

THE MILITARY'S AUTISM TREATMENT POLICY

By Lt. Col. Scott Campbell, US Army, February 2006

On 1 September 2005, the health care agency for military families, TRICARE, began a new program called the Extended Health Care Option (ECHO). It replaced an existing program for military families with special needs children with a new and supposedly improved version. Most importantly, it increased the monthly reimbursement cap for Applied Behavior Analysis (ABA) therapy for military children with autism and mental retardation from \$1000 to \$2500. This should have become a moment for rejoicing with families finally getting access to the ABA therapy that had long been recommended and approved for their children, but not available due to the lower level of reimbursement. Instead, it has become a bureaucratic disappointment of monumental proportions.

The reason for the despair and frustration is the sudden enforcement of a previously ignored and overlooked interpretation of the TRICARE health care policy manual. The interpretation declared that all ABA providers that provide hands-on therapy to a child must be a Board Certified Behavior Analyst (BCBA). In effect, this urgently needed entitlement and critical medical service became an unnecessarily empty promise. As opposed to another section of the same policy manual, ABA therapy providers were singled out into a separate category. Most health care providers are companies in which a number of employees of various skills provide the needed medical services. However, providers of ABA therapy are now defined to be a person, not a company by the military's health care agency. That difference in the definition of a provider has resulted in restricting access to the medically-necessary ABA therapy hours for nearly all military families. In essence, TRICARE is now demanding that all therapists on a team be certified, when that's neither necessary nor even feasible.

On the surface, TRICARE's current definition interpretation may make sense. Only certified providers can give safe and effective ABA therapy to these children. Not quite! Properly trained therapists working under the supervision of a BCBA could also provide this vital medical service effectively, safely, and for far less cost without the currently required certification. Additionally, there are not enough of these board certified therapists to provide this therapy, and most of the military children end up with very insufficient or no therapy as a result. As of today, there are only 3772 certified ABA therapists in the country. However, not all of them are practicing ABA therapists, and few of those that are practicing accept payment from the military's health care agency. As such, the practical amount of ABA therapy available for military families is often close to zero. From the 2001 National Research Council report on "Educating Children with Autism" at <http://www.nap.edu/books/0309072697/html/R1.html>, "The committee recommends that educational services begin as soon as a child is suspected of having an autistic spectrum disorder. Those services should include a minimum of 25 hours a week, 12 months a year ...". The current, conservative estimate is that at least 1300 military children with autism should be receiving ABA therapy. This is a small portion of the estimated 206,000 American children with autism between the ages of 3 and 22 from the Fighting Autism clock at <http://www.fightingautism.org/clock/index.php>. If 1300 military children would get their needed minimum of 25 hours a week, they would require 32,500 therapy hours a week, or 22% of all available ABA therapy hours in the nation for the entire American population of autistic children each week. Instead, only about 200 children are currently receiving a less than recommended amount of this critical medical service. Again, if the only ABA therapist in your town does not have any available hours to see your child, I doubt anyone would call that effective therapy.

Another consideration is that BCBA's doing hands-on therapy is not the current normal, accepted medical practice when it comes to the delivery of ABA services nation-wide and industry-wide. Typically, the company of a BCBA screens, hires, trains and supervises the hands-on therapy by a number of employees who provide the vast majority of the actual therapy under a treatment plan developed and overseen by the BCBA. This is the "group staff" model that is permitted per TRICARE's own policy manual for every other delivery of medical services within the military's health care agency, except for ABA therapy. Ironically, this was the generally accepted model by the military's health care agency for ABA services delivery under the previous program for about 10 years, until the start of the ECHO program and the change in the interpretation of the definition of an ABA service provider. I would never advocate the use of untrained high school students to

do this therapy. It needs to be done by fully-trained and educated therapists, who have been properly checked and have sufficient experience.

One of the reasons for this tightening of this definition interpretation is the claim that the children would be put at risk by any sort of looser definition. Of course, this assumes that very protective families of children with profound developmental delays would allow their children to be put at risk in the first place. This also assumes that the hiring and background screening practices of the BCBA company are non-existent. However, the "placing children at risk" rationale seems to contradict the standards for respite care providers under the same ECHO Program. Respite care is the other significant new benefit of the ECHO program. It provides families with 16 hours a month of respite care (if the child receives a service under that program). The current TRICARE standard for a respite care providers is for the person to be a certified nursing assistant (CNA). The requirements for certification vary from state to state. The education required to achieve these skills varies widely. In some states, no formal education is required. In most states, this means as little as a two week class and a basic test, if they are a high-school graduate or have passed their GED. However, individual ABA therapists working for a BCBA are typically university psychology graduate students or full-time special education teachers with Master's degrees in some cases. Even someone who has completed their academic coursework to be BCBA-eligible may not be considered qualified enough to work under the supervision of a BCBA. As such, it is hard to understand the concept that a child is possibly considered to be "at risk" with a well-educated, screened and trained ABA therapist working under a program developed by a BCBA and while the parents are usually in the house, but they are "not at risk" with a far-less educated and trained CNA watching them while the parents are normally gone from the home. Risk aside, the respite care turns out to be another empty promise for most military families. Since most single-parent military households cannot find a BCBA to provide any ABA therapy for their child, they are then not eligible for the respite care. I know of few other people that need respite care more than the spouse of a service member on back-to-back multiple rotations away from home, who is trying to care for a family with one or more autistic or mentally-retarded children. Restricting access to care for this "extremely vulnerable patient population" should never be the answer.

One solution frequently suggested by the military's health care agency to satisfy the obvious lack of certified ABA therapists is to train the parents in lieu of providing trained, but not-certified ABA therapists. However, that practice has already been found to be an unsatisfactory solution in the 4 October 2002 District Court's Decision in Bucks County, PA (Bucks County Department of Mental Health v. De Mora). Reimbursement was ordered to parents who received training and provided ABA for their child as directed by the local public school system. Admittedly, this case is about educational ABA versus the medical ABA provided by the military's health care agency, but there seems to be some direct parallels between these two policies in which the educational one could be considered illegal and not in keeping with normally-accepted ABA practices as defined by this court. While training parents in ABA would permit some measure of continuity of care, the best accepted practice is not to have the parent being the primary ABA provider for their child. Again, a single parent would probably not be the best person to provide ABA therapy for their child, no matter how good their intentions, training, or education may be. Would it be acceptable for a parent to practice psychiatry on their child after it was "explained" to them by a licensed psychiatrist? Of course not!

What is the solution? Simple! The military's health care agency should go back to interpreting their definition of an ABA provider to the same way it was accepted under the previous program. An ABA therapy provider is a company and not a specific person. That is the same way that their policy manual currently defines every other provider of medical services for military families, and is the current industry norm. To be economical, the majority of the hands-on therapy should be provided by trained therapists who are not BCBA's in order to provide sufficient therapy hours as recommended by their pediatrician and the 2001 National Research Council report. To be effective, the majority of the hands-on therapy should be done by trained therapists and not by their parents. To be done safely, the hands-on therapy should be done by properly-screened and qualified ABA therapists as currently defined in the military's own policy manual to reduce any potential liability issues.

There are over 1300 military families serving their nation today that are trying to also do the correct thing for their son or daughter who faces the many difficulties of autism or mental retardation, while they serve their

nation to the risk of losing a limb or their life. Imagine yourself as a mother whose husband has been away from home for more than five months with a child that has self-injurious or aggressive behaviors that they simply cannot control. Your three year-old will not stop banging his head against walls when we wants something to drink, since that is the only way that he thinks that he can communicate that need. Your seven year-old autistic child who has never said a single word bites himself to the point of bleeding when he hears a sound or sees a certain kind of light as his only way of coping with sensory overload that is very, very painful to him. Early intervention using ABA therapy has proven to be very effective for many of these children. There is a solution for getting these children the ABA therapy that can dramatically improve their lives and may even save it. All it takes is a change to a policy interpretation, which will permit more ABA therapists to help these children and their families. More ABA companies to provide critical medical services can turn a bureaucratic disappointment for many military families into a sincere hope for a healthy future. Hope for a safer tomorrow without the pain of behaviors that are not understood by the child or the parents. Hope for a way to communicate the basics of needs. Hope that we do the right thing for our kids as we do the right thing for our country.