



A Military Family's Experience with Autism

By Kyla Doyle

EDITOR'S NOTE: KYLA DOYLE IS A MILITARY WIFE, MOTHER, AND ADVOCATE FOR HER DAUGHTER WITH AUTISM. IN THIS ARTICLE, KYLA OPENLY AND HONESTLY RELATES THE STRUGGLES AND TRIUMPHS THAT HER FAMILY HAS EXPERIENCED IN SECURING SERVICES FOR HER DAUGHTER. MRS. DOYLE ENCOMPASSES SOME OF THE BEST QUALITIES OF A PARENT ADVOCATE—FORTITUDE, RESILIENCE, A POSITIVE ATTITUDE, AND A DOGGED DETERMINATION. AN *EP* STAFF MEMBER RECENTLY MET MRS. DOYLE AND HER HUSBAND, MSgt. BUCK DOYLE AT CAMP PENDLETON, WHERE MSgt. DOYLE SERVED AS A SPEAKER AT AN ON-BASE AUTISM CONFERENCE THAT DREW POLICY MAKERS, SENIOR EXECUTIVES, MILITARY AND CIVILIAN HEALTH CARE PROVIDERS AND SUPPORT PERSONNEL, OTHER NAVY AND MARINE CORPS LEADERS, TRICARE REGIONAL OFFICE WEST STAFF, TriWEST STAFF, EDUCATION COMMUNITY REPRESENTATIVES AND OTHER MILITARY FAMILY MEMBERS.

I am writing in the hopes

that by sharing our family's experience—that of a military family with a young child diagnosed with autism—I might shed some light on the unique difficulties faced by service members and their families who find themselves literally fighting on two fronts. One spouse is engaged in

multiple deployments to support our country's efforts in Iraq, and the other is at home fighting the daily battle to acquire and maintain minimal therapy and services for a child whose immediate and future independence, safety, and quality of life depend on it.

My husband, MSgt. (Master

Sergeant) Buck Doyle—a Marine with over 19 years of service, three tours to Iraq, and an enemy sniper's bullet still lodged in his thigh—often jokes that it is his *wife* who should be earning combat pay since, at least for all of the battles he faces, he has been highly trained and properly equipped. I found myself largely unprepared, and certainly unequipped almost three years ago when our daughter was diagnosed with autism just after her second birthday. We were even more unprepared to find that those who we

MSgt. Doyle conducting counter-improvised explosive device operations during one of three combat tours in Iraq



assumed were our allies – the local school district and regional center, even the military healthcare system – would present us with the greatest challenges to our daughter's needed intervention.

Kate

In April 2003, during my husband's first tour in Iraq, I gave birth to Kate, our second daughter, whom Buck greeted via satellite phone from somewhere on the outskirts of Baghdad. Kate was a beautiful, quiet toddler who sat, crawled, and walked earlier than most. At a year old, we began to notice that Kate was not talking—in fact, she was not even babbling and didn't seem to be interested in communicating verbally. She would keep herself busy by spinning in circles, stacking or lining up blocks, or staring for long periods at her own wiggling fingers, quietly bobbing her head to a tune only she seemed to hear. By 18 months, Kate had become even more solitary. We began to notice that Kate rarely made eye contact and would not respond when we called her by name—soft, loud, near, far—not even a glance in our direction. We took her to an audiologist to have her hearing checked. "Her hearing is normal," they said. Then came

the speech pathologist, the developmental pediatrician, and a host of others. When the diagnosis of autism came, it explained a lot, but also led us to the research that told us that we needed to get our daughter help—and that time was of the essence.

Finding Help – Delays, Desperation, and Hope

In April of 2005, we were referred by a military speech language pathologist to the San Diego Regional Center, the local agency responsible for the implementation of the California Early Start Program for infants and toddlers with developmental delays from birth to age three. Soon after Kate's autism diagnosis, we also completed our application for the military's Program for Persons With Disabilities (PPWD). We were hopeful that with the help of these agencies and programs, coupled with an early diagnosis, Kate might have an even better chance of improving her prognosis through effective, intensive early intervention. We had no idea at the time that the services that were supposed to be provided by California's Early Start program in the name of early intervention would take months to begin. In spite of numerous phone calls, it was not until August that a Regional Center psychologist would first see Kate and September – over four months since contacting the agency – before Kate would finally receive applied behavior analysis (ABA) services. In the months following Kate's diagnosis, we had learned that this research-based intervention would give our daughter the best chance at reclaiming the skills and language that she had so far not been able to develop because of her disorder.

During that summer, as we waited for Regional Center and military services to begin, I desperately searched the Internet and scoured the library for



Kate works with her ABA supervisor, Jessica, at preschool, where she has been fully mainstreamed with a support aide since age three.

something, somebody who could help our daughter. I came across the Web site for the Brent Woodall Foundation for Exceptional Children (<http://www.woodallkids.org>), and I was struck first by its namesake, then by its mission. Coincidentally, Brent Woodall had been a college classmate of mine at University of California Berkeley and who, tragically, was killed during the attacks of 9-11 on the World Trade Center. His widow, Tracy, started the foundation in his name to continue and expand her work helping families with young children who could benefit from applied behavior analysis. Tracy's assistance was immediate! Just three days after we contacted her, Kate and I were on a plane to Dallas, Texas, where Kate would receive almost a week of evaluation and intensive intervention, and I would receive training in the principles of ABA, the Picture Exchange Communication System, Pivotal Response Training, and the start of a home program for Kate that I could begin implementing as soon as we returned. During our stay, Kate spoke her first functional word—Cheetos—her favorite food. The most important thing we received that week with Tracy, however, was hope for our daughter's future.



More Hurdles, More Delays

Shortly after returning from Texas, I was thrilled to learn about TRICARE's new Extended Health Care Option (ECHO) program, which would soon take the place of the PPWD program. Its higher benefit cap and coverage of ABA therapy seemed to be the answer that we were searching for, in terms of getting the additional hours of ABA that Kate needed. We found the authorization and implementation of her therapy benefits to be a series of hurdles and dead ends. From August to December of 2005, with my husband again deployed, I called and e-mailed TriWest supervisors, trying to find out the status of our daughter's authorization. With no follow-up, I, in desperation, called Camp Pendleton's Exceptional Family Member Program (EFMP) Coordinator to explain our difficulties and found myself weeping over the phone in frustration. She was the first person to listen. The next day I received a phone call from a no-nonsense-sounding Staff Sergeant from Marine Corps Headquarters in Washington D.C. He assured me that he would be in contact with TriWest and would "solve the problem." Kate's authorization was processed within the next week.

Authorization was just the first hurdle, I found – the implementation of these benefits required that I find a Board Certified Behavior Analyst (BCBA) to provide one-to-one services. When I inquired with our TriWest case manager, she was unable to give me a name or agency in my area that had TRICARE-authorized personnel to provide ABA therapy. I quickly found that of the few BCBAs in our area, many were professors, researchers, or in supervisory positions, which were not conducive to the hands-on, one-to-one delivery of ABA that TRICARE required. After all our work getting Kate authorized, it



looked like there would be no one to actually deliver the services for which she was authorized. Finally, we were able to convince the ABA agency that was delivering the few hours we had funded by the San Diego Regional Center to also become a TRICARE provider. After going through the paperwork process, they sent their Regional Director, a BCBA who supervised and trained the program supervisors in the area, to do five to seven hours per week of one-to-one ABA with Kate. By the time Kate was able to begin using any of her TRICARE-funded ABA benefit in January of 2006, almost seven months had passed since her initial autism diagnosis.

Still, even combining the fee-capped ECHO benefit with Kate's Regional Center services, the number of hours of therapy she was receiving fell far short of the 25-hours-per-week minimum recommended by the National Research Council, and even further from the 40 hours shown effective by widely accepted research for a child her age. I did my best to make up the shortfall by providing hours myself. I

went to every parent training I could find and even enrolled in a year-long graduate program through Pennsylvania State University that I was able to do almost entirely online (<http://www.worldcampus.psu.edu/AppliedBehaviorAnalysis.shtml>). I would eventually earn a Graduate Certificate in Applied Behavior Analysis for Special Education and will continue to work toward a Master's Degree in Special Education. Still, the additional challenges of my husband's frequent deployments and my day-to-day parenting responsibilities made it difficult to keep up. Because we had not been able to access ABA services at first, we were not qualified for the ECHO respite benefit as a result, so there was rarely a break from the kids or our daily schedule. The pace of Buck's operations in Iraq had increased, making our communication less frequent than in previous deployments. There were times when I didn't hear from him for a couple weeks. Even then I chose not to use those precious moments of conversation to complain or to vent, when I knew that what he needed to hear was that we were o.k.,

so that he could continue to focus on his mission and keep himself safe. The day that I emailed Buck a video of Kate's progress in her therapy session, he called me on the satellite phone, practically in tears. It was the first time he had ever heard Kate's voice in conversation with another human being. He begged me to send more video; he knew he was missing his little girl's transformation with each passing day.

School District – “When Are You Leaving?”

With my husband still deployed, my first encounter with the Solana Beach School District, a small but affluent district in North San Diego County, was a conversation with the administrator in charge of Special Education. “When will you be leaving?” was her first question. Sensing my confusion, she attempted to clarify by saying, “I mean, I heard your husband is in the military – how long until he goes to his next duty station? I know how military families are.” We had not yet heard the stories about districts who, when dealing with military families,

offered minimal or wholly inappropriate services in order to “wait them out,” forcing families to decide whether to just accept inadequate services and placement or fight the district through the due process system—something that would take both an emotional and financial toll on families who had little to spare in either category. Often, by the time relief is found and services are won, families are called to the next duty station, where the fight for services begins anew. In California's broken due process system, parents spend upwards of \$25,000 to go to hearing and fully prevail less than ten percent of the time. During Kate's initial Individualized Education Program (IEP) session, the district refused to disclose any information on the training or qualifications of their staff and offered Kate a placement in a Severely Handicapped Special Day Class where Kate would be the only child with the ability to use language without adult prompting. When we voiced our concerns, we were

abruptly told that we needed to “learn to separate” from our daughter—that we ought to trust them as they were the “experts.” We were convinced, and her current program providers agreed, that what Kate needed in order to continue her progress was access to peers who were appropriate language and social models and continued one-to-one ABA instruction and support by qualified personnel. So, in spite of the expense and because of the odds of prevailing in a legal fight with the district, we ended up placing Kate in a local preschool and settling on services after battling with the district for several months.

By Kate's fourth birthday, my husband had returned home and left again—his third Iraq deployment in her four years of life. By Kate's second annual IEP, she had been making remarkable progress in her language and social skills, was fully mainstreamed with an aide in a typical preschool class, and was receiving ABA instruction at home after school. Our little girl who was once considered non-verbal, with a severe diagnosis, was now getting invitations to birthday parties and going on play dates with a couple of her classmates she now considered “friends.” In spite of the progress, the district once again offered a placement that included putting Kate in their Severely Handicapped Special Day Class and refused to give us any information on the qualifications of their staff. When the district refused mediation and our letters of concern to both the Superintendent and the School Board were ignored, we made the difficult decision to continue on to a due process hearing, finding expert witnesses and preparing for what would be an 11-day administrative hearing.

Finally, six months after filing and halfway through the school year, the



Kate hides in her father's body armor at home

judge ruled that the district had denied Kate a Free Appropriate Public Education (FAPE). In the meantime, for the two years since Kate's autism diagnosis, our family had been living in the small upstairs of my parents' home in order to afford the thousands of dollars for extra ABA therapy during service fluctuations and gaps, in addition to legal costs and expert fees. We were relieved and happy to finally be vindicated but continued to be frustrated at the obstacles to appropriate treatment faced by our family and others like ours—wondering how many others were losing the battle for their children.

Wounded Warrior

As the battle for appropriate services was just beginning on the home front, Buck was battling insurgents in Iraq. In May of 2007, I received a phone call from a hospital in Fallujah, Iraq. My husband had been shot twice by an enemy sniper as he tried to pull a wounded Marine to safety after they came under fire. While I was grateful that he was alive and would be coming home, I knew there would be a long road ahead. For the next six weeks, he would be moved from the hospital in Fallujah to Baghdad, then to Landstuhl, Germany, and finally to the Naval Medical Center in San Diego (NMCS), undergoing multiple surgeries in order to save his left arm. At one point, he was sent home, but it was only a few days before he developed a severe infection requiring more surgery and specialized care back at NMCS.

Juggling therapy sessions, school, kids, and IEP meetings, I managed to make daily visits to the hospital, often taking the girls along with me. I would place a blanket on the floor of his room where they could play while I sat at his bedside, catching a conversation here and there between his heavy doses of pain medication.

Nerve damage in Buck's arm, while healing slowly, had left him unable to feel or use his lower arm and hand. Skin and bone grafts left him somewhat disfigured but still with a hopeful prognosis.

We found it difficult at times to explain Buck's injuries to Kate, who was adjusting to all of the changes in her schedule and environment. Her sister, Halle, was missing soccer practices and other activities because I simply could not be that many places at once. After being released from the hospital, Buck continued to receive intensive therapy while I worked to prepare for our due process hearing and keep Kate's program on track.

Buck would eventually be awarded the Purple Heart and the Bronze Star, with a "V" for Valor for his actions, and is back on full duty, having reenlisted for another four years. While some might question why, after all of these challenges, Buck wouldn't just pack up and retire this year—get a nine-to-five job where the biggest risk involved is driving the morning commute—you'd have to know a Recon (Reconnaissance) Marine to understand. He has been known to say, that while "other people have jobs," he has "a duty and obligation to serve." Being in the service of his country is something that neither he, nor our family, have ever taken lightly. In fact, we consider it an honor. In his mind, there is still a job to do and as long as he is physically and mentally able, who better to do it than him? Which brings me to my final point.

If Not Me, Then Who?—Turning Adversity into Advocacy

I share the story of Kate and our family's journey thus far not to evoke sympathy, but rather to bring those who read it to question the current state of affairs as it pertains to autism diagnosis and treatment, particularly

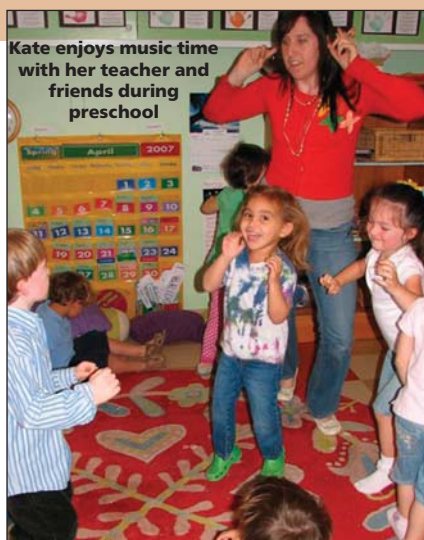
for military families who are already asked to sacrifice and adjust more than most. I would also hope to share some of the most important lessons we have learned along the way with families who are facing similar situations. At the outset of this journey, I quickly realized that the systems and bureaucracies in place, that are supposed to be serving our children, are often failing. Still, as Kate's mother, I also had to ask myself, "If not me, then who?" If I was not willing to stand up for my child who could not speak for herself, how could I expect others to do so? If I was not willing to make sacrifices in order to give Kate the best chance at an independent future, how could I expect others to do the same? Each time I was met by obstacles or adversity, instead of allowing myself to feel overwhelmed or victimized, I had to turn my anger, my worry, my passion, and my disillusionment into action. When I realized that the only power I had in this process was my ability to educate myself and advocate for my daughter, I put all of my energy into that purpose. While every child and every family is different, I would pass along the following advice to parents:

- **Educate yourself** in your child's diagnosis, treatment, local resources, and the laws that govern their education and services. You are already an "expert" on your own child—you are with your child for most of his or her waking hours and have valuable insight into their strengths, weaknesses, personality, and needs. Do not underestimate the importance of your input as a member of their educational and medical team. By learning about your child's disability, and your child's rights as an individual to be educated and treated in an appropriate, dignified, and inclusive manner, you become their best and most important advocate. As the child's parent, you are often the only person in

the room with a vested interest in his or her long-term progress and independence.

● **Network with other families** with similar experiences. After the first year of struggling through the education system, I was surprised that there were no local support groups for parents of children with disabilities. I started Solana Beach Special Parents with a few other parents in my area, and it has since grown to include parents from six other surrounding districts—all who have similar experiences and are able to network and support one another at our monthly meetings. We have been able to host guest speakers on inclusion, IEPs, and other topics that are of interest, but most importantly provide a source of friendship, inspiration, and education for parents who might otherwise feel isolated. We reach out to others in order to share ideas as well as each other's burdens.

● **Focus on your family.** Military families have much to contend with in terms of family stress, particularly with multiple wartime deployments and frequent relocations. Add to that the financial and emotional stress of a child with autism, and it is understandable why so many of our families find themselves in crisis. I consider myself blessed to have such a strong relationship with my husband. I always say that when you have a husband who gets shot at for a living, you begin to realize that the dirty socks on the floor aren't that big a deal. We have long ago decided that letting the little things get between us is a waste of the very little time we have with one another, so we have learned to cherish it instead. The same goes for our children. While our efforts to help Kate to progress and to learn can be intense at times, we love our children and enjoy them for who they are today and want to help them to be all they were meant to be tomorrow. Our family continues to be centered around our



faith, which reminds us that what we are trying to accomplish for our children is not for them to get to Harvard one day, but to teach them how to lead joyful, satisfying lives.

● **Take care of yourself** so that you can take care of others. All right, so I haven't got this one quite mastered—I'm usually the last one to get to the dentist and will often sacrifice my rest or free time in order to accommodate other people's schedules. But I have found that I am a much better mom, wife, and advocate for my daughter when I take the time to do things that I enjoy occasionally. It is important that we do not lose our own personal identity to our child's disability. If you like to sew or paint, schedule time to do it. Do your best to find respite care or support from family members so that you can have a date with your spouse or can get your hair colored at a salon, instead of out of a box. Trust me, it makes a difference.

● **Take action.** I have found that turning adversity into advocacy is all about being willing to act where others may not. When we realized that Kate and other children were suffering from service gaps at the age three transition from Early Start to the schools, we lobbied for legislation at the State Capitol that would help ease this burden for families. Laws like the Individuals With Disabilities Education Act (IDEA) and the current changes in the military healthcare system's treatment of autism originated with families

of children with disabilities who demanded change and better treatment for them. Certainly, not everyone has the time or the energy to lobby Congress, let alone the local school board, but recognize that there are moments when we must ask ourselves, "If not me, then who?" Taking action is one way to empower yourself and to effect change in the systems and organizations that affect the lives of our children.

These days, Kate continues to make progress—her program is still cobbled together with three sources of funding, we still struggle with the school to implement her IEP, and we still work to improve the military healthcare system's coverage of autism services. We also realize that while Kate's wonderful progress is probably the exception, our journey and struggle to obtain services is all too common. There is much to be done in order to ease some of the burden of our military families who are raising children with autism. We also believe that while adversity can pull families apart, it can also be the glue that binds them. Our experiences these past few years have changed our priorities as a family and made us appreciate one another more. I have learned much about myself and my capacity to overcome obstacles. Our older daughter, Halle, has become a compassionate, mature, and responsible child who will no doubt credit her sister for teaching her many life lessons. We are grateful for all of these things. We can't help but hope, however, that for the next military family with a child with autism, the journey won't be as hard. It doesn't need to be. ●

Kyla Doyle is the wife of U.S. Marine Corps MSgt. (Master Sergeant) Buck Doyle. They have two children. Kyla Doyle has a Bachelor of Arts degree in Political Science and a Graduate Certificate in Applied Behavior Analysis. She is pursuing a Master's degree in Special Education, with an emphasis in Autism Spectrum Disorders.