duty service members since the late 1990's under a supplemental program to the TRICARE Basic Program for special education purposes. Since that time, ABA therapy has been deemed medically necessary by the Office of Personnel Management for Federal employees and by the legislatures of thirty states. It is time for the Department of Defense to similarly declare this crucial therapy to be medically necessary, so that it is also available to the affected dependents of retirees and applicable Guard and Reserve families that can benefit from this life-saving therapy.

If you would like any further information, please feel free to contact me at (703) 241-2640 or at campbellsservices@gmail.com. Thanks very much for considering this information in your deliberations.

Respectfully,

Scott A Campbell

Scott A. Campbell
Lieutenant Colonel, United States Army
3537 Devon Drive
Falls Church, VA 22042

The Chen Family US Army

In March of 2010, Casey Chen was diagnosed with PDD-NOS, ADHD, and an adjustment disorder with anxiety, while his family was stationed in Germany. At the time, he was significantly behind his peers in all areas, and would not speak above a whisper in the presence of unknown people. He was profoundly afraid of other kids his age, and would avoid interaction.

In December of 2010, the Chen family was granted a compassionate reassignment to JBLM due to lack of services and his inability to access ABA. Within 3 months of arriving, Casey began receiving ABA, in addition to private speech and OT. Within 5 months of beginning ABA, Casey began speaking with his regular volume of speech, starting interacting with his peers, and had almost caught up with his peers in school. His teacher and ABA therapist have worked closely together to help him.

Casey's father is currently deployed. The above picture was their last hug. Under the current regulations, Casey will lose his much needed ABA benefits if his father is injured to the point that he is no longer able to serve or worse. ECHO is only for active duty families. Ling's father will be eligible to retire in 3 years. However, if he chooses to retire, Casey will lose his ABA benefits. If ABA is made a benefit directly under TRICARE, he can continue receiving it.

Casey continues to make huge strides and is now ending the school year on grade level, and is continuing to make friends. We fear that he may not do as well in the future without this much needed therapy. His father is willing to serve as long as he can to enable his son to continue to receive ABA. However, after 20 years of deployments to Iraq and Afghanistan, peace keeping missions in Bosnia, TDYs to Korea, and countless training exercises, Ling would like to retire and physically be able to help his son more. He is currently on a path that will lead to an independent life as an adult. Please allow our son to continue receiving this amazing therapy.

The Cunliffe Family

Aurora - Age 3

Panhypopituitarism Survivor
Adrenal Insufficiency
Autism Spectrum
Sensory Issues
-Non-Verbal
-High Wandering Risk

Averie - Age 11

Extreme Prematurity

Ulnar Club Hand
Autism Spectrum/ Aspergers
Sensory Issues

Serena- Age 44

Brain Tumor

Neurological Issues
Sensory Issues
PTS, Depression
-Unable to Drive

Struggles with Barriers to Care:

- Varying Educational Support Eligibility across State lines - Autism diagnoses does not guarantee school services
- Denied ECHO coverage for our oldest daughter without an IEP
- Limited coverage for ABA therapy does not meet recommended hours
- Need for specialized equipment covered under same cap
- Access to needed medical specialties not available at MTF and limited locally. Waiting times are up to two years under some circumstances.
- System does not accommodate or assist caregivers/spouses with authentic transportation issues. This results in care being simply inaccessible independent of the service member
- Complementary therapies such as Speech/Language Therapy and Occupational Therapy are not available to take place in the home after the age of three

June 18, 2012

To the Senate Armed Services Subcommittee on Personnel:

I write this letter, hopeful, as Tricare's stance on ABA coverage and the financial aid for military retirees' dependents is being reviewed. On April 11, 2007, my son, at the age of two, was diagnosed with one of medicine's greatest and most frustrating mysteries: Autism. Upon his diagnoses, my heart broke. My every desire became giving my son the best chance for a normal life that I could. At his initial diagnosis and the recommendation of Developmental Pediatrician, Lt. Col. Dr. James P. Vandercar, my husband and I enrolled Zachary in ABA Therapy. It was urged by the doctor that Zachary receive the maximum number of hours (40) of therapy. Unaware of exactly what we were dealing with, as parents new to having a child with disability, we began Zach's therapy one month later in May of 2007. Our son initially received ABA therapy 3 hours/week, progressing to 12 hours/week and now is receiving 24 hours/week. This increase in therapy hours is still far less that what is prescribed for the best outcome of a child on the Autism Spectrum as severe as my son, but it is what our income could afford financially.

Since this process began, five long years ago, I have battled insurance companies, filing claim after claim with Tricare for ABA Therapy to be paid for. Repeatedly, I was denied. Their representatives stated that "military retirees' were exempt from ECHO, and Tricare would not cover ABA therapy." Frustrated, but persevering, I continue this battle.

After months of disheartening attempts, I was blatantly told one day, by a Tricare Representative, that if I did not like the way the law was written I could contact my Congressman, Jeff Miller (FL). Again, I plead my case. Although my Congressman has sympathy, and has tried, the bills enacted to revoke the present statute denying military retirees' dependents ABA coverage, were not passed. What could I do? Here I stood, doing everything in my power to get treatment for my son, and finding myself useless in this battle. It was then, that a fellow autism mom, Karen Driscoll, whose husband serves in the Marine Corps, provided me with a spark of promise. A lawyer in Michigan, Dave Honigman, had joined the fight for families just like mine. His firm had recently won a case against Blue Cross Blue Shield, regarding the coverage of ABA therapy. Somehow renewed and hopeful, in December of 2010, I contacted Mr. Honigman and joined the class action lawsuit to change the present ruling. Regrettably, the case is still waiting to be heard.

As I continue the battle of finding a way to financially give my son the tools he needs, he is fighting his own battle. Zachary is enrolled at the Emerald Coast Autism Center in Niceville, Florida, where he receives 24 hours per week of ABA therapy. In the past quarter, Zach has made the largest gains on the Verbal Behavior MAPP, an assessment used to chart knowledge acquisition, since beginning treatment. I could not be more proud or a stronger believer in ABA. When he first began, his vocabulary consisted of about 20 words. He now has over 200! He is able to functionally communicate with 2-3 word requests, and is able to understand 2 word commands. He has learned self-control and is more personable with therapists and family. While Zachary is still considered an early-learner, with the mental capacity of a 3-year old (he is now 7), I am confident that his gains are a direct result of ABA therapy. Sadly, at a cost of $53,000 per year, my family is financially tapped and may soon have to dis-enroll my son from the Center. I am beyond words at the thought of stopping treatment and doing this disservice to Zachary. I fear for a loss of what progress he has made and worry that once the ball stops rolling, we may never be able to start it again.

I fervently plead that you assist military retirees in ABA coverage for their dependents. My husband served in the USAF for 22 years, and put his life on the line for our country. He chose to remain in the military not only out of a love for his country, but a love for his family, understanding that medically, his family would be provided for in exchange for his service. It is ludicrous to deny our son the therapy he desperately needs, because my husband is retired. It is a daily challenge for any family to raise a child with Autism Spectrum Disorder, but the trial becomes infinitely larger as the battle with insurance companies to obtain coverage, is constant. I appeal to each of you to help us change this legislation, not only for my family, but for each family that bears this same cross.

Thank you for your time and consideration in this vital matter.
Dawn L. Berge (wife to Ret. MSGT. Kenneth Berge, mom to Carson and Zachary)

My name is Dr. Lois-Lynn S. Deuel and I am a proud military spouse. My husband, LTC George L. Deuel, U.S. Army, is currently stationed at the Pentagon, Headquarters, Department of the Army. We live with our son, Lance, 8, in Arlington, VA. Lance is an EFM. We have been stationed at multiple locations throughout CONUS, Germany and Italy over 20+ years of service. We are honored to serve and are grateful for the comprehensive health care that Tricare provides. With few exceptions, we believe that the military system takes good care of services members and their families. This note is to inform of you of two areas where policy changes, with respect to medical care, can and should be made to improve care for service members in EFMP.

As both a psychologist and parent of a child with special needs, I have always found it curious as to why Tricare ECHO would require a medical doctor to provide a prescription for something that they consider an "educational modality." We don't ask our pediatricians to write prescriptions for Social Studies or Science. Outside of military medicine, other medical, psychological and educational professionals view Applied Behavior Analysis (ABA) as an evidence-based medical therapy (not an educational one) that is considered the standard of care for individuals with autism spectrum disorders. In addition, the arbitrary rationing of ABA through Tricare ECHO falls short of the standard of care (25-40 hours/week), as military families can only receive 3 to 5 hours of ABA therapy per week. Indeed, the effectiveness of delivering ABA in such small, rationed amounts is questionable and there is absolutely no scientific evidence supporting delivery in the manner used by Tricare ECHO. I ask you to: 1) eliminate Tricare ECHO which only serves as a barrier to military families, 2) provide ABA as an ordinary medical therapy through Tricare prime or standard, 3) provide an appropriate number of ABA therapeutic hours that adheres to the standard of care, and 4) ensure that ABA therapy continues for families of all retirees, including wounded warriors who are medically retired.

The military currently has many avenues that accommodate the extra special needs of families that are in the EFMP program. Commanders and career managers routinely consider assignments that ease the burdens for service members and their families. Please commend them for this! We are grateful for the effective supports provided by EFMP and associated efforts. Frequent moves and deployments are the new normal and all military families understand this. However, the structure of Tricare into three regions detrimentally affects the continuity of care for families with special needs. Every PCS between regions results in a complete cessation, often for several months, of all critical medical therapies for special needs families. Until a service member signs into a new unit, and the family is entered into the system for the new Tricare region, families cannot make any medical appointments, cannot get any referrals for speciality care and cannot get on any waiting lists for therapies. For example, your current PCM in California cannot make a single referral for you in your new duty station in Virginia. I ask you to either 1) eliminate Tricare regions or 2) streamline the PCS process and make it seamless so that special needs family members can get medical referrals, make medical appointments and set up therapeutic services at the new duty station BEFORE/DURING their PCS.

Please contact me directly at (703) 340-0585 or lsdeuel@hotmail.com if you have any questions about issues facing military families with special needs. Thank you for your interest and concern.

My husband is an active duty Army officer. He has served 21 years so far. We have a 16 year old, autistic, mentally challenged, daughter named Shaylin. In the sixteen years we have moved 5 times. Each move caused a set back in Shaylin's behavior. We are now dealing with a very aggressive, irritable, 159 lb, 5'11" child.

With each move we have to reestablish Shaylin in a self contained, autism specific, classroom. During our last tour (my husband was at the Pentagon & the Natl. War College) we spent $15,000 in legal fees. The IEP team wanted to admit Shaylin into Key Center which was not appropriate for Shaylin for several reasons. We ended up with a questionably suitable placement at a district middle school.

In the previous duty station, Hawaii, we had to obtain an attorney to force the local elementary school to establish an autism specific classroom. After it was established we struggled for 4 years to keep the setting and the services related to it. When our daughter was transitioned into middle school the prior elementary school did away with the autism program. And yes, there were still autistic children there in need of such a program.

We now have a very serious problem on our hands. Since my husband is training to deploy for the fourth time, we opted to move me & our three daughters near family for support. Unfortunately, Shaylin's behaviors have escalated to a level that it is not safe at times to have her live in our home. Not safe for us nor Shaylin as she is self injurious & lashes out at us with no regard to her own safety. For almost a year we have attempted to get support services for Shaylin. As I write this note, we still have no services. There is no ABA therapist in our area that works with adolescents. And there are no respite caregivers that provide that service in our area either. Attempts to have Shaylin admitted into psychiatric clinics for evaluations have failed as well as our attempts to have her placed into residential settings designed to treat autistic children.

Our military, normal-functioning, children have issues with the frequent PCS's and deployments much of the time. When you have a special-needs child those issues are compounded tenfold. Autism is a very complex disorder that can be improved. These improvements are only seen with constant training and oversight by individuals highly trained to provide therapy. A care-over support system is imperative for a family dealing with an autistic child in their home. When needed, residential schools designed for autistic children should be a viable option. This is especially true if the active duty service member (or reservist) is on deployment. These schools and services are expensive. They are nowhere near as expensive as government financial support needed to sustain these children once they become adults.

Our military children and their families have to fight for services for their children. This is outrageous when it is those same families that are already sacrificing so much to support our military.

Thank you for listening to a parent of a special child that is very much loved.

Shawn Diaz

240 Tidewater Road

Hattiesburg, MS. 39402

My husband and I both served in the Army when our older two children were born. We began to realize something wasn't quite right with our children. I was medically discharged from the service fairly soon after that and began looking for answers as to what was going on with our children. Eventually the heart stopping answer came, autism. After our initial shock wore off, we began researching treatments. Our children have been very lucky to have all the services they needed paid for through the Tricare system and excellent service providers. These amazing children have gone from the possibility of being declared moderately mentally retarded to children whom most people cannot tell have autism. They no longer need IEP's or behavioral modification plans at school and are academically equal with their peers .

These successes would not have been possible without the support of Tricare. They still see specialists on a weekly basis. I cannot imagine, after serving for so many years and retiring, losing those benefits or having to shoulder the financial burden of paying out of pocket on a reduced retirement budget.

Jeremy, let me know if this is what you were looking for. I'd be happy to make any modifications.

V/R, Maureen

Hello, my name is Sheila I. Almendras-Flaherty and I am an Active Duty Navy Nurse. I have 4 beautiful children Dakota Skye Flaherty age 6, Chase Robert Flaherty age 8, Sheila Renee Velasco age 16 and Desiree Jasmine Velasco age 17. And as the years went by my husband, Robert Joseph Flaherty, and I noticed changes in our children and had them evaluated like any good parents. The providers provided us multiple diagnoses for our children ranging from mild reflux to ADHD and Autism. Needless to say our world was turned upside down and our family went through all the stages of grief. I wish I could tell you more about all the issues we had to go through as a family with each of our children, but that would take up your whole day. Please know that Our Family has and continues to meet all the challenges that come along with having a special needs family, especially one that has 3 out of 4 children with Special Needs. It has not been easy an easy transition for our family but I can tell you that our pain and struggle were made a lot easier by the support and dedication of those in the Exceptional Family Member Program (EFMP) especially in the Marine Corps. We established stability and sense of normalcy through the information and opportunities we were given through EFMP. Even with their guidance, I can tell you from my own experiences as a Medical Professional and a Mother of Special Needs Children that the Military still has much opportunity to grow and improve on regarding the issues that affect their Military Members' Families with disabilities.

I would like to give you a few bullets on the issues Our Family has experienced to give you a better understanding.

- Not having the Specialists needed to provide the care needed either by none in the Network or not available in the area where the family resides even after the Detailer and EFMP cleared family for area according to Category. (i.e. Developmental Pediatricians)
- Traveling 2-4 hours in each direction for One Specialist Appointment. Active Duty Member needed as Medical Escort to provide support to Spouse. (i.e. so child didn't hurt himself or jump out of car)/
- Not having an EFMP Case Manager like the Marines Corps have. EFMP Case Managers knows the family, offers assistance the entire time the family is enrolled and direct them to local community programs and services. Navy only offers EFMP Coordinators who basically assist with the application process that is it and families are left out in the cold wondering "Now What?", "What do I do next?", "So I'm a Category X, what does that mean for the Active Duty Member and the family?".
- Issues with Schools especially when moving since many times the Individual Education Plan (IEP) is from another state. The new receiving school may not offer similar programs or may just refuse since they know the family may not be aware of their rights because state or city laws may be different. Need More Local Military Special Needs Advocates and continuation of School Liaison Officers. Large need for Military Special Needs Lawyers so families don't have to spend their own money fighting the School System each time they move. This is especially important because the schools that educate children from base housing know the families don't have much of a choice and many families choose to stop fighting because of money, time and energy.
- Continue and expand the Navy EFMP Respite Care. It has helped my family plan and deal with all the struggles of having Special Needs Children especially when geographically separated from any type of social support and the Military Member is away 50-80 hours a week or deployed in harms way serving their country.
- Continue the ECHO Services as this has supplemented other needed services and treatments not covered under Tricare-Prime. This service has made a huge positive impact not only to my child but the family because of all the progress made.

I am an Army Veteran, spouse to a retired 1st Sergeant, mom to 3 fabulous children and advocate for my son with autism.

Currently, "TRICARE" military healthcare provides less than half the recommended treatments for autism, and only to children of active duty service members. Service members who retire after more than twenty years and Wounded Warriors forced to medically retire are stripped of what little treatment TRICARE allows via the Extended Care Health Option (ECHO).

Our son was the lucky recipient of such services. He received these services known as ABA, Applied Behavior Analysis. This is a scientifically proven medical treatment for children with autism. Scott received these services for nearly 6 years. During this time of treatment, we have seen marked improvement with his behavior and educational assessments. With the support of ABA, Scott was able to learn how to talk, write and even go potty. This one-on-one therapy played a major part of his development and overall well being. Since his father retired from the Army after serving 25 years, this service was no longer available to Scott.

Congress and the Department of Defense have been denying what our military children need, what my child needs all in the name of saving money and trimming the budget.

Scott stopped receiving ABA therapy 6 months prior to my husband's retirement in April. Those 6 months and the months up to today, without ABA have been met with great challenges for our son. His behavior has dramatically worsened and he no longer participates in school activities. He refuses to complete simple tasks he once mastered such as going potty or brushing his teeth. Everyday we are met with temper tantrums and rage. His behavior has changed so much that he has recently begun treatment through medications. Drugs he never needed prior to the absence of ABA therapy.

In late 2003 my husband purchased a vintage hobby car, a 1969 Mercury Cougar Convertible. He loved that car! It was to be the kind of thing that every father dreams about doing with their only son. Father/son bonding while rebuilding a classic car only to pass it on to his son when he becomes a teenage driver. That was until 6 months later when Scott was diagnosed with autism at the age of 4. That dream of rebuilding the car became a memory as we were thrust into the world of disabilities. Then in 2006 Scott started to receive ABA therapy. Once Scott started to gain skills through the work of his ABA therapists, that dream started to look more like a reality. Scott started to learn. He was beginning to talk and learn how to communicate his needs to his father and me. We were so excited with his development. After 6 years of therapy and progress, Scott was denied access to these remarkable services. All because his father served his country and retired from active duty. Now that car sits collecting dust, never to be worked on by this father/son team.

My husband served his country, your country for 25 years. He earned most of his stripes and commendations as a Special Forces Soldier. He served in Operation Desert Storm-Iraq, Operation Joint Guardian-Kosovo, Operation Silent Warrior-Turkey and Operation Iraqi Freedom-Iraq. He has missed most of the important milestones each of our 3 children reached during his service. He has watched his children grow up from the battlefield.

My husband has faced many enemies over the years battling for his country and other countries in support of honor and duty. Now he has to stand up and fight against the very same government he fought for, all so his son is able to have the same opportunities as others and to learn and BE a citizen of this country he loves.

Each day, month that passes our son looses a little more of himself. Without the ABA Therapy that was denied him when his father retired, Scott's future no longer looks as bright as it once did. We worry more everyday what his future may include. Unfortunately one of the topics has included the "what if's" and the possibility of an institution.

It is time to do the right thing here.

It is not too late for Scott. Approve this funding to all military children, active and retired, for a better life of these children and for the brighter future of our community. More funding and therapy NOW will mean less funding and institutionalization when these children become adults

Our brave service members never leave a fallen soldier behind. Can our government say the same?

Thank you.

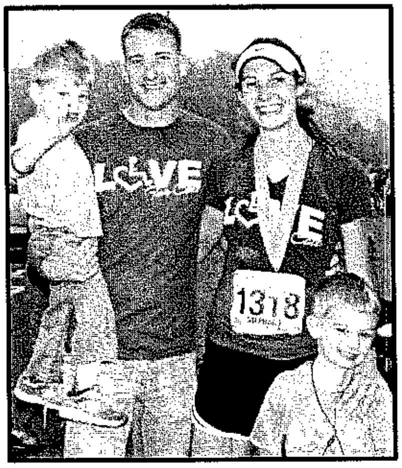
Retired 1SG Brian & Christine Garton,

Shaylynn, 16

Scott , 12

Laura, 8

Moore County, NC



Hello and thank you for taking time to read our story. We are the Geraghty's, a proud Marine Corps family with two sons, Caden and Cole, and a baby girl on the way. I have the honor of serving as Military Spouse Magazine's 2012 Marine Corps Spouse of the Year and my platform revolves around Stroller Warriors Running Club. This nonprofit organization encourage military wives to live happier healthier lives through running, goal-setting, networking, family-building, and community outreach. These women have been a source of joy, inspiration, and support for me, especially during our son's diagnosis. Cole has a genetic neuromuscular disorder called Spinal Muscular Atrophy (SMA). He may never gain the ability to walk and the nature of the disease is to worsen. There is no cure but growing attention for the disease has supported research.

Our military community and Brian's unit have supported us throughout testing, diagnosis, and treatment. TRICARE, Extended Care Health Option (ECHO), and the Exceptional Family Member Program (EFMP) have also been a huge asset. Without them, we would not have the care and equipment that Cole needs. TRICARE and ECHO have been extremely prompt in authorizing referrals and the coverage far exceeds other insurance companies. However, THESE PROGRAMS MUST RETAIN FUNDING AND NEED EVEN MORE ATTENTION in order to continue accommodating our needs and those of many other military families. Despite the positives, our experience has not been without trials and tribulations and I would like to share with you some areas that need attention and revision, from our perspective as a special needs family.

TRICARE:

- We were unable to pursue testing for Cole before he turned 18 months. Until a child misses a milestone, they are discouraged to pursue testing. The entire process should have been accelerated so Cole could receive the physical therapy he needed earlier. **MILITARY DOCTORS SHOULD NOT BE FORCED TO ADHERE TO STANDARDS WHEN PROFESSIONAL OPINION OVERRULES.**
- Every time I call the TRICARE Benefits Department and ask for clarification on coverage, they supply ambiguous answers or no information at all. I have called numerous times so this is not an isolated occurrence. **THE BENEFITS DEPARTMENTSHOULD BE KNOWLEDGEABLE ABOUT COVERAGE AND WILLING TO HELP CUSTOMERS.**
- TRICARE refuses to cover transportation for necessary durable medical equipment. It can cost up to $25,000 to modify a vehicle to accommodate a wheelchair and several thousand dollars to purchase a trailer. Cole needs his wheelchair 100% of the time but they deem transportation "not medically necessary." **TRANSPORTATION FOR NECESSARY DURABLE MEDICAL EQUIPMENT MUST BE COVERED TO ACCOMMODATE PATIENTS' NEEDS.**
- Specialists are too far away for remote military locations. We drive 4 hours each way for each of Cole's neurology appointments. They authorize 1 night of hotel stay, even if the appointment is mid-day. That means we leave the house obscenely early or drive into the night. I have paid for rooms out of pocket for our own health and safety. **TRICARE NEEDS TO ACQUIRE MORE SPECIALTY DOCTORS SO PATIENTS DO NOT NEED TO TRAVEL GREAT DISTANCES.**

Extended Care Health Option (ECHO)

- ECHO possesses the same policy as TRICARE and will not cover transportation for necessary durable medical equipment. **TRANSPORTATION FOR NECESSARY DURABLE MEDICAL EQUIPMENT MUST BE COVERED TO ACCOMMODATE PATIENTS' NEEDS.**

Exceptional Family Member Program:

- The staff at our base does not show concern for our family. The case manager and staff contact us only to correct paperwork. During these numerous calls, they never once inquired about Cole's progress, nor offered assistance. **EFMP EXISTS TO HELP FAMILIES AND STAFF SHOULD BE TRAINED TO PAY ATTENTION TO CLIENT NEEDS.**
- The childcare respite program is a wonderful resource but the paperwork is excessive. They change formats frequently and require perfection. I personally know of several families that would use the program but do not because of the time, effort, and turmoil. **EXCESSIVE PAPERWORK SHOULD NOT PREVENT CLIENTS FROM WANTING TO USE THE PROGRAM.**

Once again, we are thankful for the benefits we have and these shortfalls can be remedied with more attention and a retaining budget. Thank again for your time and consideration for our needs. We appreciate your concern and advocacy.

Regards, Stephanie and Brian Geraghty of Camp Lejeune, NC

Gerwig Family

USN – Active Duty stationed at NIOC MD and living on Ft Meade

Our son, four years old, was diagnosed with autism at age 2.5. He receives ABA services through ECHO, attends speech and behavior management therapy through TriCare and ECI services through the county under IDEA. We also anticipate an upcoming appointment with a Developmental Pediatrician will result in our 2.5 year old son also being diagnosed.

We have had a huge problem with the county school on post not complying with federal and state laws in regards to special education children. It is a huge disservice to send military families into a school district that does not comply with existing laws and makes families work to get some semblance of these protections for their children. I recently filed an Official Complaint with the Maryland State Board of Education and their Letter of Findings has been issued. Of the four violations they investigated, the school was found in violation for each item. There is no reason military families should have to invest so much time, energy and sanity exhausting all resources when it comes to special education. No family should have to truthfully, but when you are known to be transient members of a community and dealing with all that comes with military life as well as whatever comes with your special needs family member(s) – there should be some way to ensure Commands are aware of existing issues and willing and able to address the family readiness issue SpEd noncompliance is. Especially when the school is located on post.

We look forward to the EFMP program being run as one rather than by branches. Having things separate can be especially confusing and disjointed at joint commands.

I very much support the efforts Mr Hilton and so many others to have ABA therapy rolled into regular TriCare in recognition of its true function for our ASD children and with full regard given to those retired servicemembers who have a family member on the spectrum.

At the top of my list of things that should exist in the EFMP is a JAG Officer stationed at all major bases/posts whose specialty is SpEd, or who is tasked with becoming meaningfully well versed in the Federal and State laws regarding SpEd. This Officer would hold some form of periodic town halls (virtual or not) or meetings with parents to pin point any possible areas needing their attention. While they would not become a lawyer to be involved in Due Process complaints or anything, they could meet with families and give them educated and on point advice re: their situation. They could also draft letters to the school referencing the specific applicable laws and asking for clarification on specific situations in the expectation that knowing families have a SpEd lawyer available to guide them on their issues many schools will stop looking at our families as ignorant or overcommitted and unlikely to tackle systemic problems in local school systems.

The Gorman Family

Active duty Marine Corps for 12 years

5 year old child Madeline survived leukemia, now suffers from multiple seizures daily with severe delay in all areas

Challenges with Tricare/ECHO/EFMP

Inconsistent policies regarding coverage of medical equipment

In our region, the Tricare Management Authority refuses coverage of certain items like a seizure safety-proofed bed. Other areas of the country allow coverage of these beds. This was an extremely large out of pocket expense for our family and it seems unfair that it is being covered without issue in other places, forcing us to question if we should just wait until we get transferred elsewhere to get it covered.

Inadequate EFMP Respite program

For families like ours with children who cannot do anything independently and who are extreme safety risks, respite care is extremely important to give the parent or caregiver a break. Service members work long hours and deploy often. Forty hours per month is not enough, especially during deployment. Respite hourly pay coverage and time allotted should be on a scale that more accurately reflects the disability and needs of the child.

Medicaid Portability

This affects families both military and civilian with special needs children, but the greater burden is on military families who move every 2-3 years on average. It puts great stress on families at an already stressful time (relocation) not knowing if their child will be able to receive similar services in the next area.

HAWKINS FAMILY STORY

Aly Hawkins was born at 35-weeks' gestation with a rare birth defect called esophageal atresia tracheoesophageal fistula (EA/TEF), which means that her esophagus was not attached to her stomach, while her trachea and esophagus were connected. After a traumatic birth, Aly was transferred to the local Children's Hospital, where she endured painful PICC lines with no sedation and was denied any nutrition for over a week. During the operation, the surgeon damaged nerves and paralyzed her stomach and intestines, as well as caused respiratory problems and heart rate and pulse issues. The physicians released her after two weeks, although her health continued to decline. She began turning blue. She screamed every time I would feed her. We would rush her to the emergency room only to be told there was nothing wrong. The physicians refused to treat my baby.

I immersed myself into research and found a doctor in Boston that specialized in EA/TEF and we hopped on the next flight, carrying an infant who was so dehydrated, she was on the verge of seizing. She spent three months in-patient at Boston Children's Hospital, enduring six surgeries, hundreds of x-rays and studies, and finally found the issues: not only was her esophagus barely opening, but scar tissue had developed. She also had two heart defects and a severe tracheomalcia that caused her airway to collapse almost 100% with every respiratory cycle. She had developed clonus and tremors in her extremities because of the previous surgeon's damage during her first operation. Aly went home three months later with a GJ tube, feeding pump, pulse oxymeter, and referrals to every specialist under the sun.

TRICARE and ECHO were great while we were stationed in California. She received 40 hours a week nursing services, a special lift reflux bed, and approved the Synagis vaccine that helps prevent RSV virus, which could have been fatal to our baby girl. All of her therapies and specialists were approved quickly, even though we were TRICARE Standard.

Then we transferred to Virginia, where healthcare for Aly is awful. It is a 6-week or longer wait to see a pediatrician and even longer to see a specialist. We have to see a civilian pediatrician now because we just can't put her care on hold like that. TRICARE has denied the referral for Aly to see a dietician, and as a result, my child, who is 100% G-tube fed has not seen a dietary specialist since we moved here twelve months ago! Therapies are non-existent, as their waiting lists are extensive. We have been fighting tooth and nail to get the Occupational and Speech therapies that she desperately needs, but they are only able to provide for her sporadically through the month. ECHO has been a nightmare, too. They have repeatedly denied nursing care here, stating "We are a different region, and you do not qualify here in Virginia." Why isn't there consistency in services?

We have been on the waiting list for much needed respite care services for two years. We pay out-of-pocket expense of $852 for the Synagis vaccine, because in Virginia, it's not covered, either. There is no available ADA military housing for us in Virginia, and the local housing office seems to be very corrupt.

Aly has fallen through the cracks in Virginia, and health care here is a joke. Why aren't services through TRICARE and ECHO uniform throughout the regions? I feel hopeless that the services that my daughter desperately needs and deserves are not being taken care of. Please help our family and others like us. Our military children deserve better!

Kris Hawkins, wife of LT Rudolf A. Hawkins, Pilot, US Navy

This is Jesse. He was born happy and healthy at Blanchfield Army Community Hospital at Fort Campbell, Kentucky. Two months after his second birthday, he was diagnosed with autism and I was told that he may never talk or be affectionate. I was promised that early intervention is critical and we were lucky to have him diagnosed so young. Our pediatrician stressed the importance of speech therapy, occupational therapy, and Applied Behavioral Analysis (ABA) therapy if we wanted Jesse to gain crucial skills. With my husband deployed and no family within 2,000 miles – I immersed myself into his world to do everything I could. We enrolled in the Exceptional Family Members Program so that we could then apply for ECHO and be eligible for ABA therapy.

It worked. Jesse will be six this September and will be entering a mainstream kindergarten classroom. Not only does he speak, he never stops speaking! He has stories to tell about dinosaurs to anybody that stands still long enough for him to talk to. He isn't without his struggles, we still utilize ABA therapy and are constantly working on behavior and social issues that pop up.

As of December 1, 2012 my husband will retire after 20 years of honorable service and we will lose our coverage for ABA therapy completely. Please don't let this happen. There are children out there that need this – not just to succeed but some need it just to make it through daily tasks that we all take for granted. We don't just want ABA therapy for our son, we need it. He needs it. We need your help.

16 June 2012

1. My son was diagnosed with autism while we were stationed in Germany. He was 15 months old. As overwhelming as the diagnosis was, it was even more overwhelming to get all the necessary care he needed. There was speech, occupational and physical therapy, allergy and immunology, etc.... and there was ABA. Stateside military members had already worked hard to have ABA recognized as a need but only under Tricare ECHO (Extended Health Care Option), which still denied it as MEDICALLY NECESSARY for children with a diagnosis on the autism. There was only one American operated ABA company available in Germany. It was very expensive, and we were constantly struggling with Tricare to receive reimbursement. By time we left Germany, private ABA and his medical necessities, that we refused to wait for months for in the system, had depleted our savings and investment accounts.

2. We fought with the Air Force assignments team, explaining that they needed to send us to a location that had available ABA for our son. With patience and persistence, we arrived at Andrews AFB. Because we had heard about schools that offered self-contained classrooms for children with autism, we decided to live in Virginia. In the meantime, we begin our journey trying to find him ABA services. There were several companies, but they had 8-12 month waiting lists. When we finally did find a company that Tricare would cover, they left billing to us. The company billed us, and we would wait for Tricare to reimburse us. At times, our credits cards were maxed well (upwards of $20,000) while we waited for reimbursement. And the interest was not low. So we are now, broke.

3. Before my son started receiving up to 12 hours a week of ABA, he did not speak, had tremendous behaviors that included hitting himself, spinning, crying constantly, and lived in constant frustration. After only one month of ABA, he began to sign then steadily began his journey to beginning to communicate. I will save the complicated details, but I will tell you that he legitimately passed the 2nd grade recently. He still however cannot leave a self contained classroom, and we long for him to be mainstreamed. ABA works. It's been proven to work. It is also MEDICALLY NECESSARY.

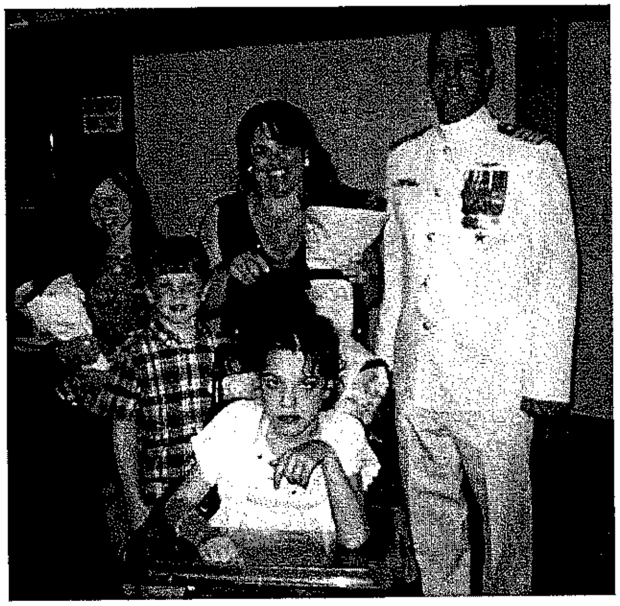
4. We are frustrated. Upset. Tired. We have the weight of the world on our shoulders. Any parent knows the pain of watching your child go through something that you just can't seem to fix. But how about knowing there is something that will benefit your child is out there, but you only get access to a SMALL portion of it. You don't only give a "little bit of chemo" if you have cancer, or a "little bit of physical therapy" to someone who was in a car accident and broke their legs. You give them what will benefit them completely. I feel like someone has dangled that carrot on a stick we continue to chase. I feel as if someone is saying to us, "There is this scientifically proven, medically necessary therapy that can benefit your child, but we are only going to give you a quarter of it."

4. Currently, my husband is stationed in Dover, Delaware and commutes home on weekends. Because he was force to move, we lost nearly $1,000 in a month in housing allowance and now have to maintain two households. There are no ABA services in Delaware. And even if there was there would be waiting lists. So, we separate our family so that my son can continue to receive his ABA services. And my husband continues his service faithfully in hopes that the military will do due diligence and take care of his family in his absence.

5. ABA should be given to us as it was found to be the most beneficial, at 40+ hours per week. It should also be made to available to military retirees. Cutting these services at retirement from active duty is a travesty. Our men & women who serve our country deserve peace of mind that their family is taken care of both during and after the completion of their military service. They earned it and our children deserve it.

MELISSA A. HENDRIX,
Military Spouse

The Samuels Family



BRANCH: US Navy
DUTY STATION: NAS Fort Worth JRB
EFMP CATEGORY: 5

Kaitlyn Samuels was born with severe brain abnormalities which resulted in severe global developmental delays, cerebral palsy, scoliosis and a seizure disorder. The family's biggest hurdle in caring for Kaitlyn has been gaining access to the Medicaid Waiver. They are entitled to this, however, Mark's military service has made this impossible at every duty station except for one. Here is their experience:

Due to Mark's career we have moved five times since Kaitlyn's birth in 1996. While we have managed to make every move successful for Kaitlyn in terms of medical care (by being on Tricare Standard rather than the more cost effective Prime) and school (by living within the best available school districts) one area that is frustratingly difficult is access is the Medicaid Waiver program. As you are aware each state handles its own program, therefore military families must start over with each move. Of the six locations we have lived with Kaitlyn, only the state of Maine did not have a waiting list for their Medicaid Waiver (the Katie Beckett Waiver in Maine). Our current waiting time here in Texas is over 4 years for one waiver and over 10 years for another. This is the typical wait time we have encountered in each of the other locations in which we have lived. As you know, military orders are rarely longer than 2-3 years, therefore, in most states military families never make it off the waiting list before being put at the bottom of the list in their new state when relocating.

One of the most helpful benefits of the Medicaid waiver is access to respite care. Military families rarely live near extended family and very often the active duty parent is gone. Therefore respite care is an even greater need for military families than most others. My daughter is 15, but requires the care of an infant. I must dress, feed, bathe and diaper her. Having respite care when we lived in Maine gave me a chance to do things with my other two children that are hard to do with Kaitlyn. It gave me time to catch my breath both physically and emotionally. And it gave me an extra set of hands when my husband was gone. There must be some way to address this problem. Possibly some type of waiver program for military families that is not tied to a particular state. I am not seeking help for something special for military families. I am asking for help for what we are already entitled to, but our family member's service denies us.

Jennifer Samuels
Navy wife of 19 years

Sir/Ma'am:

We are an active duty family with an autistic 6 year old daughter and an 8 year old daughter that is recovering from difficult leukemia treatment and currently receiving her treatment at the New Walter Reed hospital in Bethesda, MD. I have over 20 years in the military on active duty and as I am nearing retirement, we are very concerned on how we are going to continue Haynah's Applied Behavior Analysis (ABA) therapy.

My autistic daughter's treatment plan for autism includes a wide variety of treatment aside from the ABA therapy to include but not limited to speech, occupational therapy, hypotherapy, gluten/casein-free diet, LDA shots, and attendance at a Fairfax Country Public School autism elementary program. The ABA therapy has and continues to be a critical part of her treatment as we cannot even imagine where my daughter would be without it. The financial burden is already very significant as we pay out-of-pocket expenses not covered by TRICARE. Even though the ABA therapy benefits are a true blessing, my daughter still requires more hours than allocated, therefore, we also pay out-of-pocket for these additional hours. However, with the current ABA policies for retirees, her treatment plan will be seriously affected by our inability to support her financially.

Please consider our huge challenges and that of many other military families that have similar circumstances. Treatment of autism is a huge financial and emotional undertaking for the families and all involved, and your help would be greatly appreciated by all, but mostly by these autistic children.

Sincerely,

Theo Kang and Family
7981 Viola St.
Springfield, VA 22152
Kang.theo@gmail.com

16 June 2012

I am the proud father of twin sons who were both diagnosed with autism while I was on active duty in the Army with more than 28 years of military service. Both sons received Applied Behavior Analysis (ABA) medical care while I was on active duty. But when I reached mandatory retirement at 30 years of military service, DOD TRICARE would no longer pay for any ABA treatment. Does my retirement change anything about my children's condition?

One of my twin sons is non-verbal and requires OT as well as speech therapy in addition to ABA therapy. Military readiness and the fair treatment of all categories of military personnel, active duty as well as retired, are important considerations for DoD health care. I have many out of pocket medical expenses resulting from the autism spectrum disorder diagnosis of my two sons.

I hope this unfair policy, in which retired military family members are excluded from reimbursement of ABA medical treatment by DOD Tricare, is finally corrected.

Kenneth D. Shive

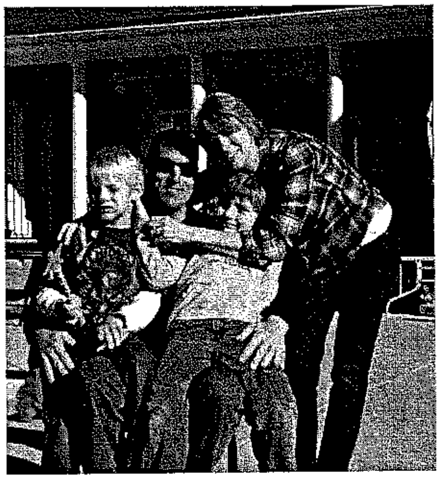
COL (ret) US Army

McIntyre-Brewer Family, US ARMY

Pediatric Needs: **Lorelei**, 7 years, hypoplastic left heart syndrome (HLHS), PTSD, OCD, Harlequin Syndrome, seizures, tics, extensive pulmonary scarring
JoJo, 5 years, cerebral palsy, plagiocephaly, residual PDA, BAV, insufficient aorta, tricuspid prolapse, endocarditis, multiple tumors

Primary Issues Relative to Access to Care:

1. Continuity of care from one permanent change of station (PCS) to next was denied despite proof of history with in-network providers through the Children's Hospital of Philadelphia (CHOP) was denied in the referral process by a doctor who wished to retain children within the Military Treatment Facility (MTF) and a written care plan previously established through the Exceptional Family Member Program (EFMP). Recourse protocol was followed and ended with a switch to Tricare Standard despite contacting the central EFMP office at the Pentagon, advocacy from CHOP, and proof that adequate care was not being provided by clinician who tagged referral for Right of First Refusal. Review of files was done in-house, rather than a third party review, and limited patient advocate recourse for proper advocacy.
2. Continued reductions in payout for services to civilian providers have caused various specialists and hospitals to refuse Tricare patients, limiting qualified care. The financial crisis has been sited as reason for limiting distance travel to visit facility used since birth and denying referral despite proven patient history with institution, willingness to forfeit travel reimbursement expenses, and limited availability of specialized services for patient.
3. MTF medical records have been lost multiple times or NOT recorded, including the entire first years of our daughter's life. MTFs also regularly ignore requests from civilian providers for information, despite using correct channels for acquisition of information. Loss of records has led clinicians to request procedures that were unnecessary and redundant, including sedated MRIs, echocardiograms, labs, and other interventions that proved a waste to taxpayer dollars and trauma to pediatric patient.
4. Communication and appointment collaboration for children with complex medical needs is disjointed and very seldom followed through. The disconnect between front desk services and inability to contact clinicians has created various instances of ignored medical requests, situations where hospitalization could have been easily prevented with early intervention, and inability to access care.
5. Right of First Refusal ultimately compromises the health and well-being of chronically and severely disabled children as it retains children who should be routinely monitored by the same team of experts who have the ability to establish adequate protocol, limit the misfiling of information, and ensure longevity of health for patient. While useful in healthy patient circumstances with temporary medical needs, it is inappropriate for life-long medical issues with established care protocol in place already.



My name is Jennifer Lockwood and I'm writing to you today to ask for your support of HR 2288, the Caring for Military Kids with Autism Act.

I've been married to military since before I was married. My father is a veteran who retired with 20+ years in the Navy; my husband is in US Army, with close to 25 years active duty.

In July of 2008, at the age of 4 my son was diagnosed with Autism. My husband and I were highly encouraged by my son's Developmental Pediatrician to enroll in both the Exceptional Family Member Program (EFMP) and the Extended Care Health Option (ECHO) Program, which would enable us to start Applied Behavior Analysis (ABA) immediately.

My husband submitted all the required paperwork for my son's enrollment into EFMP by mid-July and in September I was told that there was no paperwork and my son was not in the system. Essentially we had to start the process over again. My son was not authorized to begin ABA therapy until he was processed through EFMP and enrolled in ECHO. For children with Autism, it is imperative to start early intervention as soon as possible to ensure the most benefit and the greatest positive impact. Because of the lengthy enrollment process and the lost applications, it was January 2009 before my son was fully enrolled and approved. Due to the demand for ABA therapy, my son did not receive his first session until April 2009. Had ABA been an approved medically necessary therapy under Tricare, I suspect we would not have lost close to a year of my son's precious time.

Although the recommended amount of ABA therapy is 30 - 40 hours/week, my son only receives 10 hours/week, not near what is recommended, but absolutely better than nothing. Due in part because of these services, my son has gone from functioning as an 18 month old to functioning of a 6 year old; and this would not have been so had these services not been available through ECHO.

Because of where my husband is currently stationed, I live thousands of miles away from my family and have no family support. When my husband was deployed, there were many days when I was so tired and exhausted from being mother, father, and therapist to my son, that I just needed a few hours to myself. I called to inquire about respite care, which is a benefit that the EFMP and ECHO program provides for their families of deployed soldiers. I was told that any respite care that was provided would be deducted from my son's already minimal ABA therapy hours. Respite for a deployed soldier's family should not be provided at the expense of a child's medically necessary ABA therapy hours. I chose to forego respite; because my son's medically necessary therapy was more important than his mother's well-being.

As I stated earlier, my husband has over 25 year's active duty Army Special Forces. He has deployed multiple times throughout his military career, potentially risking his life each time. He recently returned from a yearlong combat deployment in Afghanistan and is scheduled to deploy again in August, for what will most likely be another year. Although my husband has more than enough years to retire from military service, he cannot for fear of losing all medically necessary autism therapies for our son; retirees are not eligible for ECHO services.

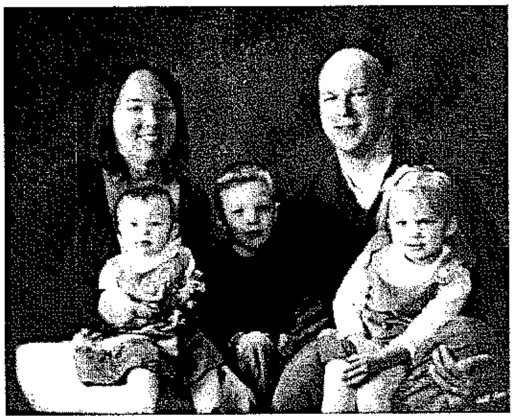
My husband has made many sacrifices for this county, so I ask you to do what is right and offer your support to him by supporting HR2288. The medically necessary therapies that our son requires should not preclude our son from having a father present in his life.

The Maki Family
USAF

Caleb, 5 years old

Diagnoses:

Autism, Celiac disease, Apraxia of Speech, Sensory Integration Disorder



Our current base is 45 minutes from the nearest city that provides the necessary services, such as, Speech, Occupational and Physical therapies. Our in-home ABA therapists travel 45 minutes each way 3-4 days a week to work with him and our BCBA drives over 2 hours each way when she comes up to supervise. Caleb received some additional ABA services through our state programs, but that has now ceased due to a health bill that was passed mandating insurance coverage. The gains made in the last 6 months when he received a total of 25 hours per week in ABA therapy are now threatened without those additional hours and Tricare cannot fill that void leaving us with the cost of maintaining those additional hours that he so desperately needs. In future months we will have to choose between providing that much needed behavioral support and continuing to provide him with the specific nutrition that he needs due to Celiac and various other allergies and sensitivities.

Struggles:

- Remote base location and limited resources available locally
- Limited amount of ABA therapy funds
- High cost of maintaining gluten free diet and nutritional supplements

Hello Committee Members,
Thank you for the opportunity to share the concern that my husband and I have regarding Autism care. We sincerely appreciate this forum to provide our family's story.

We live in Eagle River, Alaska. Dave is an active duty member of the Alaska Air National Guard. His active duty status allows us the benefits of the Tricare insurance coverage. He has met the time requirements for retirement, and one month ago we had to make the difficult decision to submit retirement paperwork. Last year Dave had to have surgery on both feet to repair severe arthritis that has developed, over the course of his military career, due to combat training injuries from when he was in the Army. Because of these surgeries, he is on a waiver for the physical fitness tests. He was told that there was a very strong chance of him being forced to retire due to these medical issues. This is so scary for us because the Tricare benefits for our son will change. He will no longer be eligible for his Applied Behavioral Analysis therapy.

Cole, our six year old son, is an absolutely precious boy who loves Star Wars. He can create the most fascinating things with Legos. He loves to snuggle with us and read stories. If you had an opportunity to meet Cole, his sweet smile would melt your heart.

Cole has high functioning autism, with horrific meltdowns that threatened to tear our family apart. For years these occurred several times a day, and required that my husband or I wrap him up and hold him tight for over 30 minutes to an hour while he screamed and raged and fought us. Our family was held hostage by these behaviors.

Over the course of two years, we sought help from a psychologist, two psychiatrists, and our son's pediatrician. While these professionals were empathetic and supportive, they were unable to help us. We were told by our psychologist that most families would not have been able to maintain as long as we had, and they would have had to place their child in residential treatment.

As horrifying as the thought was to have to put our 4 year old into such a restrictive setting outside of our home, we understood families who had to make that choice. With the exception of strong psychotropic medication, and weekly counseling, there was not the intensive support available that we needed. That is until we found out about Applied Behavioral Analysis (ABA) therapy.

Our family was so fortunate because we found out that we were eligible for this therapy due to Dave's active duty status. This therapy was a God's send to our family. Our son is progressing and learning the necessary skills to interact appropriately without defaulting into explosive rages. His therapists are highly trained, amazing people. They come into our home and work with him for three hours, four days each week.

This last school year, Cole was only able to attend Kindergarten half of the day. He becomes overwhelmed very quickly, and can only handle a few hours of the incredible sensory stimulation that occurs at school. He struggles during play dates, and usually leaves crying or angry after a short amount of time. He is so very aware of how others perceive him, and desperately wants to fit in and have friends and be "normal" as he says. His ABA therapists are trained to work through several goals at a time, and when he attains each goal, they tackle another area of need. It is a slow process, but IT WORKS! It is amazing to see the difference in our child after the last year and a half of ABA therapy.
I would like to make an important point that many people may not understand. ABA is NOT provided in the classroom for most children who have autism in this country. Perhaps severely autistic children who do not speak will be placed in the intensive needs classrooms with special education teachers who may use parts of ABA to get them through the day. However, this is not the case for the high functioning child who has the greatest chance of being able to function independently with this therapy.

As we think of Cole growing older, we have great hope for him. He is an extremely smart boy, and has the potential for a life that includes friends, a college education, and a self-sustaining career. ABA therapy is a critical resource for Cole during this important developmental time in his life.

Once Dave retires, although we will be able to retain our Triwest insurance, the ECHO program under Triwest that provides for the ABA therapy changes. Cole will no longer be eligible for this vital therapy that is helping him become the person he is meant to be. Our family desperately NEEDS this therapy to continue.
Thank you for taking the time to review this extremely important matter to thousands of families.

David and Laurie Matthews 19801 War Admiral Rd Eagle River, AK 99577

My son was diagnosed with autism at three years of age. He has been in an ABA program for about 3 years now. Last September we were able to double his ABA hours thanks to a behavior waiver. He know receives 25 hours of ABA a week. With this increase in ABA, he has been able to learn how to dress himself with assistance, check the family mailbox with assistance, and learn all of his colors, some letters of the alphabet, and numbers, all the while he is unable to speak.

With ABA, my son is able to communicate without being able to speak. ABA has opened a doorway for my son. My husband has about 5 years left until retirement can happen. Until he retires, we work to use full benefits for my son. When retirement comes, we do not know if ABA will be available. We would like to see more hours of ABA added, as 12 hours a week of ABA through Tricare simply isn't enough for children who are severely affected by Autism, especially those who are nonverbal.

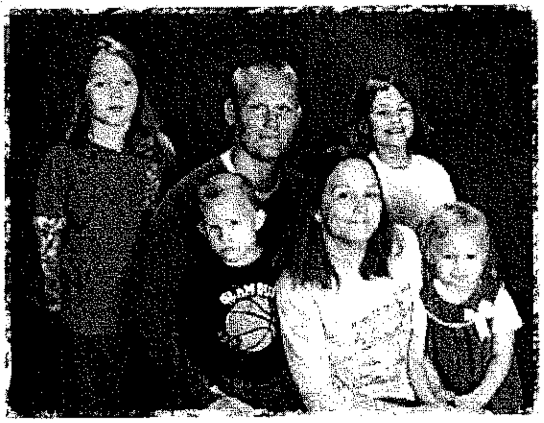
In my experience as a parent with a child with Autism, I have spent many hours trailing leads, ans jumping thru hoops to get my son the services that he needs. I am doing this all on my own, and I have no one to lead me thru it. A special needs liaison would be beneficial for military families. It is my experience within the military healthcare system to simply get a referral for a doctor, and have some mention of EFMP and some services, but mostly the military doctors have no real knowledge of what services we can obtain for our children, and so we spend countless hours finding these things out on our own.

More training on the doctors part can aid the military family that is struggling thru a diagnosis of special needs, and alleviate some stress.

Military families shouldn't have to navigate the system on their own, and they shouldn't have to fight for these services that are considered conventional therapies in the civilian healthcare system.

ABA should not be capped for our military families, including retirees and national guard. The more intensive the ABA for children with Autism the greater the capacity for learning, and recovery of skills. Costs can be minimized in the future if we invest in scientifically proven behavior therapy today for our children that need it.

Tara McMillan



The Mendiola Family

Our son, Michael, was diagnosed with autism on his third birthday, November 23, 1994. At the time we were stationed in Yokosuka, Japan, and the doctor informed us that we would need to return to the states ASAP because appropriate therapies were not available in Japan. It took six months for the Navy to finally get us transferred to the states.

At that time, ABA was not covered by CHAMPUS (which has since been replaced by TRICARE), but we tried multiple times to get our son approved for speech therapy. We were finally approved for speech therapy and occupational therapy when he was in third grade, age 8 or 9. By then a great deal of time had been lost that we couldn't recover.

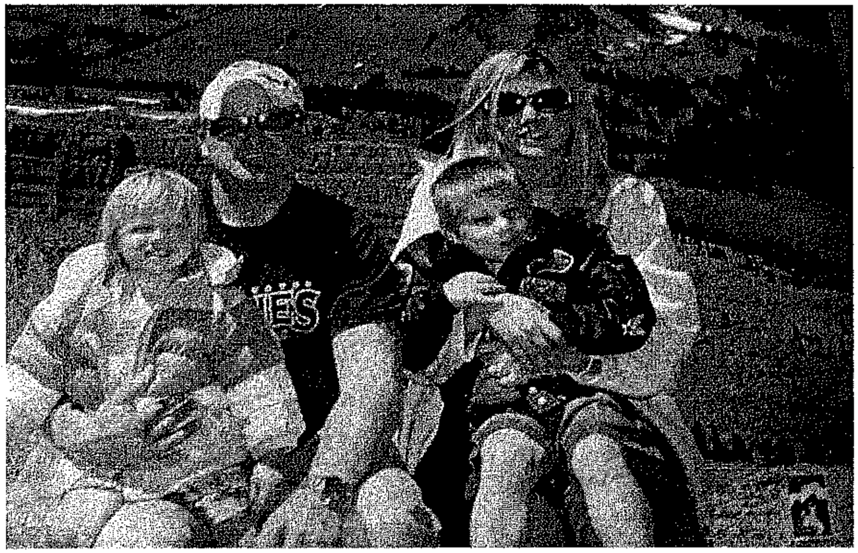
When ABA became a covered therapy under ECHO in 2005, we were preparing to transfer, so we waited until we had moved before we pursued it. After the transfer, it took over 18 months to find an ABA provider with space on her schedule for our son. During that time, we saw much regression, as we had no therapy for our son. Once ABA started, we were very pleased with the progress we saw. Language progressed impressively, independent living skills were becoming a reality, and his interaction with those in the community was becoming more age-appropriate. Through all of this great progress, the dark cloud hanging over our heads was the knowledge that upon retirement from the military, ABA therapy would no longer be covered by our insurance, and we would likely have to discontinue it.

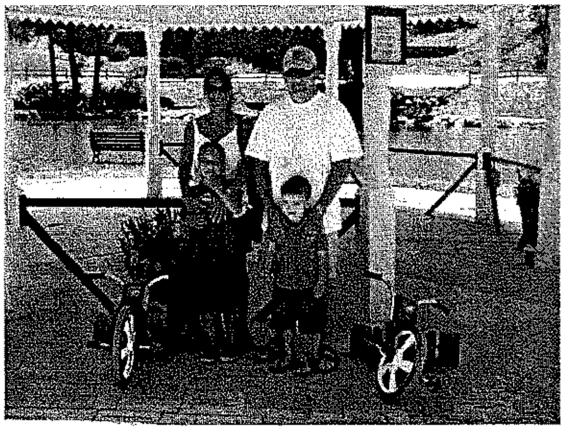
My husband retired from the US Navy with over 30 years of service to our country on August 31, 2011. We could not afford to continue ABA therapy for our son as private-pay clients, so we had to discontinue it. Since that time, our son has visibly regressed. At first we thought it was just our perception, but everyone (bus drivers, school teachers, friends in the community) has noticed and mentioned it to us. It is very difficult to get him to speak with people anymore. His ability to focus and complete a task is almost non-existent. He is retreating into "his own little world", and we are finding this heartbreaking to watch. We do everything we can to encourage progress, using techniques we learned from his therapists over the years, but it just isn't enough.

The only change in services he has had in the past year is the loss of ABA therapy; we therefore believe that this has to be the reason for his regression. At this age (20 years old) his options are very few. He will age out of public school in 18 months and will then have no services whatsoever, as the waiting list in our state for medwaiver services is decades-long. ABA therapy is the only proven method to treat autism. Our son needs this therapy to make progress and become a happy, productive, independent adult. Please make the changes necessary to include ABA therapy under regular TRICARE coverage so that families of retirees are able to provide this therapy for their children on the autism spectrum. This is the right thing to do for these families who have sacrificed so much to serve our nation.

The Mills Family

- Dad was wounded severely in Fallujah Iraq by an RPG and forced to retire because of the severity of his injuries
- As a retired Marine and disabled veteran, the family relies on TRICARE for coverage of medical services
- Son Shane has autism
- Because Dad is retiree, Shane's ABA care is not covered by TRICARE
- Family faces out of pocket costs of nearly $5,000/month
- Family has sold their home to pay for the medically recommended ABA treatments for Shane





From the Mosser Family; Jim (dad), Trish (mom), Jesse James (age 7) and Wyatt (age 5)

Hi and thank you for taking the time to read my letter about our family.

I am a Military spouse, my husband Jim is in the Army and has served Our Country for almost 29 years. He has been deployed twice and received two Bronze Stars, one for Desert Storm and one for Afghanistan. He has had various other tours stateside and has served over seven years overseas with about 15 moves in total.

In February of 2009, Jesse James was diagnosed with Autism. To add, a Genetics Test revealed he has a 10p15 Chromosome Deletion. Also, he has asthma and a seizure disorder. Wyatt was diagnosed with Autism in July of 2009. To add, he has asthma and sensory processing disorder and multiple allergies to antibiotics which, if taken, can cause febrile seizures.

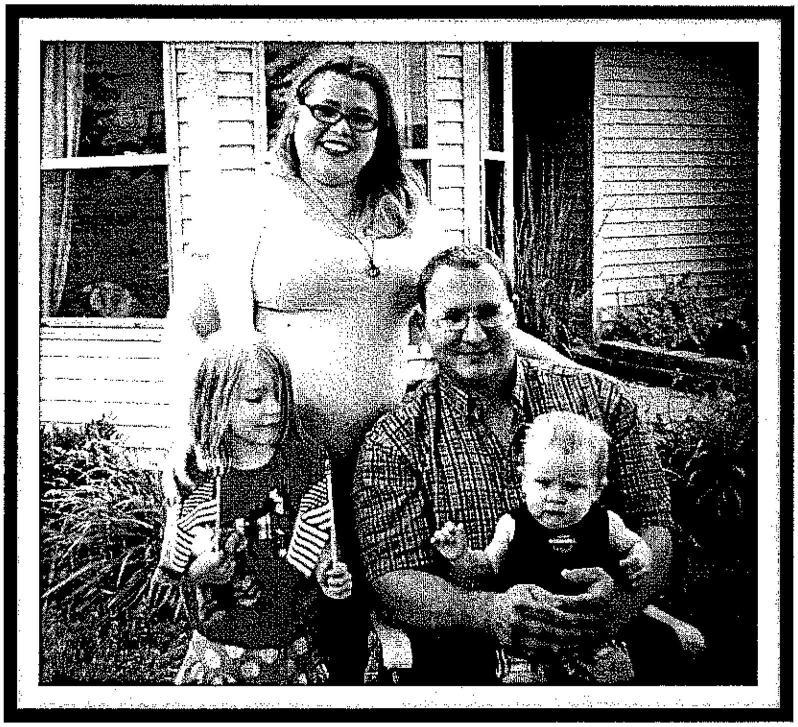
Jesse and Wyatt have been in early intervention with Occupational Therapy (OT) and Speech Therapy since they were 18 months old. Jesse and Wyatt started Applied Behavioral Therapy (ABA) in February of 2010 and we have seen a tremendous change for the positive for both our boys in spite of their health issues, including three more moves in total. Actually, the learning curve they have achieved has far surpassed our expectations and has made our life so much more fulfilling. We can now do things as a family!!! Had we relied on ONLY Speech and OT we know our boys' progress would have been much slower and their lives much more challenging.

My husband is eligible to retire and it scares the LIVING DAYLIGHTS out of both of us. Even having faith, we are still very concerned about retirement because we know the boys will no longer receive ABA therapy. To financially afford ABA therapy is completely out of our realm to achieve which no parent should have to bear that burden knowing we are unable to pay for a life changing and lifesaving therapy we know will save our children's lives and give them a better future. A future we dream of for them. My husband is also a wounded warrior and we are fortunate he is still able to remain in the Military yet I see that he struggles to do the things he used to do and I know why he puts those boots on everyday and his uniform because he knows that Jesse and Wyatt count on him to have the best possible medical care and he is proud to Serve His Country. We appreciate your time and we have faith that you will give our kids a hopeful and bright future by passing this bill.

17 June 2012

Dear Senate Armed Services Subcommittee on Personnel,

My husband was a dedicated solider, who dreamed of a lifelong career in the Army. He devoted his time to serving his country well. Unfortunately, he was injured in a training accident, which has permanently deteriorated his knees. Things might have been different had his unit at the time allowed him to seek proper medical attention immediately, but he was told to work through the pain. He did and working through that pain cost him his career. He was medically retired in July of 2007.



We have a five year old daughter, Samara, who we tried so long to get. We went through a lot of heartache before we were blessed with our miracle little girl. Although things on the civilian side of life were more challenging than we had hoped we were and are thankful for our Tricare Standard. When our daughter was diagnosed with Autism we were confident that because we had such amazing insurance we would be fine. Much to my dismay it has been a repeated no. It was even suggested that my child be adopted by someone on active duty so that she could have the therapy she needs.

We are grateful for the Occupational and Speech therapies she receives as a beneficiary, but everyone knows she will flourish with also having ABA therapy. It is dumbfounding that through our medical insurance our country has turned their backs on our child, and countless others like her with autism. He father fought and served honorably, for our country. Being retirees with a child with Autism is like a slap in the face. You cannot provide the therapy they need, and no one seems to think your sacrifice to your beloved country maters anymore.

We are respectfully asking that you make ABA therapy available to all Tricare recipients, and to make it affordable. We need to give kids with autism the best life possible, without ABA it isn't the best possible. Her father gave his best; show some appreciation and allow his daughter to possibly achieve her best too.

- Samara is a five year old with Autism, whose father is a disabled Army Veteran.
- She needs 20-40 hours of ABA therapy a week to help her achieve the best life possible.
- If ABA becomes a benefit for all Tricare recipients. Please somehow make it affordable for us. Currently our Tricare has 80/20 coverage. However, even with a 20% co-pay it may place it out of our and many others financial reach due to the sheer amount of therapy involved. Please keep this is mind, and make the out of pocket costs zero to minimal for all recipients.
- Her disability is preventing her from joining her peers in Kindergarten in the fall, with ABA therapy we are hoping she will "catch up" to her peers academically, and socially.
- We have a 9 month old son, Sabastian, who is already showing developmental delays, and has started early intervention therapies. If we receive the diagnosis of Autism we would need him to receive ABA therapy as well.

Respectfully,

Travis, Tami, Samara & Sabastian (Booth) Ort, US Army Retired family

16 Jun 2012

I have served 14 years as an Air Force Dental Corps officer. I am the mother of three children. My second child, Peter, is 9 years old and is autistic. He does not speak or read, has minimal imitation skills, does not understand many social concepts, and lacks many life skills. We have been fortunate to be able to utilize Tricare Extended Care Health Option (ECHO) for services when needed at various bases. However, I believe that these benefits have concerning limits. The present $36,000 per year allotted by Tricare ECHO may cover 9 hours a week of Applied Behavior Analysis (ABA) therapy--far short of recommended intensive therapy.

Presently, Peter, his siblings, their father, and my mother-in-law live near Joint Base McGuire-Dix-Lakehurst, NJ where I was assigned. Peter is receiving year-round schooling at an ABA-based school paid by the Pemberton, NJ Public School District. Since May, I am living in San Antonio stationed at Joint Base San Antonio where I'm now assigned. I am anticipating my family will remain in NJ for the two years that I will be here. The public school systems in San Antonio do not use ABA therapy, has higher student to teacher ratios, and will not provide summer school for Peter. If we move Peter, his ABA therapy will be reduced from 25 hours per week in school to 10 hours a week using Tricare ECHO funds in a center-based or home-based program. He has lost skills with inadequately trained DODEA teachers when we were overseas and when he was living in San Antonio using the public school system. If we move him back to San Antonio, he would most likely not continue with the same progression of learning.

Our family separation is our solution for now, but we are concerned what will happen to Peter when I retire and when he is no longer eligible to use the public school system . Peter makes consistent but very slow progress learning important life skills. In order to become as independent as reasonably possible and less of a burden on society, Peter will need continued teaching beyond my permitted active duty time. These skills are being taught through his ABA education and not through medical therapies. We are fortunate for now. But other families with special needs family members are not as fortunate due to military status and cannot use services funded through Tricare ECHO. Shouldn't these vital benefits be considered basic medical needs for all--active duty, retirees, guard, and reservists? Shouldn't these special needs dependents be given the opportunity to learn in a way effective to them?

If you have any questions, please contact me via phone (609) 845-7689 or e-mail cc_garin@hotmail.com.

Very respectively,

Cecilia I. Garin

My name is Linda Reilly and my husband, Shane, is a Major in the US Army. We have 2 kids: Charlotte, who is 7 and Alexander, 5. He is on the Autism Spectrum and has been diagnosed since he was 2. Shane was on Active duty when Alexander was diagnosed so we were enrolled in EFMP and Alexander received ABA therapy through the ECHO benefit. This has helped him tremendously where he went from not even looking at us to speaking in full sentences. We are enrolling him in regular Kindergarten this year because of the progress he has made.

My main concern is continuing benefits once my husband's duty status changes. He has actually taken an assignment overseas to Kuwait to stay in Active duty so we can keep Alexander's benefits. With the upcoming transition to school, it would be devastating to lose these benefits. The company we work with only deals with military benefits and our therapists and ABA has been vital to his growth.

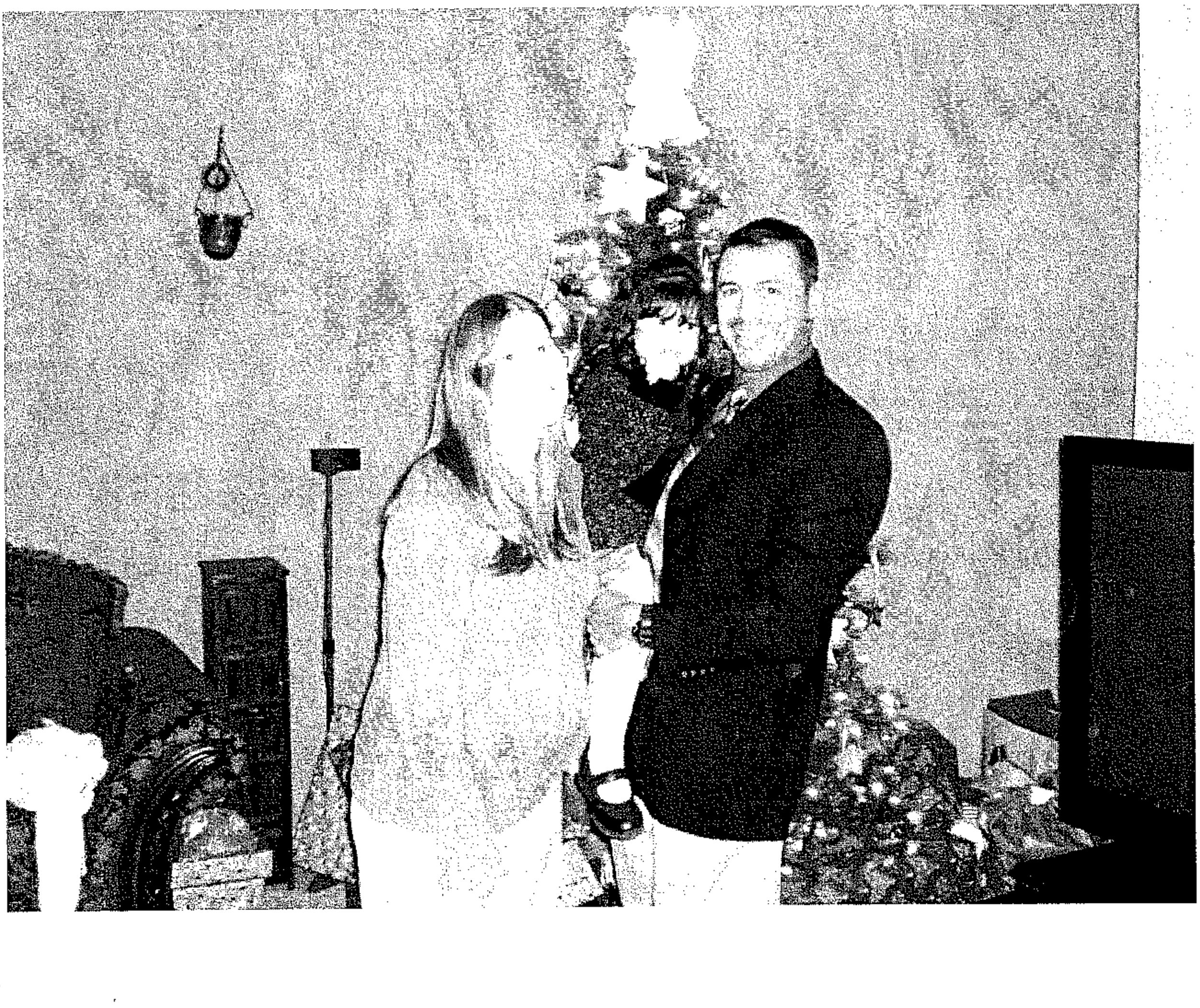
So we are sacrificing our kids' time with their Father for the benefit of Alexander. Why can't ECHO coverage be extended to Guard and Reserve families? It is not fair to just cut off these life-changing therapies.

I hope the current legislation will extend these benefits to ALL military families regardless of status. We need to honor the sacrifice our troops have made for their families and help our kids succeed.

Thank you!

The Reyna Family

Our daughter Karsyn was diagnosed on the Autism Spectrum with PDD-NOS. My husband is currently on Active Duty and we are enrolled in the ECHO program in order to receive ABA benefits. My daughter has made tremendous improvements with that I'm not sure she would have otherwise made without this therapy. Unfortunately, due to the dollar amount $36,000, Karsyn only receives 6 hours per week. Furthermore, this coverage is only available while my husband is on Active Duty. If he were to get injured in combat, die on active duty, or just retire not only would my daughter face significant difficulties coping with the loss of her father or permanent disability (excluding retirement) but she would also lose the therapy that has will most help her become an independent functioning member of society. Please consider making ABA coverage available for all military, active duty, retired, and medically retired/discharged. It will make a significant difference in many lives of the military members that have sacrificed so much for the United States.



My name is Susan Reynolds and I am married to AF TSgt Jeremy Reynolds. We have a son named Ian who is 22 months. My family is currently assigned to Fort Bragg, NC which is home to the 82nd Airborne Division, and the 18th Airborne Corp. My husband is a Combat Weatherman also known as a Battlefield Weather Airman. Jeremy has deployed twice both to Iraq and Afghanistan and we are now preparing for him to deploy again sometime next year.

Ian, our son was born at 36 weeks and 6 days weighing only 5lbs and 10oz and was only 19 ¾ inches long. Within a few weeks of having Ian home we noticed a flat spot on the back of his head. With our upcoming move, I didn't push the flat spot issue until we settled into our new clinic at Fort Bragg. On April 16th, our rental home was hit by the tornadoes that came through NC. My husband also left for Afghanistan and my son and I moved into my parents' home over an hour away from post.

Ian started having ear infections around that time, and I was pushing more and more about the flat spot and getting a referral. I was told by his pediatrician that Tricare policy stated that Ian had to be a year hold and have head x-rays completed before a consult for a pediatric neurologist could be given. I have now discovered that that Tricare policy is not true nor does it exist. I got Ian's x-rays and kept pushing for a consult. Finally in August for Ian's 12 month check up, I was given a consult.

Helmets are most effective for children under the age of 12 months. By the time Ian was in his helmet, he was 14 months old. I was informed that Tricare does not provide coverage for helmets and he recommended another company in Cary that would provide a 50% discount to active duty military families. Ian went to Level 4 Orthotics in Cary (http://www.levelfour.us.com/). I chose to pay for my son's helmet because the potential long-term negative effects were unacceptable.

The lack of education on plagiocephaly is ridiculous and the made up policies from my base clinic made the situation worse.

My group is called: Cranial Helmets: Re-Shaping Our Children's Future By Using Our Heads. My son is my inspiration and when I see that he wasn't able to get the best possible care afforded to him, I became upset. Instead of complaining though, I decided to be a part of a solution. That solution is to change the policy and ensure that our military children are receiving the best possible care.

My husband has served his country and been deployed twice. He will be gone again next year. I hear a lot of talk about the sacrifices of military families. When my husband comes home from a deployment or training my son experiences horrifying nightmares because Ian is unable to understand that his father is home. Our lives are dictated to us and our military serves this great nation without question. The least that we can do as a nation is to have the best medical care for the family member.

Congress, help us!
Our son's ABA coverage stops in one week!

My name is Jesus Rodriguez, and I have recently retired from the U.S. Navy after faithfully serving 20 years of active duty. My wife and I have a 9-year-old boy with Autism. Alex is a remarkable success story of the effectiveness of early intervention, specifically applied behavior analysis (ABA). He has been receiving ABA therapy for the past 5 years, and it has made a significant impact in his communication and self-care skills.

Unfortunately, my TRICARE ECHO benefits are due to expire on 28 June 2012 and cannot be renewed because I am no longer active duty. Our son will cease to have any insurance coverage for this crucial therapy that has made a difference in our family's life. Although Alex has made great strides, Autism is a life-long disorder that did not go away upon my retirement. We are very worried that we will not be able to afford the amount of ABA therapy hours that my son currently receives and will no doubt need in the future. This type of therapy is most effective when consistently applied in childhood, but it is ineffective when it is not provided or is severely limited in hours provided.

I have never asked Congress to take specific action on an issue as important as this. Similar to many in my situation, it is absolutely personal. Just put yourself in our shoes. We retirees have served our country to the best of our abilities, enduring military life in peacetime and during war. Our spouses have supported us and made numerous sacrifices. Don't we deserve some help when we need it?

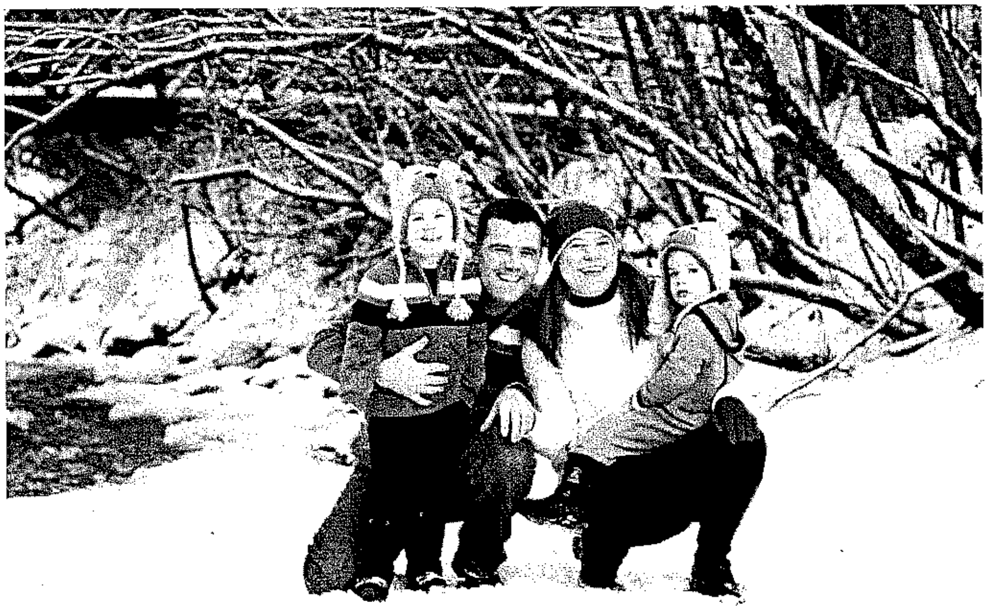
All I am asking for is to give my child the support he needs to learn and grow. He may one day thank you himself. I implore Congress to help our children immediately.

Sincerely,

Jesus A. Rodriguez
United States Navy (retired)

Dad, Michael, Alex & Mom

The ROUTHIER Family



- On November 3, 2009 our oldest son, William, was diagnosed with PDD-NOS, an autism spectrum disorder.

- 7 days later, David deployed for Afghanistan leaving Michelle with 2 year old, William and 7 month old, Benjamin, who was diagnosed with GERD and failure to thrive. David spent his last days before deployment NOT spending time with his sons and wife, but on base, trying to get William enrolled in EFMP and gather the steps for Michelle to complete the process for ECHO.

- With no help from anyone of base and conflicting answers, it was January 2010 before Michelle managed to find out that Liam had been successfully enrolled in EFMP and then several weeks to complete the ECHO process.

- In terms of therapy, that meant William lost 2 months of potential therapy.

- Since starting ABA therapy under the ECHO program, William has shown significant improvement: gone from not communicating and 35% delayed in social skills to near age level in both language and social skills.

- The Routhier family is about to make their second PCS since David's return home in June 2010, which means more months of waiting list and lost therapy.

The Schuchs-Gopaul Family

BRANCH: US Air Force

DUTY STATION: Davis-Monthan AFB, Arizona (355th Fighter Wing)

The Schuchs-Gopaul family is a dual-military family with two children. In 2008, while stationed at Maxwell AFB, Alabama, they began to suspect that their 16-month old son, Evan, was different. He did not speak at all. This is their story:

In 2006, after 3½ years of being stationed apart, my husband and I were both assigned to Maxwell AFB, Alabama. It was a wonderful assignment that reunited our family, but introduced us to challenges we never could have imagined. Our son, Evan, was born in May 2007 while his father was deployed to Afghanistan. Evan was a happy, healthy and quiet child. He never talked. While other children in his pre-school class were singing songs at circle time, Evan was mute and becoming hard to control. By 16 months, we decided that something was wrong. We found ourselves with few places to turn for help. As EFMP assistance for Air Force families was in its infancy, we were referred by the Air Force to the State of Alabama (Department for Retarded Citizens) as Evan was viewed has having an "educational problem." The State of Alabama tested him, determined that he was delayed, and then provided speech therapy for him once a week.

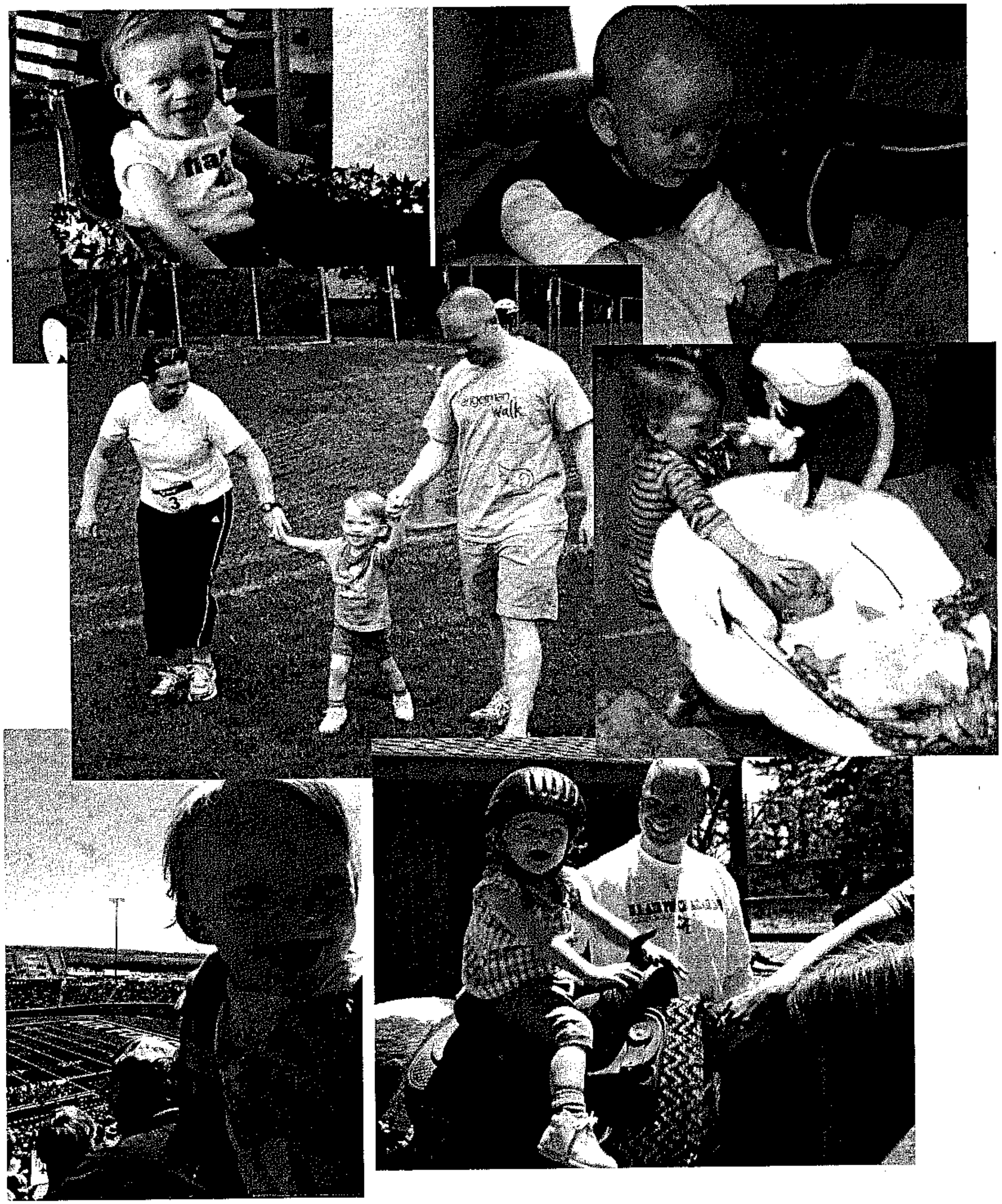
In 2009, we were assigned to the Pentagon. The State of Virginia accepted Evan's IFSP, provided him even more therapy, and then provided us the bill. While services for an IFSP in Alabama had been paid for by the state, Virginia required parents to cost-share. While we absorbed this increasing and unexpected cost, we were finally given a referral to a developmental pediatrician at Walter Reed Hospital. Evan was diagnosed with autism spectrum disorder (PDD/NOS) and we were told that he needed 20+ hours a week of ABA therapy to progress. Facing thousands of dollars in therapy costs, we finally discovered TRICARE/ECHO. While it would not fully cover the 20+ hours of ABA therapy prescribed by the military doctor, it would help us provide 15 hours a week. At 30 months old, and after only a few months of ABA, Evan said his first word.

Evan is now five years old. Our move to Arizona was challenging. With a different view of PDD/Autism than we found in Virginia, the first thing the school system did was slash Evan's speech therapy services (IEP) by over 50%. With ECHO-provided ABA therapy helping to fill the gap, Evan still progressed. In May, he graduated from an inclusive preschool program and he will start kindergarten with his peers next fall. Evan talks, sings, and loves to pretend he is a pirate; each new step representing a tremendous victory.

We are, and continue to be, grateful for the TRICARE/ECHO program. While every state we move to re-defines "free appropriate public education" for Evan, the ECHO-provided ABA services have given this military child a chance to progress -- no matter where we live. We will lose this benefit upon retirement from the military. As parents, we worry if our nomadic lifestyle has affected Evan's ability to succeed -- a worry that will not end upon retirement from active duty. We ask that ECHO benefits continue to be available to our military child who has served along with us -- even after we retire from active duty.

The Stones

- Branch: Air Force
- Status: Both Active Duty (Join Spouse)
- Awesome Warrior Kiddos:
  - Anna, 2 ½
  - Katie, 3 months
- Anna's Diagnosis: Angelman Syndrome
  - Severe neuro-genetic condition
  - Lack of speech
  - Significant developmental delays
  - Feeding difficulty (feeding tube)
  - Life threatening seizures
  - Lifelong care required
- Our experience thus far
  - Air Force works hard to accommodate our complex situation
- Our concerns
  - ECHO benefits after retirement (including ABA for non-Autism diagnosis)
  - Childcare that can handle significant special needs
  - Post 9/11 GI bill transferability for special needs dependents
  - IEP transfer across states



The Tarwater Family

Bob, Adreanna, Nathan (12), Addison (6), and Caden (2)
Currently stationed at Lackland Air Force Base, Texas

Nathan was born with a rare chromosome disorder that has made him dependent on us for all of his care. He is medically fragile, nonverbal, uses a g-tube and is not able to walk or sit on his own. Addison and Caden were both born with cleft lip and palates. Both of them face a lifetime of surgeries and speech therapy.

Concerns:

- **Continuity of health care services for our children.**
  - Nathan is followed by 17 specialists and every time we move we have to start over with his health care. The nature of his medical needs makes it very difficult for a new physician to understand his needs quickly. We have moved three times since Nathan was born and each time, his health declined because of lack of continuity of services.
- **Nursing services.**
  - Through TRICARE, we receive 12 hours, nightly. However the remaining 40 hours are provided by the Texas Medicaid Waiver program. Nathan will continue to have the extra nursing support as long as we remain in Texas. Once we move we will be placed on the bottom of a waiting list for a waiver program and potentially not receive services during a tour. It would be very detrimental for our family, as Nathan's care is so intensive that we really couldn't keep him at home with us without the support. Our other children's lives would be impacted greater since our ability to leave the house or do anything as a family would be compromised.
- **Ease of finding new resources in a new community.**
  - Most EFMP workers do not have the knowledge of physicians, hospitals, nursing services, Medicaid waivers, schools, organizations, etc. Each time we have moved, most information we have obtained has come from other parents, and Adreanna has done the majority of the legwork in getting services set up.
- **Respite Care**
  - Finding a caregiver who can provide respite for all three of our children's' special needs has been extremely difficult.
- **Diapers**
  - Thankfully the Texas Medicaid waiver covers our diapers but, if we move from Texas, again, we are at the bottom of a waiting list. TRICARE should be covering them.

The Babiarz Family

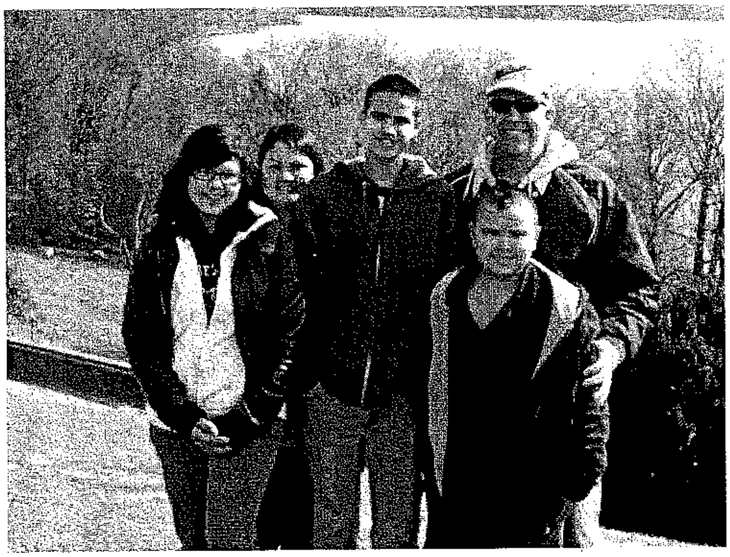
Diagnoses:

Our 9 year old son has Autism and our other son has Processing Deficits and Inattentive ADHD.

Military Support System Struggles:

ABA therapy is only covered under the ECHO program while service member is Active Duty. We are eligible to retire, but must stay active duty as long as possible to receive the needed ABA therapy for our Autistic child. This therapy has allowed our son to engage others in conversation and attempt to relate to the world. This therapy has lowered the frequency of violent outbursts, setting fires, and running away. We cannot do without it.

Limited local service providers result in long waiting lists for Occupational Therapy, Speech Therapy, Pediatric Psychiatrists, and ABA Therapy. Appointments are often located at least one hour away from our home. This means it is nearly impossible for the active duty spouse to be employed and maintain the medical appointment schedule.



The Batchelor Family

Branch: US Air Force
Duty Station: Nellis AFB, Las Vegas, NV
EFMP Category: Q coded Assignment Deferment
Children on EFMP program: Age 12, bipolar and ADHD; Age 10, Severe autism, Mental Retardation,Silent Seizures, and No communication disorder; Age 4, reactive airway disease, currently being tested for Behavioral Issues; Age 2, Pervasive developmental disorder-NOS, traumatic birth injury among multiple health conditions.

Nearly five years ago I joined the Air Force after a lengthy wait on the surgeon general to clear me for active duty because I had open heart surgery at three years old. After going through basic training and technical school, it was time to go to our first duty station. The day before it was time to leave we were told that we could not go to our projected assignment at Moody AFB because they did not have the capability to care for our children. It took two months and countless times of telling me I may have to retrain or possibly be administratively discharged to find a base for us. This was our first and sour taste of the EFMP program.

Eventually we were assigned to Nellis AFB, NV and shortly after visited the EFMP office. This visit also left a sour taste in our mouth as we asked for local resources and were told, "Google is your best friend." The EFMP program has improved very little over the past four years of us being here but still does not provide resources, only a basic package with general information is available, and very little "Family Support is" offered here at Nellis.

Tricare ECHO does provide applied behavioral analysis therapy for our 10 year old who is severely autistic and our 2 year old recently diagnosed with pervasive developmental disorder-NOS. However, they will not pay for a wheel chair or car sear for our 10 year old who has silent seizures that send him into fits of rage and he experiences loss of control of his bodily movements(in short he sometimes falls to the floor like dead weight hitting whatever limb is headed down first.) Also in crowded environments he becomes over stimulated and lashes out at anyone around him, restraints are needed in both of these scenarios and we had to buy one, paying out of pocket. We also tried to use ECHO funds or regular tricare to buy a car seat for our son which was also denied due to being considered a form of restraint. Well our son got out of the back seat walked up to the front of our van and grabbed my wife by her hair while she was driving and she almost wrecked with ALL of our children in tow. We had to get one on our own as well. I also get aggravated that children the Autism Demonstration Program is not case by case. My son who is VERY severe gets the same as our 2 yr old who is NOT as bad. Why can't this be fixed and it be case by case to determine how many units/funding a child can get? Also why can't it be a service covered under Tricare instead of ECHO? Why can't ABA be extended (case by case) to ALL special needs children if determined it's needed?

We have been able to get respite care for twelve weeks through the Airman and Family Readiness Center (because if we use the ECHO for respite then it takes a huge chunk of ABA funds away),after the 10 year old was no longer allowed to go to give parents a break because he is not completely toilet trained "which is silly after they made a class just for him and a couple of other special needs kids." The problem is after the twelve weeks is over, we have to provide financial hardship in order to receive this service any longer. Another losing battle for us, and it seems like we are being punished because we have special needs children. Please take into consideration these issues not just for our family but all our past, present, and future members of theArmed Forces.

The Beattie Family

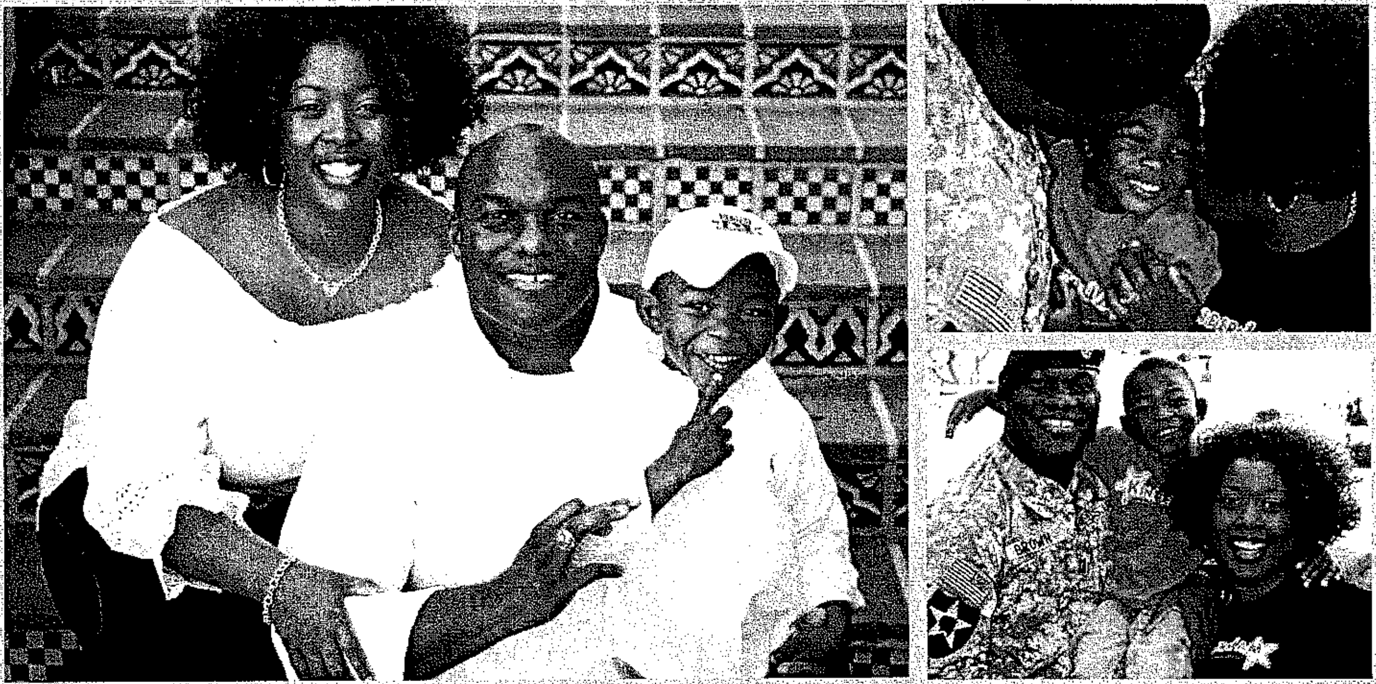
Diagnoses:

* James and Earnesto have Autism.

Military Support System Struggles:

* After 28 years combined service in the Navy, the Beatties no longer look forward to retirement. They know are left worrying about how their sons will lose services when they need them most, when they become school age.

The Browns



Branch of Service: US Army

Child: Ricky II

Age: 5

Diagnosis: Autism Spectrum Disorder (ASD)

Duty Station at Time of Diagnosis: Monterey, CA

Origin of Diagnosis: Lucile Packard Children's Hospital at Stanford University

Current Duty Station: Fort Belvoir

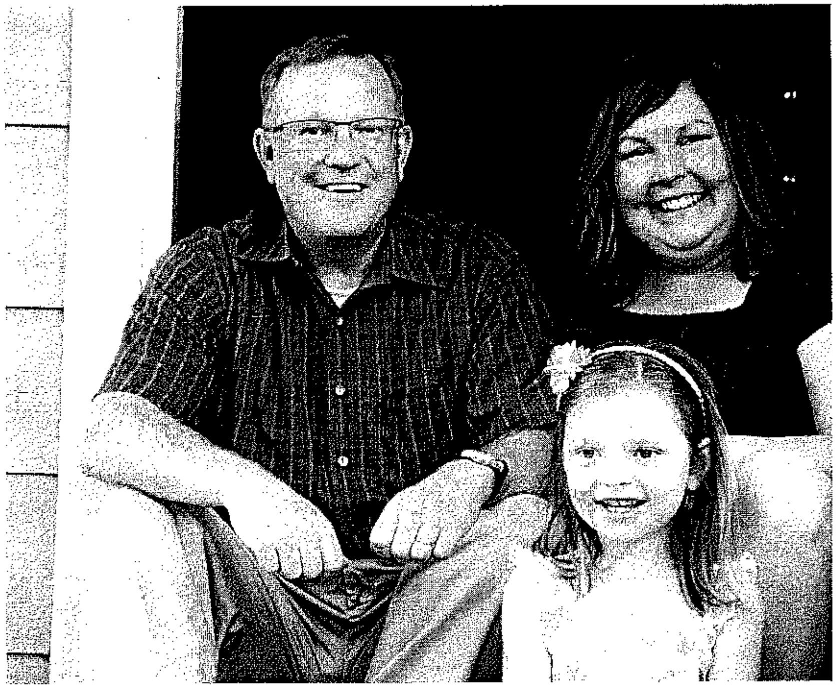
- Mother noticed delays at 18 months
- Concerns were brought to family's civilian pediatrician.
- Son referred to Speech and Language Services.
- Son placed on IEP for Speech and Language at 2 1/2
- Mother was concerned it was more than Speech and Language
- Reached out to Stanford University when son was 3 1/2
- Received referral to Lucile Packard Children's Hospital at Stanford University by civilian pediatrician
- Diagnosed with ASD at age 4
- Started TriCare funded Floor Time therapy sessions with civilian Licensed Clinical Social Worker
- IEP updated
- Currently a happy, thriving, well adjusted Kindergartener fully mainstreamed

The Bryan Family

Colorado Springs, Colorado

Jeff Retired Air Force
Lisa Stay At Home Mom
Sara 5 year old with Autism

- Our hearts sank when Sara was diagnosed with Autism January 2011.
- For our little girl to reach her potential, the Developmental Specialist recommended 25 hours of therapy per week.
- We were shocked when we found out Tricare ***does not*** cover ABA Therapy for Sara because we are a **Retired** Military Family.



- Our greatest wish is for Sara to be a happy and productive member of society some day.
- The OPM recently confirmed what our medical team has told us all along. ABA is a proven medical therapy for Autism.
- Our daughter deserves to have access to prescribed therapies for her Autism including Applied Behavior Analysis

Please help us give Sara and all military children with Autism every opportunity to "be all they can be" by saying yes to Senator Gillebrand's Amendment.

The Cartwright Family

BRANCH: US Army (retired)

In 2006, Julia, age 2, was diagnosed with autism. She was completely non verbal and had virtually no cognitive abilities. The diagnosing doctor, who was from the National Naval Medical Center, prescribed intense therapy targeting communication and social skills development of 15 hours per week of ABA therapy.

This is their story.

We requested authorization from TRICARE to cover the expense of the ABA therapy the diagnosing doctor had ordered for our daughter. That's when we discovered that ABA therapy was not available through the basic TRICARE prime program we had. ABA therapy was available to active duty military through the TRICARE ECHO program but I, as a military retiree, was not eligible for ECHO and thus coverage for my daughter for ABA therapy was denied by TRICARE.

We had to foot the entire ABA therapy program. For the last six years, we have paid from $35,000 to $50,000 per year out of our pocket for Julia's ABA therapy. This huge outlay for our daughter's therapy has forced our family into a financial crisis and curtailment of all of our family plans – at the same time we have had to deal with the trauma of having a child who suffers from the devastating effects of autism. As devastating as the financial effect of paying for ABA therapy is, there are other effects of having an autistic child in the family which are indescribable to any family who has not experienced it personally. *Autism is worry. Autism is despair. Autism is fear for the future of your child.*

Julia has or had a number of symptoms of autism in addition to not being able to talk. Julia engages in frequent tantrums. Often the tantrums are minutes, or seconds apart and can last 20 minutes or longer. Julia's tantrums are characterized by crying and shouting at the top of her lungs, accompanied by hitting, kicking and spitting.

We have to watch Julia constantly because she picks at wounds on herself – and on other people. If Julia sees or feels a wound of any kind on herself – or on anyone else, she will quickly lance and dig at the wound. We have had put socks on her hands at bed time to prevent her from doing damage to herself.

In the past, Julia frequently ran away from us. In spite of our best efforts to watch her every second; there have been times when we turned our heads for a moment. On one occasion, at a mall, Julia was completely out of the sight of her desperate mother for 20 minutes. Her mother finally found the Julia ¾ of a mile from where she first ran away, and she was still running. *Real fear is losing sight of your beloved child who has no means to protect herself.*

The results of ABA therapy which we paid for out of pocket are nothing short of dramatic. Since kindergarten, she has been in typical classes and just passed second grade. She scores at or in advance of her grade level in all subjects and reads at an advanced level. She still has communication, social and cognitive problems associated with her autism for which she continues to receive ABA therapy but now, at age eight, Julia functions near that of a neurologically typical child.

Julia's progress would not have happened without ABA. We are members of several autism organizations and have regular contact with many other families which have autistic children. The children we know who have autism and have had no ABA have made little or no progress in being able to communicate, relate to their family or peers and have few if any life skills or cognitive abilities. On the other hand, if they had ABA therapy at an early age, they, like our daughter have demonstrated remarkable progress.

It my fervent hope you will recognize the medical necessity of ABA which is supported by the Surgeon General, NIH, OPM and professional associations such as the American Academy of Child and Adolescent Psychiatry.

the Chafoses and our Zachary:

We are a military family living on Fort Meade in Maryland. We are blessed with three beautiful boys: Andrew, age 12, Zachary, age 10, and Anthony, age 2. My husband, Colonel Timothy Chafos, is an active duty Army officer who graduated from the Army War College last weekend and is deploying in two weeks to Afghanistan for one year. We enjoy serving our nation as a military family and we feel fortunate to give our children the fantastic opportunities we have experienced with the Army.

Our middle son, Zachary, was diagnosed with autism at the age of two in 2004. We struggled to understand what he needed when we began our journey. Shortly after Zachary started Early Childhood Intervention services, my husband deployed to Iraq for one year. I had to navigate the complicated world of autism alone. Through lots of research and phone calls, I started Zachary on an intense schedule of speech therapy, occupational therapy, and behavior therapy in addition to educational services. Over the years, my husband has been able to manage his career so we have been able to stay in the D.C. area to keep our family stable. Zachary has flourished and thrived and we are happy with his progress. I believe a lot of his progress is from Applied Behavior Analysis (ABA) therapy. Although we have had to navigate a very complicated TRICARE system and have had numerous therapists over the years, Zachary has done very well with intensive ABA therapy after school each day.

Achieving the proper educational services for Zachary is one of the most significant struggles we have faced. Our local schools have failed to provide appropriate modifications and services required under Zachary's Individual Educational Plan. We had so much trouble in our school on Fort Meade that we hired an advocate to attend all of our meetings and fight for our son. This past school year, after Zachary was forced out of our local school we had the good fortune to place him in a fantastic non-public setting where the teachers are specifically trained for autism and he is doing very well. Zachary attends the Kennedy Krieger School in Baltimore. We know of many military families around the country with autistic children who have faced similar challenges. The military provides little help in navigating the complex world of autism, education, and therapy.

When my husband returns next summer from Afghanistan, we will be moving to San Antonio, Texas so he can command a brigade there for two years. While we are excited for this great career opportunity, I am very nervous about moving our son. We have significant concerns about achieving appropriate school placement and support, as well as delivering the therapies Zachary needs.

We clearly see the benefits of ABA therapy and pray it remains covered under TRICARE. My husband's time left in the military is limited; our son will almost certainly require continued ABA therapy after his retirement. I request that you make ABA therapy available to active and retired families so we can provide our son with continued care after my husband finishes his military career. I am not sure what we can do about the struggles we face with our children and their educational needs, but there is definitely a lot of room for improvement in educational policies, approaches, and resourcing for children with autism. Our schools are failing our children miserably, the scale of the problem is growing. Military families face particular challenges, as continuity of services is extremely difficult to maintain and detailed knowledge of local school services and systems is difficult to attain.

Thank you for your time. Cheryl Chafos, Army Wife

I am Rebeka Edge the mother of 4 and a Board Certified Behavior Analyst. My Husband is an Lt Col and a Pilot in the USAF and we are the proud parents of 4 beautiful children, all with developmental disabilities. Our oldest, Corbin is diagnosed with High functioning autism. Magnola has a learning disorder, dyslexia. Lily-Anne had a significant language delay and our youngest son, Jett, is severely dyslexic and was recently diagnosed with PDD-NOS, a pervasive developmental delay, which is on the autism spectrum.

I am the owner of Behavior Matters, a company that provides Behavior Analytic Services. We work to improve the lives of children and young adults using this behavioral science. Between my 12 therapists, and myself we are privileged to serve 28 families in the state of Alaska. We work with individuals up to 12 hours 1:1 weekly to teach functional skills that reduce aversive behaviors including injurious ones to themselves and others while teaching life improving skills such as functional communication, daily living skills and social skills. Another facet of this program is to collaborate with the parents so that programs and interventions continue after therapy.

Every week I receive calls from veteran families inquiring about Applied Behavior Analysis ABA and funding options. I have talked with families as to how these services can be extended to children. At this time there are no funding options for families that are not active duty military dependents.

By providing training and consultation to families, we will improve the quality of life for the individual, the families and ultimately the community. The training will also significantly reduce the risk of moving to a more restrictive and more costly environment.

These children and adults, including my own, are counting-on- you to provide our children with ABA services after we retire. Our country needs a program that provides individual-specific training and ongoing consultation. It will enrich the country and provide for our veterans, in that it will return dignity to individual, provide hope for the family, and help to build a work force that will have specialized training in developing and implementing programs to effectively deal with challenging behaviors.

Sincerely, Lt. Col. Jarrett and Rebeka Edge

THE FISHE' FAMILY

Good afternoon. My name is Katja Kox-Fishe' and I've been an Army wife for 15 years. When our son Quinn was 3, he was not really speaking yet and had many meltdowns. At the time we were stationed in Germany, my husband Charles was in Iraq and I was pregnant with our daughter Kinzey. I can tell you that this was a very trying time for our family. It took me about a year to get Quinn an autism diagnosis, enroll in the Exceptional Family Member Program and the military insurance Tricare Echo which pays for our son's ABA therapy. ABA therapy, also known as Applied Behavioral Analysis, is the only scientifically researched and proven therapy for children with autism and is recommended by the American Association of Pediatrics.

Quinn is now 7. He is able to have a conversation, has no meltdowns and is on grade level with some special education support in a 1st grade inclusion classroom. We still have a way to go to overcome his language and social delays but he has also come such a long way which I can only credit to ABA.

In a year my husband will have 20 years of service. Being faced with the fact that once we retire we will lose Tricare Echo, retiring is not an option for us. We are proud to be an Army family and feel very taken care of by the Army. It is a life unlike any and we accept the challenges, the separation, the uncertainty, the deployments. But when our children are affected that is not a sacrifice we should be expected to have to make.

Unlike civilian special needs families, military families are at a disadvantage with a lack of continuity for their special needs children faced with waitlists for specialists and therapists, varying levels of support from different school districts, years long waitlists for Medicaid waiver services for ABA. Military special needs children have to start all over again with every move with new therapists, new schools, new teachers and hopefully new friends. If teachers were trained in ABA then we could rely on schools to provide this service but until a law is passed to train each teacher in autism best teaching practices we are thankful to have Tricare Echo to provide ABA . So I ask to please close this loophole for our military special needs kids and extend ABA coverage to our Wounded Warriors and other military retired and Guard/Reserves families. Thank you for your attention to this important issue.

Katja Kox-Fishe'

katjaworld@hotmail.com757-6036903

My Autistic daughter Morgan is high functioning, and like other kids on the spectrum she has several other diagnosis' in addition to Autism. She is learning disabled, dyslexic, has an expressive language delay, suffers from anxiety and severe ADHD. Life with Morgan is filled with challenges that add to the already unique lifestyle of a Navy family.

Morgan was always different. She didn't have the "normal" Autistic symptoms. We went thru several physicians in Central California trying to discover what was going on with our little girl. At age 6, Captain Carol Forrsell, a Developmental & Behavioral Pediatrician from Portsmouth Virginia, was temporarily assigned to Naval Hospital Lemoore. We were luck enough to get a highly coveted appointment. After listening to our concerns, reading the reports from school testing, and examining Morgan, she changed our lives forever with the diagnosis of Autism.

I expected Autism to change our lives. What I didn't expect was the many hats I'd have to wear to ensure Morgan's equal treatment and appropriate education. I have had to become a lawyer, a teacher, a therapist, an advocate.

In 2009, I had to leave my job after Morgan was diagnosed as the CDC and Youth Center at NAS Lemoore do not have staff specifically qualified or trained to care for special needs children. We travel 80 to 800 miles round trip for medical care. Sometimes several times a week. There are no Behavioral Pediatricians at the Naval Hospital. The nearest one is in San Diego. Our Occupational and Speech Therapy providers are located in Fresno, 47 miles away. Our Applied Behavior therapist travels from over 30 miles away. Our pediatrician has recommended we leave California's Central Valley as they are considered to BR 10-15 years behind other areas in providing services for Autism.

The schools here on station, while state distinguished schools, lack the funding and knowledge needed to teach Morgan. Her dyslexia is ignored and last year she was struck in the head by a substitute teacher, in an attempt to redirect her attention. I have been asked to provide solutions for problem behaviors rather than the trained district Psychologist and I must keep abreast of new legislation and law, to ensure the school provides Morgan's accommodations.

I've had to do all of this in addition to caring for my other daughter and my disabled spouse, who is currently recovering from back fusion surgery, a result of injuries he sustained as a F/A-18 mechanic, and has suffered from for almost 10 years. This year we are faced with the possibility that his career may be over. What is most frightening is not an end to his military career, but the fact that if he is medically retired from the military, our daughter will lose our ABA therapy. This therapy has changed our lives for the better and the chance of losing this life altering therapy keeps me awake at night.

Ladies and Gentlemen-I urge you to make the necessary changes for our Military families. Our men and women in uniform put their lives on the line to defend this great nation. Knowing that their family members at home are receiving the needed care and support, allows them to fully focus on the mission. Most importantly, the diagnosis of Autism does not disappear when the military member leaves service. Ending ABA is a crushing blow to these families. I implore you to continue to improve the quality of life for military families with special needs and to extend ABA coverage to all military families and retirees, not just Active Duty.

Health & Happiness,

~Sara Gain~

6-17-2012

Information for the Senate Armed Services Subcommittee on Personnel:

We discovered ABA therapy for our autistic son, Andrew in 2000. By the time we were approved for services, it was 2010. This benefit provided some amazing therapy for our son, even at the age of 18! We observed encouraging progress. Sadly, that summer my husband retired from active duty and we lost the ABA benefit. We were so discouraged to learn that being retired meant the end of ABA therapy for our son. Families should not have to face that reality. A child receiving a proven and effective therapy, should be able to receive that therapy regardless of location or his parents' military status.

We ask that you approve ABA therapy as a medically necessary therapy for all service members, whether active duty or retired. Our children deserve the best the medical profession has to offer.

Sincerely,

Mary Beth Geringer

June 17, 2012

To Whom It May Concern:

We are a military family living near Eglin AFB. My husband is an active duty soldier in the Army and prior to having children I worked as an ABA tutor for individuals with disabilities, primarily Autism; however I gave up that roll to become a full time mom. Marissa is our 3 year old daughter and happens to have Down Syndrome. In addition to Marissa we have twin boys (Ben and Brayden) that are 19 months old, one of which has a speech delay. We had no idea that Marissa was going to be born with something extra special, but we have been blessed beyond measure having her in our lives. Due to her being born with a heart condition we were re-routed to Fort Bragg North Carolina, which was a location better equipped with a variety of service providers to help care for Marissa.

We immediately enrolled Marissa in North Carolina's early intervention program, which included a developmental therapist, speech, occupational, and physical therapy. Not all the services begin upon our arrival, each happened in their own time. Given my background with ABA, I wanted to get her connected with an ABA tutor and I was elated to learn that Tricare offered a supplemental insurance for individuals with special needs that approved ABA services. I had no previous experience with Tricare Echo, but found that Marissa's enrollment into the program was fairly easy once all the necessary paperwork was gathered and submitted. The case managers took their time to explain the program and ensure I felt comfortable with the information.

Roughly, by the time Marissa was 20 months old, she was receiving ABA therapy through and incredible provider, Creative Consultants, whom we were referred to through Tricare Echo. Our provider took great care in developing and implementing a plan using an approach to increase verbal and communication skills. Sign language, PECS, and verbal skills were taught to increase my daughter's ability to communicate with her family and people within the community. Although we have be reassigned to Eglin AFB, we continue to receive ABA services through another provider, which continues to work on improving Marissa's verbal skills.

Marissa is an amazing little girl. She has a spirited personality and a smile that can light up any room. Although each targeted therapy has played a role in her continued success, I strongly believe that much of the credit is due to our ABA providers and their constant diligence in updating her goals and plans to ensure continued growth and success for her long term future. There is not a doubt in my mind, as a parent and a professional, that Marissa would not be as far along as she is without the services that have been available to us through Tricare Echo and the offering of ABA services. I can only hope these services continue to be offered.

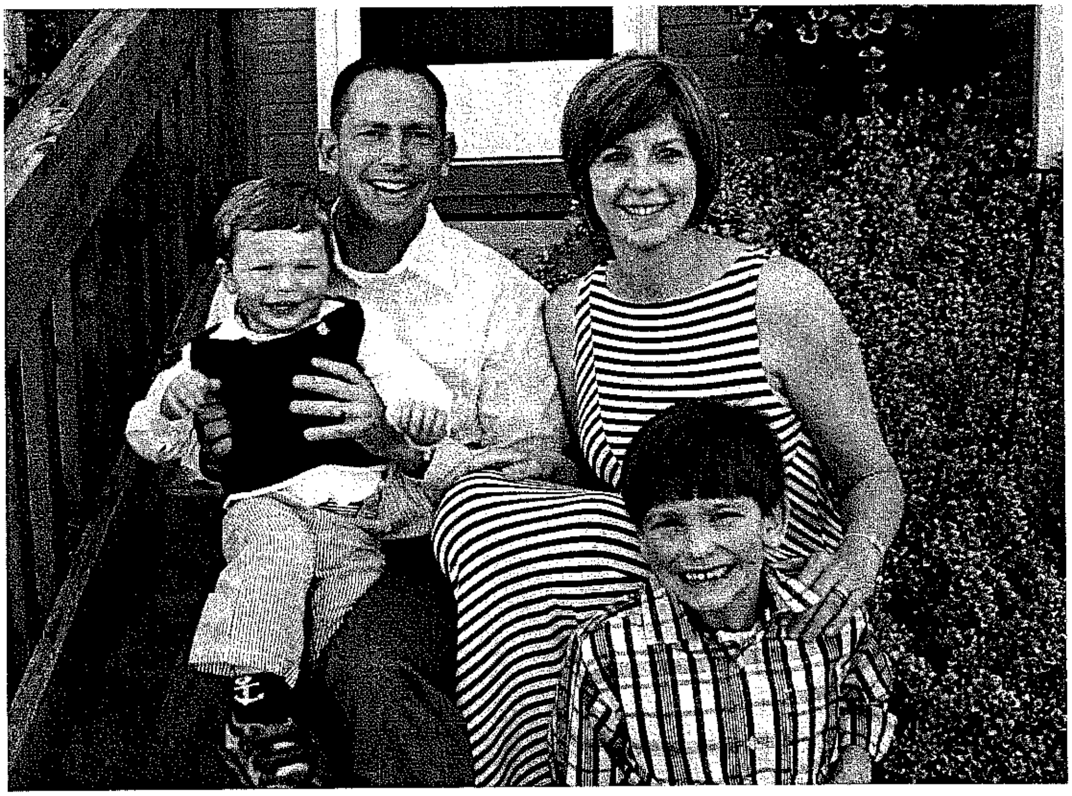
Very sincerely,
Patricia Heath

The Love Family

U.S. Army Special Forces

- ☐ Have 2 Children with Autism
  - ☐ Patrick age 10
  - ☐ Conner age 3
- ☐ North Carolina Does Not Recognize Educational or Medical ABA Therapies
  - ☐ Patrick regressed in the public school environment
  - ☐ ABA is the ONLY treatment that both Love boys respond to
- ☐ Significant Debt Incurred to Cover ABA Therapies Not Covered by TRICARE
  - ☐ Patrick medically prescribed 30-40 hours per week
  - ☐ Parents mortgaged home to save Patrick from being institutionalized
- ☐ After 9 Years at Ft Bragg, the Loves are currently in the process of a PCS to Camp Blanding, FL
  - ☐ Medicaid Waiver is NOT portable across state lines
  - ☐ Patrick will loose a crucial component that he has had for almost 6 years
  - ☐ Parents told that Florida's Medicaid Waiver waitlist is approximately 10 years

The McCall Family



Branch: U.S. Army

Stationed: Ft. Leavenworth, KS

- Eldest son, Kyle (6), diagnosed with PDD-NOS and ADHD.
- ABA provider is headquartered in Missouri and has difficulty fulfilling our recommended weekly therapy hours.
- Respite care has become impossible to coordinate since December 31, 2011 with new stringent requirements and reduced wages for our previous respite care providers. Under the current circumstances, they are no longer willing to work. As a result, we have not had respite care since the New Year. During this time, my husband had extended TDY for 6+ weeks.
- Social skills groups are non-existent in our area yet these skills are critical building blocks that my son needs to practice frequently and master in order to be successful and accepted in society.

The Mellott Family

CDR Frank Mellott, USN Ret., Sheri Dyas Mellott and children
Alex, Nathaniel and Francesca

During our last 24 months at Naval Air Station Lemoore (CA)... my husband's last 24 months on active duty... all three of our children were diagnosed with special needs. It was a blow to the family like we have never experienced nor ever could have imagined. Our dreams for the future began unraveling faster than we could anticipate.

- **July 2007 – Alex (age 10) diagnosed with Asperger Syndrome and with severe OCD 12 months later, now also suffers from PTSD due to 6 years of bullying in public schools, no early intervention and no behavioral therapies like ABA**

- **February 2009 – Nathaniel (age 10) diagnosed as going blind in one eye, due to amblyopia. Eye doctors missed the diagnosis at age 3, 4 and 5 when surgery would have been recommended**

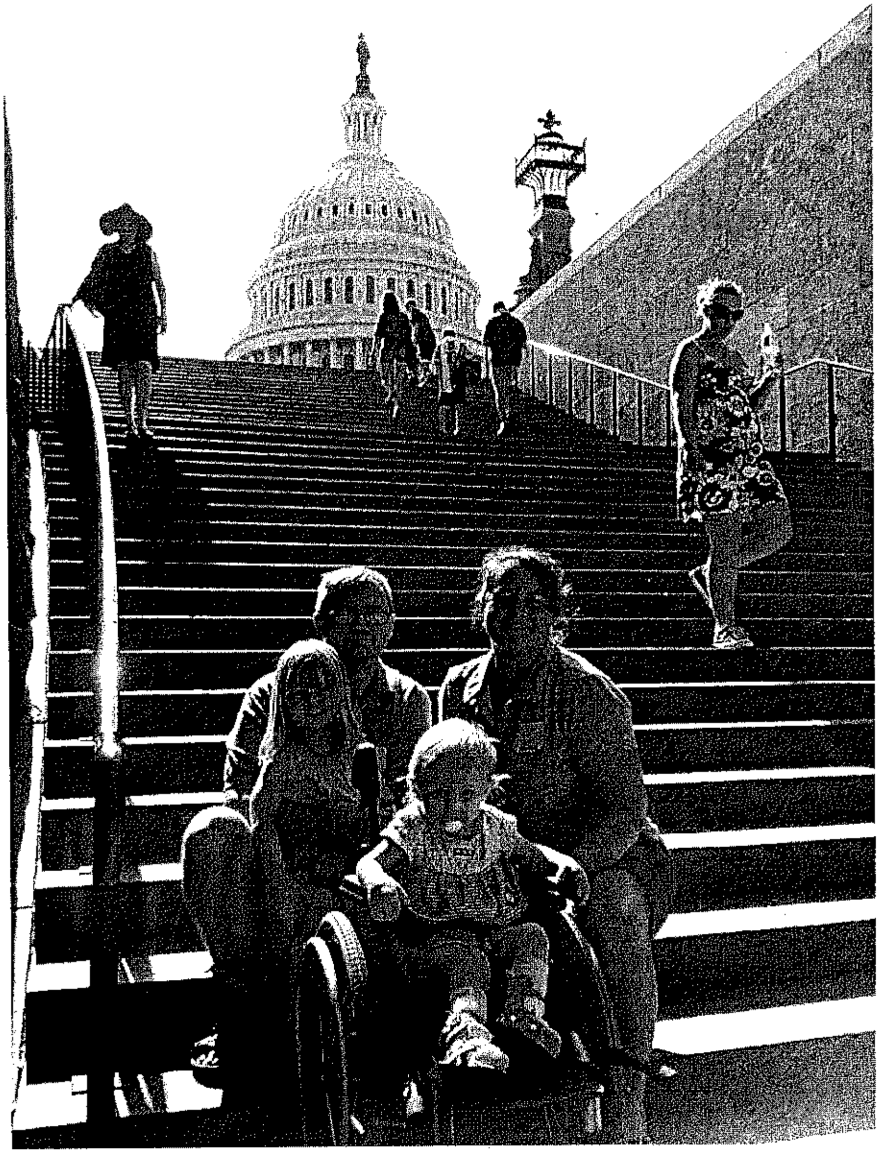
- **June 2009 – Francesca (age 5) diagnosed with Autism after many other diagnoses to include phonological disorder and severe verbal apraxia. A year later, OCD diagnosis was added.**

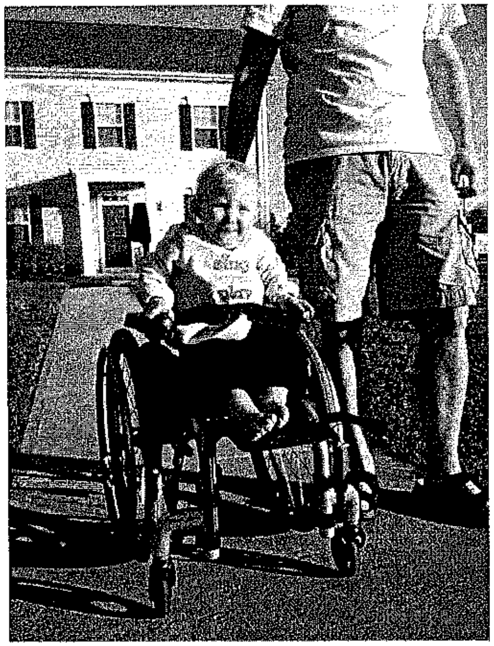
Between March 2008 and September 2008, we spent more than $80,000 of our 20+ years of retirement savings in a Due Process fight to acquire special education services for Alex in the public school system.

My husband retired in June 2009, one week after Francesca's diagnosis, and after 23 years in the Navy, so that our family could find appropriate educational and medical services for all three of our children.

The Nielsen Family

- **Diagnosis:** Robyn has Sheldon Hall Syndrome – a variant of Arthrogryposis
- **Difficulties within the Military Treatment System:**
  - Therapies and equipment approved in one Tricare region then denied in a different Tricare region.
  - Equipment that is necessary for Robyn to be mobile took 8 months to be delivered. Parts of that equipment necessary for function (wheels) were denied and a work around had to be found.
- **Positives with Military Treatment System:**
  - Our Pediatric Orthopedist , Major Jefferson Jex has fought for us every step of the way for everything Robyn needs to be successful in her treatment, including getting her to see the premier Dr in the Country for consultation on her treatment.





The Nielsen Family

Branch: US Navy

Duty Station: Branch Health Clinic Washington Navy Yard

EFMP Category: 5

Our story: Robyn was born at Tripler Medical Center, Honolulu, HI. She was immediately diagnosed with Arthrogryposis. We met with Major Jefferson Jex to determine a treatment plan. He has been with us ever step of the way. When he needed a second opinion about our treatment plan he fought to have us sent from Hawaii to Shriner's Hospital Philadelphia to see the expert in Arthrogryposis, over all of the hurdles the Military put in front of us.

When he was transferred here to Walter Reed National Medical Center, he made sure we were able to transfer with him to continue her care as Arthrogryposis is a very rare disorder effecting 1 in 10,000 children. Here in the Capitol Region we have started having trouble getting the braces and equipment we need to continue her care. These braces and equipment we know would have been approved had we stayed in Tricare West.

There is a large difference between Regions within the Tricare system for what is approved from Region to Region. What we would like to see if the same set of rules across all Regions so when a family PCS's we know the care our family members are receiving will be available.

Jeremy and Scott: My wife Julie forwarded me your email - you'll see below that I'm writing this from Afghanistan. Here's my input - hope you use it. I've also cc'd Ms Jean Winegardner, Washington Times writer and advocate for military families rights; CSM(USA ret) Jim Hussey and Nancy Bobbitt, military assistants to US Senators Chambliss and Isackson. I'll keep the prayers going. Lastly, Scott, I hope that your treatments go well and you're given a clean bill of health. r/ DJ Reyes

TO THE SENATE ARMED SERVICES COMMITTEE FOR PERSONNEL:

I am honored to endorse your passage of this most important piece of legislation that ultimately and positively impacts the morale and health of our military force and their families.

For context, I am currently on a one year deployment to Kabul Afghanistan and will complete my tour next month. Prior to deployment, I commanded the National Security Agency - Georgia (NSAG) which continues to provide critical intelligence support to the Global Fight against Terrorism. I've briefed Senators Saxby Chambliss and Johnny Isackson several times on the great accomplishments of this 3.5K military, civilian, DoD contractor, and allied (UK, AUS, NZ, CAN) force.

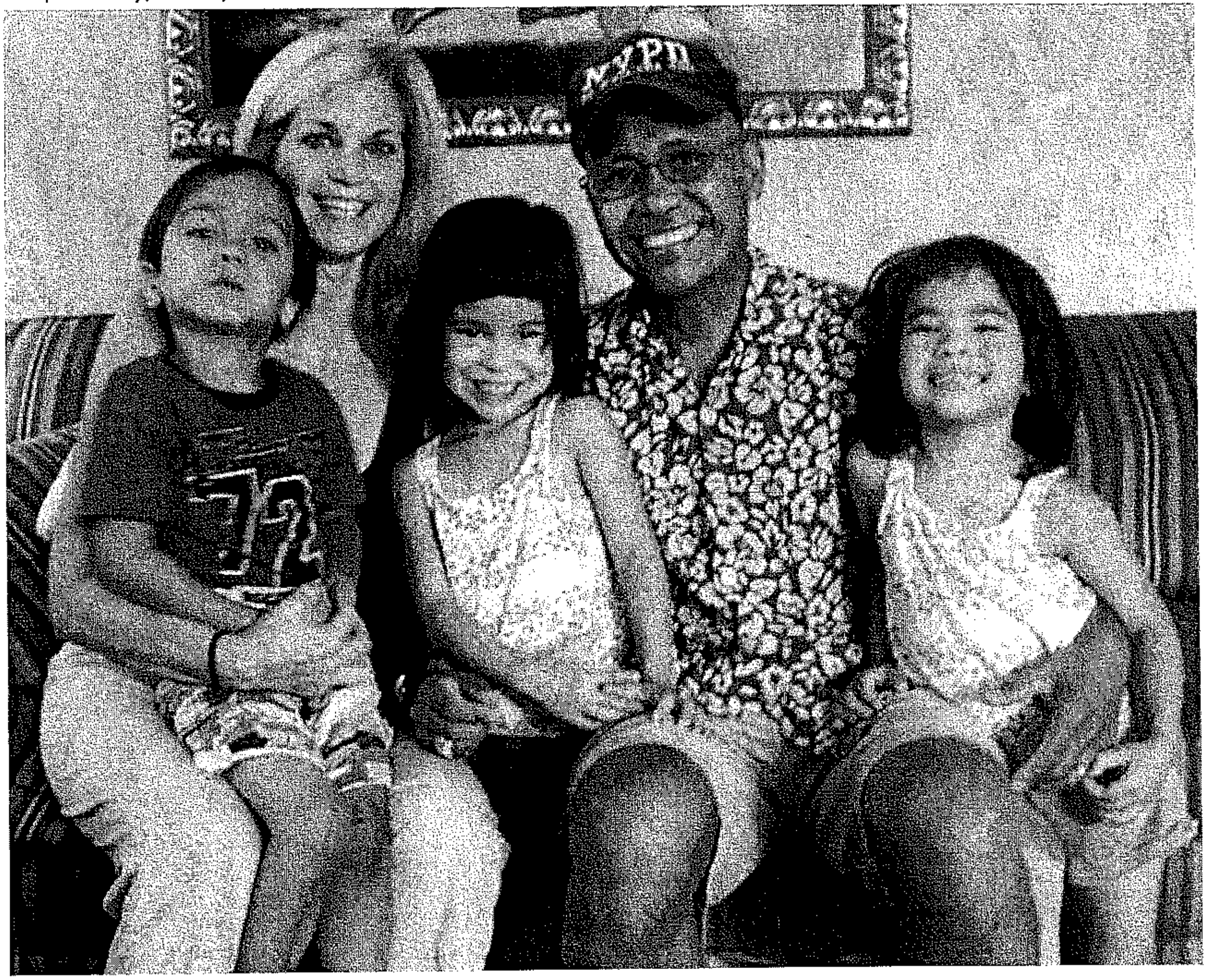
I attached a picture of my family the day after I relinquished brigade command in Georgia. My wife Julie and I were blessed with triplets - they were born in Cambridge, UK, while I was commanding the US European Command Joint Analysis Center, circa 2005-2007. Immediately upon relinquishing command, I redeployed to Iraq for another 1 year combat tour.

I share these facts with you because in addition to the "normal" stress of constant deployments while managing multiples, my wife notified me that our son Christian was diagnosed with autism while I was deployed in Iraq in 2007. Long story short, through persistent education, networking, advocacy, and Faith, my wife has been thus far able to 'cobble together' a program of therapeutic support for my son. It has not been easy - at times it has been downright difficult and emotionally turbulent - but like any military family, we persevere, we adapt, we overcome.

I won't lie to you. Statistically, autism appears to be more than just an nuance issue. There's something terribly wrong and it's permeating through our military families. It's putting a tremendous stress on our troops, both deployed and at home station. It's affecting morale. I saw it as a former brigade commander running the Unit Exceptional Family Member Program, and as an active member of the local Autism Now Chapters in Georgia. And more importantly, as a parent of an autistic child.

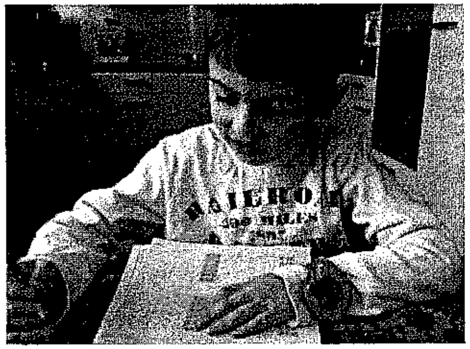
The next issue you're confronting is that of military servicemembers who are retiring or are retired with children who desperately require continuing autism therapeutic support programs. I strongly support your approval of support that continues through active duty service in into retirement. In addition to the obvious financial aspects of support, I believe that it sends the right strategic message to our troops - we never leave a fallen comrade on the battlefield, and we will never leave a fallen comrade's family in their time of need.

Respectfully, DJ Reyes



The Serna Family – A retired military family

Nicholas Anthony Serna retired after 20 years of service in the U.S. Army in 2007. Our son **Bryson** was born in 2003 and **diagnosed with autism** when he was 6 years of age in 2009. Bryson lost all his speech between 18-24 months of age and was non-verbal until he was nearly 6 years old. Life as an active duty family can be challenging with deployments, international moves and stress, but nothing prepared us for the stress and hardship our family faces daily. **Our family receives NO support** because we are a retired military family. We need our son Bryson to be eligible to receive ABA therapy, a medical necessity, through Tricare. Don't let Bryson's smiling face in the pictures below paint the wrong picture. Beneath the smile is a lot of hurt and sadness because he can't communicate very well, because he doesn't have the abilities to make and maintain friendships, and because he has to spend countless hours working hard to achieve things that come very easy to others. **Bryson needs ABA therapy** to improve his speech / communication skills, his social skills, his self-help skills and his academic abilities. Bryson needs ABA therapy in order to be able to live independently one day. Retired CW4 Nicholas A. Serna served his country for 20 years; now his family needs help and support. Please support our retired military family and please support Bryson and all the other military children affected by Autism who will need support past the active duty days.



Wh

Sincerely,
Retired CW4 Serna, Fabienne Serna, Bryson Serna and Sarah Serna

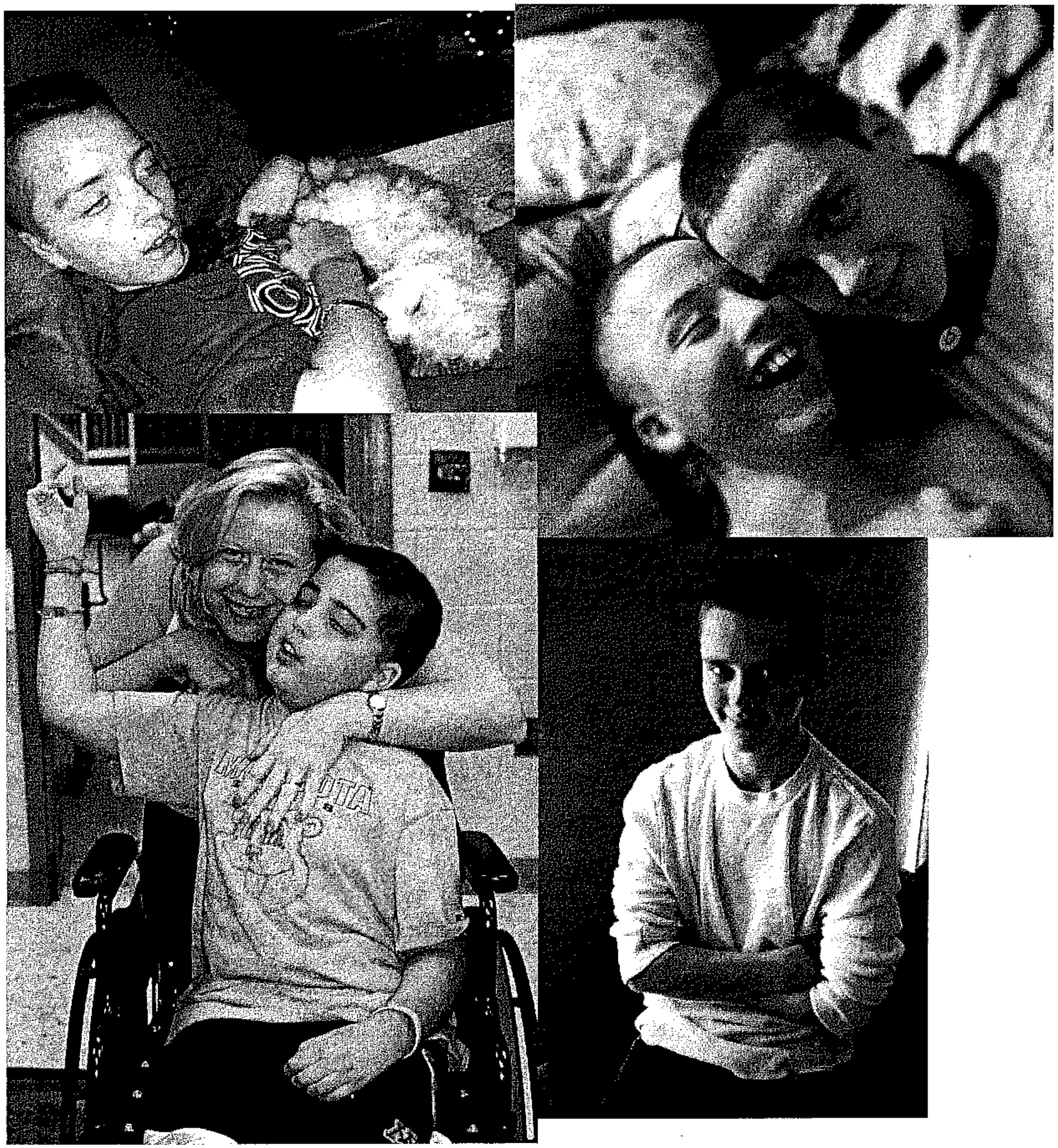
The Stockwell Family

We are an **active duty Air Force** Family living in Colorado Springs, CO.

- Our son Tom was diagnosed with **moderate-severe autism** in 2009, one month before a PCS.
- Almost had **last competitive in-residence** school opportunity **cancelled** because of **lack of services** at Air University location.
- PCS'd to CO in 2010. PCS initially **medically declined** because of '**lack of services**' (one month prior to PCS), but **information held by SGH was incorrect**. Denied because of lack of **'25 hours of ABA per week'** medically recommended for our son. **Tricare covers approximately 12 hrs per week**. Using this rationale, we could not have PCS'd anywhere. Eventually got decision overturned and PCS'd.
- **Services don't share information** – Colorado Springs is a Compassionate Reassignment location for Army. AF were denying clearance.
- **Our family did EFMP/SGH work for them** – they had incorrect information and were unhelpful, as we were preparing to PCS from IDE at Maxwell to a competitive leadership assignment – **VERY STRESSFUL**.
- **Our son is now thriving**. With **ABA therapy** and **great schools** in Colorado he is preparing to transition to kindergarten and will be **mainstreamed**.
- **ABA therapy has been a huge part of his improvement, giving us hope for his future and independence.**

The Wales

- Branch: Air Force
- Status: Husband, retired (22 years) , wife forced to get out of USAF after 14 years to care for son
- Awesome Warrior Kiddos:
    - Zachary, 15
    - Alexander. 12
- Alex/Zach's Diagnosis: X-linked Adrenoleukodystrophy
    - Rare brain disease, destroys myelin sheath in the brain
    - No cure—after 6 years of age, bone marrow transplant will slow the progression
    - High doses of Chemo pre-transplant
    - Disease speeds up until transplant takes hold
    - Eyesight, speech, mobility affected
    - Alex received transplant in July 2009—lost the above attributes and is now quadriplegic
    - Requires nurses in home to monitor at night
    - Lifelong care required
- Our experience thus far
    - Dept of the Air Force works hard to accommodate our complex situation
- Our concerns
    - Tricare Prime Benefits at risk—medicaid benefits at risk
    - Schooling that can handle special needs, specialized clinical services not available in most military areas
    - Post 9/11 GI bill transferability for special needs dependents
    - IEP transfer across states—need for Tricare to provide better long-term benefits for chronic patients and their families



The Walker Family

Branch: US Army

Duty Station: The Pentagon

Eighteen years of active duty service, eight duty stations; six with our 13 year old daughter, Madeline and five with our 11 year old son, Ethan. Both children are enrolled in the Exceptional Family Member Program (EFMP). Madeline was diagnosed at the age of four with severe ADHD, GAD, Allergic Rhinitis; and at the age of nine Eosinophilic Esophagitis. Ethan was diagnosed at the age of 20 months with severe Autism, Sensory Integration Dysfunction Disorder, Auditory Processing Disorder, severe Allergic Rhinitis and Environmental Allergies.

Our daughter is doing well and our primary focus is our son and his services. Ethan is mostly non-verbal and requires 24 hour supervision. Ethan requires a specialized diet (gluten, casein and soy free), HFCS free, peanut free and no artificial colors, flavors or preservatives. He requires specialized classrooms to include ABA, OT and Speech. Ethan currently has a military PCM, an autism clinic and a pediatric allergist and immunology specialist that is non-network (not covered by Tri-Care). Ethan is treated with allergen extracts for his environmental allergies which subdues inflammation and greatly improves his behavior. Inflammation is a direct cause that leads to violent outbursts and self-injurious actions in Ethan. Ethan has been receiving home ABA since 2008. We cannot express enough the positive impact the home ABA services have had on Ethan's quality of life.

Our Concerns:

- Our greatest concern is the loss of ABA services after retiring from the military
- Better coverage from Tri-Care for non-traditional treatments that have proven effective
- MEDICAID services that transfer from State to State for active duty family members
- Enrollment in EFMP programs such as Respite Care that transfers from duty station to duty station without requiring reapplying and being put on a "wait-list"

The Samuels Family

BRANCH: US Navy
DUTY STATION: NAS Fort Worth JRB
EFMP CATEGORY: 5

Kaitlyn Samuels was born with severe brain abnormalities which resulted in severe global developmental delays, cerebral palsy, scoliosis and a seizure disorder. The family has recently experienced a long and costly battle with Tricare regarding physical therapy coverage for their daughter. Kaitlyn is now 15 years old. Here is their experience:

Kaitlyn has received physical therapy utilizing a horse as a therapy tool since 2005. These services were covered by Tricare until 2009. All physical therapy notes documented the use of the horse. These notes were requested and received by Tricare prior to claim approval. In 2010 Humana Military determined Kaitlyn was receiving "hippotherapy" and not physical therapy. It is important to note Tricare does not exclude hippotherapy, in fact, the term is nowhere in the Tricare manual or website. Given this fact, plus the previous payment of services, we had no reason to question coverage. In 20010 Humana Military began denying claims and subsequently recouped all funds they had previously paid. We returned the funds to Humana Military, paid the therapy center for all outstanding therapy sessions and appealed the decision of Humana and later TMA. After losing those appeals we hired an attorney and were granted a hearing on February 10, 2012. Kaitlyn's physical therapist and neurologist both testified on our behalf. Our attorney was told by the judge, Claude Heiny, that he had turned his decision over to TMA on March 30th. Today is June 14, 2012 and we still do not know the outcome. According to Judge Heiny, DOD policy is for his decision to be released with TMA's final decision. There is no regulation requiring TMA to release its decision within a certain time frame. TMA is accountable to no one. TMA makes the rules and TMA enforces the rules. This is a disturbing situation. We followed the proper procedure required of us as beneficiaries, but there are no procedures to ensure TMA meets its responsibilities. Unlike Tricare, private insurance companies are regulated. The situation we experienced would not have been possible with a private insurance company due to those regulations. This situation has cost us a great deal of stress and money and a loss of services for our daughter. At the very least we deserve to know the judge's findings. The fact that TMA is taking such a great deal of time to come to a final decision suggests that the judge may have likely found in our favor. If not, their delay is only exacerbating a very stressful situation for our family.

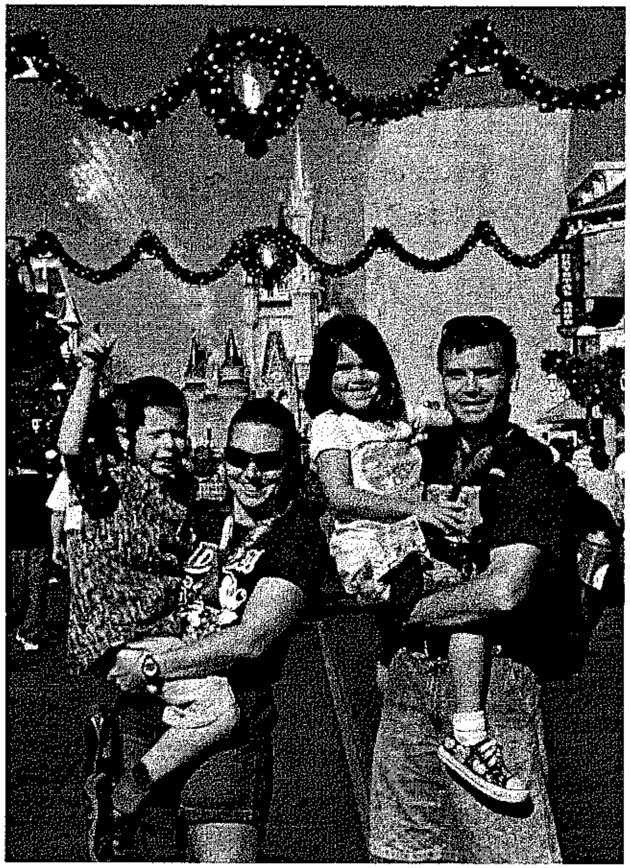
Jennifer Samuels
Navy wife of 19 years

The Vetter Family

bout Ryan:
Diagnosed at 26 months
vith PDD-NOS

6 Different Addresses with
our different schools in 8
ears– 3 of those schools all
vithin the last 3 years

6-9 month regression with
ach move



Struggles:
-Constant moving has disrupted development, and caused significant regressions

-Husband's career has been affected by limited bases we can go to.

-Continuing legal battles with various school districts to get my son appropriate support in school.

Ryan (8, Autism), Jodi (36, Aspergers/Disabled Veteran),
Sophie (6, gifted), Shane (Active Duty)

The Vitaliano Family

Branch: US Air Force (Active Duty)

Duty Assignment: Joint Base McGuire-Dix-Lakehurst

Advocacy Initiative:

1. Common bench-marked EFMP support services across all services of the DOD. A family should not have to consider leaving their chosen service to get better service in another branch of the military for their EFMP dependant.

2. Benchmark of successful EFMP programs. Why re-invent the wheel when we have programs out there that work? Lets capture those successful methods/programs and replace failing programs with them across the DOD.

3. Modification of TRICARE ECHO to continue supporting into retirement. Our children never asked for their disabilities but they are demanding the best care possible especially considering the sacrifices their military sponsor's have made over a 20+ year military career.

Our son Spence was born prematurely at 26 weeks gestation while stationed at Kadena AB, Japan on 22 December 2006. The cause of his prematurity was a genetic defect (chromosomal deletion) which went undetected during his prenatal care. Following his birth he was admitted to the NICU at Lester Naval Hospital in Okinawa, Japan where he experienced a severe hemorrhage to his brain on his 3rd day of life. The bleed damaged his pituitary, hypothalamus, and optical nerve resulting in a diagnosis of Cerebral Palsy, Central Diabetes Insipidus, and Cortical Visual Blindness to name a few. During his stay at Lester I worked diligently with the Kadena EFMP staff to get a reassignment for Spence's long term care. Prior to his birth we had an assignment in-hand to Hurlburt Field, FL however, they were unable to support his needs. We submitted EFMP Facility Determinations to Kirtland AFB and Little Rock AFB both of which were denied.

After being stabilized at Okinawa for approximately a month he was transported by an NICU transport team via C-17 to Tripler Army Medical Center in Hawaii where he received laser eye surgery for his Retinopathy of Prematurity and continued care. During his stay at Tripler I continued to work with the AF EFMP Division at AFPC (Randolph AFB, TX) through my close friend and AF Functional Manager (SMSgt (ret) Ian Wightman). Since I was presently assigned to AF Special Operations Command they worked feverishly to keep me within the command due to my special qualifications & experience level however, it was to no avail. It was later determined after direct consultation with Little Rock AFB that they could in fact accommodate Spence's medical needs through the Arkansas Children's Hospital in Little Rock. At this point I received formal EFMP orders to the 314 AW at Little Rock AFB.

Two months into his stay at the Tripler NICU, Spence experienced a severe medication overdose at the hands of one of his NICU nurses. I petitioned the chief physician to transport my son to our follow-on assignment in Arkansas, where he could get civilian care and we could prepare a home for his eventual discharge. With his approval, they coordinated another NICU team to transport Spence via C-5 through Travis AFB and then transferred him on to a civilian Gulfstream aircraft where a civilian team completed his transport to The Arkansas Children's Hospital (ACH). Upon arrival his quality of care improved by 3-fold. The staff was immediately able to diagnosis him with Diabetes Insipidus (this had eluded all of his previous neonatologists), established a nutrition plan, and started him on oral feeds. His condition remained stable over the ensuing month until it was determined that shunt placement was necessary to control his worsening hydrocephalus. After the shunt placement, his condition improved substantially and he was discharged 2 months after arrival and approximately 5 months after his traumatic birth in Okinawa, Japan.

During Spence's course of treatment in all of the various hospital, I have consistently received amazing support from my commanders, supervisors and coworkers at each location. I was afforded a great deal of leeway with duty status and permitted to remain with my son daily in lieu of reporting for duty. I without a doubt, am deeply grateful to the commanders and supervisors who allowed me to be a part of my sons ongoing care. It's because of my ability to provide continuity of care, remain actively involved, and advocate daily for my son that he continues to receive some of the best care in the world.

Unfortunately our story is not without its share of problems mostly due to the shortcoming of the Air Force EFMP Program and my sons overall condition. Many months after our arrival to Arkansas, we determined that the EFMP paperwork completed by the neonatologist in Okinawa was inaccurate and failed to identify the complete medical needs of our son. As a result we were assigned to a location that did not have the ability to provide the full range of services required for a medically complex child such as Spence. It's unfortunate that when I reflect back on all the rushed coordination I did before leaving Kadena to get the EFMP process started, I recall being very alone and without any guidance. I recall the Kadena EFMP office telling me they're EFMP Coordinator has PCS'd and that the new guy wasn't trained. I also recall repeatedly being advised of how difficult the process would be and how I couldn't get the package completed in less than two weeks (it was done in 6 days). While we were in Hawaii, I called back to the Kadena EFMP office for support and they refused to assist me stating, I was no longer within their area (how horrible of a person can you be to leave a family such as ours stranded in the system, without any support or semblance of guidance). Unfortunately this continues to be a constant experience in the AF EFMP program even to this day. I continue to advocate for change in our current AF EFMP policy and program overall.

The single most beneficial source for my family's journey has been the parents, Specialized Training of Military Parents (STOMP) staff, JBMDL Military 360 Project and other professionals communicating through the STOMP Listserver. It was through these refreshing resources that I was able to educate myself on policies, processes, and methods to get the best care possible for my special boy. As a result I submitted a 335 page request to AFPC for EFMP reassignment due to lack of medical services with enough justification to make your eyes water. I prioritized McGuire AFB, NJ as our #1 location of choice due to its proximity to the Children's Hospital of Philadelphia (CHOP) and the abundance of medical support in the community. I opted to completely erase any thoughts of Spence receiving care or support from the military medical community and focused on finding the best civilian care in the country. We were of course denied; denied because the inexperienced/newly assigned Chief of Medical Staff (SGH) at McGuire felt the drive time to CHOP was excessive and his pediatricians were unable to get specialty appointments in a timely manner.

I was floored by his response, but I refused to give up. I'm accustomed to dealing with government bureaucracy and receiving the easy answer of no when the hard but correct response often times is yes. So I contacted a very kind and sincere doctor at the Little Rock MDG who coordinated a teleconference between us and the McGuire SGH on Spence's behalf. During the course of the conversation we came to the realization that this was a battle of might - the McGuire SGH was flexing his muscles without concern for the truth. In the end we closed the discussion with a challenge on my part. I informed him I could prove his reasons for denial regarding timeliness of acquiring appointment could be overcome and would prove it in writing; he chuckled and said if I gave him something proving my side he would approve the request (he had no doubts I would be unable to prove this). So I coordinated with the CHOP Complex Scheduling Department and within a week was able to acquire a list of appointments for Spence showing all of them scheduled within a 3 month period following his expect arrival as well as a back-up plan should he need to get in sooner. The doctor was of course floored and then requested I sign a statement that my son would not receive any medical care in the McGuire MDG - I signed and we had orders 3 days later. It just amazes me that this doctor who runs an entire medical staff couldn't understand the impact of triage on appointment scheduling; anyone with any semblance of medical experience knows that those who are more severe get seen faster (it's just a fact of life).

We arrived at McGuire about two weeks after receiving orders and immediately things began to improve. Spence now receives home nursing 16 hours/day to include on the bus and during school. He also received therapy services (OT, PT, Speech, vision, etc) at his school and are working on getting him additional therapies after school in an outpatient environment. Overall the relocation to McGuire AFB has been the best choice for Spence & our family. We've had some hard times since we moved here and the AF EFMP program has been of no help to us however, STOMP & the JBMDL Military 360 Project continues to be our sounding board and the bedrock of our success. I remain deeply grateful to those families/professionals that have and continue to support my family in our journey with Spence.

Hi there!

My name is Abby and I am ten years old. I have an extremely rare genetic condition called Aicardi Goutieres Syndrome, or AGS-1. I can't talk, walk or hold my head up, but I can smile real big! There are only about 300 kids worldwide with AGS and less than 30 that are just like me! My daddy, David, is a police officer with the United States Air Force, and he has served our country for 19 years on active duty. My mommy, Stephanie, is a kindergarten teacher at a church in St. Mary's County. My big sister, Riley, is in seventh grade and is the best sister ever!

Because of my condition, I am wheelchair bound and 100% dependent on my family for my care 24 hours a day. My daddy has to go away a lot for his job and that leaves Mommy and Riley to take care of me. Because my family moves so much with the military, we get no state or federal help to get me a van and the modifications I need.

Tricare does cover monthly feeding supplies, an wheelchairs for Abby. With Papa retiring in a few months, all of Abby's benefits will increase our out of pocket expenses. This will include monthly feeding supplies, incontinence supplies, specialty care appointments, and therapy treatments.

June 12, 2012

Dear Members of Congress,

I am writing to you on behalf of military dependents with autism, and specifically, my two daughters Caragh and Camille.

At five and six years old, Caragh and Camille are two AMAZING little girls who would light up any room you enter. They laugh, they play, they dress like princesses, and they have autism spectrum disorder. Both were diagnosed very young, which has changed their lives. However, there is a long road and life ahead of them and our family.

Our girls started intensive ABA therapy when they were two and three years old. It has changed their lives. Because of caps in coverage through the EFMP program we have had to work to juggle hours, take fewer hours than prescribed, and cancel sessions at the end of the fiscal year-aka beginning of school year. This is hard on the girls and certainly hard on our family.

The reality now is that I will retire. Autism for my two girls will never retire. They will need ABA for years to come; and we can only ask for it to become part of Tricare coverage so we can continue to give our children the services they need to function as adults.

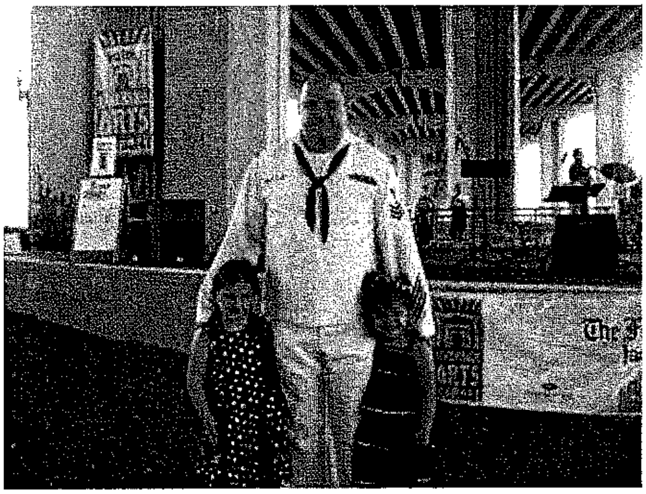
Autism is hard. Helping families living with autism is not hard. Just help us help our children.

Again, thank you for all you do,

The Zeigler Family

Branch: US Navy   NAS Jacksonville, FL

EFMP Cat: Caragh 5 Camille 4



Margaret Stubbs
6631 Hazel Lane
McLean VA 22101

June 18, 2012

Dear Sir or Ma'am,

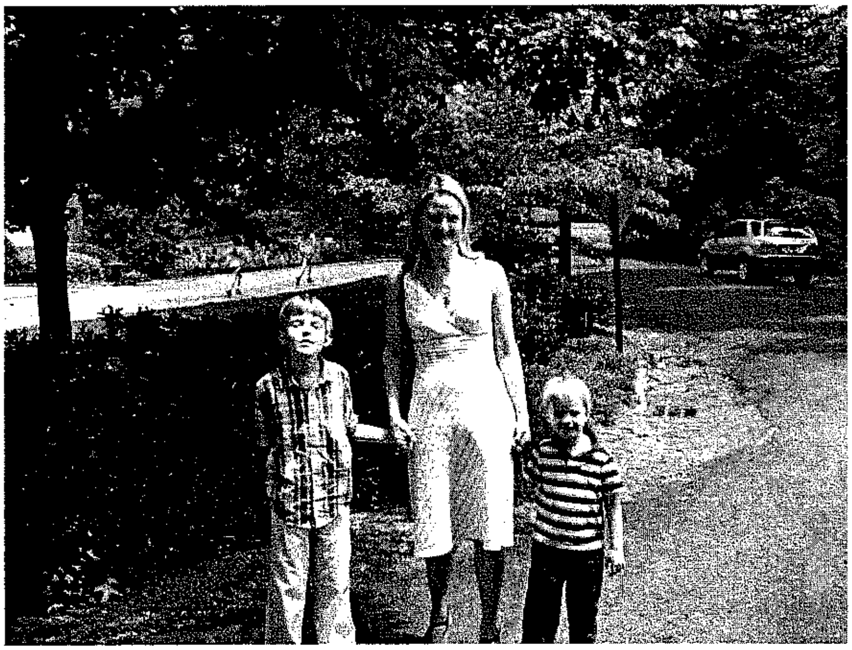
My husband is an active-duty Naval Officer, and we have a nine year old son named Wilton who is diagnosed with autism. Over the years, Wilton has greatly benefited from Applied Behavior Analysis (ABA) after school. ABA helps him to mitigate his aggressive behaviors (like biting, spitting, hitting, and kicking) and his anti-social behaviors (like screaming and removing his clothes public). In addition, his ABA therapists have been able to teach him self-help skills such as dressing himself, brushing his teeth, and using utensils when eating. If it were not for ABA, Wilton would be guaranteed to have absolutely no ability to care for himself as an adult. However, because of the skills he has learned from ABA, Wilton may be able to live in a group home as an adult with minimal to moderate assistance and supervision. It is also possible that he may be able to have a low-skill job, making him less of a burden to the tax payers in the long run.

We are concerned because my husband has served for 27 years in the military, and is now at the end of his career. When he retires, Tricare will no longer cover the cost of ABA. This is a problem because we will not be able to pay out of pocket as it costs $3000 a month for the 15 hours a week he receives outside of school. If Wilton no longer does ABA, I fear that he will never have to skills to live outside of a heavily staffed medical facility once his father and I pass away.

In my view ABA is a good investment. Although it is a weighty initial expense, it will benefit society in the long run. If my son can live a semi-independent life, he is far less likely to end up in jail, prison, or a mental hospital.

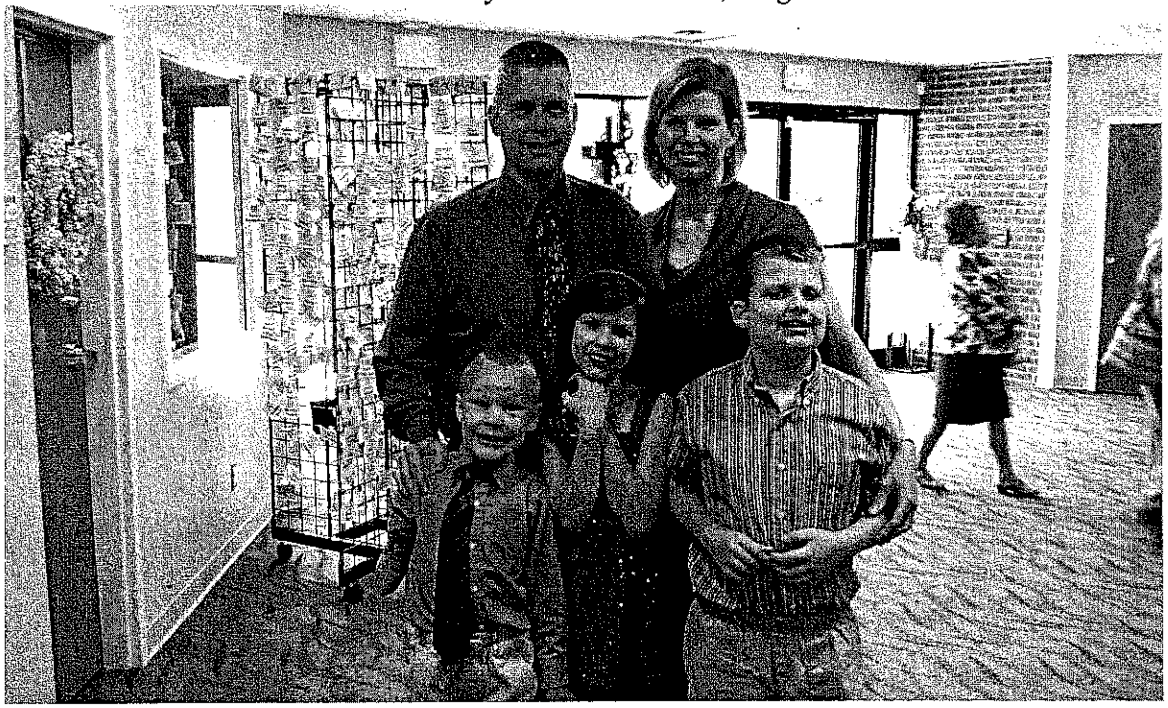
Thank you for your attention to my concerns.

Sincerely, Margaret Stubbs



The Rupe Family

Home of Record: Pearland, Texas
Current Duty Station: Norfolk, Virginia



Kyle, 11 years old, EFMP category 4, Autism
Michael, 7 years old, EFMP category 2, congenital limb defect (no special services)

- **EXPERIENCED EDUCATION ADVOCATES:** Kyle has attended 8 schools in 4 public school districts. Advocating for appropriate services for a military child can often be difficult because the school often assumes he will not be attending long enough to fight the system. Experienced advocates in highly populated EFMP areas like Virginia Beach and San Diego would be beneficial to many families.

- **MEDICAID WAIVERS:** Kyle received a Medicaid waiver slot for ABA therapy in one state. He made considerable progress with 25 hours of Applied Behavior Analysis (ABA) therapy a week, which is the minimum recommended by the American Academy of Pediatrics. Now he will be at the bottom of another Medicaid Waiver waiting list and will likely never see the top. Allowing military families to move with their waivers would help so many children—even keeping their spot on a waiting list would help.

- **ECHO - LIMITED ABA:** The TRICARE ECHO program pays for ONLY 6 hours of ABA per week on the Demo program. This is less than 25% of the recommended minimum hours. Moving the ABA benefit to TRICARE Basic would remove the limit and make it available to retirees who still have children with autism when they retire.

- **CONTINUITY OF CARE:** Finding qualified private therapists even in a large city is difficult. Waiting lists are often months long, if you can even get on a list. Contracting with more therapists may help.

- **NO RESPITE:** Our area of the country has a Navy Respite program, but the waiting list is almost ONE YEAR long! ECHO has a respite program, but if you use your ECHO dollars on ABA you don't have any left for respite. It is necessary to fund existing programs and provide respite for all EFMP families.

- **LIMITED MEDICAL KNOWLEDGE OF AUTISM:** Autism is being treated medically with great results all over the world, yet military doctors remain untrained and pass this sense of hopelessness on to the parents of children with autism. Children with autism are entitled to proper non-discriminatory medical care.

The Jamesons

Navy **SEAL Reservist activated** - March 2012; **Mobilized** and **deployed** - May 2012

Our son **Ronan has several diagnoses** – mitochondrial diseases, autism, non-verbal, developmental delays; his **siblings are being screened for mito disease** as well

Local schools wouldn't provide ABA and civilian **doctors gave us little hope**.

We found a private ABA school-based program; **he thrived, gained skills** and transitioned to a public school special needs classroom upon a move to a new community

With the private school and private therapies **we paid for out-of-pocket**, we were knee-deep in medical, educational, therapeutic and emotional **debt**.

Becoming a Reservist presented itself; the **benefit of a sign-on bonus as well as a second income** was welcomed **to offset debt** incurred to care for our son

We are now an **active-duty family** and Ronan qualify for **Exceptional Family Member Program (category 5)**. Through the **Autism Demo Program** we aer **awaiting approval for Applied Behavior Analysis** (ABA), the same therapy that made an consistent difference for Ronan

But, as with all things government-military related, it has been **an exhausting, paperwork-ridden maze** trying to figure out how to correctly apply, who to go to to get questions answered, and then knowing when that entire the process is complete.

What we had hoped would be a simple process has become labored. 4.5 months later, we are still jumping through hoops to secure ABA therapy. Now we hear that these benefits **might be in jeopardy even before Ronan has the chance to use them!**

Funding for Ronan's ABA will end when my husband returns to reservist status in 2013. Ronan has yet to start specific therapy for his needs. **Ronan might not lose his autism diagnosis when my husband returns home from deployment, but sadly the ABA benefits will.**