

**TRICARE and Other Benefits for
Military Parents with Children with
Autism and Other Cognitive Disabilities**

Fort Belvoir, VA

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From Autism Society of Northern Virginia (ASNV) and
Parents Of Autistic Children of Northern Virginia (POAC-NoVA)

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TRICARE-Prime versus Standard

- **Prime:** No yearly deductible and most access to local MTF, but primary care manager's referral and pre-authorizations ARE needed. More info is at <http://www.tricare.mil/tricareprime/default.cfm>.
- **Prime Point-of-Service Option:** Yearly deductible and additional co-pays or cost-shares, but option to see any TRICARE-authorized provider without a primary care manager's referral or a regional contractor authorization. More info at <http://www.tricare.mil/Factsheets/viewfactsheet.cfm?id=183>.
- **Standard:** Yearly deductible and additional co-pays or cost-shares, but primary care manager's referral and pre-authorizations are not needed. Provides option to see any TRICARE-certified/authorized provider, since less services at local MTF. More info: <http://www.tricare.mil/tricarestandard>. List of commonly asked-for services requiring preauthorization: <http://www.tricare.mil/TRICAREStandard/preauthorization.cfm>.

How to Get your Referrals Through

- If not sufficient or adequate at school, request additional services for “behavioral” or “medical” and not “educational” purposes.
- Any MD can submit a referral for any service, if you can convince them of the medical necessity by specifically requesting autism medical services.
- Helps to have a provider already picked and listed on the referral for all TRICARE requests.
- Get a copy of referral ASAP after it is submitted to preclude problems with utilization personnel filling it.
- If you hit resistance, ask for a second opinion or request to speak with the supervisor, if not what the MD had requested.
- Always state “continuity of care” in subsequent requests.
- MTF > network > non-network providers!

Basic TRICARE-Covered Therapies (Not Under ECHO Program)

- **Speech and Language therapy (SLT)- authorized three times a week.**
 - Recommended by DAN! MD and two SLT evaluations (paid for by TRICARE).
 - “Continued PROMPT speech and language therapy from ... at three times per week from ... through ...”
 - **Auditory Integration Therapy (AIT)** for twice a day for ten days approved as OT referral in NOV 02 for “He is very adverse to certain sounds and needs a formal program to help with sound sensitivities and aversive behavior responses.”
- **Pediatric Occupational Therapy (OT) & Physical Therapy (PT):**
 - At Walter Reed a couple of times a month for a couple of years.
 - Then, we got increased OT to an hour a week and also PT consultations at school.

Defeat Autism Now! (DAN!) Doctors

- Find a DAN! Doctor by using the Autism Research Institute web site of <http://autism.com/dan/danusdis.htm> for within the U.S. and <http://autism.com/dan/danforeigndis.htm>.
- Sample questions for DAN MDs are at <http://autism.com/dan/ques2ask.htm>.
- Initial referral for an "autism medical specialist to evaluate and treat autism" under section 3.10 on treatment of mental disorders, chapter 7 of the TRICARE Policy Manual at <http://manuals.tricare.osd.mil> OR have them become your Primary Care Manager (PCM).
- Subsequent referrals to “have our son continue to see ... for additional developmental pediatrics services as part of an ongoing treatment plan.”
- Have the specific DAN! Doctor listed on the referral, since that makes the authorization process go a lot faster.
- They have ordered additional testing, recommended specific biomedical interventions, and began heavy metal (NOT Mercury) chelation (authorized under TRICARE section 2.7 of chapter 7).
- After getting an authorization up-front from TRICARE, we have been reimbursed for most of the costs for these visits.
- Our regular DAN! doctor is Dr. Pamela Compart with Heartlight Healing Arts in Columbia, MD. at (877) 641-8472 or (410) 880-4215.
- Our DAN! doctor for chelation is Dr. Richard Layton with Allergy Connections in Towson, MD. at (888) 337-2707 or (410) 337-2707.

HBOT, ACDs and SGDs

- **HyperBaric Oxygen Therapy (HBOT)** is listed Section 20.1 of Chapter 7, but the approved list is very limited from the Hyperbaric Oxygen Therapy Committee of the Undersea Medical Society (<http://www.uhms.org>).
- **Augmentative Communication Devices (ACDs) and Speech Generation Devices (SGDs)** are listed at Section 23.1 of Chapter 7 and as **Durable Medical Equipment** (Section 2.1 of Chapter 8) used to improve, restore, or maintain a medical function or prevent further deterioration. They are medically necessary services and supplies that provide an individual who has a severe speech impairment with the ability to meet functional speaking needs are covered. ACDs/SGDs are characterized by:
 - Being a dedicated speech device, used solely by the individual who has severe speech impairment;
 - May have digitized speech output;
 - May have synthesized speech output, which requires message formulation by spelling and device access by physical contact with the device-direct selection techniques;
 - May have synthesized speech output, which permits multiple methods of message formulation and multiple methods of device access; or
 - May be software that allows a laptop computer, desktop computer or personal digital assistant (PDA) to function as a speech generating device.

Testing Basics

- All but one test has been paid for by TRICARE.
- Any doctor can order tests for kids with autism using outside labs.
- We recommend Great Plains Lab (GPL) or Doctors Data (DD) that do tests specifically for autistic kids and are TRICARE- authorized.
- GPL info is at <http://www.greatplainslaboratory.com>, or send an email to gpl4u@aol.com, or call (913) 341-8949.
- DD info is at <http://www.doctorsdata.com>, or call (800) 323-2784.
- Genova Diagnostics is also TRICARE-authorized.
- Metamatrix Lab is NOT TRICARE-authorized.
- Quest and Lab Corp are also TRICARE-authorized, and tests should be able to be ordered electronically through TRICARE.

How to Testing

- How to have TRICARE pay for it, if an outside lab:
 - First, you or your doctor order the appropriate test kits from the lab at no cost to you using their web site or by phone.
 - Have your doctor sign off on the paper test request form.
 - A military lab will take and process a blood sample if that is necessary, if you have a valid test request form.
 - Then, you send the sample to the lab using the express package service that they provide.
 - You should verify with TRICARE claims that they will pay for these tests BEFORE you take the samples and send it to the lab, just to be sure.
 - You can pay using the insurance option, but you usually get more fully reimbursed if you pay first and then get reimbursed by TRICARE
 - TRICARE has paid for a comprehensive food allergy test, three microbial organic acid tests, two comprehensive stool with yeast sensitivity tests and a hair analysis test for our son. Due to chelation, we intend to do CBC (done by military lab), metabolic profile (Quest or LabCorp), fecal metals (DD), RBC trace minerals (DD) and fractionated urinary porphyrin (Quest or LabCorp) tests on a regular basis.

Diets

- First, most significant change for our child resulted from putting him on a gluten (whole grains) and casein (dairy)-free or GF/CF diet in March 2002.
- We deduced that he had a problem before the food panel was done.
- Confirmed with a comprehensive food panel done in March 2003 by Great Plains Labs, showing sensitivity to most nuts, dairy (casein) and whole grains (gluten) products.
- Normal reaction if he eats a dairy or whole grains food is increased hyperactivity for a short time after he digests that food.
- A increase in bad behaviors could occur for a short time, if there is a period of yeast die-off in the gut. It takes at least a month for the toxins to get out.
- Only liquid that he usually drinks is vanilla-flavored rice drink, but he is now also drinking fruit juices.
- After years on the diet, he now has a greatly improved food variety and may soon be slowly taken off of the GF/CF diet.
- Local Whole foods and Trader Joe's stores are the source for his rice drink, gluten-free pasta, cereal, waffles, and soy yogurt. They also have a list of all gluten-free foods in their stores at the service counter. Locations and more info are at <http://www.wholefoodsmarket.com>.
- Other diets include the Specific Carbohydrate Diet (SCD) and Feingold Diet.

Nutritional Supplements

- Currently on 14 nutritional supplements based on the advice of his DAN! doctors and deficiencies from testing.
- These are NOT covered by TRICARE, unless they are fed only by tube, are ordered by an MD, can be gotten only from a pharmacy and are the child's primary source of nutrition.
- Most supplements from Kirkman Labs at <http://www.kirkmanlabs.com> or call (800) 245-8282.
- As of June 2008, Kirkman is offering a 25% military discount. To get it, call and speak to someone in customer service. This is ONLY for military families. Depending how much you order at a time, also ask for free shipping and handling.
- However, we used to order all these Kirkman Labs products and most of his other supplements through the River Wellness Center Apothecary at <http://www.riverhillwellness.com> or (410) 992-4747, since they offer a 15% discount on Kirkman Labs products and free shipping for all orders over \$125.

Prescribed Supplements

- Prescription for Nystatin and lactobacillus acidophilus to counter our son's gastrointestinal yeast overgrowth problem in 2002 from Dr. Ed Coll at Walter Reed/ Bethesda.
- However, the lactobacillus acidophilus available from the military pharmacy has a low concentration (about 30 million) of live cells, and it probably does not do much good.
- May need to order a higher concentration product from Kirkman Labs (currently use the 75 billion unit Super Pro-Bio).
- After Nystatin, we had him on Milk of Magnesia for three years, which helped but did not totally fix the problem of alternating constipation and/ or diarrhea.
- In 2005, we saw Dr. Carolyn Sullivan from Walter Reed who prescribed Miralax/ Glycolax to clean out his chronic constipation at that point, which required x-rays since he was so backed up.
- Now back to as normal as he will probably get, is partially potty-trained and gained 20 pounds in the process.
- Also prescribed DMPS (DiMercaptoPropaneSulfonate), then EDTA (EthyleneDiamineTetraAcetic Acid) suppositories and Methyl B-12 supplement injections by Dr. Layton, his chelation DAN! MD.
- Both products ordered from Hopewell Pharmacy and Compounding Center in New Jersey at <http://www.hopewellrx.com> or (800-792-6670).

Nutritional and Prescribed Supplements

- 5-Hydroxytryptophan (5-HTP) supplement twice a day.
- EnZym-Complete/DPP-IV (multi-spectrum digestive enzyme) at each meal.
- GABA (Gamma-Aminobutyric Acid) twice a day.
- Glutathione liquid supplement for brain stimulation once a day.
- Magnesium Sulfate cream for brain stimulation thrice a day.
- MinerAll/ WP Minerals supplement once a day, due to chelation.
- Nu-Thera with P5P (multi-vitamin and mineral) supplement twice a day.
- Super ProBio twice a day.
- Taurine for more solid poops twice a day.
- Trimethylglycine (TMG) for brain stimulation thrice a day.
- Vitamin C supplement twice a day.
- Vitamin D3 liquid supplement once a day.
- Yeast Aid (digestive supplement) twice a day.
- Zinc supplement for brain stimulation thrice a day.

- Transdermal DMPS once every other day just before bedtime; then to DMPS and then EDTA suppositories once a week after he is sound asleep.
- Methyl B-12 supplement injections twice a week after he is sound asleep.
- Miralax/ Glycolax laxative for constipation once a day at evening meal.

Extended Health Care Option Program

- **MUST be enrolled in Exceptional Family Member Program (EFMP) first!**
- From Section 1.1 of Chapter 9, “Extended Health Care Option (ECHO) is a supplemental program to the TRICARE Basic Program and provides eligible active duty family members with an additional financial resource for an integrated set of services and supplies designed to assist in the reduction of the disabling effects of the beneficiary’s qualifying condition.”
- Congress created the ECHO program to make services accessible to active duty service members in one state that are not accessible in another state because they are required to move frequently and are not in one area long enough to wait to become eligible for services through Medicaid waivers in most states.
- Program started with **\$2500 of services per month for each family member enrolled in ECHO**, but with a monthly co-pay depending on sponsor’s rank.
- TRICARE ECHO info is at <http://www.tricare.osd.mil/tricaresmart/product.aspx?id=294&CID=0&RID=3>.
- Health Net ECHO info is at:
<https://www.hnfs.net/common/caremanagement/echo.htm> and
<https://www.hnfs.net/common/caremanagement/ECHO%20FAQs.htm>.
- More Health Net ECHO registration info at
<https://www.hnfs.net/NR/rdonlyres/5CFD7AB0-E4C4-49D9-8332-8B018CC73590/0/02511MedicalManagementReferralForm.doc>.
- Health Net ECHO registration phone numbers are at:
https://www.hnfs.net/common/caremanagement/echo_registration.htm.

Applied Behavior Analysis (ABA) Therapy Under ECHO

- Initial request stated: “ECHO Program enrollment and Applied Behavior Analysis (ABA) Therapy for 15 hours/ week x 12 months and 2 hours/month for evaluations, training, or team meetings by ... from ... through ...”
- Our son was authorized 15 hours per week during the school year and 30 hours a week during the summer months, along with a two-hour evaluation once a month. However, it was reduced by the case manager to only 15 hours a month based on the monthly funding limit and not his medical needs.
- Eligibility criteria listed in Sections 2.2 through 2.4 of Chapter 9 of the TRICARE Policy Manual at <http://manuals.tricare.osd.mil>.
- Most individuals qualify for services under the "**Significant Physical Disabilities**" at **Section 2.3** by having problems with “**unaided performance**” of at least one of the following major life activities is an ECHO qualifying condition: breathing, **cognition**, hearing, seeing, and age appropriate ability essential to bathing, dressing, eating, grooming, **speaking**, stair use, toilet use, transferring, and walking.” Some TRICARE personnel may insist that the individual must also have a mental retardation (MR) diagnosis too or a specific autism label to get into the ECHO Program, but that is **ABSOLUTELY NOT** correct.
- This program is not available to families of retirees at this time.

Applied Behavior Analysis (ABA) Therapy from TRICARE?

- 27, 104 individuals associated with the military having an Autism Spectrum Disorder (2,848 for Virginia)
- 17,899 individuals in active-duty families as of December, 2008.
- About 16,844 Children are age 21 or under, which provides a ratio of 1 in 70 children for active-duty families. (Nationally, 1 in 91 to 112!)
- 6,958 individuals in retired families as of December, 2008
- 2,401 enrolled in the ECHO Program or ABA Demo as of December, 2008 or 8.9% of 27,104.
- 1,283 receiving some amount of ABA therapy as of December, 2008 or 4.7% of 27,104.

Applied Behavior Analysis (ABA) Therapy Under ECHO

- TRICARE will **NOT** approve ABA therapy for what is viewed as only educational issues, but only for behavioral or medical problems.
- Once approved, you will be assigned an ECHO case manager who will help you complete the rest of the paperwork.
 - Public Use Certification Form (Section 5.1 of Chapter 9) signed by your school system special education director or a county health agency official.
 - Have to provide a copy of current Individualized Education Program.
 - Other documentation from provider, including treatment plan.
- Current Procedural Terminology (CPT) code to be used is 99199 for ABA.
- List of certified providers is on the certificant registry at http://www.bacb.com/consum_frame.html.
- Current problems with finding TRICARE-approved ABA providers (Section 17.1 of Chapter 9):
 - “Where such State license or certification is not available, are certified by the Behavioral Analyst Certification Board (BACB) as either a Board Certified Behavior Analyst or a Board Certified Associate Behavior Analyst”.
 - BCBA’s and BCABA’s develop ABA programs, but do normally not deliver hands-on ABA therapy.

2007 National Defense Authorization Act

- **SEC. 717. REPORT AND PLAN ON SERVICES TO MILITARY DEPENDENT CHILDREN WITH AUTISM.**

- (a) Plan Required- The Secretary of Defense shall, within 180 (18 April 2007) days after the date of the enactment of this Act, develop a plan to provide services to military dependent children with autism pursuant to the authority for an extended health care services program in subsections (d) and (e) of section 1079 of title 10, United States Code. Such plan shall include--
 - (1) requirements for the education, training, and supervision of individuals providing services for military dependent children with autism;
 - (2) standards for identifying and measuring the availability, distribution, and training of individuals of various levels of expertise to provide such services; and
 - (3) procedures to ensure that such services are in addition to other publicly provided services to such children.

- (b) Participation of Affected Families- In developing the plan required under subsection (a), the Secretary shall ensure the involvement and participation of affected military families or their representatives.

- (c) Report Required- Not later than 30 days (18 May 2007) after completion of the plan required under subsection (a), the Secretary shall submit to the Committees on Armed Services of the Senate and the House of Representatives a report on the plan. The report may include any additional information the Secretary considers relevant.

Possible ECHO Program Improvements

- DoD Report and Plan on Services to Military Dependent Children with Autism, dated July 2007:
 - Will initiate a demonstration program to “expand the availability of ABA services to ECHO beneficiaries with autism”.
 - Expands the pool of possible certified supervisory providers to more than just BCBAs and BCABAs using a modified corporate services model.
 - Hands-on ABA tutors will be able to provide therapy when they work for a certified supervisory provider within a modified corporate services model.
 - Standards for ABA tutors not defined yet, but will probably require a bachelor’s degree, at least 250 hours of training/experience, and mandatory background checks.
 - Standards on direct and indirect supervision and other competency requirements will need to be established.
 - Also, looking at “increased use of the ECHO respite benefit” and “consider changes that are necessary to make it available to more families”.
 - Other concerns include “the perceived lack of support at the base level for families with autistic children, the stated need for case management of autistic beneficiaries, and assignment policy based on special education needs of the service member’s dependent children”.

2008 National Defense Authorization Act

- **SEC. 587. EDUCATION AND TREATMENT SERVICES FOR MILITARY DEPENDENT CHILDREN WITH AUTISM.**

- (a) Assessment of Availability of Services.
- (b) Review of Best Practices.
- (c) Personnel Management Requirements
 - (1) Limited Stationing Options.
 - (2) Stabilization Policy.
- (d) Case Managers and Services.
 - (1) Case Managers.
 - (2) Individualized Services Plan.
 - (3) Autism Support Centers.
 - (4) Partnerships and Contracts.
- (e) Demonstration Projects- Case Managers, Supervisory Level Providers, and Services Under Corporate Services Provider Model.
- (f) Relationship to Other Benefits.
- (g) Reports.
 - (1) Report Identifying Covered Military Installations.
 - (2) Reports on Demonstration Projects.
- (h) Covered Educational Services Plan.

DoD Autism Demonstration Highlights

- From “**DoD ENHANCING ACCESS TO AUTISM SERVICES DEMONSTRATION**, *An Overview of Main Provisions*”, dated March 3, 2008:
 - “More educational intervention providers
 - Expanded definition of supervisors should quickly increase # available
 - Newly defined provider class (Tutors) will make thousands of new providers available to implement services such as ABA to military families
 - Incentives for supervisors to bring on and train tutors
- Expanded services
 - Functional definition of covered services should permit families to have access to a greater range of existing evidence-based services”

2008 Autism Demonstration Project

- **Details in Section 10 of Chapter 20 of TRICARE Operations Manual at <http://manuals.tricare.osd.mil>, dated 15 March 2008 with changes on 20 March, 22 April and 17 September.**
- Only cover ABA; no other types of behavioral interventions reimbursable.
- Must enroll in EFMP, then in the ECHO Program and then in the Demo.
- Starting with FY09, the \$2500 per month goes to \$36,000 a year (on average \$3000 a month). Unused portions should be able to be rolled over from month to month until the end of the fiscal year on 30 September of each year.
- **Eligibility (Section 6.0):**
 - Diagnoses of only AD, PDDNOS, AS, and CDD.
 - Over age of 18 months and receiving special education under an IEP or IFSP.
 - Nonverbal or verbal intelligence testing or a letter of “inability to participate in intelligence testing every six months”. **(IQ of over 35 DELETED!)**
 - Between ages 18 months through 8 years, standardized testing of language skills and adaptive behavior must be completed “within 12 months of initiating services”. **(ALL TESTING DELETED!)**
 - Clinical review by TRICARE required, and a denial cannot be appealed. **(DELETED!)**

2008 Autism Demonstration Project

- **Providers (Section 4.0):**
 - Must sign participation agreement and undergo a criminal history review.
 - Tutors employed by or directly contracted with TRICARE provider.
 - Certify tutor education, training, experience, competency, supervision, and that have successfully completed a criminal background check.
 - Certify tutor supervision requirements quarterly. **(DELETED!)**
 - Maintain all records for three years. **(DELETED!)**
 - Complete Behavior Plan (BP) and EIA Progress Report (EPR) for each child every six months. (Section 9.1.4). **Pay up to \$47.65 using CPT 99080.**
- Must be a pediatrics MD, clinical psychologist PhD, BCBA, or BCABA. **(Other options deleted, but added back in a state license!)**
- Authorized provider list for the Demo Project in the Tri-North Region is at <https://www.hnfs.net/res/tricare/provider/resources/pdf/1533342083/EIA%20Supervisor%20North%20Region%20Directory.pdf>.
- Carry liability insurance of \$1M per claim and \$3M aggregate.
- “Shall organize and direct required quarterly family treatment progress meetings”. (Section 9.1.5). **Pay up to \$65.08 using CPT 90887.**
- Provider rates: Up to **\$125/ hour** for BCBAs, up to **\$50/ hour** for tutors.

2008 Autism Demonstration Project

- **Tutors (Section 4.5): (Requirements prior to billing TRICARE)**
- Education- **Minimum of 12 semester hours** of college coursework in psychology, education, social work, behavioral sciences, human development or related field) -or- **minimum of 48 hours** of any college course -or- H.S. diploma or GED and **500 hours of ABA services employment.**
- Classroom training- **40 hours required.**
- Experience- 50 hours of prior directly-supervised fieldwork and a minimum of 500 hours of prior indirectly-supervised fieldwork -or- 40 hours of directly-supervised fieldwork over no more than 12 weeks within the past 12 months.
(DELETED!)
- Competency- no specific requirement in the policy.
- Ongoing Supervision- If have 500 hours of prior indirectly-supervised fieldwork, then a required minimum of 1 hour of direct supervision and 2 hours of indirect supervision for every 40 hours of services -or- if not yet completed 500 hours of indirectly-supervised fieldwork, then a required minimum of 2 hours of direct supervision and 2 hours of indirect supervision for every 40 hours of services.
(DELETED!), now just 2 hours of direct supervision a month.

2008 Autism Demonstration Project

- **Parent/ Caregivers training (Section 7.1.4)**
- Classroom training- 6 hours are required in the first year by one parent. This can be waived through certificate to contractor by sponsor. **(DELETED!)**
- Practical training- 6 hours are required each year by one parent/ caregiver. If child is between ages 18 months through 8 years, then 10 hours are required each year by one parent/ caregiver. **(DELETED!)**
- Reimbursement- Up to \$1500 per parent/ caregiver and \$4500 per family each year. **(DELETED!)**
- **Now, only provided during billable ABA therapy. But, detailed training plan must be included on the semi-annual Behavior Plan.**
- **TRICARE will not cost share (Section 13.0)**
 - Training for tutors.
 - Program development or administrative services and assessment required for developing the EIA Progress Report (EPR) and updating the Behavior Plan (BP) .

2009 National Defense Authorization Act

- **SEC. 732. INCREASE IN CAP ON EXTENDED BENEFITS UNDER EXTENDED HEALTH CARE OPTION (ECHO).**
- (1) ... striking “month shall not exceed \$2,500,” and inserting “year shall not exceed \$36,000, prorated as determined by the Secretary of Defense,”
- Signed on 14 October 2008, but the TMA did not get implementing instructions to the contractors until 1 April 2009.
- Respite care, assistive services and durable equipment limited to only \$2,500 per month and the \$36,000 per fiscal year limit, but the cost of durable equipment can be spread out over multiple months.

2009 National Defense Authorization Act

- **SEC. 731. REPORT ON PROVIDING THE EXTENDED CARE HEALTH OPTION PROGRAM TO DEPENDENTS OF MILITARY RETIREES.**

- (a) ... report on including dependents of military retirees in the ECHO program for a limited transitional period following retirement.
- (b) Contents of report:
 - (1) The most current data on the number of military retirees with dependents who are eligible to receive extended benefits under the ECHO program and an estimate of the number of future military retirees with dependents who are eligible to receive such benefits.
 - (2) The cost estimates of providing extended benefits under the ECHO program to dependents of all current and future military retirees.
 - (3) The feasibility of including dependents of military retirees in any ongoing demonstration or pilot programs within the ECHO program.
 - (4) The statutory and regulatory impediments to including dependents of military retirees in the ECHO program.

2010 National Defense Authorization Act

– SEC. 563. SUPPORT FOR MILITARY FAMILIES WITH SPECIAL NEEDS.

- “(a) ESTABLISHMENT.—There is in the Office of the Under Secretary of Defense for Personnel and Readiness the Office of Community Support for Military Families With Special Needs.
- “(b) PURPOSE.—The purpose of the Office is to enhance and improve Department of Defense support around the world for military families with special needs (whether medical or educational needs) through the development of appropriate policies, enhancement and dissemination of appropriate information throughout the Department of Defense, support for such families in obtaining referrals for services and in obtaining service, and oversight of the activities of the military departments in support of such families.

Other Benefits Under ECHO

- From Section 11.1 of Chapter 9, “Transportation of an **institutionalized** ECHO beneficiary to or from a facility or institution to receive otherwise allowable services or items through the ECHO may be cost shared.” No longer for ABA therapy as of 3 December 2009.
- From Section 12.1 of Chapter 9, “ECHO registered beneficiaries are eligible to receive a maximum of 16 hours of **respite care** in any calendar month in which they also receive any other ECHO-authorized benefit.”
 - Request stated; “Respite care through the ECHO Program for 16 hours/ month x 12 months by ... from ... through ...”, even though Health Net can only do the authorizations for 6 months at a time.
 - Get list of possible providers from ECHO case manager for non-skilled nursing providers (usually certified nursing assistants).
 - Respite care provider **MUST** be a TRICARE-authorized "home health care agency" provider.
 - Call possible providers to verify that they do accept and bill TRICARE, and have non-skilled nursing providers to determine which provider would be the best.
 - Current Procedural Terminology (CPT) code to use is 99600 for respite care.
 - Only for your disabled child, and they may not also watch any of your other children (unless there no increased charge to TRICARE).
- From Section 14.1 of Chapter 9, “**Durable equipment** is a device or apparatus which does not qualify as Durable Medical Equipment under the TRICARE Basic Program but which is essential to the efficient arrest or reduction of functional loss from, or the disabling effects of a qualifying condition.” (Adapted car seats & beds)
- From Section 15.1 of Chapter 9, “ECHO Home Health Care (EHHC) benefit provides **medically necessary skilled services to eligible homebound beneficiaries ...**”

Another Respite Care Source

- Exceptional Family Member Program (EFMP) respite care available as of June 2007 for active-Army and AGR families enrolled in EFMP. Marine Corps started a similar program in August, 2007.
- Navy started with five locations for only CAT4 or CAT5 families in March 2009 through the National Association of Child Care & Resource Referral Agency (<http://www.naccrra.org/MilitaryPrograms/NavyEFMP>).
- Qualifying families may be eligible to receive up to 40 hours of EFMP respite care monthly for each certified EFM. It is “consumer-directed”, and the pay and number of hours varies according to the medical needs of the individual.
- EFMP certification, respite care qualification and administration of the entitlement are through the local EFMP manager. For Army enrollment and more details, contact Marcia O’Connor at (703) 696-8467/3510 or marcia.a.oconnor@us.army.mil from Fort Myer or Laury Bitecofer at (703) 805-5435 or laury.bitecofer@us.army.mil from Fort Belvoir.
- Sources of potential respite care providers are at the bottom of the POAC-NoVA web link at http://www.poac-nova.org/base.cgim?template=new_parent_resource_suggestions.
- Do NOT recommend Jesse Kushner and Professional Education and Respite Service at (888) 664-9886 or www.vacationrespite.com for ABA therapy or respite care.

Autism Research Institute Offers

- **FREE "Recovering Autistic Children" book**, a 468 page paperback book, which normally costs \$24.00. To order- print, complete and fax or mail in the form at the web link of <https://www.autismwebsite.com/ari/militarybookrequest.htm>, along with a copy of the front of your military ID card. Please fill out all the blocks, so we can start a database on what services military children with autism may be getting from TRICARE. Fax the form to 619-563-6840 with a copy of your military ID card along with your name and postal address, or mail it to Autism Research Institute, 4182 Adams Avenue, San Diego, CA 92116. There is a strict limit of one copy per family. Recovering Autistic Children, edited by Stephen M. Edelson, Ph.D. and Bernard Rimland, Ph.D. is the extensively updated and enlarged revision of Treating Autistic Children, which was published in 2003.
- **25% discount on Autism Research Institute's (ARI) Defeat Autism Now! (DAN!) conferences**, including this one. To request a military discount for a DAN! conferences, please email Tanya from ARI at Tanya@DANconference.com. She will then provide simple instructions as to how to register online and receive the 25% discount. You will need to show your military ID when picking up your materials at the on-site registration booth at the conference. More info on this offer is at <http://www.danconference.com/SpringConference/AngelMoney.html>.
- **ARI web link for military:** <http://www.autism.com/families/military/military.htm>.

Other Financial Assistance Sources

- Heroes With Handicaps may include the following for Military Special Needs Children at <http://www.heroeswithhandicaps.org/Services.html>.
 - 1. Medically documented therapies for autism (i.e., ABA, DIR, IBI, etc.)
 - 2. Therapies not covered by insurance, TRICARE, local school districts, or state/federal monies.
 - Services will be considered on a case-by-case basis.
- Generation Rescue family grants at <http://www.generationrescue.org/rescue-family-grant.html>.
- National Autism Association Helping Hand Project at <http://www.nationalautismassociation.org/helpinghand.php> and <http://www.nationalautismassociation.org/familyfirst.php>.
- NeighborHeart grants at <http://www.neighborheart.org/grants.asp>.
- Project Devin (a partner of Abilities Network Project ACT) at <http://www.abilitiesnetwork.org/services/act/ProjectDevin.html>.
- America the Beautiful - National Parks and Federal Recreational Lands Pass - FREE Access Pass at http://www.nps.gov/fees_passes.htm.

Other Financial Assistance Sources

- Aid for Autistic Children Foundation at <http://www.aacfinc.org>.
- Air Warrior Courage Foundation at <http://www.airwarriorcourage.org>.
- Lend4Health facilitates community-based, interest-free "micro-loans" as a creative funding option for individuals seeking optimal health. Currently, Lend4Health is facilitating loans for the biomedical treatment of children and adults with autism spectrum disorders at <http://lend4health.blogspot.com>.
- Autism Care and Treatment (ACT) Today at http://www.act-today.org/about_2.html. ACT Today! will begin accepting grant applications in September 2008. Please submit your grant application before their annual deadline in October. You will be notified of our decision by December.
- Easter Seals Champions for Children at <http://www.championsforchildrenga.org>. Families of medically fragile and special needs children across Georgia are now able to apply for and receive direct financial assistance and support services from a state-wide nonprofit collaborative to help cover the costs of caring for children at home.
- Grants from the United Healthcare Children's Foundation at http://www.uhccf.org/apply_applicant.html.
- Grants from Friends of Man at <http://www.friendsofman.org/index.php>.

Other Financial Assistance Sources

- Autism Cares at <http://www.autismcares.org> provides up to \$1,500.00 assistance to families who have 1 or more children with autism who make under \$65,000 and have had the following issues occur within 90 days: loss of job by sole wage earner, major disaster, loss of family member (nuclear family). Please see site for additional information and criteria.
- Angel Flight at <http://www.angelflightmidatlantic.org> or (800) 296-3797, Mercy Medical at <http://www.mercymedical.org>, and Patient Travel at <http://www.patienttravel.org> or (800) 296-1217 offer free air travel for special needs families.
- Kirkman Labs at <http://www.kirkmanlabs.com> provides a 25% discount on all of their own products, but not items that they distribute for other folks. However, you MUST call (800) 245-8282 to get this discount, since it is NOT available for online orders.
- Master Supplements provides a \$10 discount per bottle of their Theralac High Potency Probiotic Supplement by calling in an order to (800) 926-2961, extension 3. More info is at <http://theralac.com>.
- Lee Silsby Compounding Pharmacy is sponsoring Autism Salutes with any proceeds going to Heroes With Handicaps. Through this sponsorship, Lee Silsby is offering a \$20 savings for first time military customers (active and retired) and they accept TRICARE. More info on Autism Salutes is at <http://www.autismsalutes.com/2008/11/autism-salutes-lee-silsbycompounding.html>.

Toileting

- Nystatin and lactobacillus acidophilus, then Milk of Magnesia, and then Miralax/ Glycolax laxative.
- In July 2005, we saw Dr. Carolyn Sullivan, a pediatric gastroenterologist at Walter Reed to get help with our son's alternating constipation and diarrhea problems. She prescribed the Miralax. Her appointment phone number is (202) 782-6101/6102. Her administrative person is at (202) 782-3273.
- Gut must be ready and cured first.
- Use regular and consistent schedule.
- Potty training involved using a reinforcer initially to get him to the potty, and then when only he has success on the potty.
- He started to go there just to get his reinforcer of long balloons and would sit there for hours if we would let him.
- We had to get a padded seat, because he wanted to sit there so long.
- Much happier kid now that he is not in constant gut pain.
- Now, he occasionally signs or pulls you to the bathroom when he needs to go.

Sleeping

- Combination of a very regular and consistent bedtime routine, GF/CF diet, ABA and a supplement.
- Milk given at bedtime would cause him to wake up a few hours later and then laugh out loud for half an hour or more.
- The EuroPharma Shop has it online from Ferrier Laboratoire at http://www.europarmashop.com/product_info.php?products_id=3287 for \$4.71 euros a bottle.
- If they stop carrying it, do a search on Goggle or another web search engine for “Noctium Syrup” or “Noctium Sirop”, which is the product in French for this good-tasting, flavored liquid.
- Found this all-natural, homeopathic product while living in France, and it definitely worked for our son. It is **NOT a DRUG**.
- Was sleeping through the night after getting a whole and then a half-teaspoon of this natural syrup about a half-hour before bedtime for about a month.
- Eventually, he would fall asleep at exactly 2130 (9:30pm) wherever he was, and then we stopped the syrup a short time later.
- Now, we tell him that it is time to go to sleep at around that time, he goes to bed, pulls the covers over his head and promptly falls soundly asleep within a few minutes with no fuss at all.
- Prescription of Melatonin may also help.

Dental Services

- The National Defense Authorization Act of 2007 legislated a change to the TRICARE dental benefit to cover anesthesia services and institutional costs for dental treatment for beneficiaries with developmental, mental or physical disabilities, and children age 5 or under. For TRICARE to reimburse claims, beneficiaries must save their bills for medical care occurring after Oct. 17, 2006. The change does not include the actual dental care services coverage through the TRICARE Dental Program and the TRICARE Retiree Dental Program. This announcement is at <http://www.military.com/military-report/tricare-expands-childrens-dental-coverage>.
- Before this entitlement, the anesthesia costs were not covered by United Concordia or TRICARE, so families would have to cover that expense themselves. For our son, dental services other than attempts at routine checkups were not possible without sedation.
- Taken our son to NNMC in Bethesda, MD for all of his dental needs, including routine checkups and sedation dental services when they needed since 2005. Call the dental clinic to get a “second-opinion” to see if they can see your child at no cost to you. Phone number for the NNMC pediatric dental clinic is (301) 295-1364 and for the main NNMC dental clinic is (301) 295-4339/40. Having all dental services done at NNMC means no invoices or claims to deal with for us.

Specialized Training of Military Parents

- Two email list servs on website at <http://www.stompproject.org/listserv.asp>.
- Publications at <http://www.stompproject.org/publications.asp> on:
 - [Fact Sheet #1, TRICARE](#)
 - [Fact Sheet #2, ECHO - Enhanced Care Health Options](#)
 - [Fact Sheet #3, TRICARE and ABA](#)
 - [Fact Sheet #4, Medicaid](#)
 - [Fact Sheet #5, Financial Resources](#)
 - [Fact Sheet #6, Supplemental Security Income \(SSI\)](#)
 - [Fact Sheet #7, Evaluation Process](#)
 - [Fact Sheet #8, Related Services](#)
 - [Fact Sheet #9, DODD 1020.1](#)
 - [Fact Sheet #10, Section 504](#)
 - [Fact Sheet #11, PCS move](#)
 - [Fact Sheet #12, Survivor Benefit Program \(SBP\)](#)

Virginia Medicaid Waivers

- Virginia Medicaid Waiver Technical Assistance Center:
866 323-1088.
- Elderly or Disabled with Consumer Direction or EDCD Waiver,
call Alee Garit at the Fairfax County Dept. of Social Services
at 703 222-0880 OR 703 704-6299.
- Individual and Family Developmental Disabilities Supports
(IFDDS) or DD Waiver, call The ARC of Northern VA at
703 324-3214, x102.
- Mental Retardation or MR Waiver and the Day Support Waiver,
call the Fairfax County Community Services Board (CSB) at
703 324-4400.
- Technology Assisted or Tech Waiver, call VA Department Of
Medical Assistance Services (DMAS) at 804 786-1465.
- More info at <http://www.dmas.virginia.gov/ltc-home2.htm> and
- http://www.workworld.org/wwwebhelp/va_medicaid_waivers.htm.

Public Education Basics

- Individuals with Disabilities Education Act (IDEA).
 - New provisions for accommodations during extracurricular activities.
- Virginia Department of Education (DoE) resources at <http://www.pen.k12.va.us/VDOE/sess>.
- Recommend collaborative and team-building approach to schools and for IEPs.
- Principals are kings or queens of their buildings, so be nice.
- Teachers are the doctors for your child's educational care with the other support staff as the nurses or other specialists.
- Individualized Education Program recommendations:
 - Do your homework and understand the applicable Virginia DoE regulations and guidelines.
 - Take a man; any man!
 - Bring food, if meeting at lunch time.
 - Do not sign an IEP at the meeting; take it home to have someone else look at it and to mull it over before signing.
- Our son gets up to four hours a day for eight weeks of Extended School Year (ESY) services.

Public Education References

- US DoE Office of Special Education Programs -Reviewed Materials on IDEA 2004 from NICHEY at <http://www.nichcy.org/idealist.htm>.
- Virginia Department of Education (VDOE) Special Education and Student Services website especially for parents at <http://www.pen.k12.va.us/VDOE/sped/parents.shtml>.
- “Regulations Governing Special Education Programs for Children with Disabilities” (7 July 2009) at <http://www.doe.virginia.gov/VDOE/Instruction/Sped/varegs.pdf>.
- “Extended School Year Services Technical Assistance Resource Document” (December 2007) at <http://141.104.22.210/VDOE/Instruction/Sped/ESYdoc.pdf>.
- “A Parent's Guide to Special Education” (2010) at http://www.doe.virginia.gov/special_ed/parents/parents_guide.pdf.
- I.E.P. Pop-Up Tool Chart from the National Center for Learning Disabilities and National Center on Low-Incidence Disabilities at http://www.handsandvoices.org/articles/education/popup/pop_index.html.

Supplemental Security Income (SSI) and Medicaid Benefits

Beginning on 1 April 2003; 2003 BAH, Combat Zone pay, hostile fire pay, imminent danger pay, hazardous duty pay and separation pay will be exempt for SSI calculations to qualify a special needs child for SSI benefits. In the past, the types of income noted above are what typically what cause a military family to be denied SSI benefits. Those who are already receiving SSI are expected to receive an increase within the next 60 days. Those who do not should contact the SSI office at (800) 772-1213. Individuals who have been turned down for SSI benefits in the past or whose SSI benefits have been cut off will not be notified by the Social Security Administration of this change. I highly recommend that any military family who has been denied SSI benefits --and even families who just never applied because they thought their income was too high to qualify-- complete a new application immediately. Do not wait. Local Army Community Service (ACS) offices should be able to direct these families to the local Department of Family Services (or other appropriate health department agency-- each state has a different name for their agency that handles this)....

Supplemental Security Income (SSI) and Medicaid Benefits, Continued

- ... Individuals should begin the process as soon as possible, because payments are retroactive from the day you apply, not the day you are deemed qualified. If the individual's family income is below a certain threshold, the individual will receive monthly SSI payments. These payments defray the costs associated with caring and providing supplies for a person with a disability. In addition, if an individual qualifies for SSI, he or she will also receive Medicaid benefits. Medicaid is a form of public health "insurance", and it will, in almost all instances, pay any portion of medical services and supplies not covered by the individual's other insurance. In the case of military families, Medicaid will cover in almost all instances, the costs not paid by TRICARE. Info is at <http://www.socialsecurity.gov/pressoffice/pr/troops03-pr.htm>.
- Supplemental Security Income Special Rules for Children of Military Personnel Living Overseas are at <http://www.ssa.gov/ssi/spotlights/spot-military-overseas.htm>.

For more information, contact:

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703 241-2640 (Home)

scott.alan.campbell@us.army.mil till May 2010

campbellsservices@gmail.com after May 2010

Autism New Parent Suggestions web link at

<http://www.poac-nova.org/base.cgim?>

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