A Guide for Military Families Affected by Autism

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A Guide for Military Families Affected by Autism

by Lisa Rupe (6/2010)

The military life is not for everyone. The whole family needs to have the commitment to serve the country and all that that entails. It can be a very exciting and challenging life. I love it. I like experiencing different parts of the country every few years, though admittedly it is getting harder for my kids as they get older to leave friends and sometimes family behind.

The Navy, Army, Air Force, Marines, and Coast Guard have many things in common, but also many things that differ including care and services for special needs families. This article cannot possibly be all-inclusive, but will hopefully serve as a starting point for a military family with a newly diagnosed child, or for the family beginning the biomedical journey.

This is written for families that are already in the military when they get a diagnosis. So, it makes certain assumptions such as you already have your child enrolled in Defense Enrollment Eligibility Reporting System (DEERS) and using TRICARE.

Getting a Diagnosis

Your Primary Care Manager (PCM) will be the one to see you most of the time for well-baby check-ups. Try to be consistent and see the same doctor if at all possible. Speak out about your concerns. Ask for referrals to a Speech Language Pathologist if your child is behind in language development or a Child Psychologist if you are concerned about the overall development of your child. If you have TRICARE Standard, you don't need a referral, go and make the appointment yourself. If you are on TRICARE Prime and are refused a referral by your PCM, you may see another doctor or go without a referral using the Point-of-Service (POS) option, but it pays to be persistent or request a different PCM. "Wait and see" is not a good option, studies show the earlier the intervention the more effective it is.

If you are referred to a Child Psychologist or other professional who does diagnostic testing and you do not agree with the diagnosis or lack of diagnosis, you may go back to your PCM for another referral. It always helps when asking for referrals to have the name and contact information of the professional you want to see so the PCM may write the referral right away.

TRICARE even offers a third opinion if your first two are not the same (ie Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) diagnosis and no diagnosis at all). For services sake, I would take the PDD-NOS diagnosis and leave it at that for the moment.

Once you have your Diagnosis

Start getting support immediately from military and non-military sources. Find your local autism support groups and online support groups. I found Talk About Curing Autism (TACA) right away – and even though they were based in southern California where I was and had multiple meeting locations, it

was hard for me to get to meetings. Instead I joined the yahoo group and was able to meet up with other parents who taught me how to cook, organize supplements and find the best doctors. Don't miss out on the advice of other parents who have been there and are helping their child recover. Doctors may have good intentions keeping you away from alternative treatments, but they are not the parent of your child. Do your research and decide for your child. Dietary changes and supplements are not dangerous. Research shows that 91% of people improve on a gluten-free, casein-free, soy-free (GFCFSF) diet (http://gfcf-diet.talkaboutcuringautism.org/defending-gfcfsf-diet.htm).

Step #1 Enrollment in the Exceptional Family Member Program (EFMP)

EFMP is a mandatory enrollment program for the Department of Defense (DoD). The paperwork will be filled out by your PCM and you must submit it, sometimes along with a few other signatures if your child is already receiving services or education.

- DD Form 2792, Exceptional Family Member Medical Summary for medical issues only, and;
- DD Form 2792-1, Exceptional Family Member Special Education/Early Intervention Summary for educational issues.

The EFM program was designed to make sure that service members are not stationed to an area where services are not available. This is a really good idea, however it does not work that well for autism. The treatment of autism and related medical problems is something that Military Treatment Facilities (MTF) do not do well overall. So requiring you be near one is not that important. The school districts, availability of TRICARE-authorized Applied Behavior Analysis (ABA) providers, Speech Language Pathologists (SLP) and Occupational Therapists (OT) are more important. Having a good Defeat Autism now! (DAN!) doctor in the area is nice, but so many will do consults via phone with you just making the trip in person once a year, that it isn't a big issue.

The job of the EFMP coordinator is to assist the family is accessing the medical and educational services needed. The standard of care is not consistent across branches and bases. I was given the phone number of the local Autism Society by one coordinator – fortunately, they had some answers for me. I believe that all branches are working on this issue. Families that do not get the care they need are more likely to leave the military and to have problems at home.

Once your child has been diagnosed with an autism spectrum disorder and the EFMP paperwork has been submitted, your child will be assigned a category in some of the services. Your paperwork needs to be updated every three years. It is especially important to have it updated when you are expecting a Permanent Change of Station (PCS).

In the Navy and Marine Corps there are 5 categories. I was told that autism is an automatic category 5 which allows the family to homestead and not move. This is nice if you are in a good place with good services. Category 4 offers large metropolitan areas with large military hospitals—San Diego, CA; Bremerton, WA; Jacksonville, FL and Norfolk, VA. I asked for it to be down-graded to a 4 when it was time to resubmit the paperwork (every 3 years). Then I asked again to be downgraded to 3 (no overseas billets) and still got a 4. Category 2 is limited overseas billets and category 1 is mainly for monitoring. This is the official Navy EFMP site

http://www.npc.navy.mil/CommandSupport/ExceptionalFamilyMember/. You will not be contacted with your child's EFMP category, you will need to check it yourself on this website.

The Coast Guard does not participate in the EFMP because they are part of the Department of Defense. Instead they have a mandatory Special Needs program

http://www.uscg.mil/worklife/special_needs.asp. However, to be enrolled in ECHO a Coast Guard member must first enroll his or her child in DoD's EFMP.

Step #2 Enroll in Extended Care Health Option (ECHO)

ECHO is an separate TRICARE program for family members with special needs. Once you have enrolled in EFMP, call your TRICARE ECHO coordinator. If you are not sure what region you are in see http://www.military.com/benefits/tricare/tricare-service-centers.

TRICARE North Region

Health Net Federal Services, LLC 1-877-TRICARE (1-877-874-2273) www.healthnetfederalservices.com

TRICARE South Region

Humana Military Healthcare Services, Inc. 1-800-444-5445 (ask for your area case manager) www.humana-military.com

TRICARE West Region

TriWest Healthcare Alliance Corp. 1-888-TRIWEST (1-888-874-9378) (ask to speak to an ECHO Coordinator) www.triwest.com

ECHO allows \$36,000/year for ABA, Durable Equipment and Respite services. That dollar amount will buy you 5-12 hours a week of ABA – a far cry from the 25 hour minimum recommended by the American Academy of Pediatrics (AAP) and Surgeon General.

Your ECHO coordinator can help you find TRICARE-authorized providers of ABA in your area. It is your job to pick one and get on the waiting list. In fact it is a good idea to get on the waiting as soon as possible, even before you have your EFMP enrollment confirmed.

There are currently two ABA programs available through ECHO. The regular ECHO program itself only allows a Board Certified Behavior Analyst (BCBA) to see your child to do the hands-on work. BCBAs can run from \$125-\$250/hour. They have master's degrees and have successfully passed the Board exam. BCBAs are usually supervisors and do not see kids, you may be lucky to find some that will see kids (Norfolk area). The second option is to find a provider participating in the Autism Services Demonstration Project, usually just referred to as the Demo. The Demo pays for a BCBA supervisor and tutors that are supervised by the BCBA who actually do the work with your child. You can get a lot more hours of ABA with the Demo program.

Only 10% of military children with autism are enrolled in ECHO. Why are so many not taking advantage of this benefit? It is often because there is no one to provide the services in the area. DoD has recognized this problem and is looking at possible solutions. But some families still do not know they

even have this benefit. If you have no TRICARE-authorized providers or no providers of the Demo in your area—ask. It is a lot of paperwork for the provider, but once authorized it is not that difficult. We are the only military client of our provider—so glad I asked!

When you ask for your ABA referral TRICARE will authorize you for a network provider if there is one in your area. If you get the authorization for one that you did not ask for, you need to get your documentation together showing that the waiting list is too long, or they do not provide the services you need and appeal to Utilization Management.

TRIWEST seems to have a lot more requirements than any other area of the country. I'm not sure how they get away with adding to the regulation, but they do.

ECHO does have a monthly cost-share based on pay grade.

Pay Grade	Monthly Cost Share	Pay Grade	Monthly Cost Share
E-1 to E-5	\$25	0-6	\$75
E-6	\$30	0-7	\$100
E-7, O-1	\$35	0-8	\$150
E-8, O-2	\$40	0-9	\$200
E-9, W-1, W-2, O-3	\$45	O-10	\$250
W-3, W-4, O-4	\$50		
W-5, O-5	\$65		

Step #3 Get on your state's Medicaid waiting list

Each state is different, check out TACA's links. Even if you do not expect to ever get to the top of the list, the state needs to see the need or they will not fund additional spots.

ECHO is an excellent opportunity to receive ABA benefits—most insurance plans in the US do not cover ABA (though states are beginning to mandate it). TRICARE is NOT an insurance plan—it is an entitlement. When used in conjunction with self-pay and state Medicaid waiver programs, your child can receive the 25-40 hours recommended of ABA.

Check your child's eligibility for Supplement Security Income (SSI). E-6 and below should apply. In areas where there is not a heavy military population, you may have a case worker who does not know how to calculate your income. Make sure that housing is not counted as a special pay, but as regular pay.

Navigating TRICARE

About TRICARE Plans

TRICARE Prime is the best option for the price, it is most like a private HMO plan. It will most likely consist of care at an Military Treatment Facility (MTF) with military doctors and specialists. There is an

option to use a Point-of-Service (POS) within Prime to see specialists without a referral, but it will cost much more. TRICARE Standard is the most flexible not requiring any referrals, but also the most expensive at up to \$1000/year. In many cases you will have to submit your own claims. TRICARE Extra is like the Preferred Provider Option (PPO) of TRICARE, you can use providers in the network, whereas Standard is outside of the network.

Comparison Table

Table with most pertinent info only

	TRICARE Prime	TRICARE Standard and Extra	
What is it?	TRICARE Prime is a managed care option offering the most affordable and comprehensive coverage.	TRICARE Standard and Extra is a fee-for-service option, which allows you the most flexibility in whom you see for care, but will cost you more out-of-pocket than a managed care plan such as TRICARE Prime. With TRICARE Standard and Extra, you can seek care from any TRICARE-authorized provider. If you see a network provider, you'll be using the TRICARE Extra option and will pay less than if you see a non-network provider.	
What are the main features?	 Enrollment required Easy to transfer enrollment when you move Enhanced vision coverage and clinical preventive services Assigned primary care manager (PCM) provides most of your care and gives you referrals for specialty care* Time and distance access standards First priority for military treatment facility appointments Fewer out-of-pocket costs No claims to file (in most cases) *Point of service (POS) option available to receive care without a PCM referral, resulting in higher out- 	 Enrollment NOT required No enrollment forms to fill out No annual enrollment fees Freedom to choose from any TRICARE-authorized provider, network or non-network Receive care in a military treatment facility on a space-available basis only Referrals are not required, but some care may require prior authorization Highest out-of-pocket costs You may have to pay for services when they are received and file your own claims for reimbursement TRICARE Standard is available worldwide, but TRICARE Extra is not available overseas 	

	I	1
	of-pocket costs. POS not available for active duty service members.	
How do I get care?	When you enroll, you must select a PCM, or one is assigned to you. Your PCM may be a military treatment facility (MTF) provider or a civilian TRICARE network provider. Your PCM:	You have the freedom to seek care from any TRICARE-authorized provider. To save on out-of-pocket costs, you can use the TRICARE Extra option by visiting a TRICARE network provider.
	 Provides routine health care Coordinates referrals for specialty care that he or she cannot provide Assists with prior authorizations, when needed Maintains your patient health records You have the first priority for appointments at MTFs, and when MTF care is not available, you'll be referred to a TRICARE network provider. 	Referrals are not required, but prior authorization is required for certain services, such as speech therapy and occupational therapy. You may receive care at a military treatment facility, but only on a space-available basis.
Will I have to file my own claims?	Your provider will file claims for you (in most cases).	If you receive care from a TRICARE network provider, your provider will submit claims on your behalf. If you receive care from a non-network provider, you may be required to submit your own health care claims.
	Yes, to participate in TRICARE Prime, you must enroll by submitting a TRICARE Prime Enrollment and PCM Change Form to your regional contractor.	You do not have to enroll in TRICARE Standard and Extra to participate. Coverage is automatic, as long as you remain eligible in the Defense Enrollment Eligibility Reporting System.
	Active duty service members and their families, activated National Guard and Reserve members and their families and transitional survivors are <i>not required</i> to pay an annual enrollment fee.	
	Retirees, their families and all others must pay an annual enrollment fee: • \$230/Individual	
	\$230/ iliulvidudi	

	• \$460/Family	
	+ .55,1 diliii	
What is the annual deductible?	There is no annual deductible unless you are using the POS option, which allows you to see any provider without a referral from your primary care manager. POS outpatient annual deductible: \$300/Individual \$600/Family Note: Active duty service members and activated National Guard or Reserve members may not use the POS option.	The annual outpatient deductible varies depending on the sponsor's military status and rank: Active duty family members (sponsor rank E-4 and below): • \$50/Individual • \$100/Family Active duty family members (sponsor rank E-5 and above) • \$150/Individual • \$300/Family All others: • \$150/Individual • \$300/Family
		care received in military treatment facilities.
How much do I pay for an	Military Treatment Facility	Military Treatment Facility
outpatient visit?	No charge	No charge
	TRICARE Network Provider	TRICARE Network Provider (Extra option)
	 Active duty service members (including activated National Guard and Reserve members) and their families: \$0* All others: \$12 per visit* Non-network Provider With PCM referral: Same as network provider costs Without PCM referral: POS fees apply 	 Active duty family members (including family members of activated National Guard and Reserve members): 15% of negotiated fee after the annual deductible is met All others: 20% of negotiated fee after the annual deductible is met Non-network Provider (Standard option) Active duty family members (including family members of activated National Guard and Reserve
	*POS Option: 50% of the TRICARE	members): 20% of allowable charges after the annual deductible is met

	allowable charge, after the POS annual deductible is met.	All others: 25% allowable charges after the annual deductible is met
What's the maximum I'll pay out-of-pocket? (Also known as the Catastrophic Cap.)	Your catastrophic cap varies depending on the sponsor's military status: • Active duty families: \$1,000.00 per family, per fiscal year • National Guard and Reserve families: \$1,000.00 per family, per fiscal year • Retired families (and all others): \$3,000.00 per family, per fiscal year	Your catastrophic cap varies depending on the sponsor's military status: Active duty families: \$1,000.00 per family, per fiscal year National Guard and Reserve families: \$1,000.00 per family, per fiscal year Retired families (and all others): \$3,000.00 per family, per fiscal year
	Note: POS fees do not apply toward meeting your catastrophic cap.	

There will be more examples with specific costs later in this article.

TRICARE Supplemental Plans

Private companies offer supplemental insurance plans to lower the costs associated with TRICARE Standard and Extra. Google for a full list or look at the ads in your branch's "Times" newspaper. Also see www.military4life.com/tricare.

Many civilian doctors charge more than the TRICARE allowed dollar amount for a doctor's visit. TRICARE will reimburse only the allowable amount and a supplement will make up the difference.

So after you have met your \$300 family deductible, TRICARE and the supplement together pay 100%.

I believe that TRICARE Standard with a supplement is the best way to go. You may move with it and not have to worry if you will have a good TRICARE Prime PCM at your next duty station.

The TRICARE supplement even covers the ECHO cost share which is far more than the cost of our yearly supplement.

Costs Compared

Let us consider that a Defeat Autism Now! doctor charges \$500 for an initial two hour visit and the TRICARE approved rate is \$166.

Let's assume that the doctor does not accept insurance at all and that you have to file it. (Most Defeat Autism Now! doctors do not accept insurance because it costs them money to have to file it and keep up with claims—it does not mean they are greedy doctors). So, in every instance you will be paying \$500

at the time of the appointment. The differences will be in how much you are reimbursed which is shown at the bottom of each column. The table is based on a \$500 new patient doctor's office visit with a TRICARE approved amount of \$166. Reimbursement is assuming the deductible of \$300 has already been met.

Plan	Referral	Math	Reimbursement
Prime with POS option	no referral	50% of \$166=	\$83
Prime	referral	100% of \$500=	\$500*
Standard	no referral	80% of \$166=	\$133
Standard with	no referral	80% of \$166 &	
Supplement		supplement pays	\$500
		20% of \$166	

^{*}this is what TRICARE will tell you, but this is not likely to be your reimbursement rate. Rate depends on the doctor's agreement with TRICARE—whether they are network, non-network or do not accept assignment (do not accept insurance). Do not expect to be fully reimbursed with this option. Make sure you discuss this with your doctor before your first appointment.

An option not listed in the chart is if your child's DAN! is also his in-network PCM. You would pay nothing. We managed to do that on both coasts, while unusual, it is not impossible.

Prescriptions

There are four ways to get prescriptions filled.

- 1. If you take your prescription to an MTF there is no cost.
- 2. Use a DoD TRRx (TRICARE retail network pharmacy, like your local Walgreens), co-pays are \$3 for generics and \$9 or \$22 for brand name depending on the formulary tier. You can only get a 30-day supply at each time. See the formulary search tool at http://www.tricareformularysearch.org/dod/medicationcenter/default.aspx
- 3. Use the TRICARE mail order pharmacy, same prices as the TRICARE retail network pharmacy, but you can get a 90-day supply, delivered to you at home for a single co-pay.
- 4. Use a non-network pharmacy- such as a compounding pharmacy.

There are some autism-friendly compounding pharmacies that will bill TRICARE for you. Lee Silsby and Pure Compounding will bill TRICARE. So if paying for your prescriptions up front is a problem, they are a good option. You will only have to pay shipping.

Submitting a claim for a prescription is not difficult. Use <u>DD Form 2642</u>, attach your receipt with amount paid. Dosing information must also be on the receipt or a separate form and the NDC needs to be on the claim also. Most pharmacies will give you a generic claim for so that you can file yourself, just ask for it. Make a copy and mail it to:

Express Scripts Attn: TRICARE Claims

P.O. Box 66518

St. Louis, MO 63166-6518

TRICARE Pharmacy Copayments*			
Where You Fill a Prescription	Generic Drugs (Tier 1)	Formulary Drugs (Tier 2)	Non-Formulary Drugs (Tier 3)
Military Treatment Facility (MTF)	\$0	\$0	Not Applicable
TRICARE Mail Order Pharmacy (TMOP) (up to a 90-day supply)	\$3	\$9	\$22
DoD TRRx Network (up to a 30-day supply)	\$3	\$9	\$22
Non-Network Retail Pharmacy (up to a 30-day supply) Note: Beneficiaries must pay the entire cost of a medication at a non-network retail pharmacy and then submit a claim (DD Form 2642) for reimbursement.	TRICARE Standard Beneficiaries \$9 (or \$22 for non-formulary) or 20% of total cost, whichever is greater, after deductible is satisfied: • E1-E4: \$50/person; \$100/family • All others: \$150/person; \$300/family TRICARE Prime Beneficiaries 50% cost-share after point-of-service (POS) deductible		
	has been met.POS deductibles: \$300/person; \$600/family		

Table from https://member.express-scripts.com/dodCustom/benefitSummary.do

The new computer system (Oct 2009) at Express Scripts seems to be causing many compounded claims to be rejected. Hopefully, they will work the problems out and we will finally be reimbursed.

My TRICARE supplement pays for my DoD TTRx co-pays.

Not all medications or treatments that may be prescribed by your doctor are covered.

Lab Tests

Most lab forms I have seen give you the option of billing your insurance company or prepaying at a lower cost. I have never had a lab refused when I prepaid it and submitted a claim. Use that option whenever you can as you are most likely to get your money back. Your doctor should fill in the diagnosis

and other codes on the form, if he did not, call and make sure you have the right codes on your form before sending in the lab test.

Lab tests are reimbursed the same way as doctor's office visits used in the compare costs examples above.

Claims

Submitting a Claim

Use <u>DD Form 2642</u>. This form can be filled out online and printed with your information in it—it prints a copy for you to keep and one to send in.

I use a "shortcut". I fill out the form except for the condition (8a) and the signature and date (12a and b) and print several copies that I keep in my "claims pending" folder. When I need to submit a claim, I pull one out, write the condition in 8a, sign and date and make a copy. I make a lot of claims in TRICARE Standard, so this is less time consuming for me.

You do not need to write in medical terms for the condition box. In fact I have found you don't have to say much at all, the codes on your supporting document (doctor's office bill, lab test) have all the official medical information coded (if you need a code – check out the list of codes on TACA). For example, for methyl-B12 shots I write "vitamin B12 deficiency" on a urine toxins test I write "lab test for toxic metals".

Tracking Your Claims

Keep a copy for yourself (a flatbed printer/copier/scanner is very useful) and indicate at the top of your copy--the date of service, what it was for, the dollar amount of the claim and when you mailed it. Both sites have a mailbox feature for correspondence. This is very useful when you work on claims after business hours.

<u>www.mytricare.com</u> is an excellent way to track your Explanation of Benefits (EOB). I turn off receiving all of mine by paper – I'd get too many, I'd rather save the trees. Because I have TRICARE Standard, they tell me what the checks are for when sent, so I end up receiving many EOBs by mail anyway. It is slow and clumsy, but it is fairly simple to see what has been paid and what hasn't. You do have to change your password often, so don't forget to write it down.

<u>www.express-scripts.com</u> is the site for prescription medication tracking. Each family member needs a different login.

Financial Assistance

Check out TACA's All Things Financial as it Relates to Autism http://www.talkaboutcuringautism.org/resources/financial-issues.htm

The Hyperbaric Medical Center of New Mexico will treat any child with cerebral palsy or autism, who establishes themselves as a patient, in their Vitaris Hyperbaric Oxygen chamber at no cost.

Integrative Hyperbarics (Wisconsin & California) also offers financial assistance for Hyperbarics and biomedical treatments. Contact 608-278-4268 for more information.

If you want to see a Defeat Autism Now! doctor and cannot get a referral and do not have the resources to pay the co-pays first get some assistance from a family that has done it, then consider applying for a scholarship. Scholarships are available for military families from Heroes with Handicaps www.heroeswithhandicaps.org. Scholarships open to all families with a child with autism are available through Talk About Curing Autism www.tacanow.org who has partnered with Autism Speaks in the Autism Cares program. Generation Rescue also offers family grants www.generationrescue.org.

Medical Records

Military OneSource offers the DoD Special Needs Toolkit and the Special Care Organizational Record (SCOR). The SCOR is available for download online and both may be requested in hard copy with a binder from Military One Source by calling 1-800-342-9647.

http://www.militaryonesource.com/MOS/FindInformation/Category/Topic/Issue/Material.aspx?MaterialITypeID=5&MaterialID=16871. From the website: The SCOR is an organizing tool that helps families keep information about their child's health and care organized and in one place. The SCOR also makes it easier for you to find and share key information with others who are part of your child's care team.

When you get ready to PCS, make sure you get copies of all of your child's (even your own) medical records to carry with you. Some civilian clinics/doctors may charge you for copies. Let them know you are military and moving, sometimes they may waive their usual fees. If not, it is worth the small price to have those records with you. Never give anyone the only set of records you have. It's OK to hand them over at the beginning of an appointment so they can make copies, but don't leave them behind, you may never see them again.

Immunizations

The military is very straight forward on this. If you are ordered to be immunized you only have two options to avoid it – a medical exemption or an administrative exemption. Army Regulation 40-562 regarding the Military Vaccine Office may be found at http://www.army.mil/usapa/epubs/xml pubs/r40 562/head.xml .

Requirements for a family member are different. Family members are civilians and may refuse vaccines. However, if your child is at a DoD childcare or school you may have to go through the same medical or administrative exemption process as noted for the sponsor above.

When PCSing overseas, you may be told that you do need immunizations. The only immunizations you are required to have are the ones mandated by the country. Often the forward command has the final

word in this. If you are looking for overseas immunization information for military, there are some very knowledgeable moms on the www.mothering.com forum.

I suggest having your current doctor sign the medical exemption form for your child's new school before you move. You can usually call ahead and get enrollment forms mailed to you, or even download them off the internet. Fewer medical exemptions are questioned.

Housing

Choosing where to live can often be the biggest headache in a move since your school almost always is based on where you live. Living on base, if housing is available, is the easiest and often most cost effective option. Ask if they allow families with special needs to be placed higher in the waiting list. When you live in base housing you do not receive your housing allowance (it gets paid to the housing company) and your utilities are also paid for (water, gas, electric).

Recently, the Navy has started privatizing housing. This means many housing areas across the country have been rebuilt and look great. But, the private firm is not in the DoD chain of command. They do not have to alter anything for your child or your family. If, for example, carpeting is going to be a problem for your child with severe allergies, think twice.

There are always places to rent in the community for military families. Buying in some markets is a nice option as well. To check your monthly housing allowance see http://www.military.com/benefits/military-pay/basic-allowance-for-housing-rates.

Legal Issues

Legal documents that you need prepared are a Last Will and Testament, Letter of Intent, Durable Power of Attorney, and a Special Needs Trust.

JAG attorneys can prepare your will and power of attorney. While the Letter of Intent is not a legal document, it should be placed with your other legal documents.

Some Army bases have civilian attorneys that are qualified to prepare Special Needs Trusts. Check with your base's JAG office first, then nearby Army bases. If you cannot find a military office to prepare it, check with local support groups for an attorney recommendation. The cost is \$2000-\$5000.

http://www.talkaboutcuringautism.org/resources/adult-legal-planning.htm

Special Education

If your child is school age this is the area in which you need to be a big advocate. You need to research schools, have a good IEP in hand before getting to the new school, and know what your child needs and how to get it at the new school.

Before moving to the area, educate yourself on the area schools. Check the <u>American Military Family Autism Support</u> website/Facebook page, ask on yahoo groups (military, TACA or other local lists) and contact your base's EFMP Coordinator to see if there are any good contacts in the area that can talk about schools—especially how they work (or don't) with a child like yours.

Review your child's IEP to see that it includes everything. If your current school has modified class work for your child, given him an aide, added extra speech services, or anything that has helped him, make sure it is added to your IEP. In our last IEP before a move I make sure everything is explicitly written out. His IEP does not say he has a full-time aide, but he does. I will make sure that is written out in our last IEP.

Every school district our son has been in has had a different IEP writing program and different rules governing IEPs. If possible, view an IEP from the school your child will be attending before your IEP meeting.

It is also very helpful to the new school if your child's current teacher will write transition notes that explain more about an average day than testing scores and goals do. The notes should including toileting routines, lunch room routines, types of schedules used, preferred rewards or break time activities, type of class he is in (how many teachers/students/aides) and the type of support he has.

Get copies of your child's entire education file—not just the documents you are presented with, but all of the data taken on your child (and sometimes you) during the time you were in that school or district. Most schools will not just hand over this information. The raw data taken on some evaluations may be a big clue to your new school of some strengths or deficits in your child. Not all school psychologists are equal and some may interpret the data differently.

Know the law. There are several good books available on special education law. The <u>Wright's Law</u> website is a good resource. Find a TACA Law Day seminar <u>www.tacanow.org</u> or buy the conference CD of the session from Autism One. I find it convenient to listen while packing or making a cross country drive to refresh my memory.

A couple of Marine Corps bases have hired special education advocates to help our families!

Respite Services

Being a parent is hard enough sometimes, but being a parent to a special needs child ALONE while your spouse is deployed can be tough. Make sure that you have supports in place—family, friends, trusted babysitters. Many people want to help, but may not be ready to babysit, maybe you can use them to help other ways such as taking your other daughter to her ballet lessons, picking up something at the grocery store, etc. Every little bit will help when you would otherwise have to do it all yourself.

Respite providers give families a much needed break. Look for a provider with experience working with children with autism. If you are not using all your ECHO money for ABA, you can use some for respite also through a TRICARE-authorized provider.

Some branches of service and some bases have respite programs of their own. Your EFMP coordinator on base should be able to tell you about special programs on your base. If not – start asking around on base and on list-serves.

Your state may also offer respite services as part of Medicaid. Make sure you have applied for them.

Deployments

Parenting a Special Needs Child When Your Spouse is Deployed from Military One Source http://www.militaryonesource.com/MOS/FindInformation/Category/Topic/Issue/Material.aspx?MaterialITypeID=9&MaterialID=15328

Legislative Efforts

TRICARE does give us some excellent coverage, but it stills falls short when it comes to hours recommended for ABA.

TRICARE created the ECHO program in order to add the ABA services on to TRICARE. This really creates a separate insurance program for the disabled child. ABA is an evidence-based, medically necessary treatment for autism and it should be a regular benefit under the basic TRICARE medical program. If it were a regular basic benefit, there would be no dollar limit and it would be accessible by retirees.

To follow the legislative efforts surrounding the move of ABA to TRICARE basic, check out www.autismsalutes.com .

Another big project that military families should start working on is Medicaid portability. If you have been somewhere long enough to get off the waiting list and receive services, the next time you move you will lose those services and start at the bottom of another state's waiting list.

Know who your state congressman and senators are as well as those from your legal state of residence. When issues arise needing your advocacy as a military parent of a child with autism you can write to both states' elected officials.

Resources

ACT! Today for Military Families http://www.acttodayformilitaryfamilies.org/ (will offer grants)

American Military Family Autism Support www.amfas.org (research your new base)

Autism Research Institute www.autism.com (video presentations)

Autism Salutes <u>www.autismsalutes.org</u> (legislative information)

Autism One <u>www.autismone.org</u> (deeply discounted conference rate)

Military HOMEFRONT http://www.militaryhomefront.dod.mil/

Military One Source www.militaryonesource.org

Specialized Training of Military Parents (STOMP) <u>www.stompproject.org</u> (great listserv and parent trainings)

Talk About Curing Autism www.tacanow.org (a wealth of autism resources from diet to advocacy)