



Autism and the Military Family

by Lisa Rupe

Families who have children with autism might cringe at the thought of moving out of state, Dad going away on a business trip, or changing the child's school. These are the kinds of things that military families deal with regularly. Here's a brief glimpse of some of what military families face in addition to autism itself.

TRICARE

TRICARE is the military health insurance plan. It is an entitlement for service members – they do not pay anything for health care other than the service to their country. Having free health insurance makes one more likely to use it. Prenatal visits are free, doctor's office visits are free, immunizations are free, prescription drugs, and any over-the-counter medication available at the military treatment facility (MTF) is free.

Using an MTF for your family's care has its pluses and minuses. If you are lucky enough to have your child see the same pediatrician every time you go, and this doctor understands autism and your desire to treat your child's medical problems, you are the envy of many families. Finding a doctor who will work with you and write referrals is not rare, but doctors also get reassigned every few years, so finding a good one and keeping



him or her is not that easy. We had a good doctor who moved, and we decided to petition the hospital for a civilian primary care manager. At that time, the hospital was short staffed and constantly changing. We were granted our request and picked a Defeat Autism Now! (DAN!) doctor for our kids.

TRICARE covers just about everything that is related to the treatment of autism. There are two major plans for TRICARE.

TRICARE Prime has no co-pay if you use the MTF. Prime requires referrals for everything from your primary care manager. TRICARE Standard requires no referrals. You can go to any specialist (e.g., speech therapist, occupational therapist, allergist, neurologist) you want, but it has considerably more out-of-pocket expense. TRICARE Standard is worth the extra money if you can afford it. Visits to DAN! doctors are billed at well above the TRICARE accepted rate. TRICARE pays the allowable amount for an office visit and you pay the difference. Families with a TRICARE Supplement (sold by an outside company) do not have to pay the difference in billing and they don't pay the co-pays either. Most laboratory tests ordered by regular physicians as well as DAN! doctors are covered by TRICARE.

TRICARE is like any other insurance company, and they don't want to pay if they don't have to. For instance, they require a copy of your child's Individualized Education Program (IEP) if you are claiming speech therapy. They want to make sure you are not already getting speech therapy at school. You also have to deal with problems that arise because of a special need. Most people do not require anesthesia to do an MRI. But a child with autism who is never still will – and then you'll work to have that covered. I would be surprised to find a parent of a special needs child who did not know the phone number for TRICARE. Hyperbaric oxygen is not covered under TRICARE. This is very

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disappointing because there are so many hyperbaric chambers on bases, especially at the amphibious bases. Supplements are covered if they are available at the MTF pharmacy or if they contain at least one prescription ingredient.

Exceptional Family Member Program (EFMP)

This mandatory enrollment program was designed with good intentions. It is supposed to help families only be moved to areas that could support family members' special needs. Educational services and the availability of applied behavior analysis (ABA) therapists, speech-language pathologists, and occupational therapists (or rather their wait lists) are not considered as highly as hospital services. This approach does not fit well for autism. EFMP coordinators on individual bases should be helping families access the medical and educational services they need. This is happening on a good number of bases where the office is staffed with enough people to handle the caseload or there are local support groups that can help with the personal attention. The U.S. Coast Guard does not participate in this program. It has its own special needs program.

An Army wife reports, "We are on our third move and third deployment in four years. I struggle supporting my husband's battalion and both my sons. Suicide rates and divorce rates are up for the Army, add special needs to the mix, and it is bad. Bottom line, we need help and we are not getting the support we need."

The training and knowledge of coordinators varies widely within each branch of the military. There is inconsistency in EFMP coordinators matching families up with new locations that have the services their children will need. For example, an Air Force family has orders to a location they know will not have the services their son needs.

They will go to a medical screening before moving to the new location, a review of all the services their son needs will be done, the family will fail the review, and they will need to have new orders issued. The consequences of this are many, such as families not having enough lead time to get on waiting lists for services in the area where their family eventually ends up.

Permanent Change of Station (PCS)

That's what the military calls "moving." This usually happens every two to four years, but there are many exceptions. Some families look forward to the possibility of better services, and some are very sad to have to leave wonderful therapists and a great IEP. The packing part is one of the easiest things in the military. They come to your home and pack everything, make sure you have emptied the trash cans before the packers arrive, and have all your kids' favorite things safely put away for the trip.

Base housing is often the most convenient place to live but may have a waiting list, sometimes more than a year long. Often, the service member will go ahead and get on the waiting list for housing while the family stays behind until the base housing is available. In other words, in order to get on this waiting list, the service person must move to the new location in advance of the rest of the family. This temporarily splits up the family. Buying or renting in the civilian world is a great option in many markets, but for many young families, base housing is the only option for financial reasons. This forces the family into the situation where the family is split up.

Many bases across the United States have privatized their housing. The private firms taking control of military housing meant huge remodeling or

complete rebuilding that really needed to be done. But some of the rules and regulations regarding those homes have not been understanding of or compassionate to military families with special needs. Physical disabilities are often accommodated, but environmental toxicity issues and allergies often have their needs ignored. A Marine Corps family had to file a Congressional inquiry for any type of action to address their housing situation. Their house was mold infested and all the family members developed terrible allergies. As a result of the inquiry, the private housing office agreed to let them move into a different house, but the family had to pay to have the carpet removed and stored and had to pay for the new flooring.

Getting your house in order might be the most urgent thing to do after moving, but setting up your child's care is next. Continuity of care is a big issue affecting the military family. Many times parents have already contacted and set up appointments and evaluations before the move or at least have done the research. You won't know exactly what services you are receiving from the school district until you hold a new IEP. We had a six-month gap in ABA for our son with our most recent move. TRICARE had misplaced the paperwork for the Board Certified Behavior Analyst (BCBA) who agreed to jump through hoops for us to become TRICARE authorized.

Medicaid Waiver

Medicaid provides medical assistance to families with low income, but some states also provide a waiver that covers children with a chronic disability regardless of income. Every state manages the Medicaid waiver system a little bit differently, but all have a waiting list. Most parents do not even bother filling out the paperwork when they know they won't be there long enough to get to the top of the list. They really should fill it out – it would at least make the state aware of the true need. If parents are lucky enough to be in one place long enough and to get services, they will lose them when they move to another state and also will have to start all over again at the bottom of the list.



Extended Care Health Option (ECHO)

Children with disabilities are given an additional health benefit in the military. The ECHO program allows \$36,000 per year, but that still did not buy a lot of ABA. Respite is offered as part of the ECHO program, also. You need to have an ABA program to use ECHO funds, but you also need to have money left over from your ECHO funds to pay for respite. Some branches of service provide respite programs apart from ECHO. Another limitation of the original ECHO program is that the person who actually works hands on with your child has to be a BCBA. This is unheard of in some areas of the country. BCBA's are supervisors. College students or recent college graduates studying for their BCBA exams are the ones who do hands-on work with the children. Some families choose to self-pay, but that is not an option for most families.

Norfolk, Virginia, is home to the largest Navy population on the East Coast. Keri Peko, founder of Mea'Alofa Autism Support Center (MASC), an ABA clinic in the Norfolk area, states, "I realized that if we weren't able to afford to provide our daughter with what she needed,

surely those of a lower rank or those with multiple children affected by autism wouldn't be able to." She started the clinic employing one BCBA, who was also a Navy wife, which has grown to serve more than 40 children in the area, many of whom are military kids.

A Congressional inquiry was filed in 2009 to study autism services in the Camp Lejeune area of North Carolina. Camp Lejeune is the largest Marine Corps base on the East Coast. One-hundred and six children with autism spectrum disorder (ASD) reside in the area. Eleven are enrolled in the ECHO program. There are no ABA network providers. There are 200 people on the waiting list for ABA services. As a result of the inquiry, the Marine Corps is pursuing the concept of establishing a treatment center of excellence for families with disabilities at Camp Lejeune.

According to 2008 data, only 10 percent of military family members with an ASD are enrolled in the ECHO program worldwide. That means more than 11,000 children are either not enrolled in the program because there are no providers in the area, or they are unaware that the program is available.

In 2008, TRICARE started an Enhanced

Access to Autism Services Demonstration (Demo) to test the possibility of using non-BCBA's with the children. The Demo program utilizes non-BCBA therapists allowing for more hours because they are less expensive. TRICARE listened to parents and responded positively with this new program. My son receives eight hours per week of ABA therapy via the Demo program. The hours are still a far cry from the 25 hour minimum for ABA therapy recommended by the American Academy of Pediatrics, but it's a step in the right direction.

Parents have once again mobilized. The 2010 National Defense Authorization Act bill in the House of Representatives contains language that provides ABA as a TRICARE basic medical service – moving it out of the ECHO program and into regular TRICARE. Being in TRICARE as a medical benefit also makes it available to the children of retirees. At the time of this writing, similar Senate wording was not in the Senate version of the bill. This kind of legislation would be tremendous for the autism community.

Deployments

Many military children have trouble when a parent deploys for a long period of time, but it may be even harder for a child who cannot communicate his or her feelings or just doesn't understand where his or her parent went. And each child reacts differently to changes in family dynamics. A joint-spouse (both parents in military) Air Force family talks about their son's regression during deployments saying, "He would shut down for a while, regain ground, and regress again when Dad would return." Of course, kids grow up while their dad is away, and my husband being able to objectively see all the progress Kyle made while he was gone was encouraging, too. Now that our son can say "Daddy," he asks where he is each day that Daddy is not at home.

Resources

Military parents of disabled children are the best resources for each other. Almost every day I see messages on online boards asking for advice about where to go next, how to apply for compassionate reassignment (a request to move because



Autism Mothers: Military Moms

the services your child needs are not available), or how to go about getting a referral. Specialized Training of Military Parents (STOMP) has one such list of parents from all over the world. (See also www.stompproject.org.) STOMP was started by a parent and offers training to other parents. Another parent and service member, Nickolas Sabula, is building American Military Families Autism Support – a Web site for military families created by military families. AutismSalutes.com was created and is maintained by Angela Warner to keep parents updated on legislative efforts related to the military.

One child in 88 in the military has autism, but one service member in 10 has a family member with a special need or disability. The care of special needs family members affects the whole military as a preparedness and reenlistment issue. I hope that some higher ranking officers will read this article and see the opportunities presented to help these families. Many thanks to the numerous families I spoke with for letting me share their stories – you are the best, and your continued advocacy for your children is what is going to change things.

Photography credit: Louis Felix Photography
www.louisfelix.com



The Rupe Family

Lisa Rupe is mom to 8-year-old Kyle and 6-year-old Ella. Lisa's husband, Lt. Comdr. Ryan Rupe, is a Navy Chaplain currently serving with the U.S. Coast Guard in Milwaukee – the hometown of both Ryan and Lisa.

Kyle was diagnosed at age 28 months in 2003 in California when Ryan was stationed at Camp Pendleton with the Marine Corps. Lisa knew Kyle had a speech delay, but her only point of reference for autism was *Rain Man*. She did a lot of Internet research and stumbled upon Talk About Curing Autism (www.talkaboutcuringautism.org) and the Autism Research Institute (www.autism.com), both based in California.

Just after Kyle's fourth birthday he moved into his fourth house and started his third school in his third school district. He must have thought this was normal and Lisa thought the three houses in one calendar year would be too much, but he handled it well, being more flexible than many children with autism.

Lisa managed the three-to-six month ship deployments in Virginia with a little help from her visiting family. For the big Iraq deployment, she felt she needed more help – and better conversation at home. So she had Russian exchange students for the two school years during which Ryan was gone.

This spring Kyle turned 8 and will be attending his neighborhood school with his little sister for the first time this fall. Kyle is still considered nonverbal, but the words are coming. He has a great home verbal behavior program and should receive his Medicaid-funded ABA waiver slot this fall. The Rupes have been treating Kyle biomedically, starting with the gluten-free/casein-free diet shortly after he was diagnosed.

Lisa is a full-time mom and autism volunteer and advocate working mostly on military issues, for Autism One in media relations, and co-coordinating the Wisconsin chapter of Talk About Curing Autism.