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EP’s purpose in launching the Exceptional Family Transitional Training Program (EFTTP) was to increase unit readiness and decrease the stress affecting Army servicemembers and their families by providing information, resources, and support for people with disabilities and special needs and all those who participate in their care and development. EP, under the EFTTP Agreement, began with eight pilot and eight distribution sites for a total of sixteen sites receiving EP Magazine. Due to demand over the two-year period of the contract, distribution has now increased to 82 Army installations and contacts worldwide. EP has provided over $26,000 worth of special needs titles to Army-selected installations, and additional installations have placed orders. EP collaborated to produce DVDs regarding the Army’s Exceptional Family Member Program and respite care. EP’s online educational seminars, whether military-specific or general, have reached large numbers of families and professionals. There were 5,270 registrants for its six military programs and 30 physicians requesting CME credits. EP’s programs, while intended for the Army, have reached all services of the United States Military. One mother, whose story ran in the magazine, wrote: “This is exactly why we wanted to get it out there—to help others.”

14. ABSTRACT

15. SUBJECT TERMS

Advanced Distributive Learning, Continuing Medical Education, Disabilities, Education, Military Physicians, Parents, Special Needs, Telemedicine, Unit Readiness
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Introduction
EP Global Communications, Inc./Exceptional Parent (EP) magazine began the Exceptional Family Transitional Training Program (EFTTP) in late November 2006, and continues the program through the present day to support U.S. Military servicemen and servicewomen who have a family member with a disability or special need as well as the many physicians and allied healthcare professionals who care for them. EPGL’s initial charge and mission was to alleviate the stress felt by families and professionals caring for loved ones with special needs as a result of frequent and extended deployments and the number of military families caring for loved ones with special needs. Today, one member of every squad in the Army is caring for someone with a disability or special need. Successfully negotiating this mission will enhance the capability of the U.S. Army to achieve full unit readiness. EPGL recognized that readily accessible education, resources, and clear, identifiable support could relieve burden and improve quality of life. EPGL’s objective was to reach individuals with disabilities as well as their immediate and extended family members, caregivers, educators, and physical and mental healthcare professionals providing care. EPGL knew that delivery of information via print and electronic media could reach broadly across installations, and that the benefits could also be experienced in the civilian sector and across other branches of the military in a global outreach. EPGL considers this initial mission accomplished, based on the expanded outreach of the program and its receptivity by other branches of service.

Work Review

Overview: 2007-2008 – Monthly Print Media for Families and Healthcare Providers
An early initiative of the Exceptional Family Transitional Training Program (EFTTP) was to place into the hands of families and professionals caring for a loved one or patient with disabilities or special needs a monthly copy of EP magazine. This was so that military families and professionals would have an ongoing source of support, education, and resources in a readily accessible format. Created under the EFTTP, the special military section within EP magazine was intended to address the needs of those in uniform and their families who are working with the challenge of a member with special needs within the unique lifestyle of the military community. From 16 initial installations slated to receive EP magazine at the beginning of the EFTTP, demand grew to the current 82 installations and military contacts worldwide now receiving the magazine. Installations continue to ask for increased numbers of the magazine. (See the survey in Appendix VI.)

During the course of the program, EPGL has added new professional relationships and contributors to the pages of its military section and has continued to maintain and build its previously established relationships. This allows EPGL to offer professional, evolving perspectives on medical and mental healthcare issues and services. EPGL also continues the tradition of sharing personal stories, creating a window of insight for families regarding others’ struggles and triumphs and providing support and reinforcement for the daily challenges and rewards involved in ongoing care for a loved one with special needs.

Over the last two calendar years, EPGL has published 298 pages of valuable military-focused editorial content. We strongly recommend that several options be considered for the utilization of this content: 1) publish all of it in book format and distribute it to base libraries; 2) ensure that the articles are captured on the Army database for easy access by EFMP Managers, librarians, and anyone associated with military affairs; and 3) store all of this on disc and distribute it to selected personnel.
**2008**

**Task 1: Develop and deliver monthly print media to families and healthcare providers.**

EPGL continued its mission of providing an eight- to twenty-four-page special military section in *Exceptional Parent (EP)* magazine each month, with military-specific articles, stories, and photos to meet the unique needs of military families and medical and mental healthcare and social services professionals. Each monthly military section contained a customized military-section cover. The April 2008 issue of *EP* magazine featured a front-cover story of a military family and their powerful efforts on behalf of their daughter with autism.

EPGL delivered 8,122 magazines monthly for twelve months, expanding its delivery from 62 to 82 installations and military contacts worldwide, due to demand. To address requests that it had been receiving, EPGL conducted a survey in July to determine current needs of installations and, with agreement of the Army, developed a magazine redistribution plan allowing it to deliver *EP* magazine to additional installations while still meeting the needs of installations already being served. At this time, EPGL also engaged in troubleshooting to help determine why for a short period of time some installations did not receive their allotted number of magazines, and discovered that there appeared to be an issue at times with the bundled delivery of magazines. This seemed to correct itself when the company bundling the magazines used stronger materials in the bundling process.

The survey revealed that some installations were demonstrating a current increased need for magazines, due to additional families with special needs being identified. Other installations were anticipating a need for an increased number of magazines due to upcoming increased troop densities and a greater number of families with special needs.

The survey also revealed that EFMP Managers and Coordinators were enthusiastic regarding the tool of *EP* magazine to deliver to their families and professional staff. Many cited their efforts to distribute the magazine as widely as possible, both within the environs of their offices as well as by delivering the magazine on foot or via vehicle to various locations on base, after hours when necessary. They indicated a strong desire to share the magazine with medical staff. Some of the places and people to which EFMP Managers and Coordinators indicated they were delivering the magazine included: schools; in-processing centers; the PX; a child development center; Children and Youth Services; early intervention programs; chief of pediatrics; monthly fairs, events, and activities; a developmental pediatrician; and the Family Resource Center in Army Community Service EFMP offices. Regarding the various issues received, one staff member revealed: “We don’t throw them away – they’re used for reference later.” That point is consistent with EPGL’s research in the consumer/civilian sector, where over 80% of subscribers tell us they do not throw away past issues. It is also consistent with feedback from several academic centers that use *EP* as a reference tool for classes on developmental disabilities.

Of a sampling of 22 of the 62 installations receiving the magazine (35 percent), 8 installations indicated a need for additional magazines, either now or in the foreseeable future. (Note: 5 installations (23 percent of the 22 installations being surveyed) were not available to respond to the survey.) Thus, 36 percent of 22 installations surveyed (or 47 percent of the 17 of 22 installations that responded) indicated that their sites needed an increase in the number of magazines being received. The total increase in the number of magazines being requested was 1,760, or 69 percent, which would increase the total from 3,425 now being received to 5,185...
EPGL continued to build its relationships with other professionals and organizations serving the unique needs of people with disabilities and special needs, including regular contributions from the Military Child Education Coalition™ (MCEC™), Specialized Training of Military Parents (STOMP), and Health Net Federal Services to expand its comprehensive selection of articles relevant to families, caregivers, and professionals. New professional relationships were formed that will continue to grow in 2009. EPGL is publishing regular contributions from May Institute regarding autism as well as the impact of deployment on children and, as a result of its relationship with Reading for the Blind and Dyslexic® (RFBD), EPGL will be offering recordings for the visually impaired on its Web site in 2009. Experts at New York University’s Department of Psychiatry have lent their expertise in the field of mental health issues, including traumatic brain injury (TBI), brain blast injury, post-traumatic stress disorder (PTSD), depression, anxiety, and substance abuse, thus shedding light on these areas of difficulty and need for returning veterans, their families, and healthcare professionals. EPGL has also established a relationship with the American Pain Foundation and its Military/Veteran Initiative program to shed light on the challenging issue of pain experienced by many returning servicemembers, the need for effective pain management, and the impact of chronic pain on family life, ability to perform daily activities, and overall physical, mental, and emotional health. This relationship will be expanding in 2009, with several articles already planned. The eighty-nine-year-old Easter Seals organization, with whom EPGL maintains a strong strategic relationship, contributed an article to the military section of the December issue of EP magazine and will be contributing more articles for 2009. Easter Seals’ Military and Veterans Initiative focuses on the lives of families affected by injury and other disabilities. By maintaining an ongoing relationship with Easter Seals and its special military and veterans program, EPGL will be able to provide information about Easter Seals’ unique programs available for military families, including its special collaboration with the National Military Family Association’s to host the Operation Purple® Summer Camp Program to provide camping experiences for children of deployed parents as well as Operation Purple Healing Adventures for servicemembers with disabilities and their families.

The broad offerings within the military section of EP magazine have included a special series about traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD), including personal stories and information regarding avenues for therapeutic treatment; parameters and treatments to consider when seeking care for autism; a special “Just for Teens” section that speaks directly to teens and their experiences as they adjust to a family member’s deployment or return home; information about the inception of the Soldier and Family Assistance Centers (SFACs) and the Army Family Covenant; Fisher House™ homes for Wounded Warriors; a family with a daughter with autism whose advocacy is helping to bring about change; a military wife and mother in a wheelchair whose physician husband is caring for servicemembers in Afghanistan while she cares for their two children with special needs at home; swim therapy, a mother of twins with autism who is a hospital corpsman and cared for mothers and children in Iraq; Easter Seals’ special Military and Veterans Initiative providing unique opportunities and support for military servicemembers and their families; and a community support system working with veterans to help them reintegrate to their families, workplaces, and communities with tools to help them cope with physical and mental healthcare needs and provide opportunities for employment.

The number of pages in each month’s military section of EP magazine for 2008 follow:
Over the course of the calendar year, EP published 152 pages of editorial content and photos, focusing on military life and the unique challenges of parenting and caring for children, young adults, or other loved ones with special needs.

(See Appendix IX for each month’s military section of the magazine, from January through December 2008 and from January through December 2007.)

EPGL continues to provide information to military families and professionals informed via its Military Channel on the EPGL Web site. Stories have included information regarding new Department of Veterans Affairs (VA) rules for housing grants that aid the most seriously injured; the VA’s commitment to veterans of the Global War on Terror; a military family’s experience with autism; seeking appropriate school resources to meet a child’s needs; helping children during a parent’s various stages of deployment; and resources from the Department of Defense and other government and civilian organizations. Readers are also invited to send their story ideas for contribution to EP magazine.

EFMP staff and families continue to offer praise and thanks for the military section in EP magazine as well as for the books and the ongoing support of EPGL for military families and healthcare professionals. (See Appendix VII for responses to the EFTTP.)

2007

(Note: The Task number for this same deliverable in 2007 was Task 3.)

Task 3: Develop and deliver monthly print and electronic media to families and other caregivers.

EP and members of the Advisory Board met via teleconference with representatives from each of the selected installations for the purpose of identifying specific topics of need and interest. EP worked in conjunction with EFMP Managers and organizations such as the Military Child Education Coalition™ (MCECTM), Specialized Training of Military Parents (STOMP), Health Net Federal Services, and Military HOMFRONT, as well as installation Public Affairs Officers (PAOs) to create a comprehensive selection of articles relevant to families, caregivers, and professionals.
Beginning with its 2007 EP Annual Resource Guide, a resource listing over 3,000 organizations across the country, EP debuted its special military section, Community of One ~ From Our Families...To Your Families. This first military section in the resource guide included contact information for Army Community Service offices. EP distributed over 8,000 copies of the 2007 Annual Resource Guide to Army installations and personnel.

In February, EP launched the military section within the pages of the monthly magazine. Each military section includes a special Army cover page with family and Soldier photos.

The broad offerings within the military section have included information about the opening of the Center for the Intrepid, the Individuals with Disabilities Education Improvement Act (IDEA) of 2004, STOMP, EFMP offices, centers for autism, transportable home files, attending college, coping with deployment, military support groups, the Department of Defense’s Special Needs Parent Tool Kit, early literacy, TRICARE’s Extended Health Care Option (ECHO), transitioning to adulthood, an Army Medical Action Plan (AMAP), visual impairment and blindness and Department of Veterans (VA) Affairs Blind Rehabilitation Centers, Warriors in Transition, Wounded Warriors, group life insurance, veterans tributes, permanent change of station (PCS), supporting children through trauma and loss, female combat medics, the Wounded Care Support Program, and an interview with Dr. Rebecca Posante, the Department of Defense’s Program Manager for Special Needs.

The number of pages in each month’s military section of EP magazine follow:

February – 8 pages
March – 12 pages
April – 16 pages
May – 15 pages
June – 12 pages
July – 13 pages
August – 16 pages
September – 12 pages
October – 11 pages
November – 17 pages
December – 14 pages

Thus, over the calendar year, EP published 146 pages of editorial content, focusing on military life and the unique challenges of parenting and caring for children, young adults, or other loved ones with special needs.

(See Appendix VI for each month’s military section of the magazine, from January through December 2007.)

EP initially delivered over 8,000 copies of the magazine to 16 installations each month, expanding delivery to 62 bases before year’s end at the request of the Army.

EP discovered that personnel at Army installations that were not direct pilot or magazine sites in the EFTT Program were talking with their counterparts at the pilot and magazine sites and expressing a desire to receive EP magazine for their EFMP families. Some of the pilot and magazine installations shared their magazines, yet there were still installations that wanted the
magazine that were not receiving it. EP spoke with the Advisory Board, and EP and the Advisory Board agreed on the desirability of a redistribution plan for the magazine to reach a broader audience. EP formulated a plan for redistribution that was implemented immediately. The magazine is now distributed to 62 Army installations, with the plan for distribution of the magazine moving forward being worldwide delivery of the magazine to every Army installation that identifies a need for the magazine.

EP also added a special Military Channel to its Web site. The channel provides links to important resources available to military families in a one-stop location. Links include the Web sites for all of the branches of the military; a government site with disability-related information and resources; Specialized Training of Military Parents (STOMP), a Parent Training and Information Center (PTI); Military HOMEFRONT, from the U.S. Department of Defense; and America Supports You. The channel incorporates articles on topics such as transitioning to adulthood, including available healthcare options, legal and financial considerations, academic and lifestyle considerations, community resources, and self-advocacy. The channel also features the addition of the streaming video for *Give Me a Break! A Family Guide to Respite*, created by EPGL. The Military Channel has received 86,000 hits since its addition to the EP Web site in May 2007.

EFMP staff and families have offered praise and thanks for the military section in *EP* magazine as well as the online seminars and books. (See Appendix V for responses to the EFTT Program.)


*(Note: The Pocket Resource Guide was a deliverable for 2008 only.)*

**2008**

**Task 2: Publish and maintain a print and online edition of the *EP 2008 Annual Resource Guide* in a format determined by the Advisory Group.**

EPGL delivered the Pocket Resource Guide with a special leadership message from the director of Family and Morale, Welfare and Recreation Command (FMWRC) and logos and graphics distinguishing the resource guide as specific and special to the Army. The Pocket Resource Guide contained all of the key content included in the full-size edition of the *EP Annual Resource Guide*. Army personnel made a decision to receive the print version only of the Pocket Resource Guide and not an online version, due to the timing of its ability to provide this information for the guide and the constraints placed upon it from internal security and systems. The Pocket Resource Guide was distributed to all of the installations receiving *EP* magazine in the first half of 2008.

**2007**

*(Note: This task was not a deliverable in 2007.)*

**Overview: 2007-2008 – Books and Guides for Family and Professional Care Providers**

EPGL delivered over $26,000 worth of books from EP Bookstore to 21 separate installations designated by the Army. Installations were able to select from special lists created to meet military needs and from the thousands of titles available through the EP Bookstore. The selected
installations ordered books as well as other installations made aware of this resource to stock their libraries for families and professionals.

2008

Task 3: Develop and deliver category-specific, professionally reviewed books and guides to family and professional care providers.

EPGL delivered over $13,000 worth of books from EP Bookstore to 13 installations selected by the Army. EPGL provided to EFMP Managers and Coordinators a list of titles that could particularly benefit their sites and meet the needs of military families and professionals. Managers and Coordinators could use the list as a guide but were also welcome to select any title from among the over 2,300 titles available through the bookstore, so that they could choose the titles to best meet the needs of their installation. Titles included information on a variety of special needs, including post-traumatic stress disorder, autism, ADD/ADHD, Down syndrome, epilepsy, and learning disabilities.

2007

(Note: The Task number for this deliverable in 2007 was Task 4.)

Task 4: Develop and deliver category-specific, professionally reviewed books and guides to family and professional caregivers.

EP and members of the Advisory Board held several meetings via teleconference and in person in Falls Church, Virginia, to discuss installation needs. They identified reliable resources as a need for families and professionals.

EP offered a list of 1,200 titles from its EP Bookstore to MWR librarians. Specially selected by EP’s Bookstore director, these titles cover topics such as Down syndrome, autism spectrum disorder, Asperger syndrome, cerebral palsy, ADHD, epilepsy, visual impairments, grief, special diets, and available therapies, among many others.

EP delivered $13,500 worth of books from the EP Library/EP Bookstore to eight Army MWR libraries. All have been delivered. Each installation was able to select titles that representatives felt would most meet the needs of its families, caregivers, educators, and professionals. These books could then serve as a foundation or part of a foundation of a special needs library, accessible by all.

Overview: 2007-2008 – Educational Programs for Healthcare Professionals, Caregivers, Exceptional Family Member Program Staff, and Families

Whether via development of DVDs in collaboration and planning meetings with Army staff and a subcontractor or via its EP LiveOnline interactive programming, EPGL delivered a variety of educational materials to military families and personnel in convenient and easy-to-use formats.

2008

Task 4: Develop and deliver a series of educational programs for healthcare professionals, family caregivers, EFMP staff, and daycare providers.
At the request of the Army, EPGL in 2008 helped to develop educational DVDs regarding the Army’s Exceptional Family Member Program (EFMP), so that both Army staff and family members could better understand its wide-ranging benefits as well as its protocol and functions. EPGL also worked with its subcontractor, Camber Corporation, and the Army to develop an educational DVD regarding respite care. (Note: Army personnel requested that other subject-matter DVDs it had originally wanted for publication in 2008 be postponed until 2009, and EPGL accommodated this request.)

EPGL held multiple meetings with Army staff through a Process Action Team (PAT) and with EPGL’s subcontractor, Camber Corporation, in order to develop and fine-tune each module to ensure that Army families received the most up-to-date and accurate information available pertaining to the EFMP and respite care. The meetings were held in person, virtually, via e-mail, and telephonically. This was a collaborative effort among the U.S. Army, EP Global Communications, Inc., and Camber Corporation. The modules are being used to educate healthcare professionals, family caregivers, and Exceptional Family Member Program (EFMP) staff about the Army’s Exceptional Family Member Program and respite care. A challenge to completion of this process was a delay in review by the Army of the modules, thereby delaying the next steps for completion by EPGL and its subcontractor. Despite this delay, EPGL was able to deliver the modules on time.

EPGL delivered the following modules:

1. **An Overview of the Exceptional Family Member Program (EFMP)**
   Module 1 offered basic information about the Army’s EFMP program: the purpose for its existence; enrollment requirements; criteria for enrollment; the enrollment process; the impact of enrolling in the EFMP; and the collaborative community support provided to families enrolled in the EFMP.

2. **Enrollment Into the Exceptional Family Member Program**
   This second module provided an enrollment introduction as well as information regarding: enrollment procedures; the overseas screening process; routine medical care; self-identification; forms and directives; the paperwork process from beginning to end; member information entered into the worldwide database; and updating one’s enrollment/disenrollment.

3. **Exceptional Family Member Screening**
   Module 3 offered an overview of screening procedures for soldiers located on/or near an Army post in the United States; for families located in remote areas, not near a military training facility in the U.S.; for soldiers located overseas but with family in the U.S.; special rules for soldiers in the Defense Attaché Program; and conclusions and resources.

4. **Respite Care**
   This fourth module provided information regarding who is eligible for respite care; paperwork that needs to be submitted; when, where, and how to submit paperwork; and how to obtain respite care.

Each of the modules offered tidbits about advocacy woven throughout the information. The modules were developed with a focus on user-friendly, detailed information.
EPGL is currently in discussion with FMWRC regarding the continuation of the project for the additional modules that have been requested and the ongoing maintenance required in order to assure that the modules remain current with the Army’s changes at all times.

2007

(Note: The Task number for this deliverable in 2007 was Task 2. The method of delivery in 2008 was via DVD and the method of delivery in 2007 was via online seminars, available through both live presentation and online archives.)

Task 2: Develop and deliver a series of educational programs for medical, professional, and family caregivers.

EP and members of the Advisory Board met via teleconference with representatives from each of the selected installations for the purpose of identifying specific curriculum and delivery needs. EP collaborated with the MEDCOM representative to refine topics and to identify key Army medical personnel who could present the unique military perspective for each topic.

Four of the six seminars included the opportunity for physicians to earn Category I Continuing Medical Education (CME) credits. Physicians also had access to CME education and testing within the pages of EP magazine. Each of the seminars that offered CME credits was in compliance with Accreditation Council for Continuing Medical Education (ACCME) Standards. Accrediting entities included the American Academy of Developmental Medicine and Dentistry (AADMD) and Rady Children’s Hospital – San Diego.

EP provided eight complete Vemics Systems (including laptop computers loaded with Vemics software and hardware, along with pre-tested, fully configured Vemics kits with portable camera, microphone, and headset) to the eight pilot sites, so that each site would be fully equipped to deliver the seminars to all members of their EFMP as well as anyone else interested in attending. Vemics conducted training on a personalized basis with EFMP Managers at the eight sites. The potential for live attendance was worldwide.

For each seminar, EP conducted a series of email blasts to military contacts, advising them of the upcoming program’s topic, date, and time. EP also ran full-page ads in EP magazine to promote awareness to military families and professionals as well as to civilians interested in the seminar topics. In addition, EP promoted each seminar on its Web site, providing the ability for attendees to register and to download full content of programs already presented at times convenient to the soldier and his or her family.

EP made each seminar available free in its EP LiveOnline (EPLO) archives so that families and professionals who could not attend the live event would have access to it at their convenience at a later date.

Seminar Delivery:
- The first of the seminars, Give Me a Break! A Family Guide to Respite®, was presented on July 9, 2007, during the EFMP Managers Training held in conjunction with the Military Child Education Coalition (MCEC) Conference in Kansas City, Missouri. This respite care seminar was received with strong enthusiasm. The seminar was recorded live during its presentation at the EFMP Managers Training session, and continues to be made available on EP’s Web site (http://www.eparent.com) via streaming video.
• In September, EPLO presented the two-part seminar *ADHD Part I: The Diagnosis, Treatment, and Management of Attention Deficit Hyperactivity Disorder (ADHD) in Children and Young Adults* and *ADHD Part II: Psychosocial Issues That Impact on the Overall Management of ADHD in Children and Adults*.

• In October, EPLO presented *Autism Part I: The Early Warning Signs, Diagnosis, Intervention, Treatment, and Management of Autism Spectrum Disorders in Infants, Children, and Young Adults and Autism Part II: Psychosocial Issues That Impact on the Overall Management of Autism Spectrum Disorders in Children and Young Adults*.

• The final seminar of the six-seminar series, *Asthma and Airflow Obstruction: Challenges, Prevention, Treatment and Coping*, was presented on December 6, and provided information about the latest treatment options for asthma and airflow obstruction.

A powerful additional benefit of these seminars through our military project has been that civilians, as well as military families and personnel, have benefited from these efforts because the programs were distributed simultaneously to all interested individuals, organizations, and professional medical societies.

Professionals attending the online seminars included: an ABA Therapist; Clinical Kinesiologists; Early Intervention Specialist; Educator; EFMP Coordinator; EFMP Manager; Licensed Mental Health Counselor; Nurse Practitioner; Optometrist; Pharmacist; Psychiatrist; Recreation Therapist; Researcher; School Psychologist; and Social Worker. (For an expanded sampling of seminar attendees, see Appendix III.)

The number of physicians who requested CME credits through the seminars to date:

September 12, 2007: Autism – 10
September 19, 2007: Autism – 8
October 17, 2007: ADHD – 7
October 24, 2007: ADHD – 5

**Total CME Requests to Date: 30**

The approximate number of physicians who registered and attended the seminars live or via streaming video in the EPLO archive follows. (Because some registrants did not fill in the Role field when registering, it is likely these numbers are higher).

July 9, 2007: Respite Care – 6
September 12, 2007: Autism – 44
September 19, 2007: Autism – 31
October 17, 2007: ADHD – 34
October 24, 2007: ADHD – 20
December 6, 2007: Asthma – 12

**Approximate Physician Registrants for All Six Military Seminars – 62**

**Total Approximate Number of Physicians Who Attended the Seminars to Date: 209**

Registrants spanned the services in the U.S. Military and Homeland Security, from the Army, Navy, Marine Corps, and Air Force to the U.S. Coast Guard. There were 450 military registrants identified, although it is likely there were more since not all registrants included their location. *It is important to keep in mind that these results are principally related to the eight test locations.*
With the expansion to additional installations, there is likely to be increased interest and utilization.

They also participated from all 50 states in the United States, as well as from the U.S. territory of Puerto Rico and other countries and areas worldwide. (See Appendix III for a listing of some of the countries and areas from which registrants participated. Note: This listing is a partial one, due to some registrants not entering their location information. From the data, it can be extrapolated that other countries and areas were represented but are not known at this time.)

Registrants also connected through notification from entities such as Air Force One Source, Army One Source, MilitaryHOMEFRONT, Military OneSource, and U.S. Army Recruiting Command as well as via notification from EP and EFMP staff. EP’s partner, Vemics, Inc., provided live, ongoing support during each seminar, assuring quality delivery and the ability for real-time interaction among attendees and presenters.

(See Appendix IV for registration figures for each seminar as well as the total number of registrants.)

Additional Contribution

In addition to achieving its mission and objectives in the Exceptional Family Transitional Training Program (EFTTP), EPGL has created a venue for discussion and resources, not only through its own programs and publications but through valuable collaboration. Recognizing the importance of pairing its expertise with that of other leaders in the field, EPGL combined its forces with Easter Seals in December 2008 to offer to over 1,400 registrants live and in real time information about Easter Seals’ Living with Autism study, in an event hosted by the National Press Club and broadcast via EPGL’s EP LiveOnline venue. Due to the high number of military families with a member with autism and EPGL’s commitment to military families and professionals, EPGL, although not contracted to provide online seminars in its FY07 continuation contract, made a concerted effort to send information to its military contacts about this program. One hundred and thirty military family members and staff registered for the event, representing a military presence of 9.3 percent for the event. (See Appendix IV for more information about the attendees at this online event.)

The relationship between EPGL and the U.S. Army has fostered goodwill and the broader dissemination of information among all U.S. Military services. (See Appendix V for Response to Exceptional Family Transitional Training Program and Appendix IX for editorial contributions from the various services.)

Key Research Accomplishments*

- EP positively impacted military families, caregivers, educators, and professionals providing care, support, and services to people with disabilities and special needs.
- Feedback from EFMP staff and family members indicates that the support and education provided is making a difference. The support extends to: the entire family leading the military lifestyle, the family member who is directly serving, and to the U.S. Military in its quest for heightened unit readiness.
- EP has provided military families and professionals information over the long term and resources that can be accessed time and time again, instilling a sense of security and the knowledge that EP can be relied upon to fulfill healthcare and educational needs.
• EFMP Managers and Coordinators describe their jobs as being made easier as a result of the resources provided by EP.
• The impact of the resources has led FMWRC staff, EFMP staff, and families to request additional services to the EFTTP base agreement. These will be delivered in 2009.
• EP has positively affected the perception of people regarding the military’s care for its families.
• EP’s project with the U.S. Army has had a lasting impact on families and professionals in other branches and services of the U.S. Military.
• EP’s seminars reached registrants in all 50 states in the U.S. and in other countries and areas worldwide. (See Appendix IV for other countries and areas reached.)

(*See Appendix VII for responses to the EFTTP.)

Reportable Outcomes
As a result of the positive feedback from Army personnel in FMWRC, IMCOM, and MEDCOM, and the feedback provided by families to EFMP Managers and Coordinators as well as from EFMP Managers and Coordinators to EPGL, EPGL was able to move forward with an FY07 continuation proposal for the EFTTP. The Army approved the continuation proposal, and EPGL delivered its services in 2008. EPGL made an additional, separate proposal to the Army for 2009, for the continuation of subscriptions and pocket resource guides for the eighty-two installations and contacts. This has also been very recently approved. EPGL has already begun these services.

EPGL’s successful relationship with the U.S. Army and the demonstration of the benefits to the military community of the Exceptional Family Transitional Training Program for those with disabilities and special needs has helped other services to increase their resources to meet their families’ and staff members’ needs. The U.S. Coast Guard in 2008 ordered subscriptions of EP magazine for distribution to Coast Guard Clinics, Coast Guard ISC Work-Life offices and Coast Guard Child Development Centers. The Coast Guard also will be distributing to its families and staff 4,000 copies of a Coast Guard customized EP Pocket Resource Guide.

(To see the impact of services on a global scale, see Appendix IV for the number of people, including physicians, allied healthcare professionals, and educators who attended EP’s military and general online seminars and for the broad participation from registrants around the world. See Appendix V for the broad distribution of EP magazine to installations. See Appendix VII for response to the Exceptional Family Transitional Training Program from people in various services within the U.S. Military.)

Conclusion
The assistance, relief, education, and reliability of the EFTTP has made an impact on the U.S. Military at a critical time in history, in the midst of a pressing need for heightened unit readiness. The services that EP has delivered tell our Soldiers that while they are gone and when they return they will have a place to turn for support and guidance, not only for themselves but for their loved ones. Due to the impact of the EFTTP, the Army Advisory Board has placed its trust in EPGL to help take care of its servicemen and servicewomen and their families now and in the foreseeable future. Additional U.S. Military services have turned to EPGL to provide expertise in the disabilities and special needs arena so that they can best meet the needs of their committed military families and healthcare and educational professionals.

Just as assistive technology devices and various therapies make life easier and fuller for individuals and families faced with the challenge of disabilities, so too does the multipurpose,
educational reference tool of *EP* magazine and its accompanying products, EP Bookstore and EP LiveOnline. Medical, mental health, educational, and comfort tool all in one, *EPGL* and its accompanying products have caused EFMP individuals, families, managers, and other caregivers and professionals to feel that they are better understood and better prepared to face the day-to-day challenges of special needs and to move forward more confidently and better prepared for the future.

The level of participation by military members in EPGL’s general online collaboration regarding the *Living with Autism* study powerfully reinforces the desire of and need for military family members and professionals to have information, support, and guidance.

It should be noted that most of the work included in the EFTTP was directed and for the primary benefit of the U.S. Army. Having demonstrated this proof of principle, it is clear that this effort needs to have outreach into other branches of service as well as to our National Guard and Reserve units and to our Veterans Administration system. We hope that this report will spur efforts to foster support for this expansion, as there is one very important consideration emanating from our experience with the EFTTP. It is this: Caring for those who have borne the burden of war is a responsibility that extends to all branches of service and to their families as well. That care is a joint responsibility of our Department of Defense as well as our citizens.

As more Soldiers return home from combat and work to reintegrate themselves back into their families and communities, and the Department of Defense seeks to find ways to help them cope with traumatic brain injury and post-traumatic stress disorder as well as other physical and mental health issues, EPGL’s relationships and ability to reach not only the professional healthcare and education communities but everyday families allows it to be a conduit to a better life for the members of the United States Military and to serve as a strong ally in the DoD’s mission of protecting and taking care of its servicemembers and its families.

**References**

None.

**Appendices**

Appendices I through IX follow.
APPENDIX I

EP Products & Resources Benefiting the U.S. Army

EP Magazine
416 Main Street
Johnstown, PA 15901
(814) 361-3860 / 1-800-372-7368   Fax (814) 361-3861

EP Web Site
http://www.eparent.com

EP Bookstore Site/Page
http://www.epbookstore.com

EP LiveOnline Site/Page
http://www.epliveonline.com
APPENDIX II

2008

Paid Project Personnel

1. Joseph M. Valenzano, Jr.
2. James P. McGinnis
3. Kerry C. Dauphineè
4. Riley C. Miller
5. Maria T. Caroff
APPENDIX II

2007

Paid Project Personnel

1. Joseph M. Valenzano, Jr.
2. James P. McGinnis
3. Kerry C. Dauphineè
4. Riley C. Miller
5. Maria T. Caroff
<table>
<thead>
<tr>
<th></th>
<th>Contract Estimate</th>
<th>Actual Expense</th>
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</thead>
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<tr>
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<td></td>
<td></td>
</tr>
<tr>
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<td>$ 46,600</td>
<td>$ 46,600</td>
</tr>
<tr>
<td>James P. McGinnis</td>
<td>$ 9,576</td>
<td>$ 9,576</td>
</tr>
<tr>
<td>Kerry C. Dauphineè</td>
<td>$ 29,043</td>
<td>$ 29,043</td>
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<tr>
<td>Riley C. Miller</td>
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<td><strong>Total Costs</strong></td>
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# APPENDIX III

## 2007

### DETAILED COST ESTIMATE

**FY 2006 Contract vs. Actual Expenses**

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<td>$102,901</td>
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<td>$  15,301</td>
<td>$  15,301</td>
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<td>Kerry C. Dauphineé</td>
<td>$  47,281</td>
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<td>Riley C. Miller</td>
<td>$  41,899</td>
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<td>Maria T. Caroff</td>
<td>$  41,899</td>
<td>$  41,899</td>
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<tr>
<td><strong>Subtotals</strong></td>
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<td><strong>$254,186</strong></td>
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</table>

<table>
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<th>Contract</th>
<th>Actual</th>
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<tr>
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<td>$194,775</td>
</tr>
<tr>
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<td>$  13,463</td>
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<td>Online Seminars</td>
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<td>$117,551</td>
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<td>$</td>
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<tr>
<td><strong>Total Costs</strong></td>
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<td><strong>$830,650</strong></td>
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</table>
APPENDIX IV

2008

EP LiveOnline Event

Conference Re: Easter Seals’ *Living with Autism* Study

Hosted by the National Press Club

December 16, 2008

<table>
<thead>
<tr>
<th>Pediatricians</th>
<th>Neurologists</th>
<th>Family Practitioners</th>
<th>Nurses</th>
<th>Speech/Language Pathologists</th>
<th>EFMP Staff</th>
<th>Parents</th>
<th>Teachers</th>
<th><em>Others</em></th>
<th>Military Registrants Total</th>
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<tbody>
<tr>
<td>8</td>
<td>2</td>
<td>3</td>
<td>10</td>
<td>2</td>
<td>5</td>
<td>37</td>
<td>12</td>
<td>51</td>
<td>130</td>
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</table>

OVERSEAS REGISTRANTS: 26

NUMBER OF STATES WITHIN THE UNITED STATES REPRESENTED AMONG REGISTRANTS: 25 plus 1 registrant in Washington, D.C. = 26

*Others ~ The list that follows includes other types of registrants for the event. (Note: This list includes only those registrants who noted their occupation.)*

Administrator, Adult Day Care, Board Certified Behavior Analyst, Case Manager, Case Worker, Child and Youth Specialist, Clinical Child Psychologist, Clinical Social Worker, Dietitian, Director of Child, Youth & School Services, Educator, Family Child Care Director, Family Resource Specialist, Grandmother, Mental Health Consultant, Nurse Practitioner, Occupational Therapist, Paraprofessional, Parent Advocate, Pediatric Neurologist, Physical Therapist, Program Coordinator/Social Worker, Program Manager, Psychologist, Rehabilitation Provider, Social Service Representative, Social Worker, Special Education Coordinator, Student.

Registrants also spanned the services in the U.S. Military and Homeland Security, from the Army, Navy, Marine Corps, and Air Force to the U.S. Coast Guard.
APPENDIX IV

2007

Military Online Seminar Statistics

<table>
<thead>
<tr>
<th>Program Title/Date</th>
<th>OTs/PTs</th>
<th>Nurses</th>
<th>Parents</th>
<th>Physicians</th>
<th>Speech/Language Pathologists</th>
<th>Teachers</th>
<th>*Others</th>
<th>Registrants Subtotal</th>
<th>Plus Registrants for All Six Seminars</th>
<th>Registrants Total</th>
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<tbody>
<tr>
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<td>15</td>
<td>114</td>
<td>34</td>
<td>6</td>
<td>31</td>
<td>104</td>
<td>331</td>
<td>550</td>
<td>881</td>
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<tr>
<td>ADHD II – September 19, 2007</td>
<td>8</td>
<td>9</td>
<td>66</td>
<td>20</td>
<td>5</td>
<td>22</td>
<td>65</td>
<td>195</td>
<td>550</td>
<td>745</td>
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<td>Autism I – October 17, 2007</td>
<td>28</td>
<td>20</td>
<td>170</td>
<td>44</td>
<td>37</td>
<td>106</td>
<td>266</td>
<td>671</td>
<td>550</td>
<td>1221</td>
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<tr>
<td>Autism II – October 24, 2007</td>
<td>17</td>
<td>16</td>
<td>143</td>
<td>31</td>
<td>48</td>
<td>77</td>
<td>165</td>
<td>497</td>
<td>550</td>
<td>1047</td>
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<tr>
<td>Respite Care – Streamed since July 2007</td>
<td>5</td>
<td>15</td>
<td>59</td>
<td>6</td>
<td>4</td>
<td>8</td>
<td>79</td>
<td>176</td>
<td>550</td>
<td>726</td>
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<tr>
<td>Asthma – December 6, 2007</td>
<td>7</td>
<td>16</td>
<td>17</td>
<td>12</td>
<td>2</td>
<td>5</td>
<td>41</td>
<td>100</td>
<td>550</td>
<td>650</td>
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<tr>
<td><strong>SUBTOTAL</strong></td>
<td><strong>92</strong></td>
<td><strong>91</strong></td>
<td><strong>569</strong></td>
<td><strong>147</strong></td>
<td><strong>102</strong></td>
<td><strong>249</strong></td>
<td><strong>720</strong></td>
<td><strong>1970</strong></td>
<td><strong>3300</strong></td>
<td><strong>5270</strong></td>
</tr>
</tbody>
</table>

| Registered for All Six Military Programs | 40 | 26 | 65 | 62 | 13 | 63 | 281 | 550 |
| **TOTAL**                              | **132** | **117** | **634** | **209** | **115** | **312** | **1001** | **550** |

*Others ~ The list that follows includes a representative sampling of other types of registrants for the military online seminars:

ABA Therapist; Administrator; Advocate; Assistive Technician; Aunt of ADHD Nephew; Behavioral Specialist; Caregiver; Case Worker; CEO; Child Psychologist; Clinical Kinesiologist; Clinical Pediatric Dietician; Dentist; Developmental Behavioral Pediatrician; Developmental Disabilities Coach; Developmental Specialist; Early Intervention Specialist; Educational Assistant; Educational Diagnostician; Educator; EFMP Coordinator; EFMP Manager; Family Counselor; Family Practitioner; Family Support Specialist; Genetic Counselor; Grandparent; Group Home Supervisor; Guardian; In-home and Parent Trainer; Internist; Job Developer/Job Coach; Licensed Mental Health Counselor; Media Professional; Mental Health Therapist; MR/DD Service Provider; Nephew with Disabilities; Neurologist; Nurse Practitioner; Ob-Gyn; Optometrist; Orthopedic Surgeon; Orthotist/Prosthetist; Pediatric Neurologist; Person with Autism; Pharmacist; Program Planner; Psychiatric Social Worker; Psychiatrist; Psychiatry Resident; Psychotherapist; Public Health Analyst; Recreation Therapist; Rehabilitation Counselor; Researcher; Sibling; School Psychologist; School Social Worker; Social Services Professional; Social Worker; Student; Teacher; Therapeutic Staff Support; Vibroacoustic Therapist

Registrants also spanned the services in the U.S. Military and Homeland Security, from the Army, Navy, Marine Corps, and Air Force to the U.S. Coast Guard.
APPENDIX IV

2007

Military Online Seminar Statistics

Registrants also participated from all 50 states in the United States, as well as from the U.S. territory of Puerto Rico and other countries and areas worldwide. (Note: This listing is a partial one, due to some registrants not entering their location information. From the data, it can be extrapolated that other countries were represented but are not known at this time. There were multiple participants in some countries, from different areas of the country. A sampling of locations follows.)

1. Alberta, Canada
2. American Samoa
3. Armenia
4. Athens Island, Greece
5. Baja California, Mexico
6. Berlin, Germany
7. Bogota, Colombia
8. Brazil
9. Brisbane, Queensland, Australia
10. British Columbia, Canada
11. Brunei Darussalam
12. Cairo, Egypt
13. Calgary, Alberta, Canada
14. Cluj, Romania
15. Cundinamarca, Colombia
16. Dubai, United Arab Emirates
17. Flinders NSW, Australia
18. Hong Kong
19. IMCOM – Europe
20. Israel
21. Kenya
22. Korea
23. Kuwait
24. Landstuhl, Germany
25. Manila, Philippines
26. Manipal, Karnataka, India
27. Manitoba, Canada
28. Nassau, Bahamas NP
29. Newfoundland & Labrador, Canada
30. Nova Scotia, Canada
31. Ontario, Canada
32. Poland
33. Quebec City, Quebec, Canada
34. Quezon City, Philippines
35. Republic of Georgia
36. Sacavém, Portugal
37. San Salvador, El Salvador
38. Saskatchewan, Canada
39. Saudi Arabia
40. Secundrabad, India
41. Singapore
42. Skudai, Johor, Malaysia
43. South Australia, Australia
44. Surco, Lima, Peru
45. Thailand
46. The Netherlands
47. Tønsberg, Vestfold, Norway
48. Trivandrum, Kerala, India
49. Uganda
50. United Kingdom
51. Victoria, Australia
52. Wellington, New Zealand
## APPENDIX V

**2008**

**Magazine Redistribution**

<table>
<thead>
<tr>
<th>Installation/Organization</th>
<th>Quantity</th>
</tr>
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<tr>
<td>1. Aberdeen Proving Ground</td>
<td>40</td>
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<tr>
<td>2. Anniston Army Depot</td>
<td>40</td>
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<tr>
<td>3. Carlisle Barracks</td>
<td>50</td>
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<tr>
<td>4. Fort Belvoir</td>
<td>100</td>
</tr>
<tr>
<td>5. Fort Benning</td>
<td>350</td>
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<tr>
<td>6. Fort Bliss</td>
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<tr>
<td>7. Fort Bragg</td>
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<tr>
<td>8. Fort Buchanan</td>
<td>40</td>
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<tr>
<td>9. Fort Campbell</td>
<td>500</td>
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<tr>
<td>10. Fort Carson</td>
<td>250</td>
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<tr>
<td>11. Fort Detrick</td>
<td>10</td>
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<tr>
<td>12. Fort Dix</td>
<td>40</td>
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<tr>
<td>13. Fort Drum</td>
<td>150</td>
</tr>
<tr>
<td>14. Fort Eustis</td>
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</tr>
<tr>
<td>15. Fort Gordon</td>
<td>300</td>
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<tr>
<td>16. Fort Greely</td>
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<tr>
<td>17. Fort Hamilton</td>
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<td>18. Fort Hood</td>
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<td>19. Fort Huachuca</td>
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<td>20. Fort Irwin</td>
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<td>24. Fort Lee</td>
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<td>26. Fort Lewis</td>
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## APPENDIX V

### 2008

**Magazine Redistribution**

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<td>29. Fort Monmouth</td>
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<tr>
<td>41. IMCOM–Europe</td>
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<tr>
<td>42. IMCOM–Korea</td>
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<td>43. IMCOM–Northeast</td>
<td>4</td>
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<td>44. IMCOM–Pacific</td>
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<td>45. IMCOM–Southeast</td>
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<td>46. IMCOM–West</td>
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</tr>
<tr>
<td>47. MEDDAC–Fort Polk</td>
<td>25</td>
</tr>
<tr>
<td>48. MEDDAC–Fort Sam Houston</td>
<td>15</td>
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<tr>
<td>49. Picatinny Arsenal</td>
<td>40</td>
</tr>
<tr>
<td>50. Presidio of Monterey</td>
<td>10</td>
</tr>
<tr>
<td>51. Redstone Arsenal</td>
<td>120</td>
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<tr>
<td>52. Rock Island Arsenal</td>
<td>10</td>
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<tr>
<td>53. Schofield Barracks</td>
<td>300</td>
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<tr>
<td>54. Tobyhanna Army Depot</td>
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### APPENDIX V

**2008**

**Magazine Redistribution**

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</tr>
<tr>
<td>56. USAG Bamberg</td>
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<tr>
<td>57. USAG Baumholder</td>
<td>160</td>
</tr>
<tr>
<td>58. USAG Benelux</td>
<td>40</td>
</tr>
<tr>
<td>59. USAG Camp Zama, Japan</td>
<td>160</td>
</tr>
<tr>
<td>60. USAG Casey</td>
<td>40</td>
</tr>
<tr>
<td>61. USAG Daegu</td>
<td>40</td>
</tr>
<tr>
<td>62. USAG Heidelberg</td>
<td>60</td>
</tr>
<tr>
<td>63. USAG Honenfels</td>
<td>40</td>
</tr>
<tr>
<td>64. USAG Humphries</td>
<td>40</td>
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<tr>
<td>65. USAG Kaiserslautern</td>
<td>200</td>
</tr>
<tr>
<td>66. USAG Livorno</td>
<td>40</td>
</tr>
<tr>
<td>67. USAG Mannheim</td>
<td>200</td>
</tr>
<tr>
<td>68. USAG Miami</td>
<td>80</td>
</tr>
<tr>
<td>69. USAG Schinnen</td>
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<tr>
<td>70. USAG Schweinfurt</td>
<td>50</td>
</tr>
<tr>
<td>71. USAG Stuttgart</td>
<td>120</td>
</tr>
<tr>
<td>72. USAG Torii Station</td>
<td>40</td>
</tr>
<tr>
<td>73. USAG Vicenza</td>
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<tr>
<td>74. USAG Vilseck/Grafenwoehr</td>
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</tr>
<tr>
<td>75. USAG Wiesbaden</td>
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<tr>
<td>76. USAG Yongsan</td>
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<tr>
<td>77. Congressman John Murtha</td>
<td>20</td>
</tr>
<tr>
<td>78. Family and Morale, Welfare and Recreation Command</td>
<td>13</td>
</tr>
<tr>
<td>79. General Dynamics Information Technologies</td>
<td>2</td>
</tr>
<tr>
<td>80. Office of the Surgeon General</td>
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</tr>
<tr>
<td>81. United States Military Academy at West Point</td>
<td>40</td>
</tr>
<tr>
<td>82. Walter Reed Army Medical Center</td>
<td>50</td>
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</table>

**TOTAL** | **8,122**
## APPENDIX V

### 2007

**Magazine Redistribution**

<table>
<thead>
<tr>
<th>Status</th>
<th>Installation</th>
<th>Desired Count</th>
<th>Cumm Desired</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. MAG</td>
<td>Fort Benning</td>
<td>350</td>
<td>350</td>
</tr>
<tr>
<td>2. MAG</td>
<td>Fort Bliss</td>
<td>250</td>
<td>600</td>
</tr>
<tr>
<td>3. MAG</td>
<td>Fort Carson</td>
<td>250</td>
<td>850</td>
</tr>
<tr>
<td>4. MAG</td>
<td>Fort Drum</td>
<td>150</td>
<td>1,000</td>
</tr>
<tr>
<td>5. MAG</td>
<td>Fort Gordon</td>
<td>300</td>
<td>1,300</td>
</tr>
<tr>
<td>6. MAG</td>
<td>Fort Knox</td>
<td>500</td>
<td>1,800</td>
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<tr>
<td>7. MAG</td>
<td>Fort Riley</td>
<td>150</td>
<td>1,950</td>
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<td>8. MAG</td>
<td>Fort Sam Houston</td>
<td>500</td>
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<tr>
<td>9. PIL</td>
<td>Fort Belvoir</td>
<td>100</td>
<td>2,550</td>
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<tr>
<td>10. PIL</td>
<td>Fort Bragg</td>
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<td>2,700</td>
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<tr>
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<tr>
<td>12. PIL</td>
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<td>3,700</td>
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<td>Kaiserslautern</td>
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<td>5,240</td>
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<tr>
<td>NEW</td>
<td>Fort McPherson</td>
<td>29</td>
<td>120</td>
</tr>
<tr>
<td>NEW</td>
<td>Fort Meade</td>
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<td>80</td>
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<td>NEW</td>
<td>Fort Monmouth</td>
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<td>Fort Monroe</td>
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<td>NEW</td>
<td>Fort Myer</td>
<td>33</td>
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<tr>
<td>NEW</td>
<td>Fort Polk</td>
<td>34</td>
<td>30</td>
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<td>NEW</td>
<td>Fort Rucker</td>
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<td>NEW</td>
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<tr>
<td>NEW</td>
<td>Picatinny</td>
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<td>40</td>
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<td>NEW</td>
<td>Redstone Arsenal</td>
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</tr>
<tr>
<td>NEW</td>
<td>Tobyhanna</td>
<td>39</td>
<td>40</td>
</tr>
<tr>
<td>NEW</td>
<td>USAG-Ansbach</td>
<td>40</td>
<td>80</td>
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<tr>
<td>NEW</td>
<td>USAG-Bamberg</td>
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<td>160</td>
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<tr>
<td>NEW</td>
<td>USAG-Baumholder</td>
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<tr>
<td>NEW</td>
<td>USAG-Benelux</td>
<td>43</td>
<td>40</td>
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<tr>
<td>NEW</td>
<td>USAG-Casey</td>
<td>44</td>
<td>40</td>
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<tr>
<td>NEW</td>
<td>USAG-Daegu</td>
<td>45</td>
<td>40</td>
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<tr>
<td>NEW</td>
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<td>USAG-Heidelberg</td>
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<td>USAG-Hohenfels</td>
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<tr>
<td>NEW</td>
<td>USAG-Humphries</td>
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<td>40</td>
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<tr>
<td>NEW</td>
<td>USAG-Mannheim</td>
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<td>200</td>
</tr>
<tr>
<td>NEW</td>
<td>USAG-Miami</td>
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<td>80</td>
</tr>
<tr>
<td>NEW</td>
<td>USAG-Schinnen</td>
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<td>40</td>
</tr>
<tr>
<td>NEW</td>
<td>USAG-Schweinfurt</td>
<td>53</td>
<td>40</td>
</tr>
<tr>
<td>NEW</td>
<td>USAG-Stuttgart</td>
<td>54</td>
<td>120</td>
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</table>
### APPENDIX V

#### 2007

Magazine Redistribution

<table>
<thead>
<tr>
<th>Status</th>
<th>Installation</th>
<th>Desired</th>
<th>Cumm</th>
</tr>
</thead>
<tbody>
<tr>
<td>55. NEW</td>
<td>USAG-Torii Station</td>
<td>40</td>
<td>7,230</td>
</tr>
<tr>
<td>56. NEW</td>
<td>USAG-Vicenza</td>
<td>40</td>
<td>7,270</td>
</tr>
<tr>
<td>57. NEW</td>
<td>USAG-Vilseck</td>
<td>160</td>
<td>7,430</td>
</tr>
<tr>
<td>58. NEW</td>
<td>USAG-Wainwright</td>
<td>80</td>
<td>7,510</td>
</tr>
<tr>
<td>59. NEW</td>
<td>USAG-Wiesbaden</td>
<td>320</td>
<td>7,830</td>
</tr>
<tr>
<td>60. NEW</td>
<td>USAG-Yongsan</td>
<td>40</td>
<td>7,870</td>
</tr>
<tr>
<td>61. NEW</td>
<td>USMA</td>
<td>40</td>
<td>7,910</td>
</tr>
<tr>
<td>62. NEW</td>
<td>WRAMC</td>
<td>40</td>
<td>7,950</td>
</tr>
<tr>
<td></td>
<td>Comp Issues to Support EFTTP</td>
<td>172</td>
<td>8,122</td>
</tr>
</tbody>
</table>

122 magazines distributed without compensation
APPENDIX VI

2008

Survey for Magazine Distribution
EFMP Managers
July 2008
Survey

Installation: ________________________________________________________________

EFMP Manager/Coordinator: __________________________________________________

EP is conducting a brief survey to ensure that the distribution of EP magazine is meeting the needs of your staff and families. As we talk with FMWRC leadership regarding current and future redistribution and/or increased delivery of the magazine to installations, we want to provide them with an accurate picture of your needs. Prompting our survey is an inquiry from OTSG regarding copies of the magazine to healthcare personnel.

<table>
<thead>
<tr>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
<th>Q5</th>
</tr>
</thead>
<tbody>
<tr>
<td># Receiving</td>
<td>Increase? (Y/N)</td>
<td>Increase by</td>
<td>Decrease by</td>
<td>Total Needed</td>
</tr>
<tr>
<td>1</td>
<td>How many copies of EP magazine do you receive each month?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>If more could be made available, would you use more?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>How many magazines do you need?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>Do you have pediatricians and other physicians on your installation? Do they receive the magazine?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>a. Do you have other healthcare professionals on your installation, such as nurses, physical therapists, occupational therapists, and speech therapists? Do they receive the magazine?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>b. Who distributes the magazines to families and staff at your location?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>Where and how do you distribute the magazines?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comments ________________________________________________________________

________________________________________________________________________

________________________________________________________________________

31
## APPENDIX VI

### Survey for Magazine Distribution

**EFMP Managers**
**July 2008**

### Results

<table>
<thead>
<tr>
<th>Installation Name</th>
<th>EFMP Manager</th>
<th>Physicians on Base?</th>
<th>Allied on Base?</th>
<th># Allotted</th>
<th># Receiving</th>
<th># Desired</th>
<th>Increase by</th>
<th>Decrease by</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Over 100 Subscriptions</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1 Fort Benning, GA – 350</td>
<td>Marsha Collins</td>
<td>Y / Y</td>
<td>N / Y*</td>
<td>350</td>
<td>300</td>
<td>400</td>
<td>50</td>
<td>NA</td>
</tr>
<tr>
<td>2 Fort Bliss, TX – 250</td>
<td>Jessica Torrence</td>
<td>Y / Y</td>
<td>Y / Y</td>
<td>250</td>
<td>250</td>
<td>250</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>3 Fort Bragg, NC – 150</td>
<td>Trisha Thurston</td>
<td>Y / Y</td>
<td>Y / Y</td>
<td>150</td>
<td>150</td>
<td>150</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>4 Fort Campbell, KY – 500</td>
<td>Tresca Ramtahal</td>
<td>Y / Y</td>
<td>Y / Y</td>
<td>500</td>
<td>500</td>
<td>800</td>
<td>300</td>
<td>NA</td>
</tr>
<tr>
<td>5 Fort Carson, CO – 250</td>
<td>Annette Hawthorne</td>
<td>Y / Y</td>
<td>Y / Y</td>
<td>250</td>
<td>250</td>
<td>250</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>6 Fort Drum, NY – 150</td>
<td>Sharon Chaple</td>
<td>Y / Y</td>
<td>N / N</td>
<td>150</td>
<td>150</td>
<td>150</td>
<td>NA</td>
<td>NA</td>
</tr>
<tr>
<td>7 Fort Hood, TX – 500</td>
<td>Joan Boykin</td>
<td>Y / Y</td>
<td>Y / ?</td>
<td>500</td>
<td>500</td>
<td>1500</td>
<td>1000</td>
<td>NA</td>
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<tr>
<td>8 Fort Riley, KS – 150</td>
<td>Laura McCauley</td>
<td>No Response</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
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<tr>
<td>9 Fort Sill, OK – 125</td>
<td>Julie Franklin</td>
<td>No Response</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>10 Fort Stewart, GA – 500</td>
<td>Mavis Crowell</td>
<td>Y / ?</td>
<td>Y / Y</td>
<td>500</td>
<td>250</td>
<td>700</td>
<td>200</td>
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<td><strong>50 to 100 Subscriptions</strong></td>
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<tr>
<td>11 Fort Belvoir, VA – 50</td>
<td>Rene Fizer</td>
<td>Y / N</td>
<td>N / N</td>
<td>50</td>
<td>25</td>
<td>100</td>
<td>50</td>
<td>NA</td>
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<tr>
<td>12 Fort Lee, VA – 80</td>
<td>Judy Eoff</td>
<td>Y / ?</td>
<td>Y / ?</td>
<td>80</td>
<td>Does not know</td>
<td>180</td>
<td>100</td>
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<tr>
<td>13 Fort Lewis, WA – 100</td>
<td>Mary Herrera</td>
<td>Y / Y</td>
<td>Y / ?</td>
<td>100</td>
<td>100</td>
<td>100</td>
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<td>NA</td>
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<td>14 Fort Meade, MD – 80</td>
<td>Sue Carter</td>
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<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>15 Fort Richardson, AR – 100</td>
<td>Shaunta Brown</td>
<td>No Response</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>16 Fort Wainwright, AR – 100</td>
<td>D'Letter Shumate</td>
<td>Y / Y</td>
<td>Y / Y</td>
<td>100</td>
<td>100</td>
<td>100</td>
<td>NA</td>
<td>NA</td>
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<td><strong>Under 50 Subscriptions</strong></td>
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<tr>
<td>18 Fort Monmouth, NJ – 40</td>
<td>Marcia Wooten (interim outreach)</td>
<td>Y / Y</td>
<td>N / NA</td>
<td>40</td>
<td>Does not know</td>
<td>40</td>
<td>NA</td>
<td>NA</td>
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<tr>
<td>19 Fort Monroe, VA – 40</td>
<td>Marie Hinton (EFMP helper)</td>
<td>Y / N</td>
<td>Y / N</td>
<td>40</td>
<td>Sporadic</td>
<td>40</td>
<td>NA</td>
<td>NA</td>
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<tr>
<td>20 Fort Polk, LA – 40</td>
<td>Victoria Scott</td>
<td>Y / Y</td>
<td>Y / Y</td>
<td>40</td>
<td>40</td>
<td>75</td>
<td>35</td>
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</tr>
<tr>
<td>21 Schofield Barracks, HI – 300</td>
<td>Jane Bruns</td>
<td>Y / Y</td>
<td>Y / Y</td>
<td>300</td>
<td>300</td>
<td>300</td>
<td>NA</td>
<td>NA</td>
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<tr>
<td>22 USMA at West Point, NY – 40</td>
<td>Josephine Toohey</td>
<td>No Response</td>
<td>—</td>
<td>—</td>
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<td>—</td>
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<td>—</td>
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<td><strong>Total</strong></td>
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### APPENDIX VI

#### 2008

**Survey for Magazine Distribution**  
**EFMP Managers**  
**July 2008**

#### Comments

<table>
<thead>
<tr>
<th>Installation Name</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fort Benning, GA – 350</strong></td>
<td>Marsha and helper hand deliver, via their vehicles. Provide a big cartload to the director of Special Education, who contacts the teachers to come and get the magazines. Drop off magazines at each school. Probably made a mistake in decreasing from 500 to 300. Also provide to Children and Youth Services – central registration, training, and curriculum. Early intervention comes and picks up copies. Take to medical EFMP office; provide to chief of pediatrics. Place in lobby. Place in the in-processing office – they really appreciate them. Schools have gotten so spoiled – send the magazines home in the students’ bookbags each month. We don’t throw them away – used for reference later. Took up to MEDDAC today. Provide to chaplain’s office, including Resource Guide. Sent Pocket Resource Guides to folks. Receiving magazines in spurts. Seems like not getting as many as before. *On Stats Page – OTs, PTs, etc., not in base clinic, but in the student services office.</td>
</tr>
<tr>
<td><strong>Fort Bliss, TX – 250</strong></td>
<td>Bliss has not had a problem with distribution. They want more magazines in the future because they are adding tactical units to their installations in the future. They support pinpoint distribution to their hospitals instead of relying on couriers to deliver the magazine to the hospital.</td>
</tr>
<tr>
<td><strong>Fort Bragg, NC – 150</strong></td>
<td>We place the magazines in multiple information areas: lobby; magazine rack; main ACS office; EFMP lobby area; at monthly fairs, events, and activities. Take them to hospitals and four outlying clinics; to EDIS (Early Development Intervention Services), which is co-located with the EFMP on the medical side. A staff person takes them over.</td>
</tr>
<tr>
<td><strong>Fort Campbell, KY – 500</strong></td>
<td>Use personal vehicles to distribute; work into schedule. Place magazines in the rack and in the lobby. Place at Family Resource Center; Education Center; and with Early Intervention Support Groups. Get to EFMP medical staff, including developmental pediatrician. Would like the magazines to be distributed to our building. Difficult to get to the building next door to get them.</td>
</tr>
<tr>
<td><strong>Fort Carson, CO – 250</strong></td>
<td>No problems with receiving magazines or with distributing magazines at the installation. 250 is sufficient at present, but do see a need for more magazines in the future as troop densities increase.</td>
</tr>
<tr>
<td><strong>Fort Drum, NY – 150</strong></td>
<td>I do most of the distributing. Place at soldiers’ in-processing center; at MEDDAC; in ACS building; provide to parents and other individuals stopping in. Place in welcome packets of those who have requested and will read it. Send them to EFMP nurse manager.</td>
</tr>
<tr>
<td><strong>Fort Hood, TX – 500</strong></td>
<td>Fort Hood is expanding with units being restationed from Germany as part of BRAC. They anticipate a large increase in soldiers and families in the coming years. They receive 500 magazines now and could use 1500 magazines now. Their distribution includes healthcare professionals at the hospital in addition to families and other family support specialists. They have an aggressive distribution plan that includes mailing magazines to selected families as needed.</td>
</tr>
</tbody>
</table>
## APPENDIX VI

### 2008

**Survey for Magazine Distribution**

**EFMP Managers**

**July 2008**

**Comments**

<table>
<thead>
<tr>
<th>Installation Name</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Over 100 Subscriptions (cont.)</strong></td>
<td></td>
</tr>
<tr>
<td>Fort Riley, KS – 150</td>
<td>No response</td>
</tr>
<tr>
<td>Fort Sill, OK – 125</td>
<td>No response</td>
</tr>
<tr>
<td>Fort Stewart, GA – 500</td>
<td>It is mostly me that delivers the magazines; two others help out. Changed mode of delivery from UPS to Post Office: not getting the magazines like we used to; getting about ½; some are torn up. Received the May and June issues around the same time. Distribute to the special needs on-post school. Provide for families at off-post schools. Provide to hospital EFMP; to the Early Intervention Program; child development center; the in-processing building; the PX; the lobbies of some buildings.</td>
</tr>
<tr>
<td><strong>50 to 100 Subscriptions</strong></td>
<td></td>
</tr>
<tr>
<td>Fort Belvoir, VA – 50</td>
<td>Assistant or I distribute. Place in the rack in our office and in the lobby, and outside the door on the main floor. Used to take to organizations, agencies, and meetings and used to distribute to pediatricians but have not been since all of shipment is not arriving. Used to take to Children and Youth Services, where they were taken quickly. Used to take to child development centers, to the hospital, and to the schools.</td>
</tr>
<tr>
<td>Fort Lee, VA – 80</td>
<td>Three of us deliver the magazines: manager and two assistants. We deliver them immediately. It truly is not a problem for us. We are back and forth once a day with paperwork. We take 1/3 to Children and Youth Services (CYS); 1/3 to our counterparts in the Kenner Army Clinic; and we keep 1/3. CYS and the hospital soak them up. They are very, very well received. Always on display in our EFMP office – when patrons come by, for trainings and support groups, they are available. We place them in two offices in the anteroom. Our resource library has back copies. We place them in welcome packets.</td>
</tr>
<tr>
<td>Fort Lewis, WA – 100</td>
<td>100 copies is just about perfect for Fort Lewis. We had problems with distribution in June when we only received 10 individual copies of the magazine.</td>
</tr>
<tr>
<td>Fort Meade, MD – 80</td>
<td>No response</td>
</tr>
</tbody>
</table>
### Comments

<table>
<thead>
<tr>
<th>Installation Name</th>
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</tr>
</thead>
<tbody>
<tr>
<td>50 to 100 Subscriptions (cont.)</td>
<td>Wainwright receives the magazine most of the time. Some shipments have seemed short but no count has been made to verify that statement. Will count next time to verify the numbers. The support group parents “love the magazine.” They share the magazine by passing the magazine from household to household. The next month, they discuss an article or two as they apply to the support group. They appreciate the information and trust it to be accurate and current. Wainwright ships magazines to Fort Greely. Greely is a sub-installation of Wainwright. Will send an address at Greely for us to ship magazines to. Greely is about three hours away by vehicle and getting magazines to them is a challenge sometimes.</td>
</tr>
<tr>
<td>Fort Richardson, AR – 100</td>
<td>No response</td>
</tr>
<tr>
<td>Under 50 Subscriptions</td>
<td>Leonard Wood is content with the status quo. There are no distribution problems. More magazines would be appreciated, to increase the number of magazines available to the hospital and medical clinics, but the priority is to families.</td>
</tr>
<tr>
<td>Fort Monmouth, NJ – 40</td>
<td>Contact is Marcia Wooten (interim contact in Outreach Services until a new EFMP manager is hired). EFMP staff members walk the magazines to the clinic, which is within walking distance. Sometimes someone from the clinic comes over, and they’ll pick them up at that time. Lots of EFM cases – most are asthma. ACS handles the civilian EFM cases; the number of military cases is small. They will place the magazine in the library and see whether people pick it up there.</td>
</tr>
<tr>
<td>Fort Monroe, VA – 40</td>
<td>We’re not getting them monthly – approximately quarterly; hit and miss. Address okay. Small installation; headquarters post – not a lot of troops. Approximately 400 troops. Try to send out to families. Distribute at events. Have a clinic, not a hospital. Do not distribute at clinic. Give to newcomers. Place in the front lobby and in mailings.</td>
</tr>
<tr>
<td>Fort Polk, LA – 40</td>
<td>Polk has not had problems with the reception of magazines. The increase of units at Polk in the recent months has increased the workload of the EFMP manager and, as a result, has increased the demand for the magazine. Polk would be interested in pinpoint distribution if available.</td>
</tr>
<tr>
<td>Schofield Barracks, HI – 300</td>
<td>Schofield is very aggressive in distributing magazines to clinics, child development centers, commissaries and other members of the Department of Defense. Distribution to Tripler Army Medical Center is difficult, due to the distance between the installation and the hospital. The time spent traveling is about three to four hours in traffic, plus the time spent in the hospital. (The time in the hospital varies, due to the availability of the clinicians and other healthcare professionals.) Schofield would support a pinpoint distribution plan if one becomes available. Schofield has not had any problems with receiving the magazines for the most part. The magazine bundles did come in one month broken and the number of magazines received that month was considerably less. That reduction had an impact on their families.</td>
</tr>
<tr>
<td>USMA at West Point, NY – 40</td>
<td>No response</td>
</tr>
</tbody>
</table>
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2008

Survey for Magazine Distribution
EFMP Managers
July 2008

Comments

Comments:
Pinpoint distribution was a hot-button issue when introduced. The initiative came originally from a manager. Pinpoint distribution means taking magazines from the installation allocation and mailing those magazines directly to a clinic or other recipient on the installation. An example might be Schofield Barracks, where they receive 30 magazines at present. Hypothetically, 50 magazines would be diverted from the EFMP manager’s allocation and directly mailed. The EFMP manager would then receive 250 at her offices and the healthcare professional would receive 50 magazines at his or her location each month. The disadvantage to pinpoint distribution is that the face-to-face contact that the EFMP manager now has with the clinicians would be lost. Fort Hood is adamant about getting the personal contact. Some other installations are not. They see the time spent delivering magazines as time spent away from families.
Response to Exceptional Family Transitional Training Program

I wanted to thank you and everyone at EP again for publishing our family’s story. Since the issue has come out, we have had tons of positive feedback. The article has been sent to several legislators and used as an example to help convince leaders to make changes on both the medical and educational fronts (TRICARE autism policy and the recent decision by California legislators to audit OAH due process system, etc.) This is exactly why we wanted to get it out there—to help others. In addition, because of the article, I have been invited to be a speaker at the end of the month at the USSOCOM Care Coalition’s 3rd Annual Conference in North Carolina. I will be speaking to a roomful of high-ranking military leaders from all branches of service and others about our family’s story and how they can better support military families affected by autism. It will be an honor, and is an opportunity I believe was a direct result of EP Magazine’s effort to get stories like our family’s out to the public. Thanks so much for all that you do for families like ours and children like Kate!

~Kyla Doyle, Wife of a Marine Corps Master Sergeant and mother of two daughters, one of whom has autism

The Doyle family was featured in EP’s April 2008 cover story.

I want to thank you and EP for the outstanding training materials and books that we ordered. We have already incorporated information into our trainings. We were needing updated information.

Thank you again.

~Laurie McCauley
EFMP Manager, Fort Riley

Thank you for your persistence in contacting us to ensure we take advantage of such a wonderful opportunity provided by EP.

~Julie D. Franklin
EFMP Manager, Fort Sill, regarding book orders from EP Bookstore through the cooperative agreement

Thanks for the e-mail. I’m looking forward to the Web Cast conference hosted by Southern University. I hope there will be an archive for those of us in Europe; however, you can be sure that I will request copies of the presentation. I appreciate Exceptional Parent Magazine providing the U.S. Army’s Exceptional Family Member Program (EFMP) Coordinators an opportunity to participate in this Web Cast.

~Liz Mulcahey
EFMP Coordinator, U.S. Army Garrison – Darmstadt

In response to EPGL’s spreading notification to its military contacts regarding Southern University’s conference, Working on the Front: Ethics in Rehabilitation of Veterans
Thank you so much for the opportunity to have these resources!
~Gail Mortensen
EFMP Manager, Fort Huachuca, one of the thirteen installations selected by the Army to receive books from EP Bookstore

THANK YOU! THANK YOU, AGAIN AND AGAIN!!
~Charlotte Peterson, EFMP Manager, Fort Knox, one of the thirteen installations selected by the Army to receive books from EP Bookstore

Thank you for allowing the EFMP Managers to “sit in” on the Conference. Excellent and informative.
~Jennifer L. Burford
EFMP Manager, Fort Leavenworth
Regarding EPGL’s invitation to military personnel to attend the presentation regarding Easter Seals’ Living with Autism study, hosted by the National Press Club and broadcast via EPGL’s EP LiveOnline venue

I just viewed the EP LiveOnline: Easter Seals-Mass Mutual Living with Autism Study. I had requested to be notified when it was available for online viewing. That in itself was great as I was not able to attend the webcast. I found this information valuable and the guest speakers inspirational. I also appreciate being able to download the Findings and Study for future use.

Thank you so much for making this available and I look forward to other topics.
~Audrey Peterson-Hosto
EFMP Manager, Fort Huachuca

I am so pleased with the article, Wounded Warriors and Civilian Communities. Thank you for all of your support and kind editorial expertise. I hope that we have the opportunity to collaborate in the future.
~Brenda Murdough MSN, RN-C
Coordinator of the Military/Veterans Initiative
American Pain Foundation

I’m noting EP Magazines now on every installation I visit, and parents mentioned them in a recent focus group I conducted as well.

Thanks for your good work!
~Ann Schulte
Family Advocacy Program Manager
U.S. Army Installation Command–Northeast Region
It is an honor to provide information and support through this publication that will assist families who are facing these kinds of challenges. The military section of Exceptional Parent is a unique and powerful vehicle through which to communicate to families across the country and across the globe. The military families served by May Institute who we have profiled in our articles have all expressed gratitude for the opportunity to share their stories. They feel — and we agree — that their experiences, struggles, and achievements can offer hope and support to other military families in similar situations.

We are privileged to collaborate with Exceptional Parent, which has a long history of supporting both military and civilian families. Thank you for the good work you do in educating and supporting all families with special needs. It has been a pleasure to work with your team, and we are so pleased to continue our relationship with you in the coming year.

~Walter P. Christian, Ph.D., ABPP
President and Chief Executive Officer
May Institute, Inc.
APPENDIX VII

2007

Response to Exceptional Family Transitional Training Program

I feel so good about the work you are doing. It is really energizing the field and Families.
~Delores Johnson
Director of Family Programs, FMWRC

Since the article about our daughter was published in EP, I’ve received a lot of nice feedback about how the military was viewed negatively about supporting their members and families but this article has opened eyes and they are thankful to see that the military does take care of its people.

~Cindy Johnson, Retired Senior Master Sergeant, U.S. Air Force

I have had nothing but positive comments in reference to the magazines.
~Mavis Crowell, EFMP Manager, Fort Stewart

Everybody asks about them. They wish they could get them.
~Jennifer Funk, EFMP Assistant, Kaiserslautern, Germany, IMCOM-Europe, regarding installations not in the initial pilot and magazine program requesting copies of EP magazine

Your magazine is a lifeline for our folks out here, to include myself. The information provided is current and excellent. ... I hope the seminar is only the “Last” for this year.
~John Boullion
EFMP Manager, Torii Station

Since arriving late August I sent a mass email to my EFMP families to inform them of the online seminar. The feedback that I have received has been positive. They have all thanked me for information. I think our Families are empowered when they can relate to other Families who have similar needs. As I learn my community demographics the feeling of isolation and loneliness comes up more frequently with each Family I meet. I feel fortunate that I have these resources to refer my EFMP Families to.
~Josephine M. Toohey
EFMP Coordinator, West Point

The EP partnership has been very beneficial for our installation. The training has assisted a new EFMP staff gain knowledge to support our EFMP families. The EP magazine is wonderful and the EFMP staff and patrons both appreciate this support.
~Judy Eoff
EFMP Manager, Fort Lee

I find the EP Magazine as an excellent source of information!
~Marlene F. Cherrye
EFMP Manager, Fort Eustis
The EFMP Families at Picatinny Arsenal were delighted to receive their own copies of EP Magazine in December.

~Marci Keck
EFMP Manager, Picatinny Arsenal

I believe the teleconferences and webinars to be a valuable tool, especially for those in isolated areas.

~Heather Fiedler
EFMP Manager, Tobyhanna Army Depot

I find that the magazine itself is very helpful and take them home to read them when I can focus and have time. I have made copies of various articles in the magazine as a handout to parents at various times. I have also given the magazine to parents when they show an interest and I know that they will read it. ... I think it is definitely worth continuing the partnership as it is one of the few resources that I have come across to keep up my professional skills and info so that I can be a more effective manager.

~Michelle Hewitt
EFMP Manager, Fort Detrick

1. The most popular EP magazines are January’s resource directory and April’s Autism. One of my support groups/classes will deplete a monthly supply. The directory is a valuable tool in the reassignment process and informs parents of the new state’s resources and POCs prior to relocation. Would appreciate more magazines in these two months.

2. Although Fort Belvoir has the capability of offering teleconferences in our catchment area and marketing is optimal, parents (1) do not want to leave their residence after long commutes home, and (2) voice arriving home too late, and being too busy in the evening hours to devote self training time, even if they can access the class from home.

3. All parents who attend Fort Myer’s noon or evening support groups/educational classes “devour” the diagnosis-specific books offered, such as Autism/ADD/Special Education Process Laws, and Special Needs Parenting, etc. I would find it helpful if all installations were offered free EP books of their choice.

~Marcia O’Connor
EFMP Manager, Fort Myer

The EFMs at Fort Meade enjoy reading the articles and learning about different resources.

~Martila Seals
EFMP Coordinator, Fort Meade

Carlisle Barracks has had several families with a very pleasant and appreciative response to receiving the EP Magazine!

~Anne K. Hurst
EFMP Manager, Carlisle Barracks

The online seminars are great.

~Parent
Fort Belvoir
The Military Families in Darmstadt, Germany have been through several deployments and we appreciate the help EP Magazine’s articles and EP LiveOnline Seminars have given our Families in Transition with special needs children. Our Garrison covers several locations; however with the EP Magazine and EP LiveOnline seminars, we feel as if we are united as one big Military Family caring for each other and our children with special needs.

Through EP Magazine and its kindness and support of Military Families, we are gaining a sense of control over our lives and the well being of our children with special needs. From EP Magazine articles and EP LiveOnline Seminars, we are gaining a better understanding of disabilities; and therefore, it is easier for us to accept the responsibility, address special needs issues, and know what help is available in the military community and elsewhere.

With EP Magazine articles which provide support of Military Families with special needs, we are not hopeless and alone, but we are empowered. EP Magazine is doing a great job in support of Military Families, and its EP LiveOnline Seminars are extremely helpful. We’re using information provided through EP LiveOnline Seminars for our GWOT Respite Care Provider trainings, and it is a most awesome tool. Having professionals providing EP LiveOnline Seminars on medical issues that are relevant to many of our Military Families living overseas is a blessing.

EFMP would like to thank EP Magazine for all its support of Military Families with special needs, and for allowing us an opportunity to participate in the EP LiveOnline Seminars.

~Liz Mulcahey
EFMP Coordinator, U.S. Army Garrison – Darmstadt

Exceptional Parent magazine is extraordinary journalism in every way for our community, military families, and our nation. If anything, EP brings a sense of unity within our diverse world by connecting everyday people to become more educated (and) knowledgeable. ... When I think of EP Magazine ... I think of learning something new that I did not already know. I believe the literature within the magazine is unique, like our many families who read it.

~Candy Reyes
Wife of an active-duty Army Sergeant and mother of two children with special needs

Please let EP know that the military family section of the magazine is much appreciated and very closely read. Thanks for all you do.

~Parent
Fort Belvoir
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EP Magazine Military Section
January – December 2008


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EP Magazine Military Section
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2007

EP Magazine Military Section
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Special Olympics Brings New Hope and Prospect to China: A Report on the International Games


A COMПЕНDIUM OF RESOURCES FOR THE SPECIAL NEEDS COMMUNITY: NATIONAL ORGANIZATIONS, ASSOCIATIONS, PRODUCTS, & SERVICES

Don’t Miss a Single Issue in 2008 Editorial Highlights and Calendar
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www.eparent.com
EXCEPTIONAL PARENT MAGAZINE (EP) introduced a new section in January 2007 to its award-winning publication. The section was oriented toward the U.S. Army and was funded by a U.S. Army Cooperative Research Agreement, titled the Exceptional Family Transitional Training (EFTT) Program. EP dedicated the section to the men and women of the Army and pledged to provide the most current and accurate information available to those families caring for individuals with special needs. The true spirit of the agreement was to share information between the civilian and military communities and to increase resources and information available to meet the unique needs of military families caring for a member with special needs.

Military leaders throughout the Department of Defense have said unit readiness is the most important facet of preparing for war. Unit readiness goes beyond making sure people and equipment are ready for mobilization; it entails providing the highest quality of life possible for the men and women who stand in harm’s way.

Leaders have long recognized that about one in ten families care for individuals with special needs. EP and the military have joined together to share information to improve the quality of life for families with special needs. EP has been a leader in the special needs arena for over 37 years and enthusiastically united with the Army to provide the information that can help our military families in transition. EP has worked in the past with the Exceptional Family Member Programs (EFMPs) of the Army, Navy, and Marine Corps.

The year 2008 offers new opportunities to share information. EP welcomes the challenges of expanding the base of information to include all families, healthcare professionals, and program managers in all service components. We do this because it is the right thing to do.

This year, the military section of EP's Annual Resource Guide includes listings for the EFMP offices of the Army, Navy, and Marine Corps. Listings were also added for the United States Coast Guard, the first line of defense for all of our nation’s navigable waterways and shores. Lastly, the listing of the medical centers for the Department of Veterans Affairs was included. All obtainable lists are included with hopes for receiving additional lists in the future from other branches and corps to provide the most comprehensive resources possible for families and healthcare providers.

In this year's Guide, EP provides the points of contact needed to help as military families move from installation to installation. The fullest listing is being offered because of EP's recognition that service members are frequently moving to installations managed by another service. Soldiers are being assigned to joint billets at Air Force bases; Marines are serving tours at Army posts. EP believes it is important to be able to find the closest EFMP manager or coordinator at your new assignment.

EP knows families are going home during deployments. Help might be a phone call away, and that phone call might be to a Coast Guard Family Resources Specialist who knows the resources available in the local community.

EP also understands that there are challenges as Wounded Warriors move from the military healthcare system into the healthcare system of the Department of Veterans Affairs (VA). For that reason, a listing of the major medical centers of the VA, their regional offices, and their benefits offices is included. Their telephone numbers may be the link to a better tomorrow.

Today and tomorrow, EP will continue to provide the opportunity for families to reach out to each other, share ideas and experiences, and break down the barriers brought on by the physical and emotional strains of caring for family members with special needs.

UNITED STATES ARMY
EP has endeavored to list all the installations in the United States Army. The listing is correct to the best of our knowledge at the time of publication. Attempts were made to call all the installations in the United States. Information for overseas installations was provided by the Installation Management Command (IMCOM). For corrections or updates, please contact Rilev Miller, EP's Western Region Coordinator of the EFTT Program, at miller@eparent.com.

CONUS
This installation listing contains all the EFMP offices in the United States, including Alaska and Hawaii. The offices are arranged alphabetically by state and then by installation. Overseas EFMP offices (excluding Alaska and Hawaii) are arranged by region and then by installation. This directory is current as of December 2007.

ALASKA
FORT GREELEY, AK
Army Community Service
Gabriel Auditorium, Building #55
Pt. Greely, AK 99731-1309
O: 1-907-873-2479

FORT RICHARDSON, AK
Army Community Service
724 Postal Service Loop
Building 600, Room A116
Fort Richardson, AK 99505-6600
O: 1-907-384-0223

FORT WAINWRIGHT, AK
Army Community Service
Building 3401 Santiago Avenue, Room 60
Fort Wainwright, AK 99703
O: 1-907-355-4243

ARIZONA
FORT HUACHUCA, AZ
ACS-EFMP
ATTN: ATZS-MWC
Building 50010, Smith Street
Fort Huachuca, AZ 85613
O: 1-520-533-5719
F: 1-520-533-3778

YUMA PROVING GROUND, AZ
ACS-EFMP
USAG Yuma Proving Ground
301 C Street, Building 309
Yuma, AZ 85365
O: 1-520-328-2224
F: 1-928-328-2597

ARKANSAS
PINE BLUFF ARSENAL, AR
ACS-EFMP
16-270 Fleming Drive
Pine Bluff Arsenal, AR 71602-9500
O: 1-870-540-3588
F: 1-870-540-3204

CALIFORNIA
FORT IRWIN, CA
ACS-EFMP
Building 548
PO Box 105090
Fort Irwin, CA 92310-5123
O: 1-760-380-3699
F: 1-760-380-3775

PRESIDIO OF MONTEREY, CA
ACS-EFMP
Defense Language Institute & Foreign Language Center
Presidio of Monterey, CA 93944
O: 1-831-247-7653
F: 1-831-242-7642

SIERRA ARMY DEPOT, CA
ACS-EFMP
Sierra Army Depot
Building 150
Herlong, CA 95631
O: 1-530-827-4190
F: 1-530-827-4636

COLORADO
FORT CARSON, CO
ACS-EFMP
6030 Wetzel Avenue
Fort Carson, CO 80913-4104
O: 1-719-526-0446
F: 1-719-526-2637

DISTRICT OF COLUMBIA
WALTER REED ARMY MEDICAL CENTER
ACS-EFMP
4900 Georgia Avenue
Building 17
Washington, DC 20307-5001
O: 1-202-782-3412
F: 1-202-782-7270

FLORIDA
MIAMI, FL
ACS-EFMP
USAG-Miami
3911 Northwest 91st Avenue
Miami, FL 33172
O: 1-305-437-2644/2734
F: 1-305-437-2716

GEORGIA
FORT BENNING, GA
ACS-EFMP
Building 2624, Soldiers Plaza
Fort Benning, GA 31905-4599
O: 1-706-545-5527/5157
F: 1-706-545-2545

FORT GORDON, GA
ACS-EFMP
Darwin Hall
307 Chamberlain Avenue
Suite 224
Fort Gordon, GA 30905-5250
O: 1-706-791-4872
F: 1-706-791-7880

FORT MCPHERSON, GA
ACS-EFMP
1350 Troop Row SW
Fort McPherson, GA 30330-1049
O: 1-404-464-2966
F: 1-404-464-4862

FORT STEWART, GA
ACS-EFMP
Building 87, 191 Lindquist Road
Fort Stewart, GA 31314
O: 1-912-767-5058/5059
F: 1-912-767-3195

HAWAII
SCHOFIELD BARRACKS, HI
U.S. Army Garrison, Hawaii
ACS-EFMP
350 Eastman Road
Schofield Barracks, HI 96857-1059
O: 1-808-655-2400

ILLINOIS
ROCK ISLAND ARSENAL, IL
ACS-EFMP
ATTN: IMWE-RM-WMA
1 Rock Island Arsenal
Rock Island, IL 61299-5000
O: 1-309-782-3049
F: 1-309-782-0395

KANSAS
FORT LEAVENWORTH, KS
ACS-EFMP
615 McClellan Avenue
Fort Leavenworth, KS 66027
O: 1-913-684-2871

FORT RILEY, KS
ACS-EFMP
Building 7264
Ft. Riley, KS 66442
O: 1-785-239-9435

FORT SCHOENFIELD, HI
U.S. Army Garrison, Hawaii
ACS-EFMP
350 Eastman Road
Schofield Barracks, HI 96857-1059
O: 1-808-655-2400

Military Family Organizations

FAMILY ORGANIZATIONS
Below is a list of organizations that might be of interest to military families with members with disabilities. New organizations and Web links are added regularly, but if you have a favorite organization or Web link that has proven helpful in the past, please forward it on so the list can be updated through the year. Please send the information to Riley Miller, the Western Region Coordinator of the Exceptional Family Transitional Training (EFTT) Program, at rmiller@eparent.com. A current listing of organizations and web links is maintained on the EP Web site at: http://www.eparent.com/main_channels_military/Military_Web_Links.asp

The listings are not all-inclusive and are provided as a guide only. This listing is oriented to the families of the men and women who serve in defense of America’s freedoms. As a result, the Department of Defense organizations are listed first. The second section contains organizations sponsored by agencies within the Federal Government. The last section, titled Other Helpful Organizations, contains private organizations of interest to military families. This section may contain state agencies and organizations.

Editor’s Note: The appearance of these hyperlinks does not constitute endorsement by EP magazine of any Web site or the information, products, or services contained therein. Exceptional Parent magazine does not exercise any editorial control over the information you may find at these locations. These links are provided consistent with our goal of providing the most current and accurate information available to the extent we are able. This directory is current as of December 2007.

United States Air Force Web sites
AIR FORCE SPECIAL NEEDS


U.S. COAST GUARD OFFICE OF WORK-LIFE
http://www.uscg.mil/hq/g-w/g-wk/ww/index.htm

COAST GUARD MORALE, WELL-BEING, AND RECREATION (MWR)
http://www.uscg.mil/mwr/

Other U.S. Government Web sites
The Web sites below are Web sites sponsored by various agencies within the United States Government.

DISABILITYINFO.GOV

U.S. DEPARTMENT OF JUSTICE AMERICANS WITH DISABILITIES ACT (ADA) HOME PAGE
http://www.usdoj.gov/crt/ada/ada.html

BUILDING THE LEGACY: IDEA 2004
http://idea.ed.gov/

SOCIAL SECURITY ADMINISTRATION - SUPPLEMENTAL SECURITY INCOME HOME PAGE
http://ssa.gov/ssfi/

SOCIAL SECURITY ADMINISTRATION ON UNIFORMED SERVICES’ PAY AND ALLOWANCES
https://s044a90.ssa.gov/apps10/poms.nsf/lnx/0500830540!opendocument

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES CENTERS FOR MEDICARE AND MEDICAID SERVICES
http://www.cms.hhs.gov

SPECIALIZED TRAINING OF MILITARY PARENTS (STOMP)
STOMP Project
6316 So. 12th St., Tacoma, WA 98465
(253) 565-2266, (800) 3-PARENT (TOLL FREE), (253) 566-8052 (FAX)
http://stompproject.org/

NATIONAL DISSEMINATION CENTER FOR CHILDREN WITH DISABILITIES
PO Box 1492, Washington, DC 20013
(800) 695-0285, http://www.nichcy.org/

Other Helpful Organizations Web sites
The Web sites below are additional sites that provide valuable information to military families with children with special needs.

Military Relief
ARMY EMERGENCY RELIEF
200 Stovall Street, Alexandria, VA 22332
(703) 428-0000, http://www.aerhq.org/

AIR FORCE AID SOCIETY, INC.
National Headquarters
241 18th Street, Suite 202, Arlington, VA 22202
(800) 769-8951, http://www.afas.org/

NAVY MARINE CORPS RELIEF SOCIETY
875 North Randolph Street, Suite 225, Arlington, VA 22203-1977
(703) 695-4904, http://www.nmcrs.org/

757 North Randolph Street, Suite 225, Arlington, VA 22203-1977

MILITARY CHILD EDUCATION COALITION (MCEC)
875 North Randolph Street, Suite 225, Arlington, VA 22203-1977
(800) 695-0285, http://www.nichcy.org/

FISHER HOUSE
1401 Rockville Pike, Suite 600, Rockville, MD 20852
(888) 294-8560, http://www.fisherhouse.org/

INTREPID MUSEUM-INTREPID FALLEN HEROES FUND
http://www.fallenheroesfund.org/

WOUNDED WARRIOR PROJECT
(888) 294-8560, http://www.woundedwarriorproject.org/

ARC OF THE UNITED STATES
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MILITARY ONESOURCE

THE DEPARTMENT OF DEFENSE MILITARY HEALTH CARE SYSTEM, TRICARE
http://www.tricare.mil/

OFFICE OF THE ASSISTANT SECRETARY OF DEFENSE RESERVE AFFAIRS
http://www.defenseLink.mil/ra/index.html

NATIONAL GUARD FAMILY PROGRAM ONLINE COMMUNITY CENTER
http://www.guardfamily.org/

United States Army Web sites

U.S. ARMY
http://www.army.mil/

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http://aw2.portal.com/

United States Navy Web sites

U.S. NAVY

U.S. NAVY EXCEPTIONAL FAMILY MEMBER PROGRAM
http://www.npc.navy.mil/CommandSupport/ExceptionalFamilyMember

United States Marine Corps Web sites

U.S. MARINE CORPS

U.S. MARINE CORPS EXCEPTIONAL FAMILY MEMBER PROGRAM (EFMP)
http://www.usmc-mccs.org/efmp/?sid=fl

U.S. MARINE CORPS WOUNDED WARRIOR REGIMENT
https://www.manpower.usmc.mil/iportal/page?_pagename=278,30652718&_dad=iportal&scheme=PORTAL
Community of One

From Our Families...To Your Families
Response to Intervention (RTI) is a hot-button issue for parents, educators, and advocates of people with disabilities. The Individuals with Disabilities Education Act (IDEA) 2004 has brought RTI to the forefront in the identification of children with high-incidence disabilities. The theory and practice behind RTI is how best to provide learning support to children before referral for special education services.

The difficulties with the traditional IQ-Achievement Discrepancy Model were acknowledged by both the House and Senate during the course of the reauthorization of IDEA in 1997. As a result, a local education agency (LEA) is now permitted, but not required, to use RTI in the identification of children who will benefit from scientifically based instruction as soon as possible. Special education would then be able to focus on children who, even with targeted supports, are not able to be successful.

The National Research Center on Learning Disabilities (NRCLD) defines RTI as: “…an assessment and intervention process for systematically monitoring student progress and making decisions about the need for instructional modifications or increasingly intensified services using progress monitoring data.”

Response To Intervention: An Alternative to Traditional Eligibility Criteria for Students with Disabilities (July 2005), a report published by Education Evolving, a joint project of the Center for Policy Studies and Hamline University, provides 10 points for understanding the implementation of the RTI model. A summary of these 10 points:

1) Description of the Problem: What difficulties does the teacher report the student as having? A statement such as “Student is reading poorly” is too general. Examples of decoding, retelling skills, and words correctly read per minute from a grade-appropriate passage and how the child responds to questions about the passage will give a better picture of needs. The teacher gathers achievement, state test scores, attendance, and relevant academic data at this point.

2) Student Strengths and Weaknesses: The focus is on creating an environment of success. Looking at the child as a whole learner, the teacher is able to give valuable input regarding the learning style and skill sets the child has in place that will be used to formulate possible interventions.

3) Relevant Health or Other Issues: Is there a hearing, visual, physical, or health impairment that would hinder learning?

4) Hypothesis Regarding Student Needs: This involves identification of an intervention to address stated concerns. The teacher formulates ideas regarding why the student isn’t learning and possible solutions. For a student who struggles with decoding, a reading program that targets alphabetic instruction and phonemic awareness would be a possibility.

5) Type of Intervention Selected: The above hypothesis helps guide the selection of intervention. The teacher now finds the appropriate intervention for the child’s stated needs.

6) Length of Time of Intervention: Intervention length will vary due to publisher recommendations, research data, student scheduling factors, availability of resources, and student attendance. Continual review of student progress in RTI will enable the teacher to see if the intervention is successful.
7) **Student Goal:** Setting a goal for the student to achieve is critical to the RTI process. This requires identifying where the student is and determining what skills the child could attain with the intervention. Information from L. Fuchs in *Best Practices in School Psychology IV* (2002) is an excellent reference for goal setting.

8) **Measures Used for Progress Monitoring and Decision Rules:** The school must identify the curriculum areas to be targeted. These areas must align with the curriculum measures for the grade level the student is in. Utilizing a Curriculum-Based Measurement (CBM) is a useful tool in gauging student growth. Students reaching proficiency levels based on universal screening tools will show progress or lack thereof to RTI.

9) **Evidence of Response or Non-Response to Intervention:** This is performed by the teacher and/or team. A consistent, planned review of student RTI provides the baseline for determining further or modified interventions, or discontinuation of interventions.

10) **Decision:** Is the student showing progress based on CBM? Evaluation of general education interventions with increased intensity in type and length of intervention provide the basis to determine if interventions at present levels should be continued as planned, increased, or decreased. A referral for special education services is recommended when general education interventions show lack of progress.

Many states have established information to help school districts understand and use RTI to determine eligibility and to help struggling learners. They point to the need for a multi-tiered approach to determining a child's need for RTI and possible need for special education. Such a multi-tiered RTI model includes the following:

- **Tier 1:** This provides Core Interventions to all students, in all settings. This is proactive and preventative. This tier represents 80-90 percent of students in the general education setting.
- **Tier 2:** This provides Strategic Interventions. This tier is targeted to some at-risk students, is of high efficiency, and monitoring occurs twice a month for 5-10 percent of students. These interventions are short-term in duration (9-12 weeks) and are in place for immediate implementation. Curriculum-Based Measurement (CBM) tools are used to monitor progress.
- **Tier 3:** This opens to individual students, is target assessment-based, and progressive. Monitoring increases to once a week for 1-5 percent of students. These interventions are usually provided in small groups and may occur for more than 9-12 weeks. Targeted assessments are typically conducted when a student enters this tier.

The IDEA 2004 regulations provide clarification on the use of RTI, in §300.307 (a) and (b). Comment and discussion of the regulations is found on pages 46646-49 of the Federal Register, published on August 14, 2004.

By researching RTI theory, practice, and law, we see a strong argument for parent education and participation in the general and special education processes. During this time of flux as states and school districts align RTI theory with practice, a parent’s skills as an advocate become increasingly important. Gaining an understanding of laws and RTI implementation plans for your state will serve you well.


For more information about STOMP and its resources for military families, visit http://www.stompproject.org.

Karen Elliott is a staff member of Specialized Training of Military Parents (STOMP). A military wife of 15 years, she and her husband have two children enrolled in the Exceptional Family Member Program (EFMP).
Like many Army families, the Pittman household is up bright and early. Felecia Pittman wakes at 5 a.m. to get Leland, 16, and Devin, 11, ready and off to school.

In stark contrast to his younger brother, the accomplished track and field athlete is more mature than his 16 years and does not require too much help preparing for school.

Major Henry Pittman heads to work at Walter Reed Army Medical Center (WRAMC) where he’s the special assistant to the command group.

Like most families, the Pittmans’ typical day is packed with work, school, track meets, and football practice. But what distinguish this exceptional family from most families are the challenges they face daily with love, patience, and understanding with Devin, who has severe disabilities. He has a rare mitochondrial disorder, epilepsy, and autism.

“Taking care of him is a full-time job,” Felecia says. “I have him all the time [now] because his school is an 11-month program. When he’s at school, I can do errands. Sometimes, things get done, sometimes they don’t.”

The Pittmans explained that one evening, exhausted after another day, they thought about all the things they went through and wished there was something in place to help military families who have children with special needs like themselves.

They began to wonder if someone was there to tell them what school districts were best for Devin, what hospitals, what programs. They came up with Project Devin to meet this need.

The Pittmans teamed up with a local non-profit organization, Abilities Network, aimed at assist-

“Having an advocate and helping, that’s what Project Devin and the Abilities Network is about,” her husband adds. “It’s like respite, taking the burden off you for a moment so you can breath, sit back and let someone else talk for you, and you know they have your child’s best interest at heart.”
ing individuals of all abilities, to create Project Devin. Project Devin hopes to provide assistance to military families as they transition into new communities by finding schools, hospitals, and other programs that meet the needs of the family and to begin this process before the family moves.

Devin was diagnosed with mitochondrial disease when he was two years old and the family was stationed in Germany. Mitochondrial disease is a cellular disorder that inhibits the body’s ability to process oxygen and convert food into energy. Soon after, his seizures intensified. For their move to Woodbridge, VA, doctors induced a coma to prevent brain damage before Devin was med-evaced back to the states. The Pittmans saw a developmental pediatrician at WRAMC, where he was diagnosed with autism.

After six months of research and speaking with doctors, the Pittmans realized they needed to move to Montgomery County, MD to get Devin the services he needed.

“With all the time it takes for trial and error and trying to get what your child needs, he’s suffering because he’s not getting what he should have,” Felecia said.

Felecia takes care of Devin while her husband is at work, clothing and bathing him, keeping records of his seizures, administering medication, and getting him ready for school and medical appointments.

Autism, a neurological disorder, is estimated to affect from one in 500 to one in 166 children. Leland finds himself explaining this mysterious disease to classmates, teachers and friends.

“There are two types,” the 16-year-old explains. “There’s high-function and low-function. My brother’s low-function, which means he develops but at a slow rate. He can’t take care of himself; we do it for him. He’s got the body of an 11-year-old but the mind of a toddler.”

At 18 months old, Devin had his first seizure, which lasted 30 minutes. He continues to cycle through several seizures daily.

“With a seizure disorder it affects everyone differently but, with him, he has a tendency to want to stop breathing for some reason when he has some seizures,” the major says. “That’s why he has to be monitored all the time.”

Finding services like this can be a challenge for newly arrived military families with children with special needs. Project Devin helps families navigate the complex service systems, supporting educational needs and advocating on their behalf.

“What supports do you need? It’s kind of hard to find the time to make all the phone calls and have to go in to see someone and figure out it may not be for you—it’s wasted time,” Felecia said.

“Having an advocate and helping, that’s what Project Devin and the Abilities Network is about,” her husband adds. “It’s like respite, taking the burden off you for a moment so you can breathe, sit back and let someone else talk for you, and you know they have your child’s best interest at heart.”

He noted that if the normal statistics of the general population are applied, anywhere from 10 to 15 percent of the armed forces probably has a child or family member with special needs—whether medical or educational.

“We don’t want this to happen to someone else,” he said. “People need help, and if you don’t help them, you break them. That’s not what the Army Ethos is about. I can’t sit on the sideline and watch people who need help. There are people out there who want to Soldier, and they want to take care of their family. It shouldn’t be an either-or situation. Devin is our fallen comrade, the world is his battlefield, and we’re not going to leave him and we’re not going to leave others.”

Kristin Ellis is a journalist for the Walter Reed Army Medical Center newspaper, Stripe. The Cleveland-native has worked for the Army since September 2005 and began work in the hospital’s Office of Strategic Communications in March 2007. She regularly covers topics concerning our Wounded Warriors and outpatient care.
Four new members have been appointed to the Advisory Committee on Women Veterans for the Department of Veterans Affairs (VA), an expert panel that advises VA on issues and programs affecting women veterans.

“I am pleased to welcome the newest members of this committee to the important job of serving America’s women veterans,” said Secretary of Veterans Affairs Dr. James B. Peake. “Members of this committee work tirelessly on behalf of women veterans to improve outreach, ensure access to VA benefits and recommend ways in which VA can better meet their needs.”

Established in 1983, the advisory committee makes recommendations for administrative and legislative changes. The committee members are appointed to one-, two-, or three-year terms. The new committee members include: Rene A. Campos from Washington, D.C.; Helena R. Carapellatti from Upper Marlboro, Maryland; Barbara Pittman from Washington, D.C.; and Rosemarie (Rose) Weber from Springfield, Virginia.

“The expertise and perspectives that the new members offer are greatly appreciated and will surely impact the recommendations presented by the Committee. I look forward to their contributions,” Peake said.

Women veterans are one of the fastest growing segments of the veteran population. There are approximately 1.7 million women veterans. They comprise 7 percent of the total veteran population and nearly 5 percent of all veterans who use VA healthcare services. VA estimates that by 2020 women veterans will comprise 10 percent of the veteran population.

VA has women veterans program managers at VA medical centers and women veterans coordinators at VA regional offices to assist women veterans with health and benefits issues.

This information was first published via VA news release on January 3, 2008.
A change in the law that allows certain seriously injured veterans and servicemembers to receive multiple grants for constructing or modifying homes has resulted in many new grants, the Department of Veterans Affairs (VA) announced.

Before the change, eligible veterans and servicemembers could receive special adaptive housing grants of $10,000 or $50,000 from VA only once. Now they may use the benefit up to three times, so long as the total grants stay within specified limits outlined in the law.

“Veterans seriously disabled during their military service have earned this benefit,” said Secretary of Veterans Affairs, Dr. James B. Peake. “This change ensures that every eligible veteran and servicemember has the chance to use the maximum amount afforded to them by our grateful nation.”

In order to ensure all previous recipients are aware of this opportunity, VA has mailed more than 16,000 letters to eligible veterans, reaching out to those who used only a portion of their grant or who decided not to use the grant even after initially qualifying.

The response over the past year has been dramatic with more than 4,600 applications received thus far. Of these, approximately 3,900 veterans have been determined eligible under the new law, and more than 200 grants already awarded. VA has averaged about 1,000 adaptive housing grant applications per year during the past 10 years. Since the program began in 1948, it has provided more than $650 million in grants to about 34,000 seriously disabled veterans.

To ensure veterans’ and servicemembers’ needs are met and grant money is spent properly, VA works closely throughout the entire process with contractors and architects to design, construct, and modify homes that meet the individuals’ housing accessibility needs.

Eligible for the benefit are those with specific service-connected disabilities entitling them to VA compensation for a “permanent and total disability.” They may receive a grant to construct an adapted home or to modify an existing one to meet their special needs.

VA has three types of adapted housing grants available. The Specially Adapted Housing grant (SAH), currently limited to $50,000, is generally used to create a wheelchair-accessible home for those who may require such assistance for activities of daily living.

VA’s Home Loan Guaranty pro-
PAYMENTS PROVIDED to veterans under two specific programs of the Department of Veterans Affairs (VA) — the Compensated Work Therapy (CWT) and Incentive Therapy (IT) programs — are no longer taxable, according to the Internal Revenue Service. Veterans who paid tax on these benefits in the past three years can claim refunds.

Recipients of CWT and IT payments no longer receive a Form 1099 (Miscellaneous Income) from VA. Veterans who paid tax on these benefits in tax years 2004, 2005, or 2006 can claim a refund by filing an amended tax return using IRS Form 1040X. Nearly 19,000 veterans received CWT benefits last year, while 8,500 received IT benefits.

The IRS agreed with a U.S. Tax Court decision earlier in 2007 that CWT payments are tax-free veterans benefits. In so doing, the agency reversed a 1965 ruling that these payments were taxable and required VA to report payments as taxable income.

The CWT and IT programs provide assistance to veterans unable to work and support themselves. Under the CWT program, VA contracts with private industry and the public sector for work by veterans, who learn new job skills, strengthen successful work habits, and regain a sense of self-esteem and self-worth. Veterans are compensated by VA for their work and, in turn, improve their economic and social well-being.

Under the IT program, veterans with serious disabilities receive payments for providing services at about 70 VA medical centers.

This information was first published via VA news release on January 7, 2008.
EP Military Channel News

Readers can access important information regarding Department of Defense news, Department of Veterans Affairs news, and TRICARE by visiting the Military Channel on the EP Web site. Information includes news releases, reports, and other relevant items. Visit the EP Military Channel at http://www.eparent.com/main_channels_military/index.asp.

Items currently on the site include:

- Report of the President’s Commission on Care for America’s Returning Wounded Warriors
- VA News Release – VA Is Leader in Hospice and Palliative Care: Consultations for Veterans Nationwide


CORRECTION: August 2007 Issue, “Considerations for the Military Child with Special Needs Transitioning to Adulthood”, page 75. Sentence read: In the Hampton Road, Virginia area, the ENDependence Center of Northern Virginia, Inc. Correction is: In the Hampton Road, Virginia area, the ENDependence Center of Northern Norfolk, Inc.
COVER STORY
Philadelphia’s Disability Arts Festival
Slippery Rock University
Friends’ Discovery Camp

NEW SERIES
Spiritual and Religious Supports

United States Military Section
Operation Giveback
Transfer During a Transition Phase in Your Child’s Care
At the American Epilepsy Society’s Annual Meeting, which took place in December 2007 in Philadelphia, Pennsylvania, Marc A. Dichter, M.D., Ph.D. presented his latest research on clinical trials in post-traumatic epilepsy in brain-injured individuals as part of this year’s Merritt-Putnam Symposium on post-traumatic epilepsy. Great concern exists among the medical community that post-traumatic epilepsy in many returning head-injured veterans from the current conflicts in Iraq and Afghanistan may not manifest for months or years after the insult. Of greater concern is the possibility that this may go unrecognized and untreated.

In his talk, Dr. Dichter discussed treatment barriers and diagnosis of “subtle seizures” as well as the impact of rehabilitation for veterans and Soldiers who may not know they are experiencing epileptic seizures. Equally important, he provided insight on Operation Giveback, the AES’s initiative to improve diagnosis and care for this high-risk population. Dr. Dichter, a leading expert on post-traumatic epilepsy, is Professor of Neurology at the University of Pennsylvania School of Medicine and former Director of the Penn Epilepsy Center and the University of Pennsylvania David Mahoney Institute of Neurological Sciences. He has been active in epilepsy research at both the basic and clinical level, focusing on mechanisms underlying seizures and epileptogenesis. He is also a past president of the AES.

For further information about Dr. Dichter and his research, visit http://www.med.upenn.edu/ins/faculty/dichter.htm.

Following is an interview with Dr. Dichter, conducted by EP magazine, on this urgent topic.

**Exceptional Parent (EP):** What is the genesis of this initiative you started within the American Epilepsy Society called Operation Giveback?

**Marc A. Dichter, M.D., Ph.D. (MD):** Operation Giveback started in Spring 2007. I was concerned about the possibility that returning veterans who had experienced TBI (Traumatic Brain Injury) in the Gulf Wars might develop subtle and difficult-to-diagnose seizures long after they returned home and left the service. I thought that we, in the epilepsy professional community, could do something to help deal with this problem. I proposed this initiative to AES, and they enthusiastically decided to support it. We assembled a task force of AES members that I chair. The task force consists of individuals who are not affiliated with the VA (U.S. Department of Veterans Affairs) system and others who work at VA Epilepsy Centers. We had monthly or bi-monthly telephone meetings all spring and summer, of the whole group, to try and formulate plans for this initiative. Our activities could be broken up into three broad categories: advocacy for increased support for the VA so they could optimally serve our returning wounded veterans, especially support for increased epilepsy services; educational initiatives; and possible direct voluntary service to help understaffed VA facilities or to offer services to veterans with post-traumatic epilepsy outside the VA system.

We created an area on the AES Web site that has FAQs (Frequently Asked Questions) on post-traumatic epilepsy so that lay people can understand it in basic, simple terms. Families who are concerned that their relative may be having seizures can go to that site and have their questions answered as best as we can anticipate. We also created a slide set meant for education of healthcare providers – not necessarily for a highly skilled neurologist, but for internists, psychiatrists, nurse practitioners, OTs (occupational therapists) or PTs (physical therapists), so we can introduce them to the issue of the kinds of seizures that people can have that would not normally be recognized. We hope to teach these healthcare professionals how to ask the right
questions and how to refer these patients to appropriate medical resources.

My feeling is that people who have grand mal type seizures will get into the system because those are pretty obvious. I don’t know whether all such individuals will be able to get the necessary help within the VA system or whether they will be working with physicians in the private sector. We are concerned that if they’ve been mustered out a year or more ago and now are trying to get their lives back and have a seizure, they might not realize that that seizure is possibly from a head injury that they sustained. This may be a particular problem for those who were injured by an IED (Improvised Explosive Device) explosion, where they were knocked out, but when they woke up they went back fighting again because the firefight was still going on. It is not an uncommon experience that the seriousness of closed head injuries, without the blood and obvious wounds, is not apparent to the patient themselves, or an observer, as with a penetrating head injury, where it’s more obvious that a serious injury has occurred. Then, if a year later, they develop a seizure or episodes involving confusion or problems relating to memory, they might not make the connection with their prior TBI. They may be diagnosed as post-traumatic stress disorder, or their symptoms may be thought of as part of the TBI, rather than as possibly being due to epileptic seizures.

So we’re trying to reach that group to make them aware that the seizures are a possibility and to seek medical attention.

EP: What was the response you received from medical practitioners within the Military?

MD: When I talked to people in the head injury program, their initial response was that epilepsy wasn’t really one of their major considerations, because they were so focused on the acute management of head trauma. They were talking about in-theater management related to getting immediate medical care, getting the patient stabilized, and getting them able to be evacuated to Germany, or elsewhere, for more extensive treatment. The epilepsy was a secondary problem. If they had an acute seizure, they’d treat it. But the possibility of developing late epilepsy was down the road. So it wasn’t really part of their consciousness. We’re hoping to bring this issue more to the forefront, especially after the initial emergency treatment.

EP: What can we do about this issue now?

MD: Unfortunately, at the moment, there’s nothing much we can do to prevent epilepsy after TBI. What we are doing at the University of Pennsylvania is learning how to do clinical trials to prevent epilepsy; although in this case, it’s with the local civilian population who have TBI. The DoD (Department of Defense) is interested on that level and is supporting our pilot clinical trial with their research arm.

We are also concerned about tracking individuals who are coming back from the Gulf Wars with traumatic brain injury, over a long period of time, by establishing a database. This could serve several purposes. We could determine how high the risk of post-traumatic epilepsy is with different types of TBI. We could also use the database to reach more of the returning veterans to make them aware of the possibility of problems that may develop later – and encourage them to stay in the system. And we can also get an idea of how often this is occurring, how serious it is, and what might we do about it?

EP: What are the hurdles that exist in being able to identify those that potentially require diagnosis and treatment?

MD: The VA hospitals are apparently not seeing large influxes of TBI-injured patients with epilepsy at the present time. They don’t know where the patients are. We hear statistics about TBI, but we are wondering, what is happening to the patients?

There are a number of possible explanations. One is that many of the returning veterans left the system and are now being treated by doctors in the community. Some of these individuals who develop seizures may not realize that what happened two years after they were discharged was related to a war injury.

I don’t know the details about what happens to National Guard members after they return from the Gulf. Do they have to sign up for VA benefits when they finish their service? I do not know if it is automatic that they receive VA benefits. At one time, I had heard that they needed to enlist in the program and that there was a charge for it, but I’m not sure about this. If this is true, for example, and when discharged they feel that they are okay, they may not want to pay anything to have that sort of insurance policy. Then, if something happens a year or two later, they may be unable to obtain proper care.

Right now, we don’t have a way of preventing post-TBI epilepsy, but once someone develops epilepsy, we have a lot of drugs that can effectively treat the seizures. Unfortunately, these drugs are only completely successful in about 60 or 70 percent of patients, and that leaves a lot of people with an ongoing serious problem.

EP: What do you see as the role of allied healthcare professionals such as nurses, OTs, or PTs in helping diag-

continued on page 89
Parents frequently think about how to help their children gain skills and knowledge that will provide the greatest opportunities when they are no longer in the educational system. They work with the schools to write good Individualized Education Programs (IEPs), help their children at home, and seek information that will enable their children to live a full and quality life. Families often ask why the schools don’t provide more one-on-one paraprofessional support for students with disabilities. People sometimes think if a child has a one-on-one paraprofessional, he or she could be in the general education classroom more and also attain higher skills, standards, or IEP goals. The belief is that if more individual time were given to a task, there would be a different result. This is not always true.

There have been a number of studies in recent years on the use of one-on-one assistants for children with disabilities. These studies have looked at the role of the paraeducator, the inclusion of the child in daily classroom activities, and the paraeducator’s role in the child’s skill building. Rulings in court cases have shown that the use of a one-on-one paraeducator could actually be more restrictive for the child than having him or her in a self-contained program. This doesn’t mean that the use of a one-on-one aide should never be considered. These considerations should be based on the child’s strengths and needs. For some students, a one-on-one paraeducator is necessary for safety or health reasons. However, this may or may not hold true when it is solely for the purpose of helping a student gain new skills.

One study showed that as students with disabilities have increasingly been placed in general education schools and classes, the use of one-on-one paraprofessional support and classroom paraeducator support has increased. Some national experts estimate that over 500,000 instructional assistants (paraeducators) are employed in public schools across the nation. The number of these individuals is expected to increase. The question is, how are these individuals being used? Are they providing additional support to the classroom teacher so that he or she can successfully include the child with a disability in the setting, or are they taking the place of the teacher?

One large study done over a three-year period in four different states provided some interesting results that families might want to consider. Some paraprofessionals “shadowed” the student, constantly being at the child’s side and accompanying the student in all school settings. While such support could at times be essential, it was not always necessary and was found to actually create barriers for the child’s involvement and participation with other students.

Often, the expectations regarding the role of the classroom teacher were not as clear. In many instances the classroom teacher did not provide the direct instruction of the student. The paraprofessional became a “substitute” for the teacher in providing that instruction.

Paraprofessionals were found to frequently separate the student with disabilities from the rest of the class during activities. Examples of this type of separation included the paraprofessional leaving the regular classroom a couple of minutes before the rest of the students to take the student with disabilities to the specialty classroom (e.g., art, music, physical education). It was noted that even when the student might be in a setting or activity in which he or she could participate with other students, such as seated on a rug to hear a story, the paraprofessional often physically separated the student with
disabilities from the group by positioning him on the edge of the group activity. It was also found that such separation from the class occurred even during activities where the student could have been successful in that class activity.

Paraprofessionals often prompted almost every behavior the student used, not fading those prompts to allow the child to become more independent or encourage the student to respond to other people (e.g., school staff, peers). This caused students to have fewer opportunities to obtain and demonstrate new skills and led to recommendations for more restrictive classroom settings, with less opportunity to participate with their non-disabled peers.

The study suggested that different service strategies include: providing needed supports in general education classrooms; training and support for the teacher and students; and increasing the opportunities for students to use natural peer support. The study emphasized that support for students needs to be individualized and flexible.

If you feel your child’s needs are not being met or that IEP goals are not being attained, call an IEP meeting to discuss these concerns with the other team members. Be creative in looking at the possibilities. Consider what would be the most natural help for your child in order to assist his or her needs and yet capitalize on his or her strengths. When considering one-on-one assistance for your child, think about his or her needs and strengths and the “why” of asking for the paraprofessional’s assistance. Don’t think of the one-on-one paraprofessional as the only answer. Consider the options and make the decision based on what is appropriate for the child.

Heather M. Hebdon is Founder and Director of Specialized Training of Military Parents (STOMP). She established STOMP in 1985 due to recognition of the need for additional support for military families. She is the mother of three, all of whom were enrolled in the military Exceptional Family Member Program (EFMP). Her husband served for over 20 years in the military.

Vanessa B. Ira is Director of Projects for EP LiveOnline™ and also works with Vernics, Inc.

The American Epilepsy Society’s Operation Giveback continued from page 87

nose epilepsy among these vets who have experienced TBI?

MD: They are extremely important because they are likely to be the practitioners who see these individuals first. By the time the patients get to a neurologist, it will be already recognized that they are at risk for having a problem. It’s when they go to a PT, where maybe the PT recognizes that the patient is not performing as expected. Maybe one day he’s good, one day he’s not, or he forgot what he was taught last week and yet he remembers what he was taught two weeks ago. There are lapses. If seizures are suspected, it is really important to investigate the situation thoroughly and make sure everyone knows what’s happening. If seizures are a component of the problem, we can treat them and try to optimize their recovery. One of the major goals of Operation Giveback is to reach the veterans themselves, their families, and the front-line healthcare professionals who are likely to interact directly with the injured veterans. If we can raise everyone’s consciousness about the problem of post-traumatic epilepsy, we will have accomplished a lot.

Vanessa B. Ira is Director of Projects for EP LiveOnline™ and also works with Vernics, Inc.
Military families may face transfer to another location at a critical juncture in their child’s care and services. It is important to know both what the law provides and when in order to ensure the best services for your child, delivered without interruption.

Statistics show that the average military child receiving special education services is between the ages of two and eight, placing them within a transition phase that occurs in available services provided by law.

Before the age of three, if a child is diagnosed with a medical need that places them at risk of developmental delays, the family can request the opportunity to move to a military installation that is closer to a major medical facility. The family will also need to enroll in the military Exceptional Family Member Program (EFMP), which provides information, resources, and support for a family with a member with special needs.

The decision regarding whether to send a family on a Permanent Change of Station (PCS) will depend on the Army’s ability to match the sponsor’s Military Occupational Specialty (MOS) with an authorized available position, as well as on the child’s needs. (The sponsor is the military member responsible for the person with special needs.) When a decision is made to move a family, it can place the parents or other responsible party in a position of not only coordinating a major transfer, but transitioning their child within the special education system.

Under the Individuals with Disabilities Education Improvement Act (IDEA) of 2004, children with special needs qualify for services from birth through 21 years of age. The act is divided into two components: 1) early intervention services for children from birth up to three years of age and 2) special educational services for children from ages three through 21. The most vulnerable time to transfer your child’s service provided by IDEA 2004 is near your child’s third birthday. During this time period, your child’s special educational program is transitioning from IDEA 2004 Part C to IDEA 2004 Part B.

Part C provides services through the Individualized Family Service Plan (IFSP), which is a family-centered model that can include medical services and can be provided at home or in other natural environments for infants and toddlers (i.e. community center, childcare, etc.). Many of the related services (i.e. Occupational Therapy, Speech Therapy, and Physical Therapy) can be paid for by TRICARE. The transition that occurs on the child’s third birthday requires the child to be served under Part B, which requires the development of an Individualized Education Program (IEP) which is a school-based educational service model provided by school district personnel and in which the local district, in coordination with the parents, determines placement and related services.

In order to receive special educational services from the new duty station in a timely manner, it is important to understand some of the transition and transfer regulations associated with IDEA 2004. Understanding the laws and being proactive can make the difference between your child receiving services once you arrive at your new installation or experiencing gaps in services. Since studies show that early intervention services for toddlers with special needs are critical, time is essential.

There are two sections of the IDEA regulations that are important to understand in relation to this transition during a PCS move:

- §300.124 Transition of Children from the Part C Program to Preschool Programs
- §300.323(f) Transfer of IEP
IDEA 2004 Regulation 34 CFR 300.124 reads:

**Transition of Children from the Part C Program to Preschool Programs**

The State must have in effect policies and procedures to ensure that:

a. Children participating in early intervention programs assisted under Part C of the Act, and who will participate in preschool programs assisted under Part B of the Act, experience a smooth and effective transition to those preschool programs in a manner consistent with section 637(a)(9) of the Act.

b. By the third birthday of a child described in paragraph (a) of this section, an IEP or, if consistent with Sec. 300.323(b) and section 636(d) of the Act, an IFSP, has been developed and is being implemented for the child consistent with Sec. 300.101(b).

c. Each affected LEA (local education agency) will participate in transition planning conferences arranged by the designated lead agency under section 635(a)(10) of the Act.

This brings us to the next protection provided under IDEA 2004.

IDEA 2004 Regulation, 34 CFR 300.323(f) reads:

(f) IEPs for children who transfer from another State. If a child with a disability (who had an IEP that was in effect in a previous public agency in another State) transfers to a public agency in a new State, and enrols in a new school within the same school year, the new public agency (in consultation with the parents) must provide the child with FAPE (Free Appropriate Public Education) (including services comparable to those described in the child’s IEP from the previous public agency), until the new public agency:

1. Conducts an evaluation pursuant to Sec. 300.304 through Sec. 300.306 (if determined to be necessary by the new public agency); and

2. Develops, adopts, and implements a new IEP, if appropriate, that meets the applicable requirements in Sec. 300.320 through Sec. 300.324.

This federal regulation means that when a child transfers with an IEP from one state to another, the new school district will accept the IEP, provide services as close as possible to those received in the previous school district to ensure that a FAPE is provided to the child, and then establish an IEP following the state or Department of Defense Education Activity (DoDEA) criteria (for children going overseas or stationed at installations where the Department of Defense (DoD) has responsibility for educational services). If the school district does not agree with the assessment from the previous placement, then the school district will perform additional assessments to determine placement and services. Until that process is complete, your child, under the law, will be provided with the educational and related services identified in the IEP you bring with you as closely as possible until a new IEP is established.

The dilemma the STOMP staff sees all too often is where a child is ready to turn three and is neither under an IFSP nor an IEP, and representatives of the system are unsure whether to move forward with the evaluation process. If a child is diagnosed with a medical condition that qualifies him or her for special education services under IDEA 2004 at two years, nine months, and the military is transferring the family closer to a major medical facility for appropriate medical services, there can be a recommendation that the family wait until arriving at their new duty station to begin the formal evaluation process. The reason for this is that the assessment process to qualify for an IFSP can take up to 45 days. The transition continued on page 92
piece from Part C to Part B is estimated to take six months, but it needs to be done by the third birthday. Since the timelines for evaluation vary, the school district or medical personnel encourage the parent to wait for an IEP or the transition piece from the IFSP until they arrive at their new duty station. Once the family arrives, the IFSP will not give them the protections of FAPE, and the new school district does not need to place the child or provide the child with special education and related services during the transition process. If the child does not have an IFSP, the parents will need to start the assessment process for the IEP, which can take up to 60 days (unless a state has already established timelines for evaluation). TRICARE has no requirement to provide educationally necessary related services when a child is of age to attend either preschool or special education services for ages six through 21. This is where the gap can come into play. Waiting to start the process can delay access to the needed services. Therefore, if at all possible, it is important to go through the evaluation process and acquire the IEP because even if the assessment is weak, it qualifies your child for placement and related services under Part B until the new school district has completed their evaluations and developed the new IEP.

If you are facing a PCS move and your child is approaching the magic transition age of three, begin now to work with your early intervention personnel and the local school district to establish eligibility. When blending a transfer of duty station with the transition piece from IDEA 2004, the more you know, the better. The more preparation you can do, the smoother the transition will be. Time is essential and a major move can be intense, without adding the stress of a gap in special education and related services for your child with special needs. For further guidance on transitioning during a transfer, call your local STOMP office for details.

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**VA Requests $94 Million**

The Secretary of the Department of Veterans' Affairs announced that $94 billion was requested in the 2009 federal budget to provide the highest quality care for the VA's highest priority patients - the veterans of the Global War on Terror.

**Military Web Links**

This article provides vital Web links to Department of Defense programs like the Exceptional Family Member and Wounded Warrior programs. It includes Web links to governmental and family oriented organizations.

The contents of the military section to Exceptional Parent are not necessarily the official views of, or endorsed by, the United States Government, the Department of Defense, or the Department of the Army. The appearance of advertising adjacent to the military section to Exceptional Parent does not constitute endorsement by the United States Government, the Department of Defense, or the Department of the Army of the products or services advertised.
I am writing in the hopes that by sharing our family’s experience—that of a military family with a young child diagnosed with autism—I might shed some light on the unique difficulties faced by service members and their families who find themselves literally fighting on two fronts. One spouse is engaged in multiple deployments to support our country’s efforts in Iraq, and the other is at home fighting the daily battle to acquire and maintain minimal therapy and services for a child whose immediate and future independence, safety, and quality of life depend on it.

My husband, MSgt. (Master Sergeant) Buck Doyle—a Marine with over 19 years of service, three tours to Iraq, and an enemy sniper’s bullet still lodged in his thigh—often jokes that it is his wife who should be earning combat pay since, at least for all of the battles he faces, he has been highly trained and properly equipped. I found myself largely unprepared, and certainly unequipped almost three years ago when our daughter was diagnosed with autism just after her second birthday. We were even more...
unprepared to find that those who we assumed were our allies—the local school district and regional center, even the military healthcare system—would present us with the greatest challenges to our daughter’s needed intervention.

Kate

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

Finding Help – Delays, Desperation, and Hope

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

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

Kate works with her ABA supervisor, Jessica, at preschool, where she has been fully mainstreamed with a support aide since age three.
we received that week with Tracy, however, was hope for our daughter’s future.

**More Hurdles, More Delays**

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

Authorization was just the first hurdle, I found – the implementation of these benefits required that I find a Board Certified Behavior Analyst (BCBA) to provide one-to-one services. When I inquired with our TriWest case manager, she was unable to give me a name or agency in my area that had TRICARE-authorized personnel to provide ABA therapy. I quickly found that of the few BCBAs in our area, many were professors, researchers, or in supervisory positions, which were not conducive to the hands-on, one-to-one delivery of ABA that TRICARE required. After all our work getting Kate authorized, it looked like there would be no one to actually deliver the services for which she was authorized. Finally, we were able to convince the ABA agency that was delivering the few hours we had funded by the San Diego Regional Center to also become a TRICARE provider. After going through the paperwork process, they sent their Regional Director, a BCBA who supervised and trained the program supervisors in the area, to do five to seven hours per week of one-to-one ABA with Kate. By the time Kate was able to begin using any of her TRICARE-funded ABA benefit in January of 2006, almost seven months had passed since her initial autism diagnosis.

Still, even combining the fee-capped ECHO benefit with Kate’s Regional Center services, the number of hours of therapy she was receiving fell far short of the 25-hours-per-week minimum recommended by the National Research Council, and even further from the 40 hours shown effective by widely accepted research for a child her age. I did my best to make up the shortfall by providing hours myself. I went to every parent training I could find and even enrolled in a year-long graduate program through Pennsylvania State University that I was able to do almost entirely online (http://www.worldcampus.psu.edu/AppliedBehaviorAnalysis.shtml). I would eventually earn a Graduate Certificate in Applied Behavior Analysis for Special Education and will continue to work toward a Master’s Degree in Special Education. Still, the additional challenges of my husband’s frequent deployments and my day-to-day parenting responsibilities made it difficult to keep up. Because we had not been able to access ABA services at first, we were not qualified for the ECHO respite benefit as a result, so there was rarely a break from the kids or our daily schedule. The pace of Buck’s operations in Iraq had increased, making our communication less frequent than in previous deployments. There were times when I didn’t hear from him for a couple weeks. Even then I chose not to use those precious
moments of conversation to complain or to vent, when I knew that what he needed to hear was that we were o.k., so that he could continue to focus on his mission and keep himself safe. The day that I emailed Buck a video of Kate’s progress in her therapy session, he called me on the satellite phone, practically in tears. It was the first time he had ever heard Kate’s voice in conversation with another human being. He begged me to send more video; he knew he was missing his little girl’s transformation with each passing day.

School District – “When Are You Leaving?”
With my husband still deployed, my first encounter with the Solana Beach School District, a small but affluent district in North San Diego County, was a conversation with the administrator in charge of Special Education. “When will you be leaving?” was her first question. Sensing my confusion, she attempted to clarify by saying, “I mean, I heard your husband is in the military – how long until he goes to his next duty station? I know how military families are.” We had not yet heard the stories about districts who, when dealing with military families, offered minimal or wholly inappropriate services in order to “wait them out,” forcing families to decide whether to just accept inadequate services and placement or fight the district through the due process system—something that would take both an emotional and financial toll on families who had little to spare in either category. Often, by the time relief is found and services are won, families are called to the next duty station, where the fight for services begins anew. In California’s broken due process system, parents spend upwards of $25,000 to go to hearing and fully prevail less than ten percent of the time. During Kate’s initial Individualized Education Program (IEP) session, the district refused to disclose any information on the training or qualifications of their staff and offered Kate a placement in a Severely Handicapped Special Day Class where Kate would be the only child with the ability to use language without adult prompting. When we voiced our concerns, we were abruptly told that we needed to “learn to separate” from our daughter—that we ought to trust them as they were the “experts.” We were convinced, and her current program providers agreed, that what Kate needed in order to continue her progress was access to peers who were appropriate language and social models and continued one-to-one ABA instruction and support by qualified personnel. So, in spite of the expense and because of the odds of prevailing in a legal fight with the district, we ended up placing Kate in a local preschool and settling on services after battling with the district for several months.

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

The page contains a narrative about a family's experience with a child's diagnosis of autism. The family faced various challenges, including legal battles for appropriate services, and shares their journey towards advocating for their child's needs. The text discusses the obstacles they faced, the legal processes they went through, and the impact of these experiences on their family. The family's story emphasizes the importance of advocacy and the determination to ensure their child receives the necessary support and services.

The narrative highlights the family's resilience and the challenges they overcame, including medical procedures, financial concerns, and legal battles for education. The text also reflects on their experiences in military life and the additional stressors that come with it, such as frequent relocation and dealing with the demands of military careers.

The family's story serves as an inspiration to other families facing similar situations, offering insights into the journey of navigating the complexities of autism diagnosis and treatment. It underscores the importance of perseverance, advocacy, and seeking support from various sources to ensure the best possible outcomes for their children.
advocate. As the child’s parent, you are often the only person in the room with a vested interest in his or her long-term progress and independence.

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

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

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

- Take action. I have found that turning adversity into advocacy is all about being willing to act where others may not. When we realized that Kate and other children were suffering from service gaps at the age three transition from Early Start to the schools, we lobbied for legislation at the State Capitol that would help ease this burden for families. Laws like the Individuals With Disabilities Education Act (IDEA) and the current changes in the military healthcare system’s treatment of autism originated with families of children with disabilities who demanded change and better treatment for them. Certainly, not everyone has the time or the energy to lobby Congress, let alone the local school board, but recognize that there are moments when we must ask ourselves, “If not me, then who?” Taking action is one way to empower yourself and to effect change in the systems and organizations that affect the lives of our children.

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

Kyla Doyle is the wife of U.S. Marine Corps MSgt. (Master Sergeant) Buck Doyle. They have two children. Kyla Doyle has a Bachelor of Arts degree in Political Science and a Graduate Certificate in Applied Behavior Analysis. She is pursuing a Master’s degree in Special Education, with an emphasis in Autism Spectrum Disorders.
In the 2004 publication of the Individuals with Disabilities Education Act (IDEA), several changes that align this law with the No Child Left Behind Act of 2001 (NCLB), also known as the Elementary and Secondary Education Act (ESEA), occurred. One of the major provisions of both the IDEA and NCLB is that teachers must use scientifically based research and best practices when instructing students.

So what does all this mean for the child, especially the military child, in the special education classroom? Parents may ask why scientifically based research and best practices are something to be concerned about. When using scientifically based research, the strategies included in the curriculum have been proven to be effective by methods that look at the results in a variety of ways. For military or mobile students, such practices are important because parents need to know that not all research is the same. What may be a best practice in one state may not necessarily be used in another state. A student may be meeting his or her goals in one school while using such practices, then move due to their family servicemember’s Permanent Change of Station (PCS). Having the knowledge of best practices can assist families in taking this information with them to their next school so that their child can continue to achieve success, regardless of their location. Prior to the reauthorization of the IDEA and NCLB, teachers and others developed curriculum they felt worked but that sometimes has subsequently been proven not to address the needs of all children in the same way.

For this reason, Congress stressed the need for students to be taught using strategies that have been proven effective by valid research. Valid research follows a standard scientific process and contains specific elements. The research must be:

1) Independent
2) Quantitative
3) Qualitative
4) Of Adequate Sample Size
5) Controlled for Variables
6) Able to Be Replicated
7) Subject to Peer Review

Independent or third-party research: The individuals conducting the study should have nothing to gain or lose based on the results of the study. Quantitative research: The data gathered is quantifiable —i.e., it can be objectively measured, reflecting observable fact versus opinion. Qualitative research: The researcher collects opinions, descriptions, and information from the people exposed to a particular product, treatment, technique, etc.

The number of people or items involved in a study is known as the sample size. In quantitative research, many samples should be tested. Samples should be selected at random, meaning the researcher does not specifically select the subjects but randomly selects them. In qualitative research, a large number of subjects should be exposed to the same product or treatment. As parents, we know that many things can vary and affect the testing; however, some of these variables or factors must stay the same for the results to be valid.

Other, independent researchers, using the same research methods, must be able to replicate or repeat the study. Before the research results can be published in a professional journal, a panel of experts in the same field—i.e., professional peers, also must review the findings to verify the validity of the research and its results.

When examining a new product or method to be used by the teacher in the classroom, parents may want to ask themselves some simple questions:

Who conducted the research on the product or method? Do the researchers have anything to gain or lose based upon the results?

What was measured? Were the methods used quantitative, qualitative, or both? What was the intent of the original research?

When was the research conducted? The age of the data may affect its current applicability.

Why was the research conducted? Understanding how the research was conducted and evaluated will allow parents to determine how a product, method, or technique will help their child.

Parents can work with the teacher and other staff to learn more about the types of curriculum used in the school. When parents know more about what is being used, they can get answers to basic questions and act in a more informed manner.

Luz Adriana Martinez is the Assistant Director for Specialized Training of Military Parents (STOMP). She is located in the Central office. She and her husband have two daughters. She began her journey with STOMP when she attended her first workshop when their daughters were young. Her husband served in the Army.
What We Know...Can Help Us

A single word can offer comfort... a few words ignite hope... a whole story change a life.

Your story.

Your life.

So many of EP's military families and professional healthcare readers have powerful, beautiful, informative, ideas-rich stories to tell.
Stories that today could change someone's life.

Did you know...?

Neither did we – until somebody told us.

EP would love to hear stories from and about:

You • Mothers • Fathers • Daughters
• Sons • Servicemembers • EFMP Managers
• Special Needs Coordinators • Family Physicians
  • Pediatricians • ABA Therapists • Neurologists • Speech Therapists • Occupational Therapists • Physical Therapists • Psychologists • Psychiatrists • Surgeons... And More

Tell us about your own experience or professional efforts with people facing the challenges of:

Autism • Traumatic Brain Injury (TBI) • Attention Deficit Hyperactivity Disorder (ADHD)
  • Cerebral Palsy • Post-Traumatic Stress Disorder (PTSD) • Spina Bifida • Asthma
  • Down Syndrome • Epilepsy • Anxiety • Metabolic Disorder • Depression
  • Hearing Loss... And Others

What programs and resources have you found helpful?

Exceptional Family Member Program (EFMP) • Respite Care • Wounded Warrior Program
• Department of Veterans Affairs (VA) • Military OneSource • Wounded Warrior Project
• Specialized Training of Military Parents (STOMP) • Military Child Education Coalition™ (MCEC™) • May Institute • Military HOMEFRONT • Art/Music Therapy • Sports... Others

I Have a Story to Tell • Tell us, so we can tell it in EP.

Contact: Maria Caroff at mcaroff@eparent.com or Riley Miller at rmiller@eparent.com

For guidelines, go to: http://www.eparent.com/main_channels_military/index.asp
Disability in both the military and civilian communities is growing more costly, with billions of dollars spent annually in both communities. The costs are felt not only financially, with dollars spent on healthcare, the loss of trained and expert personnel, and lost income, but in a variety of other ways, including reduced ability to engage fully in day-to-day activities and subsequent overall decreased quality of life. A research group has undertaken a study of disability in the United States Army, funded by a grant from the U.S. Army Medical Research and Materiel Command. This first of five planned studies has been published in Disability and Health Journal, January 2008. The group analyzed disability data spanning 25 years, from 1981-2005. Excerpts of the study appear here, followed by an interview EP conducted with Dr. Nicole Bell, a co-author of the study. A full copy of the report can be found at the Disability and Health Journal Web site (http://www.disabilityandhealthjnl.com).

Abstract Excerpt

**Background:** We sought to provide a profile of U.S. Army soldiers discharged with a permanent disability and to clarify whether underlying demographic changes explain increasing risks.

**Results:** Disability risk has increased seven-fold over the past 25 years. In 2005, there were 1,262 disability discharges per 100,000 active-duty soldiers. Risk factors include female gender, lower rank, married or formerly married, high school education or less, and age 40 or younger. Army population demographics changed during this time; the average age and tenure of soldiers increased, and the proportion of soldiers who were officers, women, and college educated grew. Adjusting for these demographic changes did not explain the rapidly increasing risk of disability. Time-series models revealed that disability among women is increasing independently of the increasing number of women in the Army; disability is also increasing at a faster pace for younger, lower-ranked, enlisted, and shorter-tenured soldiers.

**Conclusion:** Disability is costly and growing in the Army. Temporal changes in underlying Army population demographics do not explain overall disability increases. Disability is increasing most rapidly among female, junior enlisted, and younger soldiers.

Study Excerpt

Between 1981 and 2002, the number of active-duty Army personnel fell by 37 percent as part of an overall downsizing effort. At the same time, soldiers reported poorer physical and mental health and increased levels of stress, depression, anxiety, and occupational stress compared with their civilian peers; these factors may be associated with increased risk for subsequent disability.

DoD (Department of Defense) Directive 1332.18 and 10 U.S. Code, Ch. 61 outline the requirements and procedures for separations due to a physical disability with the primary requirement being that the soldier must be unfit to carry out duties of his or her rank, office, or grade due to a physically disabling condition that substantially limits or precludes fulfillment of the purpose of their active-duty employment.

Causes or major types of disability are defined in the Veterans Administration Schedule for Rating Disabilities (VASRD). They fall into the following categories: musculoskeletal conditions; neurological conditions; mental health disorders; cardiovascular conditions; respiratory conditions; endocrine disorders; digestive conditions; diseases of the eye; skin disorders; genitourinary conditions; infectious diseases, immune disorders, and nutritional disease; hemic and lymphatic disorders; diseases of the ear; diseases of other sensory organs; gynecological conditions; and dental and oral conditions.

Musculoskeletal-related disability is the fastest growing category of disability, increasing from 70 per 100,000 in 1981 to 950 per 100,000 by 2005.

Disability discharge risks are 7 times higher today than
they were 25 years ago. The increase appears primarily attributable to disorders of the musculoskeletal system. Preliminary findings (in unadjusted models) indicate that rates of musculoskeletal-related disability are increasing faster than any other type of disability and the increase is occurring more rapidly among women, whites, blacks, those without a college education, and soldiers aged 35 or younger.

By 2005 more than 7,000 people with life-altering disabilities were being discharged from the Army, even before the full impact of conditions related to deployment in support of Operation Iraqi Freedom had a chance to work through the system.

This is only a fraction of the problem as it does not include soldiers who have disabling conditions but nonetheless seek evaluation and treatment for their conditions in the VA (Department of Veterans Affairs) or through other healthcare systems only after their discharge from the Army (as it is their right to do). There is currently no mechanism in place to link DoD and VA data resulting in a discontinuity of service over time and an inability to explore individual-level healthcare data longitudinally.

Ideally, soldiers seeking care outside of either the VA or DoD compensation programs should also be identified and followed.

Because the Army only discharges individuals with conditions that preclude active service while the VA also provides compensation for functional limitations caused or aggravated by military service, both systems need to be evaluated in order to fully appreciate the magnitude and characteristics of service-connected disability.

**Dr. Bell provided information on the details of the group's research:**

**Nicole Bell, ScD, MPH (NB):** We do secondary data analysis, which means we combine information from a wide range of administrative and health-related military databases (personnel records, hospital records, disability files, health and behavioral surveys, etc.). The advantage of this approach is it allows us to look at a lot of different factors on a very large population fairly rapidly. The disadvantage of this approach is we can’t always answer the specific questions that we most want answered. We are limited by the data that has already been collected.

It can be difficult to study the problem of disability among military populations because of loss of follow-up. When servicemembers leave the Armed Forces after their military tenure, we often can’t follow them. Even if they continue to receive care in the VA system, we may not be able to access data on them due to restrictions and limitations in data sharing. Moreover, the data we have on disability is likely just the tip of the iceberg since many who may have experienced a service-related disability may not be eligible for compensation and for this reason, or others, may not seek disability evaluation. Consequences of some problems may not be realized until well after they have left the military and thus may not be included in Army disability files.

**Exceptional Parent (EP):** What prompted your group to undertake this study?

**NB:** Most of our earlier research focused on the topic of acute injury (both intentional and unintentional), as these are by far the most common causes of morbidity for active-duty soldiers. Whether we consider the economic or quality-of-life costs, we soon learned that perhaps the most significant consequence of injury was permanent physical disability. Therefore, a shift to the study of the natural history of injury-related disability was a logical one for our research group. We actually started studying disability alongside some of our other acute injury studies several years ago. We collaborated with a VA study team in a pilot test of how well active-duty Army injury exposure and disability outcome data could be linked to VA data from soldiers who leave the army and are ultimately treated by the VA for knee- or back-related disabilities. Data sharing restrictions made this a challenging undertaking, but we learned a lot in the process. For example, we learned that not all soldiers who are eligible to receive VA care necessarily seek/receive post-active-duty care at the VA. Likewise, many individuals whose disabilities are not recorded by the Army before they are discharged are nonetheless rated and oftentimes treated by the VA subsequent to their discharge from service. In many cases, these individuals receive compensation for these disabilities from the VA only. We also learned that the sum of the payments to all living veterans dating back to WWII is staggering. Not surprisingly, a significant portion of the disabilities compensated appeared to be related to musculoskeletal injury. Little research was being done. Full understanding of the nature and natural history of disability would ultimately require study of both DoD and VA data, and ideally a direct linkage of the two.

Between the Army and the VA, there were many potential sources of disability data available for exploration. We started with what we knew best and with what we had most immediate access to: the Army data—initially, the electronic records. While very robust for analysis, these records do not contain all the information useful for study. Hard-copy records generated by the Army during medical board processing of soldiers are archived in St Louis where it was impractical to review them, and, even more worrisome, we learned that these copies were actually being destroyed to save space for new files. We worried that a tremendous
The Changing Profile of Disability

opportunity for thorough study of disability in the Army would be lost if those records could not be saved. We were able to obtain permission to acquire some of these records and begin digitizing them for direct review as well as possible text-mining in the future. We believed we would then be able to identify important health-related risk factors or patterns that might otherwise be missed. In collaboration with the Army, we helped build infrastructure for the focused study of disability. Later, the Army obtained necessary resources to complete the scanning themselves and are just finishing this process. We believe those data will provide important information for understanding how disability occurs.

In addition to these text records, we were also provided access to electronic data (more summarized information in an electronic format, which is easier to use for analysis purposes) that included details on the type of disability, type of compensation award received, and whether or not the disability was considered combat-related. As we did this early work, we were astounded to learn about how much money was being spent on disability or disability-related care. While this is not an exact-enough estimate to quote me directly, the amount the VA spends per year on disability runs in the neighborhood of $50 billion (about equally split between direct medical care and direct personal compensation payments). With all the money that was already being spent on disability we were even more surprised when our data revealed that the disability rate has been increasing fairly steadily for more than a decade, and musculoskeletal disability was increasing the fastest.

The policies and procedures for assessing disability and then receiving a compensation package are complex and a topic of great national debate. The recent problems at Walter Reed (Army Medical Center) and complaints from veterans have drawn even more attention to the disability problem. I just read this morning that beginning in 2008 the military disability system will have to align more closely with the VA system for rating disability. In the past, the active military side of disability evaluations usually resulted in a less favorable rating than that which the soldier typically received at the VA (particularly for conditions such as mental health disorders). The main reason for that was ostensibly because the military was concerned more about a service member’s ability to serve and the VA was more concerned about functional limitations in general. There are other remaining challenges that face veterans trying to navigate their way through a confusing morass of policies and benefits outcomes. There has been a long-standing principle that no one should be able to receive concurrent retirement benefits and disability benefits based upon the same service. However, because retirement pay was offset 1 for 1 with disability compensation, the net effect had been that individuals who retire healthy receive retirement pay and can gain unfettered civilian employment while those with disability who can’t work receive only retirement benefits. Military and veterans’ advocacy groups have tried for many years to have that inequity rescinded. Starting with the Defense Authorization Act of 2004, concurrent receipt restrictions for certain veterans have been removed. A series of bills approved since, or which are currently under debate, aim to further reduce restrictions. While this may be a good and just occurrence for our veterans, it is going to increase the already substantial cost of military service-connected disability to the U.S. taxpayer significantly.

As we learned more about these issues, we became more intrigued by the problem of disability. We realized that very little had been done to document the extent of the problem of disability and to describe risk factors. We believe that to reduce the burden of disability we have to begin by describing the extent of the problem and then looking back in time at the natural history or exposures and risk factors that occurred earlier in the military career. We put together a grant proposal with this goal in mind and submitted it in the Spring of 2005. It was funded, and we began work on it during the Summer of 2006. The paper you are featuring was the first product from that grant-funded effort.

EP: Has the Army had the opportunity to assess and respond in any way yet to your research findings?

NB: The Total Army Injury and Health Outcomes Database (TAIHOD) that we use is housed at the U.S. Army Research Institute of Environmental Medicine (USARIEM) in Natick, Massachusetts. I should mention that because of privacy concerns and protection of human subjects data, all work is done by Social Sectors Development Strategies, Inc. (SSDS) staff located on the base, using files that have all personal identifiers removed. The military department chair responsible for the oversight and protection of the TAIHOD data, Dr. Edward Zambraski (Chief, Military Performance Division), has been very supportive of our work, as has the USARIEM Commander. USARIEM was provided an advance copy of the manuscript and had no objection to its content. They have asked that we help them put together a summary of key findings that they can use in their briefings to help raise awareness of the problem of disability. The Madigan Army Medical Center also reviewed the manuscript since one of the co-authors is on staff there.

To the best of our knowledge, no one else has had a chance to review and respond to the findings.

EP: What outcomes does your team hope might be achieved by an assessment of your findings and any subsequent implementation of new plans?

NB: Ultimately, I hope that the information will be useful in both focusing more attention on the sheer magnitude of the disability problem AND in developing targeted
intervention programs. The ultimate goal is to find a way to reduce the burden of disability and to improve health outcomes and quality of life (and in the process reduce the amount of money needed for disability-related care and compensation benefits).

EP: While your group is merely reporting its findings, do you have any concern that this data, which includes the monetary cost of disability in both the civilian and military populations, will promote a backlash of sorts in people’s perceptions about funding and other resources being spent on disabilities?

NB: I hope that it does shock people. I believe people ought to know how much is being spent on problems that may be preventable (at least in part). Ideally, I hope it motivates us as a society to take steps to reduce the burden of disability simply because it is the right thing to do. While we are pleased to have received funding to pursue this research, the magnitude of the resources devoted to the study of disability are still inadequate given the magnitude of the problem (in this researcher’s opinion). So we certainly hope that increased awareness will result in more study. The men and women who serve in the Armed Forces are doing a service for their country and ought to know that steps will be taken to mitigate their injury and disability risks. But, sometimes idealism is a less potent motivator than the desire to reduce costs. So, if wanting to reduce the burden of disability is not motivation enough, I hope that wanting to reduce the enormous costs associated with caring for and compensating those who are disabled will provide sufficient motivation to seek ways to lower the risk of injury or other exposures that ultimately cause or contribute to disability.

EP: Given that females in the military constitute one of the groups among which disability is increasing most rapidly, do you think that these findings could inadvertently lend support to those who argue that women should not be serving?

NB: It would not be particularly useful to eliminate or restrict any particular demographic group at greater risk for one health outcome (in this case disability) from the Army. The disability increases are largely occurring within one particular category of disability: musculoskeletal disorders. While musculoskeletal disability is the fastest growing category of disability and women are at greater risk than men for this type of disability, the fact remains that the vast majority (approximately 85 percent) of soldiers are men and a sizable proportion of them will experience musculoskeletal disability. It’s also important to note that the rate for musculoskeletal disability is also increasing among the male soldiers, just not as rapidly as the rates are increasing among female soldiers. So, even if there were no women in the military, there would still be a lot of men experiencing these conditions. In addition, even though women were at greater risk for musculoskeletal disorders than men, other research we are working on suggests that men are at greater risk (relative to women) for certain other types of disability outcomes. There are also other health conditions for which women’s risks are lower than men’s risks. In sum, it makes more sense to focus on underlying causal factors rather than eliminating one particular demographic group from the risk pool.

EP: Which study does the group anticipate will be published next?

NB: Our next paper has just undergone peer review, and we are in the process of revising it based upon peer feedback. It focuses on differences in risk factors for different types or causes of disability and variation in compensation packages. The paper that has just been published and this second one that we are revising both address the need for baseline documentation of the extent of the problem of disability. Remaining papers focus on trying to uncover important modifiable risk factors that can then be used to inform intervention strategies.

We have started on an analysis of risk factors for mental health disorders and will soon begin a study that focuses just on musculoskeletal disability. We are nearing completion on a report that explores occupational exposures, such as heavy physical demands, and injury and disability risk. In the out years of our study, we will take a closer look at the influence of pre-existing conditions and on combat-related disability. As important as these early papers are, we are just scratching the surface.

EP will continue to follow the results of the studies being conducted by the research group.


Authors of the study include Nicole S. Bell, ScD, MPH; Carolyn E. Schwartz, ScD; Thomas Harford, PhD; Ilyssa E. Hollander, MPH; and Paul J. Amoroso, MD, MPH.

Dr. Nicole S. Bell, is a member of the Board of Directors and Vice President of Social Sectors Development Strategies, Inc. (SSDS). She is an adjunct assistant professor in the Department of Social and Behavioral Sciences at Boston University School of Public Health and is an affiliated faculty member at the Harvard Injury Control Research Center at Harvard University School of Public Health. Dr. Bell’s husband, Dr. Paul Amoroso, also a member of the research group, is a colonel on active duty in the U.S. Army, and was deployed to Iraq in 2003.
It certainly is not news that the military lifestyle and regular school moves provide military families with some unique challenges. This reality is especially true for families who have children with special needs.

Visualize a military family who moves every two to three years. Think of the tasks of preparing your child’s school paperwork and identifying the variability in testing, available services, schedules, and programs in each state, with every move. Now consider the added challenges of transitioning a child with special needs. How much additional paperwork and preparation is needed to ensure that your child receives all necessary accommodations at his or her new school and is best prepared for success? One military spouse and mother, when asked about preparing her two children with special needs for a summertime move, compared herself to a military commander preparing for war. While the imagery may seem strong, the amount of logistics and time and the importance of each step involved in both preparing for war and preparing for transition does seem comparable.

Over the years, the United States Armed Forces and other concerned organizations have joined together to simplify this battle preparation. In 2005, the U. S. Army Community and Family Support Center (CFSC) commissioned the Military Child Education Coalition™ (MCEC™) to conduct a research study on the issues faced by transitioning military families who have children with special needs. Specifically, the study was to focus on children enrolled in the U.S. Army’s Exceptional Family Member Program (EFMP), a program of coordination among military and civilian agencies to meet the medical, educational, housing, personnel services, and community support needs of families with special needs.

Through a structured series of surveys, focus groups, and interviews, the Military Child Education Coalition concluded that families who have children with special needs require consistency, predictability, and coordination of educational services from one location to another in order to transfer seamlessly. Effective communication between military families and the programs that serve them is also key to transition success and, ultimately, quality of life. An additional, though not surprising, finding stated that those families that understood and openly acknowledged that school rules and regulations vary by state, or even district, were the most successful in experiencing a smooth family transition. Due to the findings of this research, the Army Community and Family Support Centers, along with many other organizations, have taken steps to ease the transition process.

The Military Child Education Coalition responded through many avenues, including the bolstering and expansion of its Special Education Leaders Institute™ (SELI™). The Special Education Leaders Institute is a two-level series with the overall goal of promoting awareness and increasing the availability of professional educators who understand the amplified challenges associated with transitioning mobile military-connected students in special programs such as special education, §504, or gifted education. The course, while targeting military and civilian education and transitional professionals who work with children with special needs, also reaches out to EFMP employees.

Phase One of the professional development series, which was already underway at the time the research was done, looks at basic transitioning issues for military children with special needs, including subjects such as navigating different state requirements, program policy implications, practical applications for schools, and supporting children through trauma and loss. To increase the impact of the Special Education Leaders Institute program, the Military Child Education Coalition created a second phase of the training.

Phase Two invites the same audience but extends the learning process by addressing subjects such
as the need for and use of technical support and advanced resources and the social/emotional needs of transitioning students, family support systems, and EFMP abilities and available accommodations. By raising awareness and giving special needs education and transition professionals the research, advice, and usable tips for smoothing the transition process, the Military Child Education Coalition is able to help thousands of families.

While the aforementioned research provided great insight into the unique challenges that face military families with special needs in transition, the U.S. Army recognized that there is always more to learn. Therefore, the Military Child Education Coalition recently began a second phase of research at the behest of the U.S. Army’s Family and Morale, Welfare and Recreation Command (formerly the U.S. Army’s Community and Family Support Centers). This new research study attempts to gain an in-depth understanding of how military installations, school systems, and communities accommodate and respond to the educational needs of children with special needs. Included in the scope of the research will be a look at both military and educational agency involvement, community services and resources, and a deeper exploration into the issues of consistency, predictability, and communication systems.

The United States Armed Forces, the Military Child Education Coalition, and other concerned organizations are working hard every day to identify and address the unique challenges that face transitioning military-connected children with special needs. In time and with continued effort, the frustrations that make a military move seem like preparation for battle will give way to consistent planning and smooth transition. Working together, anything is possible.

To learn more about the Military Child Education Coalition or the Special Education Leaders Institute, please visit http://www.MilitaryChild.org or call (254) 953-1923.

Joan Barrett is the Director of Research and Evaluation for the Military Child Education Coalition. A military spouse for over 30 years, she has a professional background as a secondary and post-secondary schoolteacher and counselor, and broad experience regarding military-connected children.

EP Military Channel News

Readers can access important information regarding Department of Defense news, Department of Veterans Affairs news, and TRICARE by visiting the Military Channel on the EP Web site. Information includes news releases, reports, and other relevant items.

Visit the EP Web site’s Military Channel often for news and announcements that are of interest to military families who are caring for a member with special needs.

www.eparent.com/main_channels_military/index.asp
When a child is diagnosed with autism, every member of the family is affected. While every family’s experience is unique, there are common challenges that most families face. These include dealing with the diagnosis, choosing the best treatment options, and building a strong and supportive family structure.

For military families, the difficulties presented by these challenges are often exacerbated by the lack of proximity to family and support networks, frequent relocation, school and training schedules, and more. Managing the stress that accompanies these challenges is critical to a family’s long-term health and well-being.

Diagnosis and Early Intervention: Keys to Success

Salina Dills, who lives on Fort Benning in Georgia, is awaiting a diagnosis for her two-and-a-half-year-old son, Caleb. His primary symptom is delayed speech, something Salina noticed more than a year ago. She expressed her strong concern to Caleb’s pediatrician at his two-year checkup, and Caleb recently had a comprehensive evaluation. Waiting for a diagnosis has placed a lot of stress on the family.

“This could be our life,” says Salina, “and what does that mean for us? What does that mean for our son? Is he going to have this lifelong struggle? Is he going to be one of those kids who can’t ever go to a regular classroom and have ordinary relationships? What will his quality of life be? What do you do? How do you do it? All of these questions swirl through your mind... it is overwhelming.”
Taking Action

Suspecting that your child is not developing in an age-appropriate manner can be very frightening and stressful for parents and families. It is important to share your concerns with a physician, therapist, or early education specialist. Make sure your concerns are heard and your questions answered. Advocating for your child to get an appropriate assessment is critical.

Accessing information and taking action are two steps that can help you manage anxiety. During this waiting period, it may be helpful to speak to other parents who have gone through this process. It can help you prepare to hear difficult information and think about different options that will fit into your family’s lifestyle.

If your child does have autism, it is crucial to identify it as early as possible so treatment and intervention can begin. Although evidence shows that intensive early intervention during the preschool years results in the best outcomes, it is estimated that only half of the children with ASD are diagnosed before they enter kindergarten.

Acknowledging the need for earlier diagnosis, the American Academy of Pediatrics (AAP) recently released two reports to help pediatricians recognize ASD earlier and guide families to effective interventions. (These reports and an autism checklist for parents are available at http://www.aap.org.)

Dealing With a Diagnosis

If your child is diagnosed with a disability, give yourself time to absorb this life-changing information. You will need to adjust your hopes, wishes, and dreams for your child and your family. Talking to other families, sharing information, accessing all of the resources available, and developing both a formal and informal support network are all helpful in managing stress. For families living on military bases, spouses’ networks and neighborhood groups can provide critical support.

Katherine Bray of May Institute’s Southeast Regional Autism Center in Columbus, Georgia, also lives on Fort Benning, and is the parent of a child with ASD. She recently shared a story about a neighbor who came to her door in tears, having just received a similar diagnosis for her young son. A mutual friend suggested to the mother that she talk to Katherine. “Word of mouth on a military base can connect families to other families,” she said. “My neighbor didn’t know how to begin to absorb the information she had received. We talked for a long time, and she is now setting up essential services for her son.”

Support groups are also useful because they decrease your sense of isolation and increase your ability to cope. Groups offer opportunities to share stories about finding effective interventions, managing difficult situations, and moving forward with your life.

Once a diagnosis is confirmed, it is helpful to learn as much as you can about the disorder. Obtaining research information about ASD and treatments from the Internet, conferences, and reading materials help families manage their anxiety about the diagnosis. Be sure to share information with siblings, family, and friends so people close to you can learn what you are learning and provide support and feedback.

Choosing Effective Treatments

How can parents of children who have been diagnosed with autism choose the best treatment for their children? Recognizing that some treatments have evidence showing their effectiveness, and that others do not, is an important part of this decision.

Many educational methods for children with autism are based on good research that has been tested and shown to be effective. One of these methods is applied behavior analysis (ABA). Hundreds of scientific studies have shown that ABA is the most effective method to teach children and adolescents with autism and other developmental disabilities. ABA facilitates

Could My Child Have Autism?

Some of the first signs that a child might not be developing typically include a lack of eye contact, no pointing or gesturing by 12 months of age, no babbling or no inflection in voice tone when babbling, no use of words by 12 months, no use of phrases of two or more words by two years, no make-believe play by two years, and a loss of language and social skills.

These signs do not mean that a child has autism, but they are an indication that parents should seek further information from their family physician or pediatrician. Most pediatricians can conduct an initial screening for autism. If needed, families should then be referred to an expert in the field for a comprehensive diagnostic evaluation.
the development of language, social interactions, and independent living by applying basic behavioral practices—positive reinforcement, teaching in small steps, prompting, and repeated practice. In addition to building critical skills, ABA can also help reduce everyday social problems and serious behavior disorders.

Unfortunately, the prevalence of methods that have no evidence of effectiveness is widespread. You see it every day in advertisements, infomercials, and treatment options offered to parents of children with autism. Extraordinary claims are made that are unsupported by objective evidence. Risks to children are minimized or denied.

It can be very stressful choosing the “best” treatment for your child, and more so if you are on your own. Contradictory information makes this even more difficult, especially when dealing with a new diagnosis. Read the research and learn as much as you can about what treatments are supported by the most evidence. Ask questions. Talk to your providers about recommended treatments and talk to other families who have gone through a similar process.

“ABA has been the best method for Gabe,” says Jodi Davidson, a military mother of a five-year-old with autism. “He progressed by leaps and bounds with ABA. Doctors didn’t think he would ever speak, but, with the help of ABA, he started talking at age four.”

Building Support Through Family

As any family would adapt and respond to the twists and turns of childhood, so too does the family of a child with autism. But families of children and adolescents with autism must face some unique challenges and stressors that those of typically developing youngsters do not.

One of the best ways to manage stress is to strive to maintain balance in your life and family. Designate time to take care of your other children, your relationship, and yourself.

Siblings can play an important role in the life of a child with autism. Include siblings throughout all life stages and encourage them to develop independent relationships with their brothers and sisters who have autism. There are many books for and about siblings of children with special needs, and many communities offer support groups.

Managing Stress to Maintain Balance

Taking care of a child with a disability puts a lot of stress on a relationship—it is important to discuss your feelings and thoughts about treatment with your spouse. Each of you may need support in different ways, and it is important to communicate about your needs. If your spouse is overseas, it is even more critical to maintain a constant dialogue through e-mail, text messaging, or phone calls about the progress your child is making, how it has impacted the rest of the family, and how to support one another.

It will take a significant amount of time and energy to develop and sustain appropriate services for your child with autism. For the spouse who is living on the installation, it is helpful to develop a support network.

Jodi Davidson, Gabe’s mother, talks about the challenges she faces when husband Christopher is deployed for six months at a time. “It’s very stressful for me, the parent left behind. It’s a very long and hard time when he’s gone,” she shares. Christopher acknowledges the burden. “My heart goes out to Jodi,” he says. “She is such a strong woman. When I’m gone, she takes on both our roles and does everything. I don’t think I would be able to do it.”

Jodi finds ways to support Gabe and find balance. “Children with autism like consistency, so it’s very important to keep life as normal as possible when a spouse is deployed.”

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About May Institute

May Institute is a nonprofit organization that provides educational, rehabilitative, and behavioral healthcare services to individuals with autism and other developmental disabilities, brain injury, mental illness, and other behavioral healthcare needs. The Institute also provides training and consultation services to professionals, organizations, and public school systems.

Since its founding over 50 years ago, May Institute has evolved into an award-winning national network that serves over 25,000 individuals and their families annually. With corporate headquarters in Randolph, Massachusetts, the Institute operates more than 200 service locations in the Northeast, Mid-Atlantic, Southeast, Midwest, and on the West Coast. Six May Institute schools serve children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities. A seventh school serves children and adolescents with brain injury.

An active center of research and training, the Institute maintains affiliations with more than forty universities, hospitals, and human service agencies worldwide.

May Institute is the first nonprofit human services organization in the country to receive top national honors from the Society for the Advancement of Behavior Analysis (SABA) and the Association for Behavioral and Cognitive Therapies (ABCT). The Institute received the 2005 Outstanding Training Program Award from ABCT and the 2007 Award for Enduring Programmatic Contributions in Behavior Analysis from SABA.

In 2005, May Institute sponsored the initial development of the National Autism Center, a groundbreaking nonprofit organization dedicated to supporting effective, evidence-based treatment approaches for autism, and to providing direction to families, practitioners, organizations, policy-makers, and funders. Together, May Institute and the National Autism Center are committed to identifying and applying universal standards for the treatment of autism and to providing care and hope to families throughout the country.
she says. “It’s good to get support from other families who have children with autism or from friends. Sometimes, you just need a short break.”

During periods of high stress, having a range of accessible activities can help you decompress. Jodi finds that short breaks help her find balance. Think about activities that might help you relax and feel good. Options include:

- Exercise
- Take a time-out for yourself – visit with a friend or curl up with a good book
- Call a good friend or close family member
- Learn how to do yoga
- Pamper yourself—take a long bath or get a massage
- Go out to dinner or on a date with your spouse or a friend
- Organize respite care
- If you are religious, turn to your faith and church friends for comfort
- Keep a journal to write down your thoughts and feelings
- Develop a new hobby
- Listen to music

Attending to your own needs, maintaining an awareness of the needs of each member of the family, and putting systems in place to support the family will help lessen disruptions, keep channels of communication open and create an environment that is healthy, loving, and supportive for everyone, including the child with autism.

With effort and communication, families can get through the challenging times and come out stronger in the end. “The last time I returned home from being deployed,” Christopher remembers, “Gabe hugged me and wouldn’t let go for about an hour and a half. I knew he still loved me just as much as when I left.”

Alan Harchik, PhD, BCBA, is May Institute’s Chief Operating Officer, a licensed teacher of children with disabilities, Board Certified Behavior Analyst, and a member of the leadership team of the National Autism Center. Dr. Harchik has extensive expertise in the areas of autism and applied behavior analysis and has been published in a variety of professional journals. He writes a monthly column on autism and other disabilities for The Republican newspaper in West Springfield, Massachusetts and serves as an expert consultant for the Civil Rights Division of the United States Department of Justice.

Lauren Solotar, PhD, is May Institute’s Chief Psychologist and Senior Vice President of Clinical Services. Dr. Solotar is an expert in cognitive and dialectical behavior therapies, and specializes in anxiety disorders. She has extensive experience working with children and adolescents. Her research has been published in professional journals, including Behavior Therapy and Journal of Consulting and Clinical Psychology, and she has written a chapter in the Child Behavior Therapy Casebook.

NOTE: Drs. Harchik and Solotar wrote all of the sidebars in addition to the main article.
COVER STORY
Life Breath: The Story of a Little Girl’s Courage, a Mother’s Determination, and the Healing Power of Oxygen

Dr. Jack Kessler: An Update on Stem Cell Research

Autism and Companion Animals

United States Military Section
Traumatic Brain Injury and Post-traumatic Stress Disorder

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Community of One

From Our Families… To Your Families
The accessible mobility dealership, Accessible Vans & Mobility (AVM), while not involved in a formal program of vehicle donation, is very open to the need for help when they are approached. AVM made a van donation to the family of First Class Petty Officer David Hall, of the United States Navy, and his wife Tanya, whose three children have a rare genetic disorder that limits their mobility and will likely further limit it in the future. One of 10 mobility dealerships contacted by EP Global Communications, Inc., when a physician for the Hall family spoke with EP’s CEO Joseph Valenzano about the family’s need for greater accessibility and mobility, AVM did not hesitate to provide its services.

According to AVM’s marketing director, Heather Roche, once a request has been made for a vehicle donation, it is often a matter of finding the right vehicle to meet the need of the person or family. The Hall family needed a van that is wheelchair accessible. In this instance, there happened to be a van at AVM’s Bethpage, Long Island, New York location that would suit the family’s needs. A longtime customer of AVM had left his vehicle on consignment with AVM when he moved to Florida. The price had already been lowered, but when AVM spoke with the gentleman about the need for a vehicle for the Hall family, he lowered his asking price by at least $4,000, making the donation even more feasible.

The presentation of the van to the Hall family on March 14 was the culmination of the efforts of a variety of people within AVM. Contact in person and via telephone and email with the personnel of AVM creates a strong impression of genuineness and caring, and a feeling that these folks fit their avocation – one had the sense that the presentation of the van was not about the employees or their efforts but an act from their hearts and a genuine desire to do good for others.

“We’re lucky,” said Roche during a later telephone interview, describing the company as having a team atmosphere. “We’re really developing relationships with people,” she indicated. “As a good corporate citizen, we want to help people find resources,” she said. “Very rarely would we say to someone, there’s nothing we can do. We always want to try to help in some way,” even if it is “finding funding resources for people,” she said. “It’s more of a family type of business.” That showed.

The Hall family drove from their home in Virginia Beach, Virginia, to pick up the van at the AVM dealership in Norristown, Pennsylvania, just northwest of Philadelphia. Prior to the family’s arrival, final touches were made to the converted van, which had been serviced and detailed. The family enjoyed exploring the vehicle and was pleased with the bonus of the unexpected DVD player, which will help to keep the children entertained during travel. Service technicians made some adjustments to the vehicle while paperwork was completed. The van is a full-sized 2002 Ford E-250. Co-owner and vice president William Blaser credited co-owner and president Jack...
Family Lives Life Fully in the Face of a Rare Genetic Disorder for All Three Children

“We give them more love than anything.”
—Mother, Tanya Hall

EP was privileged to be able to talk with its contacts in the accessible mobility industry when a United States Navy family’s developmental pediatrician, Dr. Gretchen Meyer, contacted EP’s CEO Joseph Valenzano to see whether EP might be able to facilitate the donation of a van to the family to help with mobility issues for the children. Many of the

mobility companies that were contacted were quickly and positively responsive. Accessible Vans & Mobility (AVM) was one of the initial companies to respond, indicating, “We want to do anything possible to help this family.” AVM made the donation of the van to the David and Tanya Hall family on March 14. EP was there for the presentation and took an opportunity to sit down and interview the family. To view a videotape of the interview with the Hall family, visit the EP Web site, at www.eparent.com. EP also spoke with the family via telephone on a few other occasions.

• By Maria Caroff

When you meet the Hall family at a van dealership in Pennsylvania, five hours away from their home in Virginia, the overriding sensation is one of normalcy, as you sit down with Mom, Tanya; Dad, David; Christopher, 13; Tiffany, 12; and Aaron, 9. The children are active. Mom and Dad allow them their freedom to explore but redirect them as needed. The kids are curious, pointing out different items and oddities that they observe in their unfamiliar environment, among a group of people whom they have just met. They smile easily.

But not so easy to smile is their Mom, whose cautious expression and demeanor make a powerful first impression. Their father speaks practically but then with some reserve when the conversation becomes specific, about the children’s diagnosis. All three children were diagnosed last August with a rare genetic disorder, GM1 gangliosidosis. There is currently no cure for this progressive disorder. There are three forms of GM1 gangliosidosis: infant, juvenile, and adult. The Hall children were diagnosed with the juvenile form. Within the United States, about five cases of juvenile GM1 are diagnosed each year, estimates geneticist Dr. Cynthia Tifft, Chief of the Division of Genetics & Metabolism at the Center
The disorder can cause developmental delays and the loss of developmental progress that has already been made.

For two parents who carry the gene that causes the disorder, there is a one in four chance with each pregnancy that the child could have GM1. It is a difficult disorder to diagnose, since the symptoms mimic other disorders such as cerebral palsy. Until a couple has a child with GM1 gangliosidosis, “you don’t even know you are a carrier,” says Dr. Tifft. “You’re perfectly healthy.”

When the Halls received the diagnosis of GM1 gangliosidosis, they felt, “not really shocked,” David said. “We were… It’s like a car accident. We’ve read about storage diseases on the Internet, and we were praying that it wasn’t that. So, it kind of took us for a ride that we weren’t prepared for and didn’t want to go on.”

When asked whether the children have any concept of all that’s transpired since last year, “No,” say Tanya and David, shaking their heads. “Thank God,” says David. “I don’t want them to know. I want them to live their lives as happily as they can, for as long as they can.”

Regardless of what he would like to see the children be able to do, he says, “Just to be able to, every day, do what they enjoy doing. They’re kids. First and foremost, they’re kids. They want to go and have fun. That’s what I want for them. I want them to go out and have a good time, to be able to have a good time. It helps that we have done it for so long, so we kind of have knowledge of what to do for them and how to give them a good time.”

And what would Mom specifically want for the children? “That they find a cure for it,” she says, emotion cracking her cautious demeanor. (See the sidebar that accompanies this story for more information about current research and potential treatments being studied for GM1.)

Since at the present time there is not a cure for the disorder, David says, “All we can do is treat the symptoms that come with it.” Christopher walked with a walker for a period of time, according to Tanya. In September 2007, “he just stopped walking. He can crawl,” she said. Christopher was scheduled for hip dysplasia surgery in April. “Hopefully, he’ll start walking again,” said Tanya. “That’s what we want. It’s not guaranteed. He wants to walk so bad. He tries,” she said.

Tiffany also was scheduled for surgery in April, to remove rods previously placed in her legs during surgery to correct pigeon toes; she also had correction for hip dysplasia during that first surgery. Prior to the surgery, she had stopped walking. She was to have her hamstrings lengthened during this April’s surgery. It is anticipated that Aaron might need surgery in a few years. Christopher, Tiffany, and Aaron all receive physical, occupational, and speech therapy. Tanya is attempting to coordinate therapies so that all three children can receive therapy on the same day.

The strongest impression you gain from the Hall family is one of love – love of the parents toward the children, love of the children toward their parents, and love, respect, and support between Tanya and David. “We lean a lot on each other,” says David of Tanya and him. “We have to. Our families help a lot, but there’s only so much they can do because
they have their own situations they have to deal with. So, we really have to rely on each other more than anything at all.” Over the course of several conversations with Tanya, it is good to feel her appear less cautious and to hear happiness in her voice as she relates family stories.

David, 36, is a first class petty officer in the United States Navy, stationed at Naval Station Norfolk, in Norfolk, Virginia, where he is a systems technician working on ships’ gas turbine engines. Tanya, 34, is a full-time medical assistant for an ophthalmologist who also performs liposuctions. She has been working there since September, after having served an externship in the office. “I wanted to do something for myself,” she says, explaining that she had been a stay-at-home mom for a while. “I love working there.”

Because of the stress of the diagnosis and the energy involved in caring for three children with varying degrees of special needs, are Tanya and David worn out? “That’s every day,” said David. “But once you get into a cycle you’re doing it for a long, long time, you get used to it. But, it’s always in the back of your mind that one day will come when you won’t be able to handle the situation. Because the end result will be … you know … I don’t want to say it out loud.”

Christopher and Tiffany have been able to make a wish through the Make-a-Wish Foundation®, and Aaron will be able to do the same. Last November, for Christopher’s wish, the family visited Montgomery County, New York, home to Orange County Choppers, Inc. “We actually stayed at West Point, at the hotel there on the grounds,” said Tanya. They were there during the weekend of the big Army-Navy game. “We got to eat with the cadets.” The children were treated extremely well by the folks from Orange County Choppers and West Point, Tanya indicates.

At the end of March, the family visited Disney World, for Tiffany’s wish. “It was good,” said Tanya. “The kids didn’t want to come home, of course. Aaron said he wants to move to Disney World.” The kids were crying when they had to leave.

For his wish, “Aaron wants to see the Superman Monster Truck,” says his mother. They will wait a little while before doing that, to be careful about taking time off from their jobs.

The children play Challenger Ball, and each has distinctive tastes. Christopher loves the radio, all kinds of music, according to his mother. He enjoyed listening to Christmas songs, she said, and after Christmas when he would hear “church music” on the radio, he thought it was Christmas music. He flips through the radio stations every night and will “sing along” to the music. Although he cannot talk, his mother says, he enjoys singing “The Star Spangled Banner” and knows many of the words pretty well.

Christopher is “so much more aware cognitively than one would know,” says Dr. Gretchen Meyer, the family’s developmental pediatrician at Naval Medical Center Portsmouth, in Portsmouth, Virginia, and this was borne out in the experience of meeting him. Additionally, although Christopher is not able to walk, he is able to do his own toileting and take his own bath after someone has put him in the tub. Dr. Meyer felt that the mobility that a van would provide, with the ability to allow Christopher to use a motorized wheelchair, would make a “huge quality-of-life” difference for him and decrease the challenge and frequency of lifting him as he gets bigger.

Currently, Aaron has the fewest limitations. He is able to walk and run. Tanya describes Aaron during the family’s morning routine. “Aaron is the hardest one to get ready,” she says. “He wants me to scratch his back every morning.” Aaron laughs shyly when his mother says this.

“And his feet,” she says, with a smile on her face. Does she accommodate him? “I do,” she says, smiling at him indulgently, while he grins back. She’ll often have to tickle him to get him moving out of bed, she said. For Aaron, a highlight of seeing the family’s new van at AVM was the beautiful big red bow that presented a bright welcome. Responding to his fascination with the colorful decoration, AVM vice president William Blaser gave the bow to Aaron to keep.

During the time that paperwork was being completed at AVM, Tiffany sat with her legs crossed in her wheelchair, looking for all the world like a teenage girl indulging in window-shopping via browsing magazines. “Every time I get a magazine in the mail, it’s hers. I can never look at it,” says Tanya. “Every time the mailman comes, she says, ‘Book, book.’”

In the Sunday paper, she particularly likes to look at babies, swimming pools, and toys, Tanya said. Tiffany is Mommy’s girl, says Tanya.

The family’s routine is well set. “I get up (by) 6:30 on the weekdays, and I wake Aaron up at 7:00 – try to,” says Tanya. Tiffany is usually up by the time she hears her father’s car leave. Christopher is usually up as well, with he and Tiffany often up by 5:30. If the children have not had their baths the night before, Tanya will get them ready that morning. Sometimes she can sleep until 6:30, and she and David take turns sleeping in one weekend morning.

While David and Tanya can receive up to two calls per week at their jobs related to a need for the children, both indicate that their jobs are accommodating. “They knew about my kids before they hired me. If I need to, they’ll let me go,” says Tanya. “The military knows what’s going on with the kids. So, they give us some leeway, which is nice,” said David. “If there was no understanding … I don’t think we’d be able to
The Hall Family

make it. You know, there are certain things we can take and certain things we can’t take.”

For school, “All three of them are in school in the same kind of class. Plus they’re around other kids, so it’s a social interaction as well,” said David. In the afternoon, Aaron and Tiffany go to daycare when they get out of school, said Tanya. “They’re there until 5:00, 5:30. If my husband gets home, then he’ll pick them up on some days. And, if not, then I’ll pick them up when I get off work and get over there by 5:30. They’re with normal kids, because she’s the only one that’s there with special needs.” For Aaron, “I don’t consider him special needs like Tiffany and Christopher, because he can do a lot on his own. He can actually make his own sandwich,” said Tanya.

The children tend to be their own playmates at home. “I’m not really sure why the kids don’t want to play with them” in the neighborhood, says Tanya. “Now, when we actually buy something new and we put it in the front yard, all the kids want to come and play on it. But once it’s gone and the kids are outside by themselves without it, they don’t come around,” she says. She indicates that maybe it is because they don’t know what to say, noting that the children look normal but talking with them can be difficult. “You do have to be around them a lot to understand what they’re trying to say,” said David.

The family is enjoying the van. “They love it,” Tanya says of the children. “On the way home from Pennsylvania, the boys watched movies all the way home. (David) didn’t hear a word from them. Every time they get in the van now, they want to have a movie,” even if they’re going to the store and there is not enough time to watch a movie. The lift has proven beneficial, and the family has had Christopher in the van both in his wheelchair and seated in one of the van seats.

The family found out about the possibility of a van donation through Dr. Meyer. Dr. Meyer “actually asked us one day if we would mind a donated van,” said David. “We didn’t at all. Anything to make our lives just a little bit easier is always something to reduce stress in the household, to brighten up the smiles or just the faces of everybody in the house.”

David and Tanya focus on brightening the lives of their children. They engage in a balancing act. There are times when they have a hard time refusing to buy a toy or another item for the children, Tanya indicates, citing an example of a toy that Tiffany wanted during a recent trip to Toys ‘R Us. Yet, “We say ‘no’ more than we say ‘yes,’” she said. “We give them more love than anything.”

In interactions with other people, the parents are clear on what they want for the children. “We don’t want them being treated any differently,” Tanya said.

The Halls receive primary healthcare through the military healthcare system. They are also working with Dr. Tiff, at Children’s National Medical Center. When asked whether they have contact with other families who have a member with a GM1 gangliosidosis diagnosis, David indicated that Dr. Tiff “mentioned a couple of families that were in the central United States. We haven’t been able to get in contact with them yet,” he said. “We don’t personally know anybody with kids with this disease,” said David. He believes that the opportunity to talk with others who have a family member with a GM1 gangliosidosis diagnosis could potentially be helpful. “You never know what one family will go through (compared) to another family. It’s always good to look for better ways of doing things. So, if one family has kids with GM1 and knows a certain way to do stuff, and we know a certain way, and one’s easier than the other, then the families actually need to talk with each other,” he said.

According to Sandra Yang, genetics counselor on the team with Dr. Tiff at Children’s National Medical Center, they are not aware of any large support group currently available for families with a member or members with GM1 gangliosidosis. However, when families that they work with are open to contact, with the families’ permission, they will connect them with one another. Yang noted the option of support groups that exist under a larger umbrella of rare disorders (e.g.: National Organization for Rare Disorders (NORD); http://www.rarediseases.org).

As one area of support and understanding, the Halls are enrolled in the Exceptional Family Member Program (EFMP) with the U.S. Navy. Due to the children’s special needs, the family has been placed in a category in which they will not be moved, to ensure that the children can receive consistent care at the level that is needed. David has been in the United States Navy for 17 years.

This simplifies matters. The family’s priorities are apparent from observation and conversation with Tanya and David. “First and foremost, my family comes first, no matter what,” says David. “I live every day with my kids like it is their last day,” says Tanya.

To learn more about GM1 gangliosidosis and other disorders or diseases, The National Library of Medicine (NLM), a component of the National Institutes of Health (NIH) within the U.S. Department of Health and Human Services, offers free searches of biomedical literature through an Internet service called PubMed. Visit: http://www.ncbi.nlm.nih.gov/PubMed. The NLM also offers extensive health information from NIH and other trusted sources. Visit: www.medlineplus.gov.

To learn more about Children’s National Medical Center, visit http://www.childrensnational.org.
EP Interview With Dr. Cynthia Tifft

EP conducted a telephone interview with pediatrician and geneticist, Dr. Cynthia J. Tifft, Chief of the Division of Genetics and Metabolism at the Center for Neuroscience and Behavioral Medicine at Children’s National Medical Center, in Washington, D.C. Dr. Tifft is working with the Hall family children. Dr. Tifft provided information about gangliosidoses (GANG-lee-oh-sih-DOE-sees), including GM1 gangliosidosis, the diagnosis of the Hall children. Highlights of the interview follow.

Exceptional Parent {EP}: In layman’s terms, how would you describe gangliosidoses?
{CT}: In order to describe gangliosidoses, you really need to describe what a lysosomal storage disease is, because gangliosidoses are one of approximately 40 to 50 different lysosomal storage diseases.

If you can remember from basic biology, there are cells, and inside the cell there is another structure called the nucleus where all the genetic information is. There are other things inside the cell, little bags of things – we call those bags organelles, as a group, and one of the different kinds of organelles is called a lysosome. A lysosome is just like the body’s recycling center. So, there are 40 or 50 different kinds of enzymes there, and large molecular compounds that need to be broken down by the body go into those lysosomes. And then they’re chopped away one little piece at a time from the end inward, so it’s just like chopping away at a piece of chemical, and each of the little chop bites takes a different enzyme.

So, for example, if you had a recycling center that recycled glass and paper and plastic, and the conveyor belt to recycle the plastic broke down, and that was all stopped and all the plastic coming in was just sitting on the conveyor belt … and the glass and the (paper) were fine, they were working … let’s say there are 40 or 50 of those. Well, the plastic starts to build up. And pretty soon, because that conveyor belt doesn’t work, there’s so much plastic in the recycling center that the whole thing is full of plastic and everything kind of breaks down. Gangliosidoses are one of the compounds that are broken down in these lysosomes, so they’re like the plastic conveyor belt.

If you start with GM1 ganglioside, which is one of the larger gangliosides, you have to chop off the last sugar first. In other words, GM1 ganglioside, one sugar, gets chopped off, and it makes a compound called GM2 ganglioside. And then there’s another enzyme that chops off the end sugar for GM2 ganglioside and makes ... basically, you’re chopping it off one little sugar at a time. But you’ve got to go from the outside in. So, if you’re missing the enzyme that does the first chop, you’re stuck. And then the GM1 builds up in the lysosome, just like plastic builds up in the recycling center.

{EP}: And why would the enzyme be missing?
{CT}: It’s missing on a genetic basis. There’s a genetic change. Genes come in pairs, and the enzyme necessary to break down GM1 ganglioside is called beta-galactosidase. So, in every cell of everybody’s body there are two genes for beta-galactosidase – one you got from your mom, one you got from your dad. But if there’s a genetic change in one of those genes so that the enzyme doesn’t work, then you’ll only have half the amount of beta-galactosidase you need. So, if you have half the amount you need, you’re a carrier for beta-galactosidase. Now, fortunately for most people, you only need about ten to twenty percent of beta-galactosidase activity in order to be perfectly fine. So, if you’re a carrier and you have fifty percent activity, you’re fine. You don’t even know you are a carrier.

But, if both parents are carriers – in other words, they’ve got one beta-galactosidase gene that works and one that does not work – if you go to have kids, each parent can only pass one copy of each gene. So, if the partner is also a carrier and they have one gene that works and one gene that doesn’t work, if you sit down and work out the numbers – you know it’s random, 50/50, which gene you give your kid – if both parents are carriers, one time in four, each parent passes the gene that works and the child has two working copies, has perfectly normal, 100 percent activity, and is fine.

Two chances out of four, one or the other parent passes the gene that doesn’t work and the other parent passes the one that does. So, there’s two out of four chances the child will be a carrier just like the parents.

But one chance out of four, both parents pass the gene that doesn’t work, and if they both pass the gene that doesn’t work, now the child has no working copy of beta-galactosidase. That’s the child that gets GM1. Their enzymes don’t work, so they’re not going to break down enough GM1 to clear the recycling center.

So, when you ask the question, in how many instances are there multiple children in a family with GM1 – well, the only way you can have GM1 is if both of your parents are carriers.
And the risk for each pregnancy to have a child with GM1 is one in four. You can actually do the math, that if you have a one in four chance, the chance that you would have three kids with GM1 is a quarter times a quarter times a quarter, or 1 in 64. So, not very common. But it’s not impossible.

Once you have a child with GM1, you know that your risk is one in four. Now, if it’s an infantile child that has onset very early, oftentimes the child will have gotten sick and the diagnosis will have been made before the family wants to have more children, and so there is prenatal diagnosis for this. You can know at 10 or 12 weeks in the pregnancy whether your child has GM1 or not.

**EP:** What distinguishes GM1 from other gangliosidoses?

**CT:** There’s (only) GM1 and GM2 gangliosidosis, and they’re very similar. They’re only one step, one sugar, different in the pathway. The only thing that GM1 kids tend to have that GM2 kids don’t is the bony changes. In the juvenile form, they’re at risk for bone changes in their spine; they’re at risk for dysplasia in their hips. Kids with GM2 would also have trouble walking, and they would probably end up in wheelchairs, but they wouldn’t have the degenerative bony changes in their hips. So, really the only thing that distinguishes GM1 from GM2 is the bony change.

**EP:** Do you have any sense of (the number of) GM1 cases or infant, juvenile, and adult cases?

**CT:** For most of the adult GM1 cases, and I’ve never seen a case, there’s a common mutation that produces adult GM1 in the Japanese population. So a lot of the people working on adult GM1 are Japanese physicians. Infantile is more what we call pan-ethnic: It can occur in any ethnic background. I would say infantile is the most common. I think we estimated there are 10-15 new cases of GM1 diagnosed in the U.S. every year. Now, for juvenile, it’s less common than that. I would say, probably in terms of new cases diagnosed per year, five or less.

Adult, I don’t know about in this country, because it’s really much more common in Japan. I don’t know of any adult GM1 patients.

**EP:** We had read online about a breed of cat with GM1.

**CT:** There’s a cat model for GM1. There’s a cat model for Sandhoff disease, which is GM2 gangliosidosis. And there are some naturally occurring mutations for these kinds of gangliosidoses. They’re hard to find, and the colonies are hard to maintain. At Auburn University, they have a large-animal/cat/vet-type presence, and then the other place where they have a lot of large-animal models is the University of Pennsylvania, in Philadelphia.

**EP:** Can much be learned, then, for humans from those (models)?

**CT:** Yes, as a matter of fact, there is a consortium of physicians called the Tay-Sachs Gene Therapy Consortium. They are working pretty much simultaneously on gene therapy for GM1 gangliosidosis and for GM2. Now, GM2 is Tay-Sachs or Sandhoff disease. There are actually two different diseases, but all three of these conditions are very, very similar to each other. And, so, they are working on gene therapy for that. They’re hoping to have clinical trials up and running for one or the other or both of the conditions within the next three years.

What they’re doing now is using what they know from mouse models and scaling up to large-animal models. As you might expect, to do something like this in terms of gene therapy, and for these rarer diseases, takes a phenomenal amount of dollars, and the National Tay-Sachs and Allied Diseases Association with other, private, donors has been trying to raise money for them to at least get these studies off the ground. They’ve applied to the NIH (National Institutes of Health) for what’s called a program project grant, several million dollars in funding to be able to actually make it happen.

That’s probably the hottest thing on the horizon at the moment. There are other types of therapies being currently worked on using small molecules.

**EP:** My perception based upon what you’re saying is there’s some hope there.

**CT:** Oh, yes. But these are very difficult diseases to deal with because they involve the central nervous system. What you should know is that gangliosides are made by every cell. But the highest concentration of them are in the central nervous system. They’re probably used for sending messages between neurons. Nobody’s exactly sure what gangliosides do, but that’s the thinking. They sit on the cell membrane of the neuron and probably help neurons communicate with each other. So, when you think about proposing a therapy that involves the brain, it’s much more difficult than a therapy that involves the body.

For example, there are a number of lysosomal storage diseases for which there is therapy replacing the enzyme. They can artificially synthesize beta-galactosidase in large bioreactors, purify it, and give it back to the patient as an intravenous infusion every two weeks. You can do that for Gaucher (go-SHAY) disease – it’s farther down in the degradation pathway. Type 1 Gaucher disease doesn’t have central nervous system problems. If you use intravenous therapy with enzyme replacement, you can actually get the enzyme to the cell that needs it.

Gangliosides fall into a class of molecules called glycosphingolipids. The biggest part of the problem with GM2
and GM1 gangliosidosis is in the brain. There is a barrier called the blood-brain barrier which prevents large molecules from getting from the blood circulation into the brain. So, even if you had the beta-galactosidase enzyme, and if you made it in large quantities and tried to inject it intravenously, it would go to the rest of the body but it wouldn’t get to the brain very well. So, the biggest problem and the biggest hurdle in trying to treat the gangliosidoses is that whatever therapy you use has to get to the brain, and if it’s a large molecule it’s not going to get there. Now, this has been a tougher nut to crack than some of the other glycosphingolipid diseases.

We’re getting further than we were before, but it’s hard, because these are lethal diseases. Part of it is, you can treat symptoms, but because it involves the brain, the brain gets sick, and parts of the brain die. Neurons begin to die, and once you’ve lost those, even if you find the therapy, you could help the sick ones, but you’re not going to get back the ones that have died. There’s a certain regenerative capacity to the brain, but it’s not perfect. At some point, there are things that are not retrievable, even if you have the perfect therapy – once the kids have already started to show symptoms. And it’s even truer with the infantile disease, which progresses much more rapidly.

The key piece was not that the diagnosis was made; the key piece was that somebody somewhere said, you know, the genetics doctors need to see you. Because we deal with rare (diseases). So, you know, we’re going to think about (these) probably faster than the average person just because that’s the kind of thing we deal with.

Often for these things, a key piece is that instead of just being delayed kind of statically, you actually start to lose skills. And that’s what’s characteristic of these lysosomal diseases. You develop normally to a certain point, and then kind of plateau in your development, and then start to lose stuff you used to be able to do. And the red flag for us is the kid who is losing skills.

But, in all fairness, for most of these – particularly the late juvenile and adult cases – the diagnostic odyssey often takes on average about five years.

It seems to me that … for anybody who reads about this, one of the more striking things is to think of a geneticist.

Yes, I think that’s a good point. Sometimes families are reluctant to do that, which is why our no-show rate for new patients is often pretty high, because you can imagine the stigma attached if somebody’s even suggesting that you have a genetic diagnosis. And, obviously, none of us have any control over which genes we pass our kids. But there is a stigma attached to having a genetic condition, and, so often, even when people are referred to genetics, it takes them two or three appointments just to get there…It’s sort of, too personal.

It makes me think that the more education there is … is rather key.

Right now, the technology is becoming available and there is a whole push to get a number of lysosomal storage diseases as part of the newborn screening panel. It’s basically at this point, disorders for which there is a therapy. But since we think that GM1 and GM2 may have some therapies in the not-too-distant future, certainly the technology is there to do testing for these as part of the newborn screening. So, what you would pick up then would be children who are affected but still haven’t shown any symptoms yet. And, obviously, therapy is going to be much more successful the sooner you deliver it. So then you begin to eliminate the damage to neurons that’s already happening, that’s irreparable. So, that’s another thing that’s kind of coming, I would say, in the next five to seven years, so that every newborn would get screening for some of these lysosomal disorders. We’re working on it from several different angles.
You see Segways nearly everywhere you look today. Police ride them through the streets of their cities. Security guards ride them through the malls. Tour groups ride them around monuments. Veterans ride them almost anywhere.

Segways are two-wheeled vehicles that look like a toy but have proved to be serious transportation. When Dean Kamen unveiled the Segway Personal Transporter (PT) on ABC’s Good Morning America, he described the machine as “the world’s first self-balancing human transporter.”

Jerry Kerr, Leonard Timm, and Fred Laplan founded Disability Rights Advocates For Technology (DRAFT) in 2004. DRAFT is a nonprofit, public charity that advocates for more widespread adoption of universal design and promotes increased access to assistive technology devices.

The underlying premise of universal design is to design products and environments so they are usable to people of all ages and with differing abilities. Universal design respects diversity and promotes the inclusion of all people in all activities of life.

The Segway is designed with the principles of universal design in mind. It is described as an electrically powered, self-balancing, two-wheeled device. The designs allow people who can stand, but have difficulty walking, an option for mobility. Segways have now been modified with a seat that allows them to be used in place of a wheelchair in many situations.

In 2005, DRAFT started the Segs4Vets program. The program awards Segway Personal Transporters to members of the United States Military who have sustained injuries while serving our nation in Operation Iraqi Freedom and Operation Enduring Freedom (Afghanistan) and whose injuries have resulted in permanent disability and difficulty walking.

DRAFT received a blanket waiver for Segs4Vets in 2006, from the services of the Department of Defense, that allows the presentation of Segways. Segways represent a donation of over $1,000 to active military members who served after September 11, 2001 and who were permanently disabled.

The Segs4Vets program has awarded 81 Segways to injured veterans since its inception. Members of the program hope to secure the funding to award about 250 Personal Transporters during 2008.

Today, four major military hospitals have been trained in Segway technologies. DRAFT has established training and assessment programs at Brooke Army Medical Center at Fort Sam
Staff Sergeant Jay Fondren, USA, (Retired) and his family take a trip around home. Jay is from Corsicana, Texas but now makes his home near Robinson, Texas and works for the VA.

Photo provided by Disability Rights Advocates For Technology (DRAFT) and Segs4Vets.

Houston, Texas; the National Naval Medical Center in Bethesda, Maryland; Walter Reed Army Medical Center in Washington, D.C.; and Naval Medical Center San Diego in San Diego, California. The training and assessment programs have allowed therapists and other healthcare professionals to be introduced to universally designed mobility devices such as Segways. The programs help assess and train potential candidates for the Segs4Vets program.

In the very near future, DRAFT plans to expand its training and assessment programs into Department of Veterans Affairs medical centers throughout the United States. This expansion of the programs will allow veterans who have been medically retired an opportunity to participate in the Segs4Vets program.

The Segs4Vets program has proved to provide greater mobility to the young men and women who have served our country and been severely injured in the defense of our freedoms. Men and women who have received the Segway transporter have used it to return to college, participate more fully with family activities, excel in their physical therapy, and live a full and high-quality life.

John Kelly, a columnist for the The Washington Post, said, “Here’s how the Segway works: Lean forward. Start slowly. Lean further. Go faster. And then go almost anywhere.” Segs4Vets is making that possible.

For more information about the Segs4Vets program, please visit http://seg4vets.org/. A copy of DRAFT’s recently released report, titled, Universally Designed Technology Solutions: People Who Have Difficulty Walking & the Segway, may be found at http://www.draft.org, via a link at the center of the home page. To view a list of veterans who have received the Segway, visit www.segs4vets.org. Click on the Seg4vets channel on the left.

Riley Miller is a military editor for EP magazine. He can be contacted at rmiller@eparent.com.

What is Universal Design?
The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.

About Universal Design
The authors, a working group of architects, product designers, engineers, and environmental design researchers, collaborated to establish the following Principles of Universal Design to guide a wide range of design disciplines including environments, products, and communications. These seven principles may be applied to evaluate existing designs, guide the design process, and educate both designers and consumers about the characteristics of more usable products and environments. The Principles of Universal Design are presented here, in the following format: name of the principle, intended to be a concise and easily remembered statement of the key concept embodied in the principle; and definition of the principle, a brief description of the principle’s primary directive for design.

What are the Principles of Universal Design?
PRINCIPLE ONE: EQUITABLE USE • The design is useful and marketable to people with diverse abilities.

PRINCIPLE TWO: FLEXIBILITY IN USE • The design accommodates a wide range of individual preferences and abilities.

PRINCIPLE THREE: SIMPLE AND INTUITIVE USE • Use of the design is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level.

PRINCIPLE FOUR: PERCEPTIBLE INFORMATION • The design communicates necessary information effectively to the user, regardless of ambient conditions or the user’s sensory abilities.

PRINCIPLE FIVE: TOLERANCE FOR ERROR • The design minimizes hazards and the adverse consequences of accidental or unintended actions.

PRINCIPLE SIX: LOW PHYSICAL EFFORT • The design can be used efficiently and comfortably and with a minimum of fatigue.

PRINCIPLE SEVEN: SIZE AND SPACE FOR APPROACH AND USE • Appropriate size and space is provided for approach, reach, manipulation, and use regardless of user’s body size, posture, or mobility.

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* Compiled by advocates of universal design, listed in alphabetical order: Bettye Rose Connell, Mike Jones, Ron Mace, Jim Mueller, Abir Mullick, Elaine Ostroff, Jon Sanford, Ed Steinfeld, Molly Story, and Gregg Vanderheiden. Major funding provided by: The National Institute on Disability and Rehabilitation Research, U.S. Department of Education.

United States Military Section

Vans of Valor Program

Ride Away assists service-connected veterans by providing modified vehicle loans through its Vans of Valor program. It started by recognizing a need. Ride Away, a national supplier of handicap-modified vehicles, recognized that veterans requiring modified transportation needed reliable transportation between the time they are discharged from the military and the time they receive a grant from the Department of Veterans Affairs (VA) to modify a vehicle to meet their individual needs. Ride Away implemented their Vans of Valor program to meet that need.

Ride Away indicated in a press release dated December 20, 2007 that it is committed to providing transportation assistance to veterans who have sacrificed for our country by helping them in their time of need. Ride Away’s Vans of Valor program was designed to ensure that service-connected veterans can obtain suitable modified vehicle transportation as soon as they need it — even before all of their benefits and paperwork are finalized through the system at the VA.

Ride Away is offering the use of an appropriate vehicle for those veterans whose injuries or illness have been deemed 100 percent service-connected and who are awaiting the processing and finalization of their vehicle grant finances from the VA.

“The Vans of Valor program was designed to assist veterans in obtaining suitable transportation so that they can access their local communities and neighborhoods again and begin their process of recovery and healing a little more quickly,” said Mark Lore, President and CEO of Ride Away. “We appreciate the opportunity that our Vans of Valor program offers to be of assistance to those who have already served us all so selflessly.”

To ensure that the vehicle the veteran receives from Ride Away will meet their unique needs, a sales consultant will discuss with the veteran his or her vehicle pref-

Vans of Valor Program Headquartered in Tampa, Florida

Tampa, Florida was chosen for the Ride Away loan program because of the office’s close proximity to MacDill Air Force Base, the home of the United States Special Operations Command (USSOCOM) and the United States Central Command.
erences and will also determine what kind of vehicle and equipment Ride Away will need to install. Once the van is modified to fit the needs of the veteran, Ride Away will personally deliver the van to the veteran’s home.

As a part of the program, the veteran will be free to use the van until their VA funding comes through and they are able to obtain their own van. During the vehicle loan period, Ride Away will cover the cost of maintenance, insurance, licensing, registration, adaptive equipment, and any other charges in connection with the ownership and operation of the vehicle. The only thing the veteran would need to pay for is fuel.

The Vans of Valor program began in early 2007 and is currently available in Ride Away’s Tampa, Florida location. Designed to give back to service-connected veterans with modified vehicle transportation needs, Ride Away indicates that it is honored to have this opportunity to help alleviate some of the returning veteran’s worries about transportation.

For more information about the program and the possibility of participating through Ride Away’s Tampa, Florida location or one of their other ten East Coast locations, call 1-800-237-7979, Ext. 3964.

Ride Away is America’s largest provider of modified vehicles and adaptive equipment for people with disabilities. Ride Away products are used by individuals with minor to profound disabilities requiring additional assistance while traveling. Products range from hand controls and lifts to raised door and lowered floor vehicle modifications. Founded in 1986, Ride Away’s eleven East Coast locations are committed to offering a broad selection of specialized vehicles and services to meet the needs of every customer. All of Ride Away’s locations are QAP (Quality Assurance Program) certified through the National Mobility Equipment Dealers Association (NMEDA), resulting in Ride Away being held to the highest standards in the industry. The company also contributes over 10 percent of its earnings to nonprofit organizations and has an

EP Military Channel News

Readers can access important information regarding Department of Defense news, Department of Veterans Affairs news, and TRICARE by visiting the Military Channel on the EP Web site. Information includes news releases, reports, and other relevant items.

Visit the EP Web site’s Military Channel often for news and announcements that are of interest to military families who are caring for a member with special needs.

www.eparent.com/main_channels_military/index.asp
The war took away the sight in one of my eyes, my arm, and the mobility in my legs, but when I got my service dog, Ruthie, I felt like a soldier again.”

These words, so eloquently spoken by 22-year-old retired Sergeant Christopher Strickland, describe the close bond between him and his service dog, Ruthie.

A Soldier and His Service Dog

By Sheila O’Brien

“T”he war took away the sight in one of my eyes, my arm, and the mobility in my legs, but when I got my service dog, Ruthie, I felt like a soldier again.”

These words, so eloquently spoken by 22-year-old retired Sergeant Christopher Strickland, describe the close bond between him and his service dog, Ruthie.

Chris was injured in Iraq by an improvised explosive device (IED). His mom and young wife rushed to his side at Walter Reed Army Medical Center and cared for his daily needs. Accustomed to being very independent, he decided to apply for a service dog to help him. When Ruthie arrived, he was able to send his mom and wife back home and move back into the barracks.

Sergeant Christopher Strickland in physical therapy with service dog, Ruthie. Photo courtesy of NEADS
Ruthie was there to pick up anything he dropped and to act as a “walking cane,” helping him to get around. She helped in other ways, too. When Chris was having a bad day and did not want to get out of bed, Ruthie would bring a toy to his bedside and “make” him get up.

Chris retired from the Army in January and moved back to Connecticut where he lives with his wife and infant son, Bradley. Chris takes care of Bradley and exclaims that “Ruthie is another parent.” When Chris is holding his son, he sends Ruthie to the refrigerator to get a bottle for him. Ruthie does so and even closes the refrigerator door. Chris has said, “Ruthie is more valuable to me than my prosthetic arm.”

With over 35,000 wounded veterans, service dogs like Ruthie will be in great demand. This new population of veterans with disabilities is young, athletic, and spirited. Many do not want canes and crutches or “typical” assistance devices but would rather have service dogs.

Sheila O’Brien is the Executive Director of NEADS (Dogs for Deaf and Disabled Americans). She is presently working to provide service dogs for wounded veterans returning from Iraq and Afghanistan. For more information about the NEADS Canines for Combat Veterans Program, contact NEADS: 978-422-9064, Ext. 11; www.neads.org; sobrien@neads.org; P.O. Box 213, West Boylston, Massachusetts 01583. The NEADS national campus is located at 305 Redemption Rock Trail South, Princeton, Massachusetts 01541.

Canines for Combat Veterans Program

In 2006, NEADS was invited to Walter Reed Army Medical Center to do an in-service about the Canines for Combat Veterans Program. Later that year, the first service dog, Rainbow, was placed with Sergeant Roland Paquette, a young veteran who lost both his legs while serving in Afghanistan.
In the coming months, EP will explore the subject of traumatic brain injury (TBI) sustained by military personnel in the line of duty and will highlight the conditions that may result from TBI, such as depression and symptoms of post-traumatic stress disorders (PTSD).

What is Traumatic Brain Injury? How Is It Connected to Post-Traumatic Stress Disorder?

Learning the facts and increasing understanding about traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD) and learning more about current research and available treatment can often be one of the first steps in seeking help for recovery.

By Lorraine Cancro, MSW

A Letter to My Brothers from an Anonymous Marine

EDITORS NOTE: THIS NARRATIVE RELATES A TRUE BATTLE EXPERIENCE OF AN ACTUAL U.S. MARINE AND IS GRAPHIC IN NATURE. PLEASE BE ADVISED THAT THE LANGUAGE AND DESCRIPTIONS MAY NOT BE APPROPRIATE FOR SOME READERS.

I was probing for land mines with 13 other men. One man detonated a mine. The detonation blew up the man who detonated it and one other. I was next to them and about 15 yards away. I was in a hole that I had dug. The mine went off, and the concussion of the blast knocked my helmet into my head and then my head into the side of the hole that I had dug. When I got out, I was unaware of what had happened. I ran over to the blown-up corpse of the man and kicked him. I kicked him and said, “You could have killed me.” A comrade came to my aid, calmed me down, and took me behind an enclosed area with the body.

An enemy combatant heard the blast and started firing at us. I took a machine gun and shot him with every round in the magazine. I grabbed another weapon and started shooting at others that I saw. A bullet ricocheted off of a rock and hit my helmet. I started firing at every silhouette that moved. Then we got orders from a higher, non-commissioned officer to withdraw.

Infantrymen came up beside us and started to fire at the enemy. Still fearing for my life, I kept firing. Someone slapped me in the back of my head and said, “Cease fire, all clear.” I did not obey the first time. The superior kicked me and said, “Everything is all clear. Stop firing, goddamn it!”

We withdrew from the area, went back to the headquarters, and explained what happened. I felt like I was hit in the head really hard. The pain in my head was inexplicable, and the ringing in my ears was deafening. To the best of my abilities, I explained to the superiors what had occurred. Our superiors left us in the room for a few hours while they discussed the confrontation, then Navy medical personnel examined us. When the experience was all over, and we went back to our normal routine, I did not feel any-
thing – no remorse, nor sadness, nor any ill feelings.

Three months after the first incident, my battalion was sent on a humanitarian mission. We were receiving sniper fire daily and lost several men. We did not have rules to engage the enemy so we took it upon ourselves to locate, close with, and destroy them with explosives. I was the one who detonated the explosives.

I was in a stairwell about one flight down behind a wall, and the impact from that blast caused by the explosives knocked me off my feet, throwing me into a concrete wall. I landed on my back and head. I walked into the room and saw the consequence of the explosion. The dead included two men, one teenage boy, a woman, a boy about age ten and a young girl. Their bodies were ripped apart. There were weapons all over the apartment.

After leaving, I felt no remorse. My head was shaking and my ears were ringing as I looked at the carnage. In retrospect, I was in a state of shock caused by the traumatic event.

Not until two years later, when I finally got back home, did I start to feel the effects of what had happened. An anonymous person gave me a ten-milligram Valium tablet, and I never felt better in my life. All the pain was gone. Every time I took this medication to escape, I felt great but was so incoherent to other people that I neglected them. Subsequently, I ruined my marriage and kept taking pills to escape the pain.

Not until I sought professional help did I realize that talking about it was the best cure. I still have trouble today dealing with it, and I still take medication prescribed to me by a doctor. Not a day goes by that I don’t feel remorse for the families of the men I killed. I will struggle with that for a long time.

When I came home from being overseas and saw civilized life, it awakened the terror that I had experienced. Large crowds would scare me. Loud noises would jar me. I always had to have my back to the wall. I would get anxiety attacks periodically and the only way I got relief without medication was to stick my finger down my throat to make myself vomit. I needed to either drink, breathe heavy, or vomit to experience a calming effect. But with the discovery of anxiety medications, those feelings went away. But I also made ALL my feelings go away, including happiness, the proper attention to my wife and family. This caused an extreme guilt that to this day I cannot cope with.

When I finally came to my senses, I realized buying benzos [benzodiazepines] from anonymous people was not the answer. Both psychotherapy along with the help of a psychiatrist to prescribe the right medications and proper dosage now help me with my daily life.

My biggest regret besides the remorse of killing was that I sought therapy too late and sunk to rock bottom. Learning the hard way is a very difficult thing, and an experience I would not wish on any of my brothers, my fellow Marines.

Take this advice to my brothers who have returned from combat and who may be suffering from having seen the same type of carnage I have: seek professional help to assist you in your recovery, not only from the emotional but physical injuries that you sustained during traumatic experiences. Never think you’re too strong or too manly to seek help, because all it will do is destroy your life in the long run.

I wish you all the best of luck in combating your psychological and physical impairments, and I pray that one day you will be able to overcome them. Just remember, recovery does not happen overnight. You must dig down deep, tell the truth, don’t be afraid to cry or tell anybody your true feelings because this is the key for the road to recovery.

This narrative was penned by a concerned United States Marine Corps (USMC) Non-Commissioned Officer (NCO). Lorraine Cancro, the author of this feature article, had the opportunity to talk with him extensively as the article was researched and written.

Research Into TBI and PTSD

Traumatic events such as the September 11th attacks, the wars in Iraq and Afghanistan, and Hurricane Katrina have made the need for research into the areas of TBI and PTSD more imperative. Traumatic brain injury is any event that causes physical damage to the brain. PTSD is an accumulation of symptoms that occur as a result of the damage sustained by the brain. Researchers need to learn more about TBI and PTSD to offer help and treat those who have sustained injury that is contiguous to the occurrence of the injury. Scientists have found that timely intervention of treatment may
serve to limit the severity of neuropsychological consequences.

**Symptoms of PTSD**

According to the DSM-IV (Diagnostic and Statistical Manual of Mental Disorders) and the ICD-10 (International Statistical Classification of Diseases and Related Health Problems, 10th Revision), post traumatic stress disorder occurs as a result of exposure to a traumatic event in which the subject has experienced or witnessed events that threatened death or serious injury. Furthermore, the individual's response involves a sense of fear and helplessness. Both the experience and the emotional response to the experience are necessary for the onset of PTSD. There is a marked tendency for the event to be re-experienced mentally in an intrusive fashion, which is difficult to control. This re-living of the experience is described as a flashback.

The flashback is associated with intense psychological distress. Typical features include dreams or nightmares, occurring against the persisting background of a sense of “numbness” and emotional blunting, detachment from other people, unresponsiveness to surroundings, anhedonia (the inability to gain pleasure from enjoyable experiences), and avoidance of activities and situations reminiscent of the trauma. There is usually a state of autonomic hyperarousal with hypervigilance, an enhanced startle reaction, and insomnia. Anxiety and depression are commonly associated with the above symptoms and signs, and suicidal ideation (thoughts about suicide) is not infrequent.

**War and Injuries**

The war in Iraq has been characterized by a large number of returning military personnel with severe brain injury. While most attention has been focused on penetrating wounds, with their dramatic and disastrous physical damage, other types of brain damage are also significant.

One of the most common sources of injury is blasts in which damage is primarily due to pressure changes resulting from explosions. This may be accompanied by injuries secondary to blunt trauma, due to sudden acceleration of the soldier or his collision with flying objects. Pure blast injuries and some of the more minor blunt trauma injuries result in MTBI (mild traumatic brain injury).

The Centers for Disease Control and Prevention (CDC) criteria for MTBIs include one or more of the following: any period of observed or self-reported transient confusion, disorientation, or impaired consciousness (i.e., altered mental state); dysfunction of memory around the time of injury; or loss of consciousness (LOC) less than 30 minutes; and/or other neuropsychological or neurological dysfunction.

This term is somewhat of a misnomer since MTBIs have other symptoms, including post-concussive syndromes and a variety of neurobehavioral disturbances. One of the most common, most studied, and most controversial of these is PTSD. The major point of contention regarding PTSD is whether it could occur in the setting of amnesia. This, together with the similarity of post-concussive symptoms to some of the symptoms of PTSD, has led some to conclude that PTSD is being over-diagnosed. On the other hand, it appears that some patients may have partial memory of the traumatic event while others, in the absence of explicit memories, react based on an unconscious set of “memories.”

**Diagnostic Tools for PTSD**

According to the proponents of this view, PTSD may be under-diagnosed since classic recollections may not be present. It has been suggested that the interviewer use his or her judgment as to whether the patient is suffering from post-concussive syndrome versus PTSD based on the nature of symptoms and their time course, even if specific recollections are not available. An alternative approach is that instead of a categorical diagnosis being made, the symptoms (which may or may not include memory or flashbacks) such as irritability and the sense of foreshortened future associated with PTSD be quantified. It also should be noted that the Breslau short screening test assists in determining the nature of a variety of clinical symptoms that can be helpful in the treatment phase of PTSD.

Another problem hindering the understanding of MTBI is the routine reliance on computed axial tomography (CT or CAT scans), for assessing brain damage. While operationally and from a practical point of view, this is understandable since the CT will identify the vast majority of cases requiring emergent treatment (e.g., hemorrhagic sequelae), its widespread use has led to its de facto acceptance as a “gold standard” for diagnosis, more commonly found with other imaging techniques, including magnetic resonance imaging (MRI) – especially techniques such as diffusion-weighted or fluid-attenuated inversion recovery (FLAIR) magnetic resonance imaging (MRI), magnetoencephalography (MEG), and nuclear scans, such as positron emission tomography (PET) or single photon emission computed tomography (SPECT).

A recent study indicates that diffusion tensor imaging (DTI) may be particularly useful. This is not surprising since diffuse axonal injury may be the most common injury in MTBI, and DTI results are based on alterations in axonal integrity.

However, as recently reviewed, positive findings abound regarding alterations in axonal integrity. The understanding of MTBI has also been hindered by the scarcity of post-mortem material due to its non-lethal nature. Surprisingly, despite the fact that quantitative electroencephalography (qEEG), or brain mapping,
is quite sensitive to brain injury and is far easier than many of the above techniques, this has been neglected.

**Recent Information on Blast-Related Injuries**

A recent study revealed that 88 percent of combat injuries treated at an echelon II medical unit in Iraq were blast-related (improvised explosive device (IED) or mortar) injuries, with 47 percent directly involving the head. Even in the absence of any obvious head injury, brain blast exposure (BBE) would have occurred.

In one Marine unit in Iraq, 97 percent of the injuries were from explosions (65 percent IEDs, 32 percent mines). The subsequent physical and mental conditions from BBE and brain blast injury (BBI) are still uncertain. In a 1998 report, it was noted that combat veterans who had a history of blast exposure and had subsequently developed PTSD had persistent electroencephalography (EEG) abnormalities and neurological symptoms consistent with mild traumatic brain injury.

**Mental Health Diagnoses and Services**

The necessity for mental health services throughout the military is obvious. Four of the five leading causes of disability days in America are psychiatric in nature. In addition, many general medical problems are associated with psychiatric comorbidity. (Comorbidity refers to the presence of one or more disorders or diseases in addition to a primary disease or disorder.) For example, serious wounds resulting in disfigurement or amputation are often associated with depressive and anxiety disorders as complicating features.

The most common form of TBI is the closed-head type. While the skull bone is unbroken, the brain has been jostled and strikes the internal surface of the bony cranium, producing brain injuries.

The resulting psychological symptoms range from mood instability to dementia. Of particular importance are functional imaging techniques such as functional magnetic resonance imaging (fMRI), MEG, and (qEEG). Structural assessments such as CT scans are important to rule out tissue damage, but more commonly, the problem is disrupted functionality.

PTSD must be differentiated from acute stress disorder because of the difference in prognosis. In PTSD, the traumatic event is persistently re-experienced. It can be associated with avoidance of stimuli as well as increased arousal. The disorder can cause significant distress or impairment in social, occupational, and other important areas of functioning. It also can occur with a delayed onset, where the symptoms do not occur until six months or so after the stressor event.

Depression with or without anxiety may appear as a comorbid symptom in PTSD and in TBI. Another common comorbid condition involves substance abuse. It is important that these comorbid conditions be recognized.

**Treatment of PTSD and Other Anxiety Disorders**

Treatment of PTSD and other anxiety disorders has two components, which can be offered separately or in combination. They are medication and psychotherapy. Both approaches alone or in combination can be effective in most of the anxiety disorders, but specific phobias respond best to specific forms of psychotherapy where the person is gradually exposed to the feared object and learns to deal with the resulting distress.

It is very important that the therapist be able to do a careful diagnostic evaluation to see what specific forms of anxiety disorder or disorders are involved. Anxiety disorders are comorbid with alcohol and/or drug abuse. These may be sufficiently severe as to warrant separate or even immediate treatment prior to taking on the problem of the anxiety disorder.

Because medication can play a role in many of these illnesses, it is useful to seek out a psychiatrist as the person involved in treatment. Sometimes the psychiatrist may choose to work with a psychologist or counselor, but there is an advantage to having one person available for total care. The choice of medication must be explained as well as the side effects and/or problems that may be associated with that medication.

References cited in this article can be requested from jhollingsworth@eparent.com.

**EP’s Commitment to TBI and PTSD Education and Awareness**

TBI and PTSD education and research are priorities for the Department of Defense in 2008. EP is working with the Exceptional Family Member Program (EFMP) in all branches of the military and is broadening its commitment in its Exceptional Family Transitional Training Program (EFTTP) by offering ongoing coverage of TBI, PTSD, anxiety, depression, and stress management. In so doing, EP continues its outreach and education to serve even more military personnel and their families as they so nobly serve us.

There is currently an inadequate amount of literature concerning the development of PTSD after TBI, particularly in war fighters. EP has plans to implement multidisciplinary educational programs, create a database for retrospective analysis, and collaborate with world-renowned neuroscientists to spearhead innovative research concerning the nature of injuries and subsequent pathophysiological mechanisms that can lead to several comorbid conditions. These programs will be aimed at healthcare providers, military members, and their families. EP’s online educational series will cover conditions including TBI and the development of neuropsychiatric conditions such as PTSD and other anxiety disorders, depression, and substance abuse.
What We Know...Can Help Us

A single word can offer comfort... a few words ignite hope... a whole story change a life.

Your story.
Your life.

So many of EP’s military families and professional healthcare readers have powerful, beautiful, informative, ideas-rich stories to tell. Stories that today could change someone’s life.

Did you know...?

Neither did we – until somebody told us.

EP would love to hear stories from and about:

- You • Mothers • Fathers • Daughters
- Sons • Servicemembers • EFMP Managers
- Special Needs Coordinators • Family Physicians
  - Pediatricians • ABA Therapists • Neurologists • Speech Therapists • Occupational Therapists • Physical Therapists • Psychologists • Psychiatrists • Surgeons... And More

Tell us about your own experience or professional efforts with people facing the challenges of:

- Autism • Traumatic Brain Injury (TBI) • Attention Deficit Hyperactivity Disorder (ADHD)
  - Cerebral Palsy • Post-Traumatic Stress Disorder (PTSD) • Spina Bifida • Asthma
  - Down Syndrome • Epilepsy • Anxiety • Metabolic Disorder • Depression
  - Hearing Loss... And Others

What programs and resources have you found helpful?

- Exceptional Family Member Program (EFMP) • Respite Care • Wounded Warrior Program
- Department of Veterans Affairs (VA) • Military OneSource • Wounded Warrior Project
- Specialized Training of Military Parents (STOMP) • Military Child Education Coalition™ (MCEC™) • May Institute • Military HOMEFRONT • Art/Music Therapy • Sports... Others

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COVER STORY
An Interview with Quickie Wheelchairs Founder, Marilyn Hamilton

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Sports and Veterans with Disabilities
Corpsman Jennifer Knuth Provides Care on Two Home Fronts

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One of the most moving photos I have ever seen was a collection of empty wheelchairs at the bottom of Colorado’s ski slopes during the 2007 National Disabled Veterans Winter Sports Clinic (see photo at right). The picture so perfectly embodied the purpose behind adaptive sporting events in the military community – to provide veterans with spinal cord injuries, visual impairments, amputations, or other severe disabilities with experiences that teach them their quality of life need not be diminished, regardless of their disability.

The empty wheelchairs belonged to veterans who were busy whooshing down the slopes and snowmobiling over fresh powder with adaptive equipment. Each year, adaptive sporting events for veterans with disabilities, such as the National Disabled Veterans Winter Sports Clinic and the National Veterans Wheelchair Games (NVWG), co-presented by the Department of Veterans Affairs (VA) and Paralyzed Veterans of America (PVA), attract hundreds of veteran athletes.

For the veterans, the events are about moving forward, overcoming challenges, and reaching out to others who understand what they are going through. And what makes these events so powerful, whether you’re a participating veteran athlete or an observer, is that you’re among hundreds of individuals who have experienced life-altering injuries and are participating as a testament to their spirit, courage, and determination to move forward.

Many of the athletes are newly injured veterans from Afghanistan and Iraq, testing their athletic abilities and skills for the first time since their injury. Making the transition from an active military lifestyle to a wheelchair is a huge adjustment. But as veterans realize their capabilities at adaptive sports, such as scuba diving, skiing, and rock climbing at the Winter Sports Clinic, and quad rugby, basketball, and maneuvering obstacle courses at the Wheelchair Games, the sense of accomplishment serves as an inspiration to tackle their rehabilitation with new zest.

Last year at the NVWG, I had the pleasure of meeting Scott Winkler, an Operation Iraqi Freedom/Operation Enduring Freedom (OIF/OEF) veteran competing in the Wheelchair Games for the first time. Less than a year before, his hidden talent for throwing the shot put and discus were discovered at another adaptive sports clinic, the U.S. Olympic Committee’s 4th Paralympics Military Summit, earning him a spot on the United States Paralympics Track and Field Team. The opportunity to participate in adaptive sports and discover his talent gave Winkler a huge boost of confidence after an emotional battle to come to terms with his paralysis that left him wondering, “What am I going to do with my life?”
Today, Winkler, an overnight sensation in the world of Paralympics track and field events, is breaking world records and training to compete in the 2008 Paralympics Games in Beijing, China. But his greatest satisfaction comes from helping others achieve their own levels of greatness at events such as adaptive sports clinics.

When someone like Winkler reaches out to another, touches a life and changes it, these are the moments when many veterans realize their life is not over by a long shot.

Health Net Federal Services is honored to serve as a sponsor of both the National Disabled Veterans Winter Sports Clinic and the National Veterans Wheelchair Games, which respond to the challenges our nation’s disabled veterans face and provide hope, inspiration, and camaraderie.

Health Net looks forward to continued partnerships with DAV (Disabled American Veterans), VA, and PVA as it continues to work with these organizations to promote programs that advocate and provide opportunities for an equitable quality of life for veterans with disabilities.

For more information about these annual sporting events within the military community, please visit the following sites: www.winter-sportsclinic.va.gov and www.pva.org and click on Sports & Recreation.

Jennifer Davidson is a senior writer for Health Net Federal Services, LLC, the government operations division of Health Net, Inc., and healthcare contractor for the TRICARE North Region. Health Net is honored to provide high-quality, cost-effective healthcare programs to the Departments of Defense and Veterans Affairs and is proud to partner with organizations dedicated to improving the quality of life for our service members, active and retired, and their families.

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**EP Military Channel News**

Readers can access important information regarding Department of Defense news, Department of Veterans Affairs news, and TRICARE by visiting the Military Channel on the EP Web site. Information includes news releases, reports, and other relevant items.

Visit the EP Web site’s Military Channel often for news and announcements that are of interest to military families who are caring for a member with special needs.

www.eparent.com/main_channels_military/index.asp
1. Determine your population’s needs. Who will be the participants in the program? What are their ages, abilities, and disabilities? What are their aquatic needs and interests? The more information you have about who your participants will be and why they will benefit from an aquatic program, the easier steps two through ten will be.

2. Decide on the type of aquatic program that will best meet the needs of the greatest number of potential participants. Will the program be instructional/learn to swim, exercise, therapeutic, or recreational? How large should participant groups be? Will the program duplicate existing community programs, or will this program be unique in its purpose to serve a population not served by existing community efforts? If this program duplicates a community program, why is duplication justified?

3. Find an aquatic facility. Consider water depth, air, and water temperatures, accessibility of the building, locker rooms, bathrooms, and pool tank. Check size of lockers. Prosthetic devices and braces take space. Visit potential pools and view each from a participant’s point of view. Pools can be found in many places. Check out schools, hotels, hospitals, rehabilitation centers, community venues, residential living facilities, and private water parks.

4. Determine what staff will be needed. At the very least, you must have a lifeguard, and most likely more than one lifeguard, each currently certified.
by a national agency. Certification should be in professional-level CPR and Automated External Defibrillator (AED), as well as lifeguard training. In addition, you will need locker room supervision and someone to check people in and out of the facility. If the program is instructional, includes exercises directed by a leader, or offers professional therapy, you will need an aquatic professional to provide those services. Also, consider the number of participants each staff member can work with at one time. (Note: A lifeguard should only be expected to perform lifeguard duties – i.e., continual surveillance of participants and response to emergencies. A lifeguard should not teach and/or lead activities while at the same time he or she is functioning as a lifeguard.) Last but not least, determine who will manage the program on an ongoing basis. This includes record keeping of participant records as well as staff data, and finance records.

5. Plan your aquatic program schedule. When will the various aquatic program activities be offered? Remember the hours children are in school. Take into consideration adult work hours, as well as family recreation time. If your population faces health challenges, it may be necessary to take into account times when there is more privacy in shared locker rooms and/or when the facility is likely to be the cleanest. Another aspect of the schedule is how many individual participation days will make up one session. While it is nice to think of aquatic programs as ongoing, holidays as well as annual cleaning will interrupt continual programming. Establishing a program calendar can help participants plan ahead, as well as provide structure for assessment of any fees.

6. Nothing comes without cost. How will the program be funded? Money will be needed to pay the lifeguards. Legally, his or her duty to respond relies on a formal employment agreement. Additional funds may be necessary to rent pool time, pay additional staff, obtain equipment, provide insurance, and cover maintenance. Have fundraisers, seek community grants, solicit corporate support, and yes, even charge fees. Start-up costs usually include publicity and facility rental fees. Ongoing costs include staff salaries, equipment, staff and participant recognition, and more publicity. Many facilities have insurance covering anyone using the facility. However, some facility management structures pass insurance costs on to facility renters.

7. Publicity not only helps spread the word to participants, but also can be used to generate funding. As soon as you start your planning (way back at step 1), you can start your publicity. Support generates ideas and can result in contributions. Use agency newsletters, public newspapers, the www.eparent.com/EP MAGAZINE • June 2008

6. Family members or volunteers must be available to help in the water, and must be at least 16 years of age.

7. A program needs to be flexible to meet the needs of participants’ varying levels of abilities.

8. Agencies such as the Exceptional Family Member Program (EFMP), the hospital, therapy clinics, or the Wounded Warrior Program may be helpful in identifying needs and individuals who would benefit from an aquatic program.

Swimming instruction for any program requires that the instructor be responsible, compassionate, patient, and have a love for teaching. EFMP aquatic Learn to Swim programs are unique in that they are not only instructional but are changing lives. All things are equal in the water. The focus is not on a disability but on being successful in the water. Everyone can learn to be water safe, and most will enjoy learning to swim, which will increase confidence, pride, and the experience of success.

Jaye Urban started the Adaptive Aquatics Swimming Class at Fort Belvoir U.S. Army installation and has volunteered as an instructor for the past two years. She is certified with the American Alliance for Health, Physical Education, Recreation and Dance (AAHPERD) and Aquatic Alliance International (AAI). She is also certified as an American Red Cross Swimming and Water Safety Program instructor.
Adaptive Aquatics Splash

Fort Belvoir Makes Swimming a Source of Fun and Therapy

By Ewa Fabijanczyk

Independence and confidence are two words often used at Fort Belvoir U.S. Army installation in Fort Belvoir, Virginia, during its Adaptive Aquatics Swimming Class. The home for these classes is the Benyuard Indoor Pool. Every Wednesday at 5:00 p.m., the fun begins for children with special needs enrolled in the Fort Belvoir Exceptional Family Member Program (EFMP). Children between four and eighteen years of age have an opportunity to splash and play while participating in developmental swimming lessons from a water safety instructor. During class, every child is assisted by a caregiver, parent, or volunteer, which enables the course instructor to spend time working individually with each child.

The program was established a few years ago by patrons of the Directorate of Family and Morale, Welfare, and Recreation (DFMWR) and Army Community Service (ACS) at Fort Belvoir. Benyuard Indoor Pool manager, John Wasserman, says he is proud to host these classes and is trying to improve the quality and accessibility of the pool for children with special needs. Wasserman works closely with the families and directors of various organizations to accommodate their needs and hopes to fund a new lift for the pool soon.

Jaye Urban, a military spouse who started the program and has volunteered her time for the past two years, is a vital reason these swimming classes at Fort Belvoir are so successful. Urban is a certified American Red Cross Swimming and Water Safety Program instructor and works with people of all abilities. The experience of helping children achieve goals through swimming “is the most rewarding,” she says. For Urban, getting to know each child individually and ensuring safety is always a priority. The class is open to children with a wide range of disabilities, including spina bifida, autism, cerebral palsy, and Down syndrome.

Games are a key component of the classes, which makes each class fun and exciting. Some of the equipment used in the class includes: foam noodles, beach balls, and floating devices. The goal for the class is to provide children with disabilities the opportunity to participate in swimming regardless of their disability. “Swimming promotes mobility, flexibility, strength, confidence, and independence,” Urban says.

These adaptive aquatics classes would not succeed without the support of parents and volunteers. Volunteers at Fort Belvoir include Sean Urban and Andrew Hurst, from Boy Scout Troop 118, and Erik Estabrook. They also volunteer for Army Community Service. Sean Urban, who is the son of the swimming instructor, indicates that he is proud to be a part of the program. “I especially enjoy seeing the kids improve over time,” he says. Andrew Hurst, whose siblings attend the classes, also loves to help. Estabrook, an EFMP client, joined the class to learn to swim and help other children, and is now doing just that. “I feel extremely proud of how the children in the class have progressed,” says Estabrook.

Stephanie Hurst, mother of two children who attend the class, Maggie and Sammy, is very proud of her children’s achievements. Each class brings a new experience for them. Her son, Sammy, “has improved muscle strength from swimming,” she says. Her daughter, Maggie, “started the swimming classes terrified of the water and after a year she has gained confidence and independence in the water.” Another mother, Kathy Thompson, loves to watch her son Caden swim. “Caden benefits from the exercise he receives from swimming as well as his comfort level in the water. He can’t wait for the next class,” she says.

Instructor Urban indicates that she loves to teach swimming to the children and is very proud of her students’ achievements. “Their enthusiasm, their smiles, and the satisfaction they get from learning a new skill makes my job one of the best in the world,” she says.

Adaptive aquatics classes can be therapeutic and beneficial to all children with special needs. The confidence and independence gained through swimming positively impacts their lives. The Fort Belvoir parents and volunteers enthusiastically recommend the adaptive aquatics swimming classes to others. Not only are the classes themselves very popular but the Fort Belvoir students can also practice their swimming skills with the family during Open Swim, every Saturday from 1:00 to 5:00 p.m.

Ewa Fabijanczyk is the Fort Belvoir Army Community Service Exceptional Family Member Program Assistant. She has worked in Army Community Service for the past four years. She is a foreign-born military spouse and mother of a teenage daughter.

Internet, school communication systems, parent/teacher groups, doctors’ offices, hospitals, and clinics. Flyers may be easier, but personal contact where information is shared can be more effective.

8. Plan for recognition. Once your program is under way (you can start actual programming any time your staff feels you are ready), you will also want to implement a system to recognize program participation as well as staff and community support. This might be through a certificate of accomplishment for a learning program or an attendance certificate for a fitness group. Staff can be recognized for number of hours worked (particularly good for volunteer staff) as well as for performing program support “above and beyond” the call of duty. Always recognize your financial supporters with a big “thank you.” Recognition helps build program loyalty and support, necessary for ongoing participation as well as for generating funding.

9. While it is great fun to be able to sit back and enjoy a well-run program, what will keep that program continuing with quality will be periodic...
evaluation. What do your participants think? Is the program meeting their needs? How could the program be improved? Is your staff meeting their obligations? Is the facility clean and well maintained? Is your financial structure appropriate? Ask everyone – participants, family members, staff, and boosters. How often is evaluation appropriate? At least every six months and, most certainly, after any serious problem and/or aquatic emergency.

10. An ongoing aquatic program requires **recommitment**. Just getting a program started may seem like a daunting task. Keeping a program going is even harder. Just as many new businesses fail within the first two years, so do new programs. Programs do not sustain themselves. They need careful tending to stay viable for the participants for whom they are intended.

Does this list seem long and complicated? The key to accomplishment is taking the aquatic program development process one step at a time. When you have accomplished one step, then move on to the next. A **planning group** has the advantage of being able to spread out the work among many individuals, capitalizing on personal strengths and community contacts. Try to keep a planning group on a **timetable**, with regular meetings to keep members up to date on the total process.

An aquatic program is within the reach of anyone who wants to build one. Given the well-known benefits of aquatic activity for individuals with disabilities, the final results are well worth the time and effort involved. •

Susan J. Grosse is the author of *Water Learning: Improving Mental, Physical, and Social Skills Through Water Activities*, available from Human Kinetics Publishers. For additional information on implementing water learning experiences, as well as a wide selection of pool and non-pool activities, visit www.humankinetics.com Contact Human Kinetics at 800-747-4457 or info@hkusa.com.
In Iraq

The phone call occurs in the middle of a sandstorm, “the worst we’ve had,” says Hospital Corpsman First Class (HM1) Jennifer Knuth of the United States Navy, but throughout the 45 minutes of the conversation, an equanimity transmits itself through the voice of Knuth in this call between Camp Taqaddum (Tuh-KAY-duhm), “TQ,” Iraq and Johnstown, Pennsylvania where EP’s main offices are located.

Fortunately, Corpsman Knuth and her fellow servicemembers are tucked safely inside while the wind fiercely whips sand around the building.

Thousands of miles away and six hours earlier by time zone, two little redheaded girls are engaged in their daily routine in the countryside outside the city of Athens, Georgia, home to their grandmother, who is caring for the twin girls while their mother is deployed to Iraq. Knuth’s daughters were diagnosed with autism when they were three years old, and their grandmother, Sarah Knuth, is following routines established by Jennifer with her girls to bring calmness and a sense of security to their day.

The toughest part of her deployment is being separated from her daughters, Rowan and Rayna, now five years old, says Knuth. “The big challenge was leaving them. This is the first time I’ve been away from them. I call them at least twice a week,” she says. She deployed with the Marine Corps in September 2007 in support of Operation Iraqi Freedom (OIF).

While separated from her own daughters, Knuth does see many children on a regular basis in her duties as a hospital corpsman, going outside the wire to provide medical care to both Iraqi women and children. (When a servicemember goes “outside the wire,” they are in the war zone itself, and therefore under less protection by the base camp. The phrase itself refers to the concertina wire – a barbed, spiraled wire used as a barrier – that surrounds the perimeter of the base for protection). Knuth sees 50 to 150 women and children in a span of four hours each time she goes out. There is time for basic treatment and to lend an ear through the female interpreter as patients talk about not just their own and their children’s health, but the lack of fuel and other concerns and dangers they face, such as Al Qaeda snipers across the canal.

Knuth has enjoyed her time and her work in Iraq, although the environment at times can be “scary and terrifying.”

Taking Care

From October to March, Knuth, 34, had been the only female provider for the mothers, grandmothers, children, babies, and the few husbands who accompany their wives to the clinics or makeshift healthcare offices in school buildings in the villages that she visits. Women are examined on one side of the building and men on the other. Since mid-March, two other female providers have also been available to help with care. (Knuth later noted that when mothers brought their babies and children to be examined, “they would dress them in the best clothes that they have.”)

“I see some pretty interesting stuff out there,” she says. “A lot of the women know me by my first name. They’re so (grateful) that we came, and we were able to bring them female care.” During her visits, she says, she sees “very, very normal children and very disabled children.” Down syndrome and cerebral palsy are two of the disorders she sees most frequently, and she has seen some children “burned or blown up from bombs. In the States, they could get it taken care of,” she says. Knuth can refer patients to Baghdad, but often “they can’t or are afraid to make the trip,” she says.

Knuth recalls eight-month-old identical twins, who had lost a triplet sibling. The children’s healthcare issue was failure to thrive (a term used to describe children whose current...
weight, or rate of weight gain, is significantly below that of other children of similar age and gender). In another case, the mother of a two-month-old baby did not have breast milk, and her husband had returned to another wife. The baby’s mother did not have money to buy milk for her baby. “We let the sheiks know” about situations like this, Knuth indicated, but beyond that there is not much they can do. She remembers one child who had had a bad fever and who is permanently brain damaged. While it appears the child’s illness may have caused the brain damage, there are “no tests (available) to prove” it, Knuth says. For the many difficult things that are seen, “you can’t dwell on it,” she says. “You kind of have to put up a wall so it doesn’t bother you too much. I try to keep it positive as much as I can,” she says of her outlook, both for herself and others.

The hospital corpsman has been gathering toys for the children, through the Web site http://www.any-soldier.com. She listed items that she wanted to have sent, and toys and school supplies have arrived for the children.

The Family Home Front
Back home, her own daughters are doing well in the care of Knuth’s mother. Things did not work out with the twins’ father, and Knuth has been raising them herself since they were six months old, with only occasional contact from their father. Family and friends have been a big support for her since the twins were born. “I was lucky that people were able to help,” she says. She indicates that she is “absolutely secure knowing my mom is watching them,” during her deployment. “Without her, I couldn’t have done this. There’s nobody else I would trust.”

Twin-to-Twin Transfusion Syndrome
Sixteen to eighteen weeks into her pregnancy with Rowan and Rayna, Knuth had an ultrasound, the one where you “can tell if it’s a girl or boy,” she said. They were able to identify Rowan as a girl, but she was told, “I can’t find one.” When the physician was called in, he was able to find Rayna, and said, “That baby is stuck.” Knuth learned that she had twin-to-twin transfusion syndrome (TTTS). (For more about twin-to-twin transfusion syndrome, see the accompanying sidebar on page 89.) She was given a few options: to abort, “which I wasn’t going to do;” to have fluid removed from Rowan’s sac every week; to have experimental surgery; or to “not do anything and see what happens.” The experimental surgery cost $10,000, and Knuth knew there was no way she could afford it. However, the Navy agreed to cover the expense.

Stationed at Beaufort Marine Corps Air Station in Beaufort, South Carolina at the time, Knuth flew to Tampa, Florida, where Dr. Rubén Quintero, who pioneered the endoscopic fetal procedure, performed the surgery at St. Joseph’s Women’s Hospital. “My family’s from Florida,” she said, and that made the trip better. Knuth went home the day after having the surgery. She did have some worry, knowing that the endoscopic surgery was still considered experimental, and there had not been a lot of research done on twin-to-twin transfusion syndrome. However, “I was confident in the doctors,” she says.

Knuth had been told that there was a 60 percent chance with the surgery that Rayna would live. She was stationed at Marine Corps Recruit Depot (MCRD) Parris Island when the girls were born. She delivered two full-term, healthy babies in February 2003, each weighing over five pounds. “That was a miracle. And they’ve just been such a joy. They’re just so much fun.”

Autism Diagnosis
As Rayna and Rowan grew, Knuth had noticed some areas of slow development for her daughters. They walked at 19 months, but she attributed that to the fact that they are twins, and twins
are often known to develop more slowly. However, when they were three years old, “one of their teachers talked to me about it. They seemed a little nervous at first to tell me,” the soft-spoken yet straightforward Knuth says. She recalls letting them know, “If there’s something wrong with my kids, I would appreciate if you would tell me now so I can get them some help.” They indicated to her that they thought the girls had autism. Follow-up appointments with a pediatrician and pediatric psychologist and a variety of tests confirmed autism. Knuth recalls her next question: “What do I need to do to fix this?” Occupational, speech, and physical therapy were prescribed, and the girls attend therapy three times each week when their mother is at home.

Knuth has found other measures that help. The family keeps a regular routine and schedule. “If anything is changed in that, it just throws off the whole day,” she says, including sleep-time. “I have to do everything the same way each time,” she says. For example, when the family comes home, they check the mail. Skipping the task at any time resulted in the girls becoming very upset. Fortunately, establishing and maintaining a routine has not been difficult. Knuth says that may be because of her military background and training, where routine is standard. For the transition to her mother’s house, Sarah kept to Jennifer’s routine and slowly changed things as necessary. Jennifer indicates that she has discovered that if she provides information, a little bit at a time, prior to a change occurring, the girls are better able to accept it. For behavioral issues, she disciplines the girls “like other kids,” she says.

One challenging area for the girls is being around crowds. Knuth’s solution during grocery shopping is to take a DVD player with her. It keeps their attention elsewhere so they don’t notice that they are in a crowd, she says. The girls select a movie to watch beforehand. She places them in the carts that can seat two and gives them each earphones. They’re so consumed by whatever they are watching, they are fine, she says.

The plan is for the girls to resume their thrice-weekly occupational, physical, and speech therapy when they are settled in again with their mother. TRICARE covers the cost of therapy, which is available through civilian healthcare providers.

**Development**

Based on the reports Knuth receives about the girls’ development, “there are some things they do better than all the children, and some things they are behind on,” she says.

The girls have spent the past year in a pre-kindergarten classroom. One teacher has told Knuth that the girls are the most performance-oriented of the children in the classroom. “They love to perform,” says Knuth. They are also adept at age-level skills, such as cutting paper in a straight line, stacking blocks, and drawing.

They can hear a song one time and get the “exact” tune and “go with it,” Knuth says. They will make up their own words, then gradually learn the actual words to the song. You can tell them something one time, “and they can repeat it back to you,” she says.

When the girls were first learning various tasks, their teacher would sometimes become frustrated because, “they won’t do it unless they think you are not paying attention,” Knuth says. Rowan could recite her entire ABCs without missing a beat, but if you sang along with her, she would stop, she recalls.

Their mother wants the twins to be able to “deal with regular kids in a regular classroom.” For the upcoming school year, depending upon the school’s resources and testing results, Knuth would like the children to be in a regular classroom and attend a classroom for children with special needs, if needed. If a classroom for children with special needs is unavailable, she would take them out of town for therapies.

Knuth’s perspective is positive and optimistic. “I’ve just always been thankful that it’s not (more) than what it is,” she says.

**Help**

The transition to Sarah’s household from Jennifer’s home went fairly smoothly. “I had been around the girls so much,” Sarah says. “They knew me so well.”
“It’s easier being a grandmother,” though, she says. “It’s kind of hard being both at the same time.” It helps that keeping them occupied is fairly straightforward. “They entertain each other so much,” she says. The best thing about having this time with the girls, she says, is “having the time with them. It’s really changed my life. When they leave, I’ll probably go through empty nest syndrome all over again.”

Sarah recalls that during a conversation between Jennifer and her, Jennifer had referred to her daughters as “my girls.” “I said, ‘You mean ‘my girls,’” Sarah says. “It’s just been fun. They just do the cutest little things.”

The most challenging aspect of having the girls has been “dealing with twins, changing my lifestyle, going places I used to go and taking them with me … because they don’t slow down.” They like to stay up in the evening with their grandmother, which can make getting them out of bed in the morning quite challenging. She has not wanted to leave them with a babysitter. Sarah emphasizes that the help of her other daughter, Christy, whose family is expecting their third child, has been invaluable.

“It hasn’t been as difficult for me taking care of the twins because my other daughter (Christy) is here. She’s been great about helping me out with the girls.” Christy and her husband have kept the girls at their house sometimes. “They love her and love her husband and love my other grandchildren. She loves these girls, and she would do anything for them. She has not wanted to leave them with a babysitter. Sarah emphasizes that the help of her other daughter, Christy, whose family is expecting their third child, has been invaluable.

They’ve Got Personality

“They’re such sweet little girls,” Knuth says of her twins. She has different stories about the girls. “They’re absolutely alike, and absolutely different,” she says, describing her twins. While Knuth had thought that Rayna was the more outgoing of the twins, she notes that she hears “different stories about them every time” from others. She had thought that Rayna was more of the leader and Rowan more of the follower but recently has been told the opposite. Some days, Rayna seems to want all the attention, while on other days, Rowan appears to seek the most attention. One day when Knuth was talking with them on the telephone, Rayna was the talker and “Rowan didn’t want to have anything to do with it,” while, another time, Rowan, older by one minute, wanted to do all the talking.

“They’ll plan things together,” she says, recounting a story her mother told her about one of the girls’ escapades. They had been fighting over a Barbie® car, and Sarah had told them it would be put away if they could not share it. Sarah put the car on a shelf at the top of the closet. Within five minutes, it had become quiet. Sarah went to the room to see what they were doing. The girls had gotten a chair from the dining room and were helping each other to get the Barbie car down. Sarah’s presence did not faze them as they discussed with each other what to do, one twin getting a pillow to add height to the chair and the other twin holding the chair in place. They retrieved the car.

“If they want something, they both want it,” Jennifer says.

“They love to exercise,” she says. When her mother bought a new Pilates book, Rayna would look at a page, grab the wall, and practice the maneuver. Then she would come back, look at a new picture, and say, “Okay, I got it!” after which she would run over and perform that maneuver, then come back and turn the page for the next exercise, and start all over.

“We have so much fun,” she says. Even when she’s mad at them, she finds herself laughing so hard, she can’t be mad at them anymore. “You can ask them what they do wrong, and they’ll tell you.” Sometimes the girls will “tag team” in misbehavior, Knuth says.

“They don’t pay attention to strangers a lot. But, at the same time, they do.” They may have no interaction with somebody while out with their mother, but later they’ll note to their mother something such as a picture on the shirt the person was wearing. “They’ll notice detail that you don’t think they’d notice, that you don’t even notice,” she says.

“They’re ‘exactly opposite, mirror twins,’ Knuth says, noting that they have parts on opposite sides of their hair, dimples on opposite cheeks, and teeth that slightly angle on opposite

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**Twin-to-Twin Transfusion Syndrome**

Twin-to-Twin transfusion syndrome (TTTS) is a condition resulting in abnormal blood exchange between identical twins through a common placenta, according to the University of Southern Florida Web site (http://hscweb3.hsc.usf.edu/health/now/?p=200).

Not all identical twins share a common placenta. When they do, the proportion of blood flow can be equal between the twins. However, in the uneven blood flow exchange present in TTTS, one twin (donor) supplies the other twin (recipient) with an excess amount of blood. Risks are present for each twin, with the donor twin often being small in size and having low amniotic fluid. The recipient twin can develop cardiac failure and have excess amniotic fluid. Other conditions can be present for both twins. TTTS can result in the loss of one or both of the twins. Without treatment, there is the risk of neurological or physical damage to the twins. A routine ultrasound during pregnancy is often the way that twin-to-twin transfusion syndrome is detected.

Some of the treatment options for TTTS include: amnioreduction, in which excess amniotic fluid is removed from the amniotic sac of the recipient twin throughout the pregnancy; monitoring of the pregnancy through routine ultrasound; or endoscopic laser surgery performed during pregnancy, in which a laser is used to seal off the placental blood vessels through which the twins are unequally sharing blood.

Textbook Regarding Twin-to-Twin Transfusion Syndrome

Dr. Rubén Quintero, who performed the surgery for Hospital Corpsman Jennifer Knuth, pioneered the endoscopic laser surgery treatment for Twin-to-Twin Transfusion Syndrome (TTTS). He is the editor of *Twin-Twin Transfusion Syndrome*, a textbook for physicians involved in the care of patients with TTTS. The textbook includes information regarding the etiology (cause or origin) of TTTS, diagnosis and management, ethics, epidemiology, ultrasound assessment and management, and neurological outcomes.

A Family History of Service

Knuth is currently stationed at Marine Corps Air Station New River, in Jacksonville, North Carolina, and returned home from Camp Taqaddam at the end of March. She may redeploy next August or September. "I'm actual-ly due to transfer next May or June," she says. There has been some talk about Afghanistan. Either one would be okay with her. "If I were single without kids, I would feel just fine," she says.

Knuth is with Marine Wing Support Squadron (MWSS) 272. (Navy hospital corpsmen serve either with the Navy or with the Marine Corps. All Marine Corps hospital corpsmen are from the Navy.) She has been taking college courses and would like to attend school to become a physician's assistant. With 13 years in the Navy, her intention is to stay for 20.

Knuth's Military Occupational Specialties (MOS) are Independent Duty Corpsman (IDC) and Fleet Marine Force (FMF) Corpsman. An Independent Duty Corpsman is qualified to take care of patients without a physician present, much like a physician's assistant in a non-military medical setting. As a Fleet Marine Force (FMF) Corpsman, she has undergone training qualifying her to be deployed with the Marines. She was recognized as Sailor of the Quarter for the fourth quarter of 2007.

This has been Knuth's third deployment in this Area of Responsibility (AOR) (a specific geographic region under a Unified Combatant Command (UCC)). She was deployed twice previously, on the USS Abraham Lincoln, in the Persian Gulf for six months. A history of military service runs in her family. Her father was a Marine during the Vietnam War. Two half-brothers served in the Marine Corps. Her paternal grandfather served in the Army Air Corps during World War II, and one of her uncles was a Navy Captain during WWII. Yet with all that history, Knuth had not planned to join the military service. However, "I was just bored one day, and drove in" to see a recruiter. "My Mom was pushing me for it." On her way home from her job at a restaurant, she thought, "Let's see what they have to say." Of her time in the Navy, Knuth says, "It seems like just yesterday. I've enjoyed it."

Regarding her encouragement to Jennifer to join the service, Sarah says, "I had wanted her to join something. She wasn't really college oriented," although she is very smart, she says. Sarah is a high school professional (guidance) counselor and was so at the time that Jennifer was in school. "I kind of wanted her to get out of a small town and see the world. I took her to a Navy recruiter one time. I knew that there were other options out there, other than college and technical school, that you really needed further education somewhere," Sarah says of her daughter. "She's very bright, very social. She's also very independent. It takes a lot to get her upset. She's real even-keeled, easygoing. She loves working with people."

Some of Jennifer's training, such as that to prepare her to go out in the field with the Marines "scared me," Sarah says. Yet, "I feel like she probably helped a lot of people over there and improved lives." Sarah notes that she has told Jennifer that she will not ask any questions about her time in Iraq, but she is always willing to listen. "I want to pretend she wasn't in the middle of all of that," she says.

Home Again

Knuth was preparing the family's home in Jacksonville for the girls' return after they complete the school year in Athens, where she thought it best they remain for the sake of consistency and routine. It will be important to re-establish their routine at home. "I want everything done before they get (here)," she says. Since arriving home, she has been able to spend some time with them, seeing them for the first time since September when her mother took the girls to the squadron at New River for her arrival, and spending some time with them since then. She was going to see the girls on May 14 again and was counting down the days. She planned to stay at her mother's for a couple of weeks and then to take the girls home with her.

The distance between New River and Athens is about 400 miles, Sarah says, "anywhere from seven to eight hours. It's a day-long drive." They will coordinate summer visits around everybody's schedules.

The Future

Regarding future deployments, Knuth says, "The only thing that stops me from going out even more than what I do is because of my kids. There's plenty of opportunity for me to go out. I need to spend time with my kids."

She notes that she wants her daughters to have the type of life that they are capable of having. She indicates that she is "trying to teach them to be able to live in the world" … in a way that "they are not going to be picked on and judged." She wants to put them in a regular school, "not making them feel like they're special. They feel special because they're mine. Not out-of-the-way special."
Returning home from war without sight is a devastating reality that often sends veterans “to a dark, bad, lonely place.” Those are the words of Corporal (Cpl.) Michael Jernigan, United States Marine Corps (USMC), Retired (Ret.) who served in the Marine Corps in Operation Iraqi Freedom (OIF) and received serious combat wounds, including the loss of both of his eyes.

Learning to live with no vision is a challenge, much as it was in 1948 for those returning from World War II (WWII). Tasks like dressing, eating, writing, reading, and traveling were changed forever for these sightless veterans. Since the GI Bill that guaranteed a college education to all veterans of the war had just been passed, the inability to read caused an exceptional amount of angst for many. The veterans were anxious to move forward with their lives but needed access to textbooks in order to complete their educations.

Macdonald’s idea would help hundreds of thousands of students in the years to come and spark the beginning of a nonprofit organization – Recording for the Blind®. Through these efforts, veterans who were blind were able to complete their educations and rebuild their lives – earning college and graduate degrees and pursuing professional development.

The organization changed its name to Recording for the Blind and Dyslexic® (RFB&D®) in 1995. This year, the organization is celebrating its 60th anniversary. More than 7,000 volunteers work in 29 studios nationwide to produce the recorded books.

Still Helping Veterans, and Thousands More, 60 Years Later

Cpl. Jernigan is one of more than 185,000 individuals who currently use RFB&D’s Learning Through Listening® Program. His membership to RFB&D gives him access to more than 43,000 digitally recorded audio-books on CD, available in RFB&D’s CV Starr Learning Through Listening® Library. The books cover educational topics for elementary through college and post-graduate school levels.

Jernigan uses the audiobooks at Northern Virginia Community College. He attends all of his classes with the help of his guide dog, Britani, and is happy to have the technology with him in the classroom.
He takes notes as he reads by speaking into a portable cassette player and is grateful for his computer skills and the assistive technology he uses proficiently.

The RFB&D technology Jernigan uses consists of a specialized playback device that provides him with independence through its portability and ability to be navigated by page, chapter, or section at the press of a button. He can read alone easily with no assistance necessary to find the correct page, place an electronic bookmark, and get a full understanding of all the elements on the page, because the recordings also include knowledgeable and detailed descriptions of graphic elements. RFB&D’s volunteers include experts in various fields to record the books, so the charts, pictures, and graphs are described in detail in the correct language and jargon. These functions make the audiobooks a very effective learning and study tool.

The accommodations provided by RFB&D have allowed Jernigan to be extremely independent. The technology permits nothing to slow him down. Like the thousands of wounded veterans before him who used RFB&D’s recorded books to continue their education, he is determined to complete his degree, begin a career, and move forward with his life. It is a joy to see his enthusiasm, especially when we learn exactly how long a road his recovery has been.

Born into a military family, Jernigan always thought he would join the military, too. With grandfathers, uncles, and his father all serving in various branches of the service, it was a proud family tradition. When he was sworn into the Marine Corps, it was his father who administered the oath, while the rest of the family looked on.

It wasn’t long before Jernigan shipped out to Okinawa, Japan, then Kuwait, and, ultimately, Iraq. In Iraq, he found himself in several firghts. Bullets flew around him, hitting the dirt at his feet, missing him at times by only inches.

Then, one day, while patrolling in an armored Humvee, two roadside bombs went off, one after the other. Jernigan was thrown through the air. He sustained severe head injuries that caused him to lose his sight. He had fingers blown off that were later reattached. He could have bled to death there on the road from a punctured femoral artery except for the quick response of medics.

What followed were years of pain, surgery, and a depression that Jernigan says sent him to that “dark, bad, lonely place.” Gradually, bit by bit, with the help of medical personnel, counselors, and a close and loving family, Jernigan has left the dark place behind. As he says, “It’s been a long, hard road.”

Jernigan feels honored to know that RFB&D was originally founded for wounded veterans like him and is thankful to the thousands of volunteers who make the recorded books possible.

Other veterans have also shown RFB&D how grateful they are for the educational materials. At a volunteer recognition event in Austin, Texas in 2007, Randy Greene, U.S. Army, Ret., spoke to 100 volunteers, thanking them for the service they provide and the audio textbooks they make available. He was an early user of RFB&D and served in many organizations to help people who are blind and visually impaired.

A USA Today article reported that 1,100 veterans of Iraq and Afghanistan — 13 percent of all seriously wounded casualties — will undergo surgery for damaged eyes. That is the highest percentage for eye wounds in any major conflict dating to World War I, according to research published in the Survey of Ophthalmology. It’s a hard truth, but one that helps RFB&D and its volunteers and supporters understand how important their work will be in the coming years.

Jenny Falke is the Communications Manager of the Regional Unit of the South Central States of RFB&D. The unit is reaching out to students in Texas, Arkansas, and Oklahoma. Noreen Braman is the Multimedia Design Editor at RFB&D’s National Headquarters in Princeton, New Jersey.

Do you know a veteran who is blind or visually impaired who would benefit from this article? Visit EP’s Web site (www.eparent.com) after June 15th and click on the Military Channel to find an audio recording of this article.
Exceptional Parent

Home Improvement

Louise Underwood, The Velvet Hammer

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UNITED STATES MILITARY SECTION

Homes for Our Troops

Soldier and Family Assistance Centers

COVER STORY

A Home For the Whole Family

www.eparent.com
The biggest fear that most brave men and women who volunteer to serve our country through military service have is that they could be killed in action while fighting overseas, leaving their families alone. However, they often do not think about how their lives and the lives of their families would change if they returned home from Iraq or Afghanistan with severe injuries.

When Sergeant (Sgt.) Eric Edmundson returned home from Iraq, his family was told that because of the serious brain injuries he had sustained, his condition would never drastically improve. Medical professionals recommended that Eric be placed in a nursing home.

Eric's wife and his parents did not take the recommendations of doctors. They took control of the situation and moved in together to care for Eric 24/7 in a house the family rented in North Carolina. That house presented additional challenges because of the way most houses are designed, with three-foot hallways and thirty-two-inch doorways. Eric spends a good deal of time in an oversize wheelchair, so he needed a home with wider doorways and hallways so he could move from room to room to fully participate in family life.

Sgt. Peter Damon was repairing a tire on a Black Hawk helicopter in Iraq when it exploded. He lost his right arm above the elbow and his left arm above the wrist. Peter, his wife, and two young children were living with his mother. Peter had always loved working with his hands, and now even basic bathroom and hygiene needs became difficult.

When Specialist (SPC) Russell Kyle Burleson returned home from Iraq to Springhill, Louisiana, paralyzed from the neck down, he and his wife Kristy and their two small children lived with his mother in a 900-square-foot house. Kyle was confined to one tiny room that did not have enough electrical outlets for the fourteen medical devices that had to be plugged in at all times to keep him alive. The family also did not have a generator to keep his medical devices going in the event of a power outage in hurricane-prone Louisiana.

Corporal (CPL) Evan Morgan lost both of his legs and sight in his right eye from an explosion while on his second tour of duty in Iraq. Evan gets around very well using prosthetics on both legs but spends much time in a wheelchair inside his home, scraping his knuckles in hallways.
that are too narrow and in doorways that are too small.

Homes for Our Troops Helps Veterans Who Are Severely Injured and Their Families

Homes for Our Troops (HFOT), a national nonprofit organization based in Taunton, Massachusetts provided Sgt. Eric Edmundson, Sgt. Peter Damon, and SPC Kyle Burleson with the keys to the American dream—a specially adapted home at no cost to these veterans who gave so much to our country. CPL Evan Morgan recently learned that Homes for Our Troops will be building a specially adapted home for him, his wife, and their new baby daughter—a home that addresses all the physical barriers he faces due to his life-altering injuries.

Homes for Our Troops has already completed 25 specially adapted home projects for servicemembers who are severely injured and their families since it was founded in 2004. They have a goal of building 100 more specially adapted homes over the next three years for veterans who are severely injured. With all items factored in, from the purchase of the land, to all the building materials and supplies needed inside and out, the average cost per home is over $250,000.

Homes for Our Troops has national corporate sponsors and also reaches out to the local community to support each project, as hundreds of professional home construction companies donate time, materials, and volunteers to build the homes. They also rely on the donation of funds and professional construction services to provide the homes free of charge to the veterans.

How Homes for Our Troops Began

As with any great organization, Homes for Our Troops began with a leader with vision who recognized a need and then did something to make it happen.

John Gonsalves was a construction supervisor and would listen to the nightly news reports about servicemembers returning home with severe brain injury or the loss of arms, legs, or vision. He wondered what would happen to these men and women who had sacrificed so much for our country. How would they get around in the comfort of their home with such severe injuries?

Gonsalves went on a mission to find out. He learned that most of the young men and women that volunteer are so young that they cannot afford to own their own home. So, most rent, or they live with their parents. He learned that their severe injuries did not allow them to move freely in their homes because houses and apartments are not barrier-free or easily adapted to take into consideration the types of disabilities incurred during combat.

With all the information he learned as he spoke to these veterans and visited hospitals like Walter Reed Army Medical Center, he was on a mission to found Homes for Our Troops.

Gonsalves is committed to running the nonprofit organization by maintaining the highest professional standards, and keeping it financially efficient and professionally staffed. His efforts were recently rewarded when the American Institute of Philanthropy (AIP) (http://www.charitywatch.org), one of the country’s premier charity watchdog organizations, reviewed Homes for Our Troops’ finances and included the organization in their Top-Rated Veterans & Military Charities listing.

Steps for a Homes for Our Troops Specially Adapted Home

The first step in the Homes for Our Troops building process is qualifying servicemembers who are severely injured for a specially adapted home. Interested family or servicemembers should go to the Homes for Our Troops Web site (www.homesforourtroops.org), choose About Us, and click on the Application for Vets channel to fill out the Request Application for Assistance page (http://www.homesforourtroops.org/site/Survey?SURVEY_ID=1661&ACTION_REQUURED=URI_ACTION_USER_REQUESTS).

Once the application has been approved, Homes for Our Troops works very closely with the selected servicemember to find out where the veteran

What is a Specially Adapted Home?

Many of the life-altering injuries sustained by our military men and women fighting in Iraq and Afghanistan include the loss of one or more limbs, varying levels of paralysis, and traumatic brain injury. Other veterans have returned with blindness, deafness, or with severe burns. These young men and women must now relearn skills often take for granted, like walking, getting dressed, eating, and talking. Many of the injured veterans need specially adapted homes that will allow them to regain their independence and help them and their families rebuild their lives.

Some of the basic requirements of a specially adapted home are:

- Ramps or lifts that are 5 feet by 5 feet, to allow for turning a wheelchair, and that also are equipped with protective railings
- Doorways that are 36 inches wide
- Americans With Disabilities Act (ADA)-compliant kitchen appliances such as roll-under cooktops
- Hallways that are 48 inches wide
- Garages or carports that allow unrestricted wheelchair maneuverability alongside a car and ease of entry and exit with all accessible vans
- Motion- or voice-activated doors, alarm systems, and other items that can be operated by those who have lost arms or who are blind
- Bathrooms with very generous floor areas, providing space for a wheelchair
- Hung washbasins that are affixed at a height to enable a wheelchair to maneuver below the fixture
- A mirror low enough for the person to easily see his or her face at wheelchair level
- Adequate grab bars, capable of bearing the person’s weight, installed for the tub and shower
- Large enough stall showers (5 feet by 5 feet) to allow for a built-in bench
- Hands-free fully automatic toilets
- Raised toilet with armrests to support body weight
- Wall switches and electrical outlets within reach from a wheelchair (minimum 18 inches and maximum 48 inches from the floor)
A Specially Adapted Home for SPC Kyle Burleson and His Family

Each home designed by Homes for Our Troops meets the individual veteran’s disabilities, so each adaptation differs, depending upon the veteran’s injury.

SPC Russell Kyle Burleson was shot by a sniper bullet that entered his cheek and exited the back of his neck, leaving him completely paralyzed from the neck down. In order to breathe, he has to rely on a respirator.

Kyle was just 22 years old, with a wife and two very young children, when he was injured. He had no home of his own, so he and his family all moved into his mother’s small home.

Homes for Our Troops and many volunteers built a specially adapted home for Kyle and his family to help improve his quality of life. The family now spends more time together, with greater independence, and less stress on family caregivers who provide 100 percent of his care around the clock. The donated home also removed the financial burden of having to worry about making a mortgage payment.

The adapted home designed for Kyle and his family in Springhill, Louisiana includes:

- An open floor plan that allows Kyle to be in every room with his family
- A lift system installed in the ceiling to allow his wife to easily move him from his bed to his wheelchair to the bedroom
- Doors that can be operated by Kyle blowing into a tube on his wheelchair, so that he can move freely in and out of his home without depending on others
- A backup generator so Kyle has the power needed to run medical equipment necessary to keep him alive
- State-of-the-art windows that resist severe impact from flying debris during tornadoes and hurricanes
- A concrete “safe room” for the family to use as a shelter if they cannot evacuate during a storm
- Multiple wheelchair exits so that Kyle and his family can get out in the event of a fire

The overall goal, working closely with the family, is to design a home to address the barriers faced by the veteran due to his or her injuries that is also appropriate for the size of the family. Each specially adapted home must be built for a reasonable cost, in line with industry norms, and be able to be built in a six-month time frame from groundbreaking.

Homes for Our Troops then reaches out to the community to identify home construction professionals who are willing to participate in building the home either at no cost or at a reduced cost. A general contractor is selected, and the process of identifying companies who will provide the labor and materials needed to complete the home gets under way.

A groundbreaking ceremony kicks off each project, involving and engaging the entire community, including the local media, politicians, the mayor, the governor of the state, and local military organizations.

After breaking ground, a three-day-long Build Brigade is scheduled. A Build Brigade is a construction blitz to get the house framed and to install the doors, windows, roof, and siding so that the home is tight to the weather. As the home construction nears completion, a Volunteer Day is planned to allow people in the community to help out by doing the landscaping and painting. The final ceremony is the long-awaited and anticipated presentation of the keys and the deed that is signed over to the veteran and his or her family.

According to Homes for Our Troops’ Gonsalves, “Our troops are bravely serving our country. It is heartwarming and emotional to see how communities throughout the United States come together to thank these veterans who are severely injured for the sacrifices they made by rolling up their shirtsleeves to volunteer in a variety of ways.” Most people want to thank our veterans for the commitment they have made to keep us safe, and Homes for Our Troops enables entire communities to contribute skills, services, and financial support.

If you are interested in volunteering your professional services, donating home construction materials, or if you want to hold a fundraiser to help Homes for Our Troops, visit www.homesforourtroops.org. Current projects are listed on the Homes page. The Get Involved channel provides information regarding how to hold an event to raise funds to help Homes for Our Troops build homes at no cost to the veterans.

Vicki Thomas is president of Thomas & Partners, a Weston, Connecticut-based public relations and marketing firm helping Homes for Our Troops get the word out about how the national nonprofit organization is helping rebuild the lives of veterans returning from Iraq and Afghanistan.
United States Military Section

Young Heroes:
Preparing Military Children for a Parent’s Deployment

By Ian Shaffer, MD

This is the first of a three-part series from Health Net, Inc. regarding deployment, its effects on children, and some of the steps that parents can take to ease its impact. The series will cover behaviors and suggested responses during the times of pre-deployment, active duty, and the parent’s return home.

“I’m scared that since he flies a Black Hawk, he may get crashed somewhere,” says a little girl about her dad, her dark eyes darting from side to side. Another child – a blond-haired boy – buries his face in his small hands. “I just want his entire body home.”

These campers attend Operation Purple® Summer Camp Program, a free program run by the National Military Family Association (NMFA) for children with deployed parents. Over 150,000 U.S. children have a parent serving in Iraq or Afghanistan. “The strain on children and parents who are dealing with deployments is tremendous,” says Shannon Hillier, manager of Child and Youth Services for the Government Services division of MHN, a subsidiary of Health Net, Inc., and a behavioral health company that supports servicemembers and their families.

Effectively preparing your child for deployment and providing extra support and attention if there are special needs can greatly reduce the toll on your child – and you. In this article, the first of a three-part series on parenting and deployment, learn how to break the difficult news about deployment to your child, and what you can do to make the transition easier.

Breaking the News
The following tips make it easier for a child to cope with news of an upcoming deployment. You know your child best; depending on your child’s special needs, tips for kids younger than your child may be more appropriate.

Preschoolers
- Tell your preschooler about an upcoming deployment one or two weeks in advance.
- Reassure your preschooler that the deploying parent is leaving due to the job – not because of anything the child has done. (Preschoolers are prone to egocentric thinking and often attribute what happens to themselves.)
- At this age, the concept of a long separation is easier to grasp when it’s explained in simple terms, such as, “Mommy won’t be home until after Christmas.” By giving a time frame, the child isn’t left guessing as to when one or both parents will return home.

Elementary School Children and Teens
- For kids ages six to eight, you will want to give up to three weeks notice about a deployment. For ages nine and above, more notice is helpful.
- Older kids may react to news of a parent’s deployment with a greater sense of fear and worry. They may use the Internet or other tools to communicate with their peers and find out information. Ask them about what they have heard or read and gently correct any misperceptions. Remind them that servicemembers are trained to do their jobs and take great measures to ensure safety.

What to Expect
You told your three-year-old about your spouse’s deployment two weeks ago. Since then, your child has been crying more than usual. Is this behavior normal?

Preschoolers
Confusion, surprise, sadness, and guilt are common reactions to learning about a parent’s deployment for this age group. Your child may become clingy and seek more attention (both positive and negative) from you and your spouse. Your preschooler may also engage in “magical thinking,” the idea that by praying or wishing hard enough, the child can make something happen. Watch for any indication that your child is trying extra hard to behave in hopes that you or your spouse won’t leave. Remember to reinforce that the child is not responsible for the parent leaving; it is because of the parent’s job.

Elementary School Children
Kids in this age group may feel sadness, loneliness, separation anxiety, and guilt (from feeling they caused their parent’s departure). Your child may also find it difficult to sleep, concentrate, or accept the reality of the situation. You may notice regressive behaviors (such as bedwetting, tantrums, etc.), and angry outbursts alternating with clinging, whining, and other behavior problems. Some kids may complain of stomach pains and headaches.

Teens
After learning of an upcoming deployment, teens may feel sad or angry. They may also have problems sleeping, miss curfew, curse, or avoid the deploying parent. Being peer-focused, teens may want to spend time with friends to dis-
Young Heroes

Avoid adult conversations about the war.

Be consistent about school and child-care pick-up and drop-off times, as well as the times the family spends together.

Be mindful of leaving the television on or having newspapers open to images that may increase your child's anxiety.

Be consistent about school and child-care providers to the situation and ask them to watch for any changes in behavior. Further, parents can let their children know when the deploying parent plans to be home, instead of guaranteeing a return. This allows the child to focus on the future.

The following tips may also help:

Preschoolers

- Encourage your child to ask questions, but give simple answers. For example, you can simply tell your child, “I will be home after your birthday,” or “I will be home after Christmas.” Children will ask questions they are ready to deal with. Avoid volunteering information or going into great detail. When responding to a question, tailor the answer to the child's age and developmental level.

- Be mindful of leaving the television on or having newspapers open to images that may increase your child's anxiety.

- Be consistent about school and child-care providers to the situation and ask them to watch for any changes in behavior. Further, parents can let their children know when the deploying parent plans to be home, instead of guaranteeing a return. This allows the child to focus on the future. The following tips may also help:

Helping Children Cope

There are several things parents can do for kids of all ages and abilities to prepare them for an impending deployment. For example, maintaining a routine is critical for kids during a period of flux—especially for those with special needs. Parents can also alert teachers and other care providers to the situation and ask them to watch for any changes in behavior. Further, parents can let their children know when the deploying parent plans to be home, instead of guaranteeing a return. This allows the child to focus on the future.

The following tips may also help:

Preschoolers

- Encourage your child to ask questions, but give simple answers. For example, you can simply tell your child, “I will be home after your birthday,” or “I will be home after Christmas.” Children will ask questions they are ready to deal with. Avoid volunteering information or going into great detail. When responding to a question, tailor the answer to the child's age and developmental level.

- Be mindful of leaving the television on or having newspapers open to images that may increase your child's anxiety.

- Be consistent about school and child-care pick-up and drop-off times, as well as the times the family spends together.

- Avoid adult conversations about the war and disagreement around your child, which can cause worry if overheard.

- Should you choose to bring your preschooler to the deployment site, you can contact your Family Readiness Group (www.army.mil/familyreadiness) beforehand to see if there will be any child activities there. If not, a grandparent or other family member may be available to keep your child company.

Elementary School Children and Teens

- Younger children and children with special needs may need more concrete ways to measure time and understand an anticipated return date. One way to do this is to create a paper chain, with each link representing a day, and have the child remove a link as time passes. Another way is to fill a jar with jellybeans (the jellybeans represent the number of days left until a parent is expected home).

- Monitor your child for excessive fascination with media coverage and overexposure to the war.

- Younger children learn and process experiences through play. You can avoid last-minute surprises near the time of deployment by showing your child via reenactment what will happen at the deployment site.

- If you decide to bring your elementary school-age child to the deployment site, bring things to keep the child occupied. Older children often do well at deployment send-offs.

- Help your child make a gift for the deploying parent, such as a painting. If your child is physically disabled, consider making an audio-tape or videotape greeting together.

- For older children, encourage volunteerism at soup kitchens, nursing homes, etc.

- Let teens know that they aren’t expected to fill the role of the deployed parent—to either in terms of running the household or supporting the at-home parent emotionally.

Being a military child isn’t easy, but preparation for an upcoming deployment can better help your child meet the challenges ahead. Next month, learn how to help your child cope after a parent leaves for active duty service.

Resources


Ian Shaffer, MD is a child psychiatrist and the chief medical officer at MHN, https://www.mhn.com/home.do the behavioral healthcare subsidiary of Health Net, Inc., https://www.healthnet.com//portal/member/home.do that serves the needs of 10 million members, including many military personnel and their families.

Depression

By Robert Cancro, MD

War is traumatic, not only in terms of physical injuries but psychological ones as well. The veterans presently returning from Iraq and Afghanistan have experienced hand-to-hand combat, blast injuries, traumatic brain injury, etc. In addition, they have experienced severe stress, loss of comrades, family separation and breakup, loneliness, etc. It is not a surprise that we face a near epidemic of depressive disorders with our returning troops. Hopefully, a better understanding on our part can be of help in their recovery. We owe them no less!

Depression – An Under-Recognized Health Crisis

Mental illnesses are an under-recognized public health crisis. They are the last of the medical illnesses, hidden because of the unrelenting stigma associated with them. People frequently are ashamed to admit the presence of a mental illness and tend to deny its existence in themselves and/or their family members. This is particularly unfortunate because of the tendency of mental illnesses to run in families. This tendency is most true for the more severe forms of mental illness, which have a significant genetic component.

Depression and Genetics

Concerning the genetic component, it is important to realize that it is frequently misunderstood that genes have an inevitable outcome in an almost Calvinistic sense. People believe that if you have the gene you must have the consequence of that gene. Though this is usually true for simple traits such as hair color, it is not true for complex traits such as mental illnesses. The genes represent a potential or a tendency. They are necessary but not sufficient to produce an illness in most cases. A common example is Type II diabetes. If the individual gains weight, they may develop the illness, but if they remain slender, they may well go through life without ever knowing that they have the tendency.

The cumulative and acute stressors of living act as the precipitating events for most mental disorders. Obviously, there are certain periods of life in which the individual is at increased vulnerability. Yet, it must be emphasized that having the potential is not the same as becoming sick.

This article will focus on the mental illness of depression. Depression is a genetically loaded disorder that runs in families but does not necessarily affect every member. Again, while genes play a role in predisposing an individual to depression, they do not preclude either successful treatment or avoidance of illness.

Symptoms and Associations

Depression is a disease that must be distinguished from unhappiness or an appropriate response to a loss or injury. Sadness in the face of unhappy events is not an illness. Depression, furthermore, is not just a disease of mood. It is characterized by a loss of energy, by fatigue, social withdrawal, confusion, cognitive dulling, a loss of ability to enjoy the activities that normally please the individual, and changes in sleep, libido, and appetite. Much more than mood is involved.

Depression is the leading cause of disability/sick days in the United States workforce and soon will be the second leading cause in the world. About half of the individuals who are challenged with depression have a recurrent form of the illness. While depression is more frequent in women, it is an equal opportunity disease, striking all socioeconomic classes, races, and age groups. It appears to be on the increase in frequency, but this may reflect greater public awareness of depression as an illness and not just as a condition of life that must be borne. Furthermore, family doctors and pediatricians are more alert to depression than they were in the past, so we cannot say if it is more frequent or simply better recognized. On the other hand, the stresses of contemporary life are such that it would not be a surprise if depression were actually on the increase.

Depression, unfortunately, is frequently associated with suicide. Suicide is on the increase in the United States, and this supports the hypothesis that depressive illnesses are on the increase. Presently, suicide is the eighth-leading cause of death in the United States and is the second leading cause of death in the college-age population.

The criterion of an official psychiatric diagnosis is a major
depressive episode. The diagnosis requires that several symptoms must be present during the same two-week period and represent a change from a previous level of functioning. Depressed mood, most of the day and practically every day, is the leading subjective criterion. But the official diagnostic system recognizes that loss of interest or loss of pleasure in activities that are normally pleasurable to the individual is an extremely important criterion as well. Classical depressions are associated with weight loss and loss of appetite. We do, nevertheless, see certain depressions that are associated with increased appetite and weight gain. Insomnia, particularly waking up early in the morning, is the classical finding in depression, but again, there are cases where the person overeats and/or oversleeps. Fatigue or loss of energy is an extremely important finding. Impaired ability to think clearly, to concentrate, and to make decisions are very important diagnostic findings in this syndrome.

As stated before, there are certain periods in life when individuals are more vulnerable to depression. Following the birth of a child, it is not uncommon to see a mother experience severe depression within several weeks after delivery. These depressive conditions are frequently mixed and have features of suspiciousness or even frank paranoia. The impact of depression is not only on the patient and the economy, but has a strong effect on the family of the patient. It can be extremely difficult to live with a person who is depressed and even more so when the condition is recurrent.

**Correct Diagnosis**

An important issue in diagnosis is to make sure the individual is free of medical problems. For example, hypothyroidism can mimic many features of depression and is sometimes treated incorrectly as a depressive episode when, in fact, it represents a deficiency of thyroid hormone. It is essential, therefore, that any person who presents with a depressive episode be worked up medically to make sure that they do not have a medical condition that mimics depression.

The important message is that depression can be treated successfully but must be diagnosed correctly. For example, depression associated with manic-depressive illness must be treated differently than recurrent depression, which is not associated with manic or hypomanic mood swings. The vast majority of patients can be treated successfully with a mixture of medication and psychotherapy.

**Variants of Depression**

An interesting variant of depression is called seasonal affective disorder (SAD). It is a depression that occurs when the days get shorter. The relative absence of sunlight is associated with a depressive illness. Such people respond to a change in location to a sunny climate or to exposure to lamps that simulate the spectrum of daylight. It is also interesting to note that the prevalence of depression increases as a function of distance from the equator. The further you are from the equator the more one sees depressive illnesses.

Another important category of depression is what used to be called masked depression. These are conditions in which the abnormal mood is not the major symptom, but rather the loss of energy, interest, ability to enjoy, etc. are the predominant features. These cases can be misdiagnosed because the absence of a depressed mood can confuse the clinician.

**Depression's Effect on the Body**

Depressive illnesses are frequently associated with other general medical conditions. Patients who have had a heart attack and who become depressed have a much worse prognosis than patients who do not become depressed. This appears to be true in a number of medical disorders. It is not clear why the depressive component adds to the morbidity of the underlying medical illness. It is certainly possible that the stress hormones that are released during a depressive episode have a negative effect on the healing process and impair resistance to infectious disease as well. It is important to understand that depression is a killer not only in the sense of suicide but in the sense of the damage that it does to the nervous system because of the body’s chronic stress response.

**Treatment**

Today, most depressive episodes are treated with antidepressive drugs. The vast majority of patients will respond adequately, but frequently, it is necessary to have them take two or more medications before a good recovery can be obtained. Electroconvulsive therapy remains the most effective and most rapid means of treatment, but it carries a serious stigma. For this reason, it is not used frequently and is restricted to those cases that are otherwise untreatable.

The emphasis on medication has caused many clinicians to deemphasize the importance of psychosocial treatment. Yet the optimum treatment for these conditions remains a mixture of medication and psychosocial treatment. Some psychosocial treatments, such as cognitive therapy, are more effective.

Nevertheless, it is important, if we are going to prevent recurrences, for the person to do a survey of his or her life and to try to make corrections where needed. People who are predisposed to depression frequently are very demanding of themselves. They often do not have a good balance in their life. They tend to do too much for other people and do not have an adequate support system for themselves. An analogy is a checking account where too many checks are being written but not enough deposits are being made.

Everyone requires emotional support. Everyone needs to feel necessary and useful. Being needed is valuable, but being valued is of even greater importance. Put most simply, we need to be loved, and that is an excellent prophylactic for preventing future depressive episodes.

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Dr. Robert Cancro, MD, Med.D.Sc., is retired Chairman of the Department of Psychiatry at the New York University (NYU) School of Medicine where he had served since 1976, and is also retired Director of the Nathan Kline Institute for Psychiatric Research (NKI). He continues as a Professor of Psychiatry at NYU. Dr. Cancro’s major academic interest has been in the area of psychoses during his extensive career.
It is not something normally associated with the sprawling campus at the United States Military Academy at West Point, with its towering buildings and thousands of cadets running from class to sports activities to training. However, there in the midst of the military academy, a community which is dedicated to turning young men and women into leaders and Soldiers whose primary mission is the defense of the nation, exists a place to take care of the military population that needs and deserves it the most—Soldiers who are injured or ill and the families who stand by them.

The Soldier and Family Assistance Center (SFAC) at West Point has a valuable mission—serving wounded and ill Soldiers, Department of Defense Civilians, and their families as well as any of their surviving family members. Since January 2008, the SFAC at West Point, New York has been at full operating capability, servicing Soldiers and their families across a 10-state area in the Northeast. The staff includes a guidance counselor, a social services coordinator, a transition and employment counselor, an outreach coordinator, a military personnel benefits counselor, a Department of Veterans Affairs (VA) representative, and an information and referral specialist.

An Overburdened Medical System

In World War II, 30 percent of servicemen wounded in action died; in Vietnam, 24 percent of wounded Soldiers died. Yet, today, a whopping 90 percent of servicemen who are injured in combat survive. In addition to utilizing advances in medical technology, the United States Army has done other things that have caused the survival rate to increase. Every squad now has at least one Combat Lifesaver (CLS), a non-medical Soldier trained to provide immediate emergency care and medical treatment during evacuation to healthcare facilities. This includes treating and stabilizing blast injury, amputation, severe bleeding, and penetrating chest injuries as well as airway management interventions and using appropriate evacuation techniques.

Another cause of the improved survival rate is the increased speed at which a Soldier can be returned stateside – now down to four days from the time of injury. During the Vietnam War, transit time back to the United States was upwards of 45 days. Many wounded Soldiers recall their first memory after being injured and losing consciousness was waking up at Walter Reed Army Medical Center, Brooke Army Medical Center (BAMC) or another major Army hospital in the United States.

Today’s amazing survival rate is testament to Army medicine and training. At the same time, it has overtaxed a military medical system that was ill-prepared for these wonderful results. For those Soldiers who do survive, the...
types of problems they and their families will face are often lifetime challenges that are a byproduct of their injuries—conditions such as blindness, amputations, critical burns, mild to severe traumatic brain injury (TBI), and post-traumatic stress disorder (PTSD).

Until recently, the Army had relied on a physical disability evaluation system that had not changed since 1947. The administrative process by which wounded Soldiers were treated when they returned from combat was antiquated. Due to the increased survival rate, this inadequate system was overburdened.

Walter Reed Army Medical Center

On February 18, 2007, The Washington Post exposed the deteriorating conditions at Walter Reed Army Medical Center. Walter Reed was commonly thought to be America’s premier military medical center. The Washington Post story, however, revealed conditions that included the growth of mold on lodging walls, rodent infestations, and unqualified, overworked platoon sergeants and case managers attempting to tackle the growing issues facing our nation’s war-wounded Soldiers. While the Army had been very good at medical treatment and care, the social services offered to Soldiers and their families were inadequate. When The Washington Post exposé was published, the poor treatment of wounded Soldiers and their families instantly became known nationally at the highest levels. To be fair, WRAMC was one of the facilities identified by the BRAC Commission to be closed and consolidated with Bethesda Hospital. So, while physical facilities were deteriorating, it is difficult to maintain any facility when funding is curtailed, as was the case at Walter Reed.

However, within days, White House and congressional leaders visited the infamous Building 18, the deteriorating former hotel that had been converted into a long-term outpatient dormitory, and realized that Building 18 was only the tip of the iceberg. It quickly became obvious that there were many problems in the way the Army cared for its war-wounded and changes needed to be made.

During a tour of Walter Reed shortly after The Washington Post story broke, President Bush said, “The problems at Walter Reed were caused by bureaucratic and administrative failures,” and later proclaimed, “We’re going to fix this problem.” Those six words spoken by the Commander in Chief caused three Major Army Commands—the Installation Management Command (IMCOM), the Medical Command (MEDCOM), and the Human Resources Command (HRC)—to begin spending in excess of a billion dollars to directly improve the treatment of wounded Soldiers and their families.

Hotline

One of the earliest initiatives the Army began was the Wounded Soldier and Family Hotline (1-800-984-8523), under the direction of the Human Resources Command. Military leaders, including the Department of Defense Secretary, the Chief of Staff of the Army, and even President Bush, collectively called for the establishment of a toll-free hotline for wounded Soldiers and their families to call with issues they experienced, ranging from poor medical care to unresolved legal issues to ignored personnel issues. The hotline began taking calls on March 19, 2007. It offered wounded and injured Soldiers and family members a way to seek assistance with their issues, and also provided a conduit for senior Army leadership to learn of Soldier issues in order to improve how the Army serves the needs of wounded, injured, and ill Soldiers and their families.

I was there when the Wounded Soldier and Family Hotline was first established. When the problems at Walter Reed became public, I voluntarily mobilized to active duty in order to work at the Hotline. I felt a calling to assist wounded Soldiers and their families.

The Hotline did a lot in those early days. Calls came in from around the world 24 hours a day. I was the Chief of the Active Component Cell, directing the team that handled every call that came in with issues related to an active duty Soldier or their family member. From the time a call was received, we had 24 hours to task the Major Army Command responsible for resolving the problem. The Major Army Command was given 72 hours to correct the issue and report their action back to the hotline. We closely monitored issue resolution and provided daily briefings to senior Army leaders.
including the Chief of Staff of the Army, on the issues plaguing wounded Soldiers and their families. If any major Army Command took more than 72 hours to resolve an issue for a wounded Soldier or their family member, that was also briefed daily to the Chief of Staff of the Army.

The hotline provided a solution by allowing senior Army leaders to see the types of issues that were affecting wounded Soldiers and their families, and it allowed Soldiers and their families an outlet to express their discontent and achieve prompt resolution for their issues.

**The Army Medical Action Plan**

However, the hotline was only a quick fix. It was a Band-Aid on the systemic problems that overwhelmed the Army’s medical and social support services for wounded Soldiers and their families. Senior Army leadership realized this almost immediately, and the Army Medical Action Plan (AMAP) was born, in April 2007. The AMAP was the Department of the Army’s comprehensive plan to fix the problems exposed during the Walter Reed scandal.

The AMAP tasked the Army’s Medical Command with forming Warrior Transition Units (WTUs), to which Soldiers were assigned. Knowing that Soldiers work optimally when they have a clear mission, the Army told Soldiers assigned to the WTUs that they had one mission – to heal and return to duty in a regular Army unit or to heal and continue serving the nation as a veteran in their community.

WTUs were staffed with specially trained staff. The ratio of nurse case managers, primary care physicians, and squad leaders to Soldiers within the WTUs was monitored closely by the Department of the Army Headquarters to ensure this special population of Soldiers would get the treatment and care they deserved and desperately needed.

The Installation Management Command was also tasked by the AMAP. Its role was to ensure that areas other than medical care were taken care of, for both Soldiers and their families. The Army might recruit Soldiers, but it retains families. Secretary of the Army Mr. Pete Geren has said “the health of the all-volunteer force depends on the health of the Army Family.” Nearly 46 percent of the graduates from the West Point class of 2001 left the military after their mandatory five years of service – the highest voluntary exodus since 1977. Topping the list of reasons for their departure from service are quality of life and family concerns. The bottom line is: Soldiers care about their families, and they want the Army to care about them, too.

**Soldier and Family Assistance Centers (SFACs)**

This is why Soldier and Family Assistance Centers were created.

If a wounded Soldier is worried about his family, he is not going to be able to focus on his primary mission – to heal. Wounded Soldiers need to know their families have been cared for, have adequate housing and are not sleeping in a hospital lobby, are not suffering financially, have counseling services available to them, and that childcare and respite services have been offered. The number and severity of issues requiring external assistance that wounded Soldiers and their families have increases as the severity of a Soldier’s injuries increases. It benefits the Soldier to have the Army properly care for his or her family—so both can heal.

When a Soldier is injured or becomes ill, mothers, fathers, spouses, children, and significant others are also affected. The likelihood that those family members will develop other issues increases exponentially. Instances of financial problems, legal concerns, housing issues, childcare troubles, or employment fears increase when a Soldier is wounded. A military family member's life is often difficult, but when that service member is injured, it becomes even more challenging. Families of wounded Soldiers have had their lives ripped apart in a matter of moments. They need to know that someone is going to be there to help them piece their lives back together.

What began as a centrally managed 1-800 hotline number at Headquarters Department of the Army where Soldiers and their families could call for assistance evolved into the SFAC: 29 facilities, under

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**Army Family Covenant**

We recognize the commitment and increasing sacrifices that our Families are making every day.

We recognize the strength of our Soldiers comes from the strength of their Families.

We are committed to providing Soldiers and Families a Quality of Life that is commensurate with their service.

We are committed to providing our Families a strong, supportive environment where they can thrive.

We are committed to building a partnership with Army Families that enhances their strength and resilience.

We are committed to improving Family readiness by:

- Standardizing and funding existing Family programs and services
- Increasing accessibility and quality of health care
- Improving Soldier and Family housing
- Ensuring excellence in schools, youth services, and child care
- Expanding education and employment opportunities for Family members
management of IMCOM, spread across the globe on individual Army installations. These SFACs are safe havens, mandated to be set up as a home away from home for war-weary Soldiers and their families to access the support services they need to make life decisions. The SFAC is a place where a spouse can relax in front of a TV or with a book, while his or her Soldier receives necessary medical treatment, or where children can play while a family member receives financial counseling or legal advice.

Wounded Soldiers have wounded families. The nature of what they, as a family, have collectively endured increases the number of other problems that they might have. Recent research shows that, after returning from deployment, the number of Soldiers with alcohol problems rose from 13 percent to 21 percent, the number of Soldiers with aggression issues rose from 11 percent to 22 percent, and the number of Soldiers planning to divorce their spouse rose from 9 percent to 15 percent. Compounding these issues, the trials a family experiences during a Soldier’s recovery from injuries often only increase these percentages. The SFAC can help. Services provided by the SFAC include benefits and entitlements, counseling, education services, employment assistance, military personnel services, substance abuse information and referral, legal services, pastoral services, financial counseling, and family advocacy services.

The SFAC is a one-stop shop for Soldiers. It is designed to eliminate the Army bureaucracy Soldiers once had to navigate on their own. Service providers bring their services to the Soldier. SFAC staff advocate on behalf of Soldiers and their families. A Soldier or his or her family do not have to look through the phone book or drive around the installation to find a guidance counselor or to file an insurance claim. Those and other social service providers are required to bring their services to the SFAC – a comfortable centralized location built just to service this unique population. Wounded Soldiers and their family members deserve service that is not only centralized, but is tailored to their unique circumstances.

Additionally, “priority service” is synonymous with the SFAC. On West Point, when a Soldier or family member brings an issue to the SFAC, a referral is made within one business day to the agency responsible for resolving the issue. Within 24 hours, an appointment must be made with the Soldier or family member and the agency must have initiated action. These Soldiers no longer have to wait in reception lines at medical centers or remain on hold for assistance with personnel actions, waiting for a bureaucratic process to help. The SFAC facilitates quick resolution for the Soldier and his or her family.

Building SFACs in the Army is a fundamental change in the way the Army responds to wounded Soldiers and their families, and one long overdue. It is an institutional change that enables a unique culture centered on healing and on supporting the families of the Soldiers who are healing. According to Brigadier General Michael S. Tucker, Director of the AMAP, “We have transformed the way we care for warriors in our Army, and we will never go back to the way it was.”

**Army Family Covenant**

As an additional measure to show Army families that they are part of an organization that recognizes their sacrifices and is dedicated to supporting them, the Army unveiled the Army Family Covenant at the Association of the United States Army (AUSA) convention by Secretary of the Army, Mr. Pete Geren, and Chief of Staff of the Army, General George Casey. The covenant is a contract signed by senior Army leaders, installation and garrison commanders, and Command Sergeants Majors across the Army, at over 80 Army installations. During the introduction, Mr. Geren said the Army is “taxing our Soldiers and Families at unprecedented levels.” He went on to say they deserve a “quality of life equal to their quality of service.”

The Army Family Covenant comes to life in the form of the Army Soldier Family Action Plan (ASFAP), a document that acts as a road map to the Army Family Covenant. The Soldier Family Action Plan outlines 112 tasks, with accompanying actions and milestones, that the Army will complete in support of Soldiers and their families. The Soldier Family Action Plan is the tool that makes the covenant a reality.

The Soldier Family Action Plan also recognizes the importance of support from local community partnerships. Another document, known as the Army Community Covenant, is tailored at the local level and “is designed to develop and foster effective state and community partnerships with the Army in improving the quality of life for Soldiers and their Families.” The Army recognizes that collaboration and cooperation with local communities multiplies the support network available to Soldiers and their families. Army Community Covenant signings are happening across the Army between April and December 2008, with leaders at both the state and local levels participating. West Point leaders and New York State elected officials signed the first Army Community Covenant on April 11, 2008. In the West Point SFAC, a full-time Outreach Coordinator works to optimize covenant relationships for the benefit of Soldiers and their families.

Soldier and Family Assistance Centers are dedicated to supporting both Soldiers who have served their country and their families. Wounded Soldiers are not victims. Each of these wounded Soldiers has an Army-approved mission—to heal. Now, the Army has given them and their families the tools they need to succeed at their mission. The SFAC and the Army Family Covenant are resources to facilitate mission success.

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April D. Moncrief is the Director of the SFAC at West Point and a Captain in the Army Reserves, assigned to the Department of the Army Casualty and Mortuary Affairs Operations Branch (CMAOC). After graduating from West Point in 2001, she spent five years on active duty in the Army, in Germany and Belgium. She has a Master’s degree in Public Administration from Marist College and a graduate certificate from Rutgers University.
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Staying Strong

Coping With Deployment

By Ian Shaffer, MD

This is the second of a three-part series from Health Net, Inc. regarding deployment, its effects on children, and some of the steps that parents can take to ease its impact. The series covers possible behaviors and suggested responses during the times of pre-deployment, active duty, and the parent’s return home.

Seeing his clothes in the closet, setting the table for two instead of three, waking up alone—the day after deployment, families are left to deal with their feelings of grief and fear as they attempt to establish a “new normal.” During this time of transition, children—especially those with special needs—require extra support.

Take eight-year-old Neil (whose name has been changed for privacy reasons), for example, who has attention deficit hyperactivity disorder (ADHD). After his father was deployed to Iraq for a second time, Neil’s behavior changed. He became increasingly hyperactive, got into trouble regularly in school, did poorly in his classes, and battled with his mother over bedtime. Concerned and overwhelmed, Neil’s mother took him to see Holly, a social worker.

During therapy, Neil mentioned that his dad was lucky to return home after the first deployment but might not be so lucky twice. Realizing that Neil was suffering from anxiety, Holly devised several ways that Neil’s mother and his teacher could help him cope. They put Holly’s ideas into place. For example, Neil’s teacher divided his schoolwork into smaller, more manageable steps. To shift the focus away from Neil’s negative behavior, his mother and other military families pooled their money to buy school supplies and other gifts for Iraqi children and their families. And, to strengthen the bond between father and son, Neil and his mother drew pictures for their Soldier and his whole military unit. Holly also helped Neil’s mother find support from various resources, such as Army Community Service (ACS) and Military OneSource, to prevent burnout.

General Guidelines for Unique Children

Although reactions, needs, and level of understanding about deployment vary by child, consider the following general guidelines for children with special needs:

- Symptoms or reactions may increase in intensity or be a sign of a separate condition. In Neil’s case, his hyperactivity was exacerbated by anxiety.
- Prolonged changes in appetite, grooming, hygiene, sleeping patterns, and mood may indicate that the child needs help coping. If these problems persist longer than three to six weeks, or four to six weeks for older children, consult the child’s behavioral healthcare provider.

- Extra support may be needed with schoolwork, which can be addressed in an Individualized Education Program (IEP). For example, consider asking the teacher for extra tutoring, additional time to complete assignments, or modified assignments.
- Consider the child’s age and developmental level when responding to a question about deployment. Specifically, answer the question that is being asked—if your child wants more information, he or she will ask for it. Reassure your child that the deployed parent is trained to do the job and is taking great measures to ensure safety.

- And remember to take care of yourself, so that you are better able to take care of your child with special needs. Build a support network (and use it); try not to overextend; exercise; and hire a babysitter once in a while.

Tips for Specific Conditions

Autism

If your child has autism, you may notice increased difficulty with social interaction. For example, younger children may throw more tantrums than usual or be more resistant to leaving the at-home parent. The child may regress in language or have repetitive behavior such as counting (typically seen in children 10 and older) or rocking (seen in younger children).

You can help your child cope with the parent’s deployment by maintaining routines. Also, since children with autism respond better to creative outlets when it comes to expressing themselves, you can encourage your child to engage in activities such as singing and dancing.

Mental Retardation

During a parent’s absence, a child with mental retardation may throw more tantrums and regress in reading, writing, and completing tasks that previously were done with no trouble. Since your child may have a limited understanding of deployment, let your child know that the other parent is doing an important job away from home and is doing his or her best to be safe. Reassure your child that the deployed parent loves him or her. To reinforce the bond with the deployed parent, you can draw pictures or write letters with your child and mail them together.

Physical Disabilities

During a parent’s deployment, a child who has physical disabilities may complain of physical discomfort, such as abdominal, muscle, or joint pain. The child may also experience low self-esteem, a loss of interest in hobbies and friends, and changes in sleep and appetite.

To assist your child with self-esteem, give praise when appropriate and spend time together, one-on-one. If
your child is having trouble sleeping, keep the same bedtime, but begin a calming activity 60 to 90 minutes before bedtime, such as coloring or reading. If your child has lost interest in a hobby, try doing the activity together or helping the child find a new hobby.

**Attention Deficit Hyperactivity Disorder**

During deployment, children diagnosed with ADHD may grow increasingly hyperactive, impulsive, and aggressive. If symptoms worsen, talk to the child's behavioral healthcare provider. He or she may recommend therapy or reassess the need to initiate medication, change the dosage, or switch medication. Also, for children with ADHD, a physical outlet, such as hiking or swimming, can work wonders to reduce stress and anxiety.

**As They Grow**

As you've probably observed, the ways in which children react to life challenges change as they mature. The following tips are categorized in terms of age, but keep your child's developmental age in mind as you consider them.

**Preschoolers**

During the absence of a deployed parent, a preschooler may have the following reactions: confusion, clinginess, aggression, attention-getting behavior, regression (e.g., bedwetting or asking for a bottle), acting out scary events, difficulty sleeping, or uncontrollable crying. These behaviors are manifestations of insecurity, and the child needs to be made to feel safe and taken care of. As much as possible, try to maintain the same routine the child had before the parent deployed.

**Elementary School Children**

Rapid mood swings, anger directed at both parents, poor concentration, and withdrawing from friends and family are all common reactions to a parent's deployment at this age. Similar to younger children, kids of elementary school age need routine and reassurance that the remaining parent will care for them. They may also benefit from having a trusted adult around (aside from the at-home parent) who can answer their many questions and concerns. Also, providing small, structured tasks that children can be successful at (such as taking out the trash or helping with the dishes) can help them feel good about themselves and their ability to cope during this time.

**Teens**

Teens who are coping with a parent's absence may experience sadness, anxiety, or significant changes in weight. They may also misdirect their anger (such as lashing out at the at-home parent), engage in high-risk behaviors, withdraw from friends and family, or struggle in their classes.

When a parent deploys, let your teen spend time with friends and also give your teen plenty of individual attention. It can be helpful to encourage conversations around deployment as well (e.g., “I know this is a tough time for you, and I'm here for you.”). If your teen is reluctant to share his or her feelings, suggest the teen write down personal thoughts and feelings in a journal. And if you're concerned about your teen's behavior, let your teen know that you understand his or her feelings, but he or she needs to find another way to cope—and you're available to help. For instance, if your teen's grades are plummeting, you can talk to a teacher or school counselor together.

**When to Ask for More Help**

If you have any concerns, or if any of the common reactions above continue after three to four weeks for children under age 10, or for four to six weeks for older children, consult the child's behavioral healthcare provider. If you notice any of the following signs, get help right away:

- Unfocused agitation
- Serious depression/withdrawal
- Auditory or visual hallucinations
- Being at risk for hurting others or intentionally hurting oneself
- Increased suspiciousness and behaviors based on those suspicions

Deployment is a challenging time for exceptional families. That being said, a child may become more independent, confident, and resilient during the absence. A child's relationship with both the deployed parent and the at-home parent can grow stronger as well. But during this transitional time, it’s perfectly okay to ask for help—just like Neil’s mother did.

**Online Resources for Caregivers**

The MilitaryHOMEFRONT Web site (www.militaryhomefront.dod.mil) provides a variety of free services, such as information and referrals regarding special needs and deployment to assist service members and their families (www.militaryinstallations.dod.mil/ismart/MHF-MIL). Click on “Exceptional Family Member Program/Special Needs” under “Program or Service”.

Military HOMEFRONT’s EFMP/Special Needs module can help military families find medical and special education services, community support, and more (www.militaryhomefront.dod.mil/efm).

The Specialized Training of Military Parents (STOMP) Web site (www.stomp-project.org) offers support and advice to military parents who have children with special needs, plus an electronic listserv so that parents and professionals can connect as they raise and help children with special needs.


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She laughs often and richly, speaks her mind without hesitation, warmly praises others, speaks with pride of family, and treasures her friendships. Deanna VanHook is not an individual going through life without purpose nor is she a “disabled” person eking out a life only just as fulfilling as she can muster. She is a vital force, with close family and friends. One gets the feeling that while Deanna fully engages in life, life itself also rushes to Deanna. 

Joie de vivre – *Joy of living.* This is the sense conveyed by Deanna. You know that she will leave no stone unturned in her quest to fulfill her capabilities in every second of time, each day.

In one of many travel adventures they have shared, Deanna, 42, and her husband, Lieutenant Commander (Commander Select) R. Thomas “Tom” VanHook, 39, a physician in the United States Navy, hiked through the Grand Canyon in December 2007–January 2008. (See photo on page 70.) That Deanna has paraplegia was no obstacle. Desire and drive have propelled Deanna plenty of places in her life, and new, “life-changing” assistive equipment has expanded her options for mobility.

**When Life Changes**

During spring break of Deanna’s senior year of high school in 1984, she traveled with her boyfriend, Neal, and his dad and two brothers on a skiing trip to Colorado. On their way back home to Dallas, they stopped to visit Neal’s grandmother in Elk City, Oklahoma. They had been on the highway again for about 45 minutes when a gasoline tanker truck hit their Chevy Suburban. Neal, 18, his Dad, Tom, and his brother Kevin, 17, were all killed instantly. Deanna, 18, and Neal’s youngest brother, Steve,
“Deanna and I worked together for one week in Orlando—so seamlessly that I knew that I’d marry her and told everyone so. Her disability never mattered to me, because it never mattered to her. If you speak to her for more than a few seconds on the subject, it’s very clear she sees her disability as an inconvenience rather than an obstacle. I’ve felt the same way since the moment I first met her.” —Tom VanHook, writing about his wife, Deanna

12, were the only survivors. (The boys had lost their mother to cancer in December.)

“We are still close to this day,” Deanna says of Steve and herself. “I’m really proud of how he’s managed to turn his life around from that tragedy at 12 years old and become the man that he is today.”

As for Deanna herself, “I was grieving so much that by the time I got more with the picture, I had already been in a wheelchair, and I was making it work. By then, I was in the rehab hospital. I don’t think from that point forward I’ve ever let anything stop me.”

Deanna attended the prom with the couple that she and Neal had already planned to join for the event. The straight-A-plus student also attended her graduation. “I was bound and determined. I figured, well, there’s no reason this should stop me. Let’s just go.”

That attitude permeates Deanna’s decisions and actions.

That fall, Deanna entered the University of Texas at Arlington, where she earned a bachelor’s degree in business administration, with a concentration in management. Then, her career took flight.

Flying High

“I had always loved travel, and I knew when I started thinking about it in my senior year of college—Where do I want to go from here? What do I want to do?—I really wanted to go to work with an airline. So, I chose American [Airlines]. I loved it. I had a great time. I met a lot of wonderful people.”

Starting in a typical entry-level job on the phones in the sales office, Deanna worked her way up, eventually moving into a position where she was flying six days a week, working with a task force with the Department of Transportation that was teaching disability awareness.

In their off hours, she and her friends “took airplanes like taxis. There would be a whole group of us. We all worked for the airlines, and we all had flight benefits. We’d find an off time to fly, and we’d say (something like), who wants to go have dinner in New Orleans?” When there were any accessibility challenges (this was prior to passage of the Americans with Disabilities Act (ADA), “we just kind of figured out what was going on, and we’d just make it work. If we can’t do it by Plan A, let’s find Plan B. Now, if it’s just something that’s absolutely ludicrous, then I will probably also use it as some sort of a teaching experience to help educate—but not to the detriment of my fun.”

“He Is a Wonderful Prince”

Deanna won the 1991-92 Ms. Wheelchair America competition (http://www.mswheelchair-america.org/). “I can thank my coworkers at American Airlines for that,” she says, laughing. Her friends put all the wheels in motion before telling her about it. At the time, Texas did not have a state program, and somebody could be appointed to represent the state in the national competition. (Ms. Wheelchair America is a competition reflecting women’s abilities and accomplishments.) “It did sound like something exciting and something neat, so I said, okay, yes, I will do this.”

The plan had been to lay the groundwork to establish a state program for the future, for opportunities for women with disabilities. “We never really looked past that to, what happens if you win at nationals?”

“We went down there, and I had an absolute blast. I was introduced to Tom. They had gone over to the Navy base and had put up a sign about the national program, and it said that they needed escorts for the women.” While initially finding Tom somewhat too self-assured, by the second evening, Deanna felt differently. “Then he called his parents on Sunday night and said
that he had met the woman he was going to marry. He told me, and it kind of scared me, because I had feelings for him, but I wasn’t quite sure I was going to marry him. He knew.”

Separated geographically, Deanna was able to use her airline benefits to visit Tom in Orlando, then in Idaho Falls, Idaho, when he was stationed there next with the Navy. As Deanna fulfilled her commitments as Ms. Wheelchair America, Tom “continued that next year to be my escort at the speaking engagements, things that I needed an escort for. He was a real sweetheart—he would fly in and escort me to anything that I needed. So, I thought, wow, this is a special guy if he’ll take time off from his schedule and come in and do this stuff for me. … And he’s always been that way.” Nine months after meeting, Deanna and Tom married in May 1992. The wedding, Deanna says, “was beautiful, it was wonderful, it just continued the fairytale.” When Deanna first mentions Tom, she says, “He is a wonderful prince. When we met, it was obviously just meant to be.” The two enjoyed extensive travel and time together before having their children, Robert, in 2000, and Laura, in 2003.

**Deployment**

Tom VanHook deployed to southern Helmand Province, Afghanistan, in mid-March. He will be deployed for nine to 16 months. “I’d much rather him be here all the time,” says Deanna, “but he loves his job, and he loves doing what he is doing, so I support him in that. He has always said that the men and women that are over there and fighting deserve the best medical attention they can get, and it’s his pleasure to go take care of them.”

When Tom is asked via email what challenges he feels in being away from his family while he is deployed,
and what challenges he feels in being deployed in light of the special needs that his family members have, he writes from Afghanistan: The actual time away seems much harder on my family than on me, because there’s so little I can do to help them. Personally, I’m faced with two choices: trust Deanna or go nuts. Since this is our fourth deployment, I trust her to handle things. On the other hand, the period leading up to the deployment is heart-wrenching for all—particularly because of her disability. During that time, my family wants me to slow down and spend quality time with them, but I’m frantic with the worries of a deploying spouse (Does she know how to turn off the gas? Reset a circuit breaker?), and doubly frantic because of the disability (Can she reach the gas shutoff valve? Reach the breaker box? Get to our daughter if she has a crisis?).

The Children

Deanna and Tom’s son, Robert, 7, has “severe ADHD” (attention deficit hyperactivity disorder). While Deanna “fought for years not to medicate him,” she was told one day by a psychiatrist and therapist, “He really is a prime candidate for medication.” So, they tried medication trials—Concerta®, Strattera®, Focalin®, Adderall XR®. It was the immediate-release form of Adderall® that finally worked, without difficult side effects.

“He’s so happy. He’s a completely different child. He likes the way he feels. He says, ‘Mommy, I can concentrate. I can do.’” They had tried “therapy, behavior modification, even the behavior contracts and stuff at school. We tried everything. He would try. He would try so hard. But he just couldn’t do it. And it was frustrating for him, it was frustrating for us, certainly frustrating for the teachers, too. He could promise me the moon – and he meant it. But he just couldn’t. I finally realized all of the talking, all of the changing the way that I deal with him, the way that the school deals with him, all of that—it isn’t making any difference. That’s when I finally agreed, let’s try meds. It doesn’t seem like it should be ‘that difficult’ for the child. Yet, then, sometimes, it really is.”

A difficult episode in February with Robert, who seemed to be acting out over his father’s impending deployment in March, after two already delayed deployments, led Deanna and Tom to make the decision to move the family to Little Rock, Arkansas, where Tom’s parents live. The decision was made on a Wednesday evening, and Deanna and the children were settled in the following Monday next to Tom’s parents, in a wheelchair-accessible rental that Linda and Fred VanHook discovered on that same Wednesday evening was available. They have retained their home in Virginia, with Tom’s home station being at Naval Medical Center Portsmouth.

“It’s really been a godsend for Robert, because he’s just really, really taken to his new doctors and therapists. The doctors here have been fabulous for him. I would say in the last three months, he has matured and grown more than I’ve seen him in the last year. If I ever had any doubts that leaving was the right thing to do, I don’t have those doubts now.

My in-laws are fantastic. What we’ve done is every night we have dinner together.” So, the children have “actually gotten to establish a relationship, and that has been incredibly important to me. Family’s always been very important to me,” she says, sharing that her own family “has
always been very, very supportive.”

Family relationships can gain added significance when there are challenges. Deanna and Tom’s daughter Laura, 4, was born with a cleft lip. Her first surgery was performed at around three months of age. She has had additional surgeries and will need to have several more.

“She was born not only with a cleft lip, she was born without a pituitary gland, so she has panhypopituitarism. Even though she’s four, about to be five she’s mistaken for two all the time.” She is given growth hormones and other medications. “She has problems with adrenal crisis—stress, sicknesses, any of those things can cause her to go into adrenal crisis,” Deanna says.

Laura’s health issues can present unpredictable, life-threatening situations. “We just kind of have to take it one day at a time. I do not keep her in a bubble. Even when she’s in school, I just tell them, anything the other kids are doing, just let her do—if she ends up getting hurt, call me and I’ll come. I carry her medicine because, for her, even a sprained ankle, a broken bone, all of those are medical emergencies. And sometimes that scares people. I say, you know what, she has got to learn, and you cannot keep her in a bubble—it’s not a life.

“Before I got my iBot®, I couldn’t go in and around that playground stuff. My wheels in my manual chair would have just sunk. So she learned. And I had to learn to talk to her and tell her when she was climbing stuff, okay, reach one hand up, now put another foot up, you can do it, keep going, all the while knowing that if she falls, somebody’s going to have to bring her to me, and she’s going to have to take some medicine, but that’s just the way it is. I wanted her to be able to do just like anybody else and not have to worry constantly.”

Life-Changing Mobility Equipment
In 2006, Deanna’s physician told her that it was time to switch from a manual to a power wheelchair. Deanna had bilateral shoulder impingement syndrome. “Your arms, unfortunately, were never meant to be your legs,” the physician said of the toll that manual maneuvering of a wheelchair takes on the body. “I was incredibly depressed,” says Deanna, “which was very unusual for me.”

Tom had done some research on the INDEPENDENCE® iBOT® 4000, and Deanna’s physician thought that this power wheelchair would be a great match for Deanna’s needs. Deanna and Tom went through a series of frustrating denials from TRICARE for the equipment, even though one of TRICARE’s own experts had agreed that the equipment was medically necessary. At one point, the only way to keep the appeals process going was to purchase the chair themselves, within six weeks, or the process would stop. “So, we immediately called the bank and took out a home equity loan and purchased the chair. My only regret at this point is that we didn’t do that sooner, because the difference that it made in me immediately was phenomenal.” Not one to take much medication, by that point Deanna had been on several anti-inflammatory medications, with the pain reaching a level at nighttime that resulted in her sometimes being unable to sleep.

The “iBot 4000 has been life-changing for me. Anywhere the kids go, now I can go. It’s like the chair was actually designed and made for me. It’s wonderful.”

Perspective
Some people are a strong reminder that life is meant to be lived fully. Deanna VanHook is a powerful example of that. “I’ve figured out that the only person that’s really going to stop me is me—and I don’t intend to stop me.”
Never would a military family describe a Permanent Change of Station (PCS) move as easy. Challenging, maybe! Intriguing, perhaps! But never easy. If that family includes a child with special needs, the level of complexity rises. As the family leaves their current home, coordination of medical, therapy, and pharmaceutical records, along with educational history, adds to an already daunting list of responsibilities connected to the move.

And on the other end—sight unseen, perhaps—is another list of responsibilities as the family settles into his or her new environment. For the family of a child with special needs, there are doctors, therapists, counselors, and specialized programs to find. Then, there is the school. What school districts are in this new location? What kinds of programs exist? To whom can a parent speak?

Those were the questions that inspired SchoolQuest™, an online school search tool specifically designed by the Military Child Education Coalition™ (MCEC™) for military families. Like typical school search databases, SchoolQuest allows the user—parents or students—to identify a location and browse for school districts within the area. Like other school sites, the user can also complete a zip code search for all schools within a given radius. These are useful tools, for certain.

But, unlike these general-use sites, SchoolQuest is focused entirely on military families, military installations, and the school districts that surround them. In addition, SchoolQuest goes a step beyond in personalizing the data that is returned for each student. Parents or their students are asked to complete a short data profile, including the student’s age, school grade, and age-specific indicators about completed courses, academic and extracurricular interests, and standardized testing.

The “quest” uses the completed student’s profile to return a customized letter, including meaningful facts, resources, and transition advice. For all children, the following information is listed:

- Web site links and telephone contacts for school districts in the area
- A customized listing of smooth transition advice, including:
  - Tips for preparing records for the move
  - Information about state assessments
  - Promotion advice
  - Specific information about areas of the student’s interest
  - Graduation requirements advice for high school students

For students with special needs, the information is even more robust. In addition to the above information, each district’s special needs coordinator’s contact information is listed, along with a checklist for parents that identifies items, records, and contacts that should be gathered for a smoother transition in both the old and the new locations.

From the old school, it is suggested that families provide for their student:

- Current or new Individualized Education Program (IEP)
- Current copies of any school assessments results
- Current work portfolio
- Photograph of any equipment the child is successfully using
- Videotape of the child with professional and/or aide
- Records from the student’s physicians
- Records from other professionals working with the child (psychologists, therapists, and others)
- Letters of introduction from teachers, therapists, and other professionals working with the student

From the new school, it is suggested that families obtain:

- District office special needs contact information
- Student record transfer policy
- Initiation of procedure to receive services policy
- When services begin policy
- Specific school special needs contact information
- State organizations, local agencies, and parent special needs groups

SchoolQuest does not limit itself to just a listing of this specific and customized data. At various spots throughout the Web site, users are encouraged to access the MCEC Education Resource Center (ERC). This site contains a carefully vetted and consistently maintained listing of state-by-state school data, including state academic standards, assessment data, English as a Second Language (ESL) information, No Child Left Behind Act information, special needs information, and much more. Beyond that, users are encour-
aged to send any additional questions or concerns they have about school transitions to “Aunt Peggie,” who will respond to each question on an individual basis.

There is an additional option for SchoolQuest users. By entering the Online Library (https://schoolquest.org/tour/library.htm), a reference source unfolds at the user’s fingertips. There is a list of resources that apply specifically to mobile families. Additionally, users will find information about private schools, home schooling, college applications, distance learning, English as a Second Language, and generalized tips about moving.

No, SchoolQuest does not dissolve all the moving woes! As a specialized online tool for military families, it does, however, provide a one-stop resource as families move to new military installations. It cannot magically pack and unpack the boxes, but it can alleviate the stress of one of the obstacles to a smooth move, that of finding a school system that meets the needs of all the members of the family. Visit http://www.SchoolQuest.org or the MCEC Web site at http://www.Military-Child.org.

A member of a military family while growing up, “Aunt Peggie” Watson is a retired educator. She served military children in the Killeen Independent School District, in Killeen, Texas, near Fort Hood, for 34 of 36 years in education. She joined the Military Child Education Coalition in 2001, helping to develop what has evolved into the online MCEC Education Resource Center. As MCEC grew, she began to answer questions for parents regarding researching a new school district and academic concerns. One day, she mentioned she felt like everyone’s knowledgeable aunt. And, before she knew it, she was indeed Aunt Peggie. View the answers to her questions in MCEC’s On The Move® magazine, as well as online at http://www.MilitaryChild.org.

School Entry and Exit Planning for Children With Special Needs

By Joan Patterman Barrett

A move with a child with special needs can be a challenge to even the most organized parents. Faced with all the details prior to a move, prepare for it by getting a notebook (in a size and style of your choice) to record all of your contacts, with room for all of your notes in one place! Plan to write down each contact’s name, phone number, and email address, and the date of any request you make, as well as any important details of the conversation or visit in your notebook.

Next, break the move to the new school down into manageable steps you can check off (not necessarily in the order they are listed at right and on opposite page). You need to contact the new school district early in the process to prevent an interruption of services.

### Notebook Checklist

#### What items are needed from the current school?
- [ ] Current or new Individualized Education Program (IEP) (2 copies)
- [ ] Current report card and grades to date of withdrawal
- [ ] Current copies of any school assessments results
- [ ] Current work portfolio
- [ ] Photographs of any equipment/devices your child is successfully using (including audio-video)
- [ ] Videotape of child with professional and/or aide using equipment noted above
- [ ] Doctors’ records (immunizations, general medical records, other)
- [ ] Records from other professionals who have worked with your child (i.e., psychologist, counselor, and therapist)
- [ ] Letters of introduction from teachers, therapists, and other professionals who work with and know your child

#### What items are needed from the new school district/school?
- [ ] Contact information:
  - [ ] District special education office
  - [ ] School-specific special education service provider
  - [ ] School-specific counselor
- [ ] Identify local policies:
  - [ ] General registration procedures

continued on next page
Joan Patterman Barrett is the Director of Research and Evaluation for the Military Child Education Coalition. She has a Master’s degree in Secondary School Counseling from the University of Dayton, Ohio. Her professional background includes 12 years as a high school teacher and another 10 years of Human Resource Development training. She now lives with her family in Kansas City, Missouri, after her husband’s retirement from a 32-year military career. She began as a volunteer for MCEC, with the MCEC Transition Counselor Institutes™, the National Guard & Reserve Institute™, and with curriculum development, as well as serving on the MCEC Board of Directors.

**Notebook Checklist continued**

- Initiation of procedure to receive services: how and when
- Student records transfer
  - Mail
  - Hand carry
  - E-mail
- Assessment/Screening required
- Initiation of services
- Transportation
- Special needs interest/support groups:
  - State level (Military Child Education Coalition™ (MCEC™) Education Resource Center; National Dissemination Center for Children with Disabilities (NICHCY))
  - District level
  - Local agencies and other community support groups

**Bonus TIP: Locate and use your military resources!**

These personnel are there to assist in your move, so contact them at both your current and next assignments:

- Exceptional Family Member Program (EFMP) Representative
- Other (Child and Youth Services)

**Online Resources**

- Specialized Training of Military Parents (STOMP) (http://www.stompproject.org)

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**EP Military Channel News**

Readers can access important information regarding Department of Defense news, Department of Veterans Affairs news, and TRICARE by visiting the Military Channel on the EP Web site. Information includes news releases, reports, and other relevant items.

**Visit the EP Web site’s Military Channel often for news and announcements that are of interest to military families who are caring for a member with special needs.**
Not until a loved one is unable to be by our side do we realize how much we miss them and how important they are to our overall sense of well-being. Not until we are misplaced from our home do we appreciate its comforts. At home, in our own little corner of the world, we are safe, we make memories with loved ones, we freely express ourselves as the unique individuals we are. At home, we thrive.

For many of our military Servicemembers who experience a life-altering injury or sickness, the comforts of family and home are stripped away as they struggle through difficult recoveries in medical installations. To ease these challenges for as many military families as possible, the Fisher House™ Foundation, Inc. has built homes since 1990 on major military installations and near Veterans Affairs medical centers to provide military families the chance to be together and have a “home away from home” during a family member’s recovery.

Jim Weiskopf, executive vice president of Fisher House Foundation Communications, explained this excellent program.

Today, there are 38 Fisher House homes—36 throughout the United States and two in Germany. Five more are being built. Once a home is built, it is given to the Army, Navy, Air Force, and the Department of Veterans Affairs as a gift from the Fisher House Foundation.

Commanders of each military hospital or installation determine eligibility criteria to stay in the home. Selections are made based on how far a family must travel to the hospital, the severity of the family member’s injury, family size, and rank of the servicemember. Once a family is accepted into the home, their stay is not limited by time, and they pay nothing during their stay.

Down to the tiniest detail, the building of a Fisher House home is carefully thought out to so that military families are served with the greatest sense of compassion and care during a most challenging time. Before a home is built, a location in close proximity to the medical center is selected for ease of traveling back and forth. When possible, the home is within walking distance of the treatment facility, Weiskopf explained. These “comfort homes,” which are between 5,000 and 16,000 square feet, are completely furnished and decorated to match the style of the region. They are designed to accommodate up to 42 family members and include elements of comfort such as a library and toys for the children.

In recent years, as a result of the conflicts in Iraq and Afghanistan, many more Servicemembers staying in Fisher House homes have a disabling injury and a long rehabilitation following their release from the hospital. To address their unique needs, the Fisher House Foundation modified all new homes to be 100 percent compliant with the Americans with Disabilities Act (ADA) accessibility guidelines. The homes feature every modification individual with disabilities needs to comfortably move about the home and function with ease, including elevators, power boosters on doors, ground-level laundry facilities, wider hallways, lower beds for easy transfer from wheelchairs, and durable furniture.

Health Net Federal Services is honored to support the Fisher House Foundation through annual donations to help pay for the cost to build new homes to serve even more military families and to help pay for the expenses to operate the homes.

Jennifer Davidson is a senior writer for Health Net Federal Services, LLC, the government operations division of Health Net, Inc., and the healthcare contractor for the TRICARE North Region. Health Net is honored to provide high-quality, cost-effective healthcare programs to the Departments of Defense and Veterans Affairs and is proud to partner with organizations dedicated to improving the quality of life for our servicemembers, active and retired, and their families.
Choosing Effective Treatments for Children with Autism

Tell Me A Story™: Using Literacy Activities with Young Children
Community of One

From Our Families... To Your Families
Tell Me A Story™: Using Literacy Activities with Young Children

By Stacye Parry

This past year, the Military Child Education Coalition™ (MCEC™), in partnership with ZERO TO THREE: National Center for Infants, Toddlers and Families, presented thirteen tell me a story for young children™ (tmass™) events at military installations across the United States. tmass is an offshoot of the MCEC’s Tell Me a Story™ (TMAS™) program, which uses literature as a tool to strengthen connections between parents and children as well as to encourage skills for resilience and to foster a caring community. ZERO TO THREE selected the tmass event to kick off their Coming Together Around Military Families project, an initiative to reach professionals who work with children in communities highly impacted by deployments with additional support and training. Installations that are currently part of the Coming Together Around Military Families project are Fort Bliss, Texas; Fort Bragg, North Carolina; Fort Campbell, Kentucky; Fort Carson, Colorado; Fort Drum, New York; Fort Hood, Texas; Fort Lewis, Washington; Fort Riley, Kansas; Fort Stewart/Hunter Army Airfield, Georgia; Marine Corps Base Camp Lejeune, North Carolina; Marine Corps Base Camp Pendleton, California; and Eglin Air Force Base, Florida.

tmass uses a wordless book, Tell Me Your Story, published by MCEC, for its program. At the event, a facilitator models how to use a wordless book with the children, and then parents and children engage in various activities that encourage language development, pre-reading, and pre-math skills. These activities all use common household materials and are adaptable to children of all ages and abilities. You may want to try some of these with your child.

Motor Skills: Both fine and gross motor skills can be improved through art. From grasping a crayon to using scissors, children learn to control their bodies.

Math: Shapes are key components of art and math. Mixing colors teaches ratios.

Reading and Writing: Scribbling, drawing, and pasting allow children to develop the muscles they will later use for writing. In fact, young children will often begin pre-writing while engaged in art activities.

Language: Art also provides the opportunity to expand a child’s vocabulary. Colors, textures, feeling, subject matter—all are wonderful ways for you and your child to talk about art while developing vocabulary.

• Activity #1: Make 3-D letters. Find a large piece of sandpaper and cut lengths of yarn in different colors and textures. Use the yarn to make designs on the sandpaper. If the child is a pre-reader, encourage the child to make letters, or make the letters for him or her, and have the child trace over the yarn with a finger.

Art

The number of skills that children learn from experiencing and experimenting with art materials is surprisingly long. They include:

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Sensory Experience: Green

One of the greatest gifts that children give adults is the opportunity to see the world with fresh eyes. You can enjoy that gift while also connecting
deeply with your child by taking time to stop and enjoy our wonderful world together. For instance, when you take time to examine the bug that your child discovers on the way to the car, she learns you value her insights. Moments like these strengthen the connection between adult and child.

**Activity #2:** A “Green” Scavenger Hunt: Find as many green things as you can and help your child describe the texture and smells.

**Activity #3:** Make “green” using yellow and blue play dough. As he works with the yellow and blue, ask your child to describe what is happening. What happens when you add more yellow? More blue?

An easy play dough recipe is 1 1/2 cups of flour, 1/2 cup of salt, 1 1/2 tablespoons of cream of tartar, 1 tablespoon of cooking oil, and 1 1/2 cups of water. Mix all the ingredients in a pan and then cook over medium heat, stirring constantly. When the mixture is play dough-like, and no longer sticky, remove it from the heat, divide it into two pieces, and put a few drops of food coloring on each piece. Once it is cool, let your child knead the food coloring in.

**Routines and Schedules**
Schedules are extremely helpful for all children. Having a routine in place helps children know what to expect. You can even have little routines for different parts of the day. For example, your morning routine with your child could include getting dressed, having breakfast, and carrying the dishes to the sink. Routines help a child feel secure and in control, and this is especially comforting to children who may be experiencing stress due to a deployed parent.

Use pictures cut from magazines to talk about what you do every day. Help your child put the pictures in order to talk about the things he or she does and what is done first, second, etc., or use a clock to talk about the time of day certain things are done.

**Activity #4:** Make a routine chart together. Use a camera to take pictures of your child engaged in the routine, or even set up scenes (use a favorite doll for a “stand-in” in the routine) so that your child can take the pictures all by herself. Use the photos to make a chart with basic labeling (“Make Bed”), paired with days of the week. You can make this chart reusable with dry erase pens and contact paper, even adding new activities as they come up.

**Sorting and Patterns**
Sorting and classifying things helps children to make sense out of their world. Stacking items, like measuring cups and spoons, helps children learn about the ways objects fit together. Children will play with objects until they figure out the “rules.” Anyone who has ever watched a child sitting in a high chair has seen them experiment with gravity over and over (and over and over) again.

**Activity #5:** Use your noodle. Manipulative toys can be found throughout stores, but it is fun to create some of your own. Our most popular was a pool noodle cut into various lengths (use a serrated knife). The pieces can be stacked, arranged in order of height, and used to demonstrate patterns. We also found children had other creative uses for the pieces that we had never imagined.

**Reading**
Reading while you snuggle with your child is one of the great joys of parenthood. But don’t feel you have to wait until things are “perfect” to read together. Here are some other ways you can read with your child as you go about your day.

**Activity #6:** Read, all the time, everywhere. You can read aloud information on boxes and cans while shopping, or even give your child the shopping list and let them read it to you and check off items as they are put in the cart. In the car, you can read road signs and billboards and play games such as “I Spy,” looking for letters to make the alphabet. E-mails and letters from loved ones are also perfect for reading aloud. This shows children reading and writing can help us stay connected. Make a collage of words by flipping through magazines and clipping the ones you can read together. Start a story with one or two sentences, and then encourage your child to use her imagination to tell the next part, taking turns. Write your story down to share with other family members.

Of course, don’t limit yourself to the activities listed here. These are simply springboards for imagination, both yours and your child’s, so be creative! If you see your child’s interest heading in a different direction, encourage it! There are no limits to what you and your child can play and learn together.

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Stacye Parry, who has a degree in elementary education, spent twenty-seven years as an active-duty spouse. During this time, she worked in the education field and served in many volunteer positions in both the civilian and military communities. (She and her husband have two children. Their son is a First Lieutenant in the United States Air Force and their daughter is a recent graduate of Texas A&M University.) She began her work with the Military Child Education Coalition™ as a volunteer trainer. She currently works as the Project Specialist for Parent Programs, which include the Parent to Parent™ and Tell Me a Story™ initiatives as well as continuing her work as a trainer for the Transition Counselor Institute and the Special Education Leaders Institute.
Choosing Effective Treatments for Children with Autism

By Alan Harchik, PhD, BCBA, and Patricia Ladew

As the number of children diagnosed with autism spectrum disorders (ASDs) continues to skyrocket in both civilian and military families, so do the number of treatment options. Through the media and the Internet, parents of children with an ASD learn about many different types of procedures to treat autism and related disorders. Wanting to do everything possible for their sons and daughters, they will often try a number of different therapies and treatments.

After their son, Cameron, was diagnosed with autism at age three and a half, Army Master Sergeant Larry Carter and his wife, Christal, made it their mission to learn all they could about the best treatments for a child with autism. In the past four years, they have tried a number of different therapies with varying degrees of success.

“We talked to other parents, read books, researched on the Internet, took courses, attended conferences, and watched autism specials on TV,” Christal told us during a recent interview. “It was quite a hodgepodge. There is no one resource for information about autism.”

The Carters have worked with many different physicians, therapists, and consultants and have tried a variety of treatments—speech and occupational therapy, hippotherapy (using equine movement to address neurological functioning and sensory processing), aquatic therapy, chelation (using drugs to remove heavy metals from the body), and biomedical therapies such as a gluten-free, casein-free (GFCF) diet and vitamin B12 injections—all in an effort to reduce Cameron’s problem behaviors that included spitting, biting, kicking, scratching, and hair-pulling.

“We were doing so many things at one time; it’s hard to know which did what,” commented Christal. “You’re scared to eliminate anything because you don’t want to see regression.”

When they needed help with Cameron’s toilet training, they turned to a program that utilized applied behavior analysis (ABA), a methodology that relies on research-based interventions to address skill deficits and behavioral problems. After seeing the
When considering different treatment options for a child with autism, it’s important to know if research has verified that a treatment is effective. There are lots of treatment options available, and while many of these may be supported by personal testimonials, many have not been shown to be effective by scientific studies. How do parents know what studies to look for and where to find them? To be a savvy consumer, it is critical to determine which treatments are based on good science and which are based on pseudoscience. Good scientific studies involve:

- a solid research design
- strong tools for measuring change
- accurate identification that the children really have autism
- evidence that the treatment was provided accurately
- efforts to show the treatment produced positive outcomes over time or in different situations

Many studies do not meet these standards and are therefore not fully contributing to our knowledge about treatment effectiveness. Pseudoscientific studies involve information that sounds scientific, but in reality is not; they are not based on good scientific methods.

The Importance of Peer Review

One way to decide if a study is science or pseudoscience is to look at whether or not the study is a peer-reviewed study. The peer review process involves having other experts in the field read the study to determine if it is of good enough quality or makes an important enough contribution to the field to be published in a professional journal. Peer review is an important process because it ensures that a study meets the minimum acceptable standards of science.

Many public libraries have access to databases that contain links to peer-reviewed articles. University libraries and the Internet are also excellent resources for locating research databases, such as PsycINFO (http://psycnet.apa.org/index.cfm?fa=search.advancedSearchForm) and Medline/PubMed (http://www.pubmed.gov), which often contain a number of articles related to autism treatment. There are also certain Web sites for locating peer-reviewed articles (such as http://www.scholar.google.com).

The National Standards Report, a document that identifies the quality of research support for educational and behavioral treatments for school-aged children and adolescents with autism spectrum disorders is expected to be released by August 2008 by the National Autism Center. This new resource will make it much easier for parents to determine the effectiveness of various treatments for autism.

Other Considerations

Evaluating the Efficacy of Treatments for Autism Spectrum Disorders

By Susan M. Wilczynski, PhD, BCBA, and Leslie Sutro, PhD

Scientific support is only a first step. There are several other key considerations when making treatment decisions. First, professional judgment should play a significant role. Even if a treatment has good scientific research support, it may only be applicable under certain conditions that may or may not be available. Second, the thoughts and opinions of parents and sometimes the children themselves should be taken into account. Third, ongoing treatment decisions should be based on data whenever possible. Data collection is crucial to determining if a child is responding positively to a particular treatment. Finally, the training and knowledge of those implementing a treatment should be considered. Once a treatment is chosen, the child’s treatment team should determine what they need in terms of training, feedback, and materials in order to provide that treatment accurately.

There are several “red flags” that parents should be aware of when trying to decide which treatment to choose for their child. Unfortunately, there is no magic cure for autism. When considering a treatment, parents should watch out for exaggerated claims of a cure, especially if the treatment requires a significant financial commitment. In addition, parents need to be aware of the marketing aspect of what they read. No one will advertise a treatment with testimonials saying that a treatment does not work, but positive testimonials do not always mean that treatments are effective. Additionally, when pursing biomedical treatments, parents should always consult with a pediatrician or some other medical professional. Finally, they should be cautious of treatments that may cause direct physical harm to their child.

Susan M. Wilczynski, PhD, BCBA, is Executive Director of the National Autism Center and chair of the National Standards Project. A licensed psychologist and Board Certified Behavior Analyst, Dr. Wilczynski has authored numerous articles on the treatment of autism spectrum disorders.

Leslie Sutro, PhD, is a licensed psychologist at the National Autism Center. Dr. Sutro has significant experience providing consultation services to schools and families seeking appropriate and effective services for children with autism spectrum disorders.

Seek Evidence of Effectiveness

It is not uncommon for families to take an eclectic approach as they search for the best treatments for their children. Although this may seem like a way to take advantage of the best aspects of every therapy, this approach often assumes that all treatments for autism are equal. Unfortunately, they are not. Some have evidence showing their effectiveness and others do not.

Fortunately for the Carter family, their approach led them to ABA, which has far more research support than any other treatment or therapy for children with autism. ABA therapists use positive reinforcement, teaching in small steps, prompting, and repeated practice to facilitate language development, improve behavior, develop social skills, and support independent living.

For Cameron’s May Institute ABA therapist, Jocelyn Priester, MS, BCBA, the Carters’ multi-therapy approach presented some challenges. “We noticed an
increase in problem behavior when Cameron was going through chelation,” says Jocelyn. “The doctor had told his mom to expect that. Because it’s an internal event (the chelation) that I couldn’t control, I would just do the best behavior management I could. We had behavioral goals in place, so I worked on those.”

Jocelyn also worked with Christal, Larry, and Cameron’s sister, Caitlyn, recommending things they could do at home to support his ABA therapy, including how to encourage full speech. The family is very pleased with the results.

“With ABA, we saw a huge increase with language,” says Christal. “Cameron had words…but he wasn’t using full sentences. His therapists required him to speak in sentences and showed us how to do it, too! Before ABA therapy, if he wanted juice, he would just say ‘juice.’ With the help of ABA, he learned how to say, ‘I want juice, please.’”

“ABA also stimulates more spontaneous speech,” Christal continues. “He’s gone from not even saying ‘Mommy’ to being able to name the people in the photos I show him. Now he can tell you my cell phone number and where his grandmother lives. He’s identifying letters and colors and animals. This is huge. For someone who is not living with autism, it may not seem incredible, but for us, it is amazing what he has been able to accomplish.”

Christal has become such a strong advocate of ABA that she established a community play group and pursued funding to bring together children with autism and their typical peers. The group teaches positive social skills and provides an opportunity for parents to support one another. Christal hopes to establish scholarships to assist parents seeking ABA services.

Cameron continues with ABA therapy, along with the GFCF diet, and supplements such as cod liver oil and vitamin B12 injections, although Christal says there are other treatments she might consider. “We continue to look at what’s out there and make decisions about treatments,” she says. “We discuss everything and make sure we are in agreement before we start any type of treatment.”

It is understandable that parents are drawn to eclectic programs because of the possibility that one of the treatments will hold the key to success for their child. When they are making decisions about their children’s treatment, however, it is critical that they look for therapies that have the most research support in order to use their precious time, energy, and financial resources wisely.

It is also important to recognize that combining treatments could dilute or compromise the effectiveness of a particular intervention—because the treatments might interfere with one another, or because the time required for one intervention could impact the amount of time spent on another intervention.

For a child with autism, time is of the essence. Decisions made about treatment can make a significant impact on that child’s long-term success. This is particularly true in the areas of language and social behavior. Early diagnosis followed by effective treatment can literally mean the difference between a child: (a) ultimately mastering language, having typical social interactions with family and peers, and fully integrating into mainstreamed public school environments, or (b) not learning to speak, remaining socially isolated, and needing intensive educational, behavioral, and rehabilitation services throughout life.

Clearly, we have not yet solved the puzzle of autism. We must continue to work incredibly hard with each and every child in an individual manner specific to that child’s unique needs, learning style, and family situation. We give children with autism the best possible chance if we use the procedures that have the greatest documentation of effectiveness.

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Alan Harchik, PhD, BCBA, is May Institute’s Chief Operating Officer, a licensed psychologist and teacher of children with disabilities, a Board Certified Behavior Analyst, and a member of the leadership team of the National Autism Center. Dr. Harchik has extensive expertise in the areas of autism and applied behavior analysis, and has been published in a variety of professional journals. For the past three years, Dr. Harchik has written monthly, autism-focused columns for newspapers in Massachusetts. He serves as an expert consultant for the Civil Rights Division of the United States Department of Justice.

Patricia Ladew is a senior writer for May Institute’s Office of Communications. She has specialized in healthcare writing for the past 20 years.

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Resources

Suggested links to information about autism, treatment, and resources:

- Autism Society of America
  www.autism-society.org
- Centers for Disease Control and Prevention
  www.cdc.gov
- May Institute
  www.mayinstitute.org
- Military OneSource
  www.militaryonesource.com
- MyArmyLifeToo
  www.myarmylifetoo.com
- National Alliance for Autism Research (Has merged with Autism Speaks)
  www.naar.org/naar.asp or www.autismspeaks.org/index.php
- National Autism Center
  www.nationalautismcenter.org
- National Institutes of Health
  www.nih.gov
- Organization for Autism Research
  www.researchautism.org
- TRICARE
  www.tricare.mil

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Caitlyn, Larry, and Cameron Carter enjoy summertime fun at the pool.
The world is not an easy place, and when you have endured a traumatic experience in combat, a servicemember can be left with a scar on the psyche. There is no way to escape the fact that an experience of heightened fear and violence casts a shadow upon its recipient. We may avoid the memories in a number of ways, through repression, denial, and forms of escape. This does not negate that the experience of pain and fear occurred. To avoid something does not mean it does not exist. It means that the one who went through the traumatic event is not willing to re-experience the memory. Unfortunately, what we try to avoid only builds momentum, becoming stronger, wielding demons in its wake.

These demons come in small sizes at first, such as inconsistent sleep, irritability, lack of concentration, and the inability to get along with others at work or at home, and then they grow into more insidious demons, taking shape in the form of self-destructive activities, such as binge drinking, drug abuse, and sometimes even violence. Trying so hard to run from the painful experiences of the past, the person is unconsciously attracted to creating destructive experiences in the present.

Avoiding pain through self-destructive behavior is not the answer. Many veterans are coming back to the United States addicted to painkillers as well as illicit drugs. They experience a lot of shame after they have taken them. For example, one veteran shared with me that he did things he was not proud of while on them, and another shared that he disappointed a family member by driving drunk and by acting irrationally. There was a theme of heavy, even if irrational, guilt that remained consistent among all of the veterans in their anecdotes about taking drugs or drinking excessively. To get past the guilt, the servicemember needs to see what drove him or her to making these potentially lethal choices in the first place. If one can get past the shame to look at how one was feeling shortly before taking drugs or drinking excessively, one may find that the feelings are the same. Some shared with me their feelings of hopelessness, general malaise, despair, and anger, which led to their desire to escape by numbing themselves or desiring to achieve that brief feeling of euphoria and elation that might come from a stimulant. They expressed that they were looking to ease the dull ache, the insidious pain, with which they were wrestling, in most cases unconsciously.

Some veterans shared that they feel as if they are bad in some way, and that is why they are taking drugs and alcohol. They seem resigned to the notion that they are not worthy of feeling good about themselves. Face it, waking up after a night of bingeing and/or drug use is not a good feeling. One is not going to wake up singing, “Oh, what a beautiful morning!” Many have said to me that to attempt to allay the urge for drugs, they imagine what they will feel like about 12 hours from the beginning of taking them, in hopes of being deterred. Generally, they will succumb to the urge, because the pull for that feeling of relief is stronger than the deterrent of a hangover the next day. It’s those 12 hours that the servicemember is after, a way to relieve the pain. What do I mean by relief? Feeling better. A way to escape feeling depressed, anxious, or half alive, as one military member described. The problem is that this relief is so very temporary and, even worse, can prove fatal.

Where can a servicemember find a form of healthy relief? Therapy is a good start. Unfortunately, some express their fear of opening up with anyone, afraid that their history would not remain confidential. There is a feeling of loss of safety after having been through some very scary, life-and-death events. Feeling trust in anyone or anything in a world that no longer feels safe is a very difficult hurdle to overcome. There is a loss of faith not only in themselves but in the world at large.

If you can relate to this, do not give up.
Learn From My Mistakes
A Narrative from an Anonymous Marine

Editor’s Note: This narrative was written by the same concerned U.S. Marine Corps Noncommissioned Officer (NCO) veteran who contributed to the first installment in the series about traumatic brain injury, post-traumatic stress disorder, and related health issues, which appeared in the May issue of EP. The piece describes the experiences of this Marine veteran attempting to cope with traumatic experiences undergone during his time in combat, his subsequent struggle with substance abuse, and his road to recovery.

The first time I ever used a substance, it was a 10mg Valium®. I was at my old job. My boss was a Vietnam veteran, and he had a prescription. I was extremely stressed out one day, and my boss said, “Try one of these.” He gave me the Valium, and I felt like a million dollars. After I experienced that, I went to my doctor and told him, “I’ve been feeling great stress, and is there any way you can help me relieve it?” She wrote me a prescription for 10mg of Valium, and I didn’t take it every day. I would take it once a month and increased the dosage anywhere from 20mg to 30mg and finally got up to 100mg in one sitting, but once a month. When I was on Valium, I would lie on my couch and listen to music by Pink Floyd. I would try to do this before my wife came home from work so that she wouldn’t see that I was altered. But still, I wasn’t using it every day. Then I would go back to the doctor and get another prescription. I went infrequently so that I would not be red flagged. This went on for six months. I switched doctors, and he was even more willing to write me prescriptions. He prescribed 10mg of Valium. This went on for a few years. Two years ago, I started getting sick a lot and had a few physical problems that required painkillers. First, I was prescribed Percocet®, then OxyContin®, and finally Vicodin®. Then I started mixing drugs. I wouldn’t be taking the prescribed amounts. I would be taking much more.

At that point, my wife started to notice that I was out of it. She warned me that I shouldn’t be taking too many medications. As my health worsened, I finally got to a point where I was out of it for a month. My wife left me at this time, since I had become uncontrollable. At that point, I went to rehabilitation, stopped taking these drugs, and went to a new psychiatrist who prescribed antidepressants and antianxiety medications. I was prescribed a large dosage of Ativan®, and I went through a month’s supply in a week. I was drinking and taking antianxiety medications. I was on a real binge. While I was abusing drugs, my judgment was very impaired.

Finally, I ran out of my antidepressant medication and my psychiatrist would not refill my prescriptions due to his understanding that I was abusing them. For three weeks, I was living in hell, going through withdrawal. I was circling around my dining room table in a panic, feeling like I was going to die. It was through prayer that I made it through that time. I went to a doctor and told him that I was going through withdrawal. He prescribed 10mg of Valium, and this was the only thing that worked. I was living feeling? There is none. It is hollow.

Dissociation is a very self-protective act, a form of defense, to dissociate oneself from feelings that were generated by a traumatic event. Unfortunately, war is a source of traumatic events. Dissociating is a way for one’s psyche to protect itself from experiencing feelings of sorrow and pain. The double-edged quality of this defense is that it leaves a person unable to experience real joy as well.

In an attempt to survive, the ability to thrive has been thwarted. One becomes like a vessel floating emptily, aimlessly, uncertain of the past and very disconnected from the future. The present is what one is attempting to endure. And the quest for the high, the quest for numbness, is a way to avoid feeling pain, an attempt to experience a synthetic form of joy or elation. It is not the kind of joy one feels when he or she sees a loved one accomplish a milestone in their lives (e.g., seeing a son or daughter graduate from college, or an elder parent reach age 80, or the feeling of joy one feels when he or she falls in love). It is a very temporary feeling of elation. As I’ve heard it described, “I felt amazing, although it was short-lived.”

Where is the future in that short-lived feeling? There is none. It is hollow. So how does one shed the pain, be alive again in a real way? How does one learn how to create and experience real joy? How can one avoid being paralyzed by the pain of the past?

No matter how low you think you
through the experience. Humans have free will. I asked God for the strength to turn away from drugs, but I had to be willing to do the work. I prayed for help and wisdom. I had hit rock bottom, and it was a real eye opener. I went to my psychiatrist, and I confessed that I couldn’t be trusted with large amounts of drugs. I asked for a lower dose of a medication that instead of providing instant relief would provide long-term relief. This was Klonopin®. I could not abuse drugs anymore. I have to take medications as they are prescribed. I bought seven-day pill holders, designating morning, afternoon, evening, etc. It structured the taking of the medication for me.

I’ve been a balanced individual ever since. I now am thinking clearly. I’m happy instead of being totally emotionless; I now feel joy. I started going out and doing things that I’ve always wanted to do, like taking singing lessons. And I feel more productive at work. Also, I don’t lose my temper the way that I used to. This new regimen, in tandem with therapy, has really helped me change my life for the better. I can have a conversation that gets to a point of disagreement and can now express myself calmly instead of becoming angry. This was not easy for me before. I also stopped drinking, since I understood that drinking was a catalyst to craving the other substances. They go hand in hand. I am clean and sober, although taking medication as prescribed by my psychiatrist.

What I would strongly recommend is instead of taking pills out of the bottle, get one of those weekly pill containers, since when I was abusing them I would take a few out of the bottle, not realizing how quickly I was consuming them. Now, I have stopped abusing drugs and feel great. I’ve improved communication with my family and friends. Again, taking medication as prescribed, I am feeling stable and at peace. If conflicts arise, I can handle them in a spirit of equanimity as opposed to angry confrontation. The only time that I do express my rage is in therapy, which is a safe holding environment and is within reason. In other words, I don’t get up and punch my therapist!!

Therapy and psychopharmacologic agents have made a huge difference in my recovery. And, again, I really recommend that weekly medicine container, since it has made a huge difference for me, since it kept me on the straight and narrow in taking my prescriptions in a correct fashion. What I went through, I don’t want anyone else to go through. Get help before you lose your family, job, and all that is important to you. We are military men and women, and we know what self-discipline is. We should remember our training and practice that self-discipline that was instilled in us to get us out of this mire. I would also recommend speaking to a professional about your problems and what you’ve been through. When I did so, it opened the pressure cooker and all that rage which had built up inside of me started to release in a positive way as opposed to a destructive one. When you are doing drugs or drinking to excess, you are only masking the pain and anger that you are feeling. You are hurting yourself. It is simple: If you were feeling good and happy, you would not be taking drugs or drinking excessively since you wouldn’t feel the need. As a Marine veteran NCO (Noncommissioned Officer) who cares about his brothers at arms, learn from my experience. I am not fully recovered from all that I’ve been through, but this problem will not defeat me.

I have sunk into an abyss, there is hope. At the root of all of this pain is a crisis of faith. I do not mean faith born only of religion, but faith whose root lives in a person’s innermost, private being—the faith that produces the momentum to believe that life can be meaningful again. To do this, one must investigate the pain born out of past traumatic experiences that led to this place. One must face it, look it in the eyes, and make peace with it, and more often than not, a person needs to seek self-forgiveness.

Mankind carries his own jury and executioner within, which when fully engaged is waiting to criticize its owner. The louder this voice is within, the harder one binges, the more one desires to escape or numb feelings and emotions, creating a vicious cycle in which one feels less and less alive.

Finding hope in the midst of so many contradictory feelings is not easy. Ideally, part of this path needs to be traversed with a trusted professional who can help a patient wade through the traumatic experiences that led to destructive behavior. This requires a person to let down his or her guard enough to let someone in. A practitioner or friend has to care enough to avoid judgment while they help the person cultivate the best of themselves, heal the hurt and anger, and plant the fragile seeds of self-esteem. As healing occurs, the seeds of success, instead of failure, are nurtured and lead to seeing the world in a very different way.

But often, one needs support to redefine personal faith in life. Man is not an island. Much of our pain and sorrow in life is sown with others—and healing will not occur without a band of brothers holding our hand along the way.

Recovery from substance abuse related to post-traumatic stress disorder can be gained through programs like Alcoholics Anonymous (AA) and Narcotics Anonymous (NA), where people find the safety to share their feelings and experiences with others. AA and NA along with individual therapy and medication prescribed by a professional are among the best forms of treatment for addictions.

Lorraine Cancro, MSW, is a Clinical Social Worker and Director of Business Development for EP Global Communications, Inc. She collaborates with scientists in the departments of Psychiatry and Neuroscience at New York University (NYU) Medical Center and Bellevue Hospital in research on traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD) among returning military members. The current research that she spearheads will be a source of new findings for the continued TBI/PTSD series in EP magazine’s military section as well as for the upcoming EP LiveOnline TBI/PTSD online seminar series, which will include several prominent scientists from NYU, Bellevue, and other medical institutions as speakers.
When Your Parent Returns Home Changed from Combat

By Jodi O’Donnell-Ames

Editor’s note to parents: This article was written for teens of a parent or parents who have returned home from U.S. military deployment with service-acquired cognitive or physical disabilities. We recommend sharing this article with these children and allowing them to read about some helpful suggestions on how to cope with this difficult adjustment to their lives.

When I was a child and teenager, my mother and I made dates of watching movies together. She loved the black and white classics. I grew to appreciate them after much insistence. One of those “tears and tissue” movies that we watched was Coming Home. The movie followed the coming home of a paralyzed Vietnam War veteran and the woman who lovingly cares for him.

I thought immediately of Coming Home when I began this article. Today, many servicemembers are coming home from Iraq and Afghanistan. Like the actors in the movie, these veterans face many challenges even once they’re safely home. There is the possibility of post-traumatic stress disorder, depression, chronic pain, and disability.

Many of these veterans are parents, and if you’re a child of a parent returning from deployment, you are most likely faced with challenges, too. According to the latest statistics, 43 percent of American servicemembers are parents and about 30,209 servicemembers have been seriously wounded in Iraq.

So, what does this mean? It means that while you’re very excited that your parent is home again, things may not be the same. Your parent may laugh less, cry more, and feel anxious or angry. You have patiently waited for your mother or father to return and now that you’ve been reunited, you’re anxious to reestablish bonds. So why can’t it just be like it used to be already?

“Coming Home Different” is the first of two articles written to help guide you through this challenging process of adjustment. Both articles are written specifically with you in mind! It can’t hurt to read and try some of these suggestions. There really is nothing to lose.

When you are a member of the Armed Services, serving your country means fighting for something in which you believe, feeling patriotic, heroic, and brave. But it can also mean seeing and experiencing the frightening and unsettling times of combat. In a book titled, Courage After Fire: Coping Strategies for Troops Returning from Iraq and Afghanistan and Their Families, by Keith Armstrong, Suzanne Best, and Paula Domenici, there is a list of possible negative results from such experiences. Anxiety, post-traumatic stress disorder, anger, and fear are just some examples.

According to school psychologist Robert Jann, PhD, who works with teens, “Family members and loved ones can’t take away a disability, but they can take away the effect of the disability on the family. Things may not be the same as before deployment, but a family can adjust to new routines.” He also assures families of returning servicemembers that “being different doesn’t have to be destructive. Families can feel whole again, but it takes time and patience.”

Your Turn to Nurture

Did you know that YOU can have a great impact on aiding your family in the process of feeling whole again? Well, you can! You have the power to assist in this process by being attentive and helpful.

In 2001, when my husband died of ALS (amyotrophic lateral sclerosis) at only 35 years of age, I was very depressed. I slept a lot and ate little. My daughter, Alina, was only nine years old. She didn’t realize how helpful she was to me. One day, when I was crying, she brought me a scrunch up ball of toilet paper (I had gone through all the tissues!) and put her hand on my shoulder. Her nurturing touch and thoughtfulness meant so much to me.

Do you remember when you learned to ride a bike? Can you recall seeing your Mom or Dad running beside you, trying to keep up with you until you gained the courage to ride independently? Hours later, you were both exhausted and proud. You may not have understood then, but your parent had to be very patient that day! It wasn’t easy to hold you up on your bike while running by your side.

There are many times that your parent practiced patience. Like when you were first born, and you never slept! A sleepy someone sat up patiently with you all night. And what about that time when you wrote your name (in permanent marker) on the kitchen wall?

Now you get the chance to nurture your parent. You can begin by realizing that a disability may be something clearly visible (like a scar or amputation), but it can also be something invisible or tough to recognize, like post-traumatic stress disorder or
depression. The fact is that your parent probably has returned different than they were before deployment, maybe even as a person with a mental or physical disability. One common outcome of deployment is post-traumatic stress disorder, or PTSD. What is PTSD, and how does it affect someone? Post-traumatic stress disorder is a psychological reaction occurring after experiencing a highly stressful event (like wartime combat, physical violence, or a natural disaster) that is usually characterized by depression, anxiety, flashbacks, recurrent nightmares, and avoidance of reminders of the event.

Signs of PTSD include quick mood changes and feelings of anger, anxiety, and depression. A person with PTSD can feel detached from his or her family or friends as well as disinterested in social situations. As you can tell, these symptoms can make reintegration to civilian life difficult for everyone involved. Dr. Jann reminds us that PTSD can last for a while and does not immediately go away when a servicemember returns home.

Another possible result of combat is physical injury. Physical injuries can include wounds, scars, burns, and limb amputations. Learning to accept and adjust to a physical disability requires an immense amount of strength and courage for the returning parent. Some injuries require relearning life skills such as dressing or walking. If you’ve ever broken an arm or leg and needed a cast, you know how awkward a simple task becomes under such circumstances. Even showering becomes complicated.

But, remember, you have the power to make the adjustment easier (that’s not always a piece of cake). For now, your job (to the best of your ability) is to practice patience, listening, and acceptance.

**Practice Patience**

You’ve heard the saying, “Patience is a virtue.” Well, it’s very true! When your parent first returns from deployment, he or she is facing enormous change, and the best place to experience that change is with you. “The safest place for a returning Soldier is at home with his family,” explains Dr. Jann. Know that just by being home with you and your family is a great start in the healing process. Practicing patience means that you and your needs may not always come first and that your parent may need help more frequently. While your parent was deployed, you may have picked up additional responsibilities like taking out the trash, putting a younger sister or brother to bed, or helping your parent with household chores. Although it may have seemed like a burden initially, it wasn’t so bad to be helpful. As a matter of fact, it probably felt really good to contribute!

As Dr. Jann mentioned, adjusting to a disability takes time and patience. Not just for the patient, but for the entire family. During this adjustment period, you must practice patience and should not take your parent’s mood personally. Many things may take longer for him or her to accomplish. Your patience, however, should not be shorter!

**Practice Listening**

You may have questions, lots of questions. If and when your parent wants to talk, be a good listener. If the conversation is going well and you have questions, don’t be afraid to ask them. Know that it may take some time before your parent wants to recall anything about their tour of duty.

As a teen, listening can be selective. Especially during this healing time, listen to your parents. Sometimes what they say they need may be obvious; sometimes you can read between the lines and know just to listen and be there for them.

**Practice Acceptance**

If your parent has returned with a physical disability, what should you expect? Learning to live with a disability takes getting used to. It may mean (depending on the severity of the injury) having to relearn life skills. Take, for example, the servicemember who returns with an amputation and needs a prosthesis.

As a teen, maybe there have been times when you haven’t always accepted your parents for who they are. For some teens, sometimes just their parents’ style of dress can be embarrassing! It can be typical for you to feel this way. What is not helpful though is to be embarrassed by your parent’s disability. Remember that not-so-attractive first-grade picture of you with bad hair and no front teeth? Maybe not your best picture, but it never stopped your parents from showing it off proudly. Your parents love you unconditionally, so no matter what, you have their love and acceptance.

Your parent was proudly fighting for his or her country and in that process became a person with a disability. There is nothing embarrassing or shameful about that. Sooner or later, we all need help in some shape or form, whether it’s physical or emotional. Hopefully, unconditional love and acceptance are available when that time comes. These are the best gifts that you can offer your parent during this time.

Now that you are a teenager, you have more opportunities but also more responsibilities. Learning to practice patience, listening, and acceptance now will only benefit you as an adult. You will have so much more to offer your friends, coworkers, and, maybe one day, your own family.

Look for my next article in the November issue of *EP*. It will focus on getting you the help YOU need to cope as well as ideas for you and your parent to bond again. And remember that Hope Loves Company! •

Jodi O’Donnell-Ames is the founder of the organization, Hope Loves Company (HLC). HLC seeks to provide daily living support to children and young adults confronting traumatic events, such as death or illness of a loved one as well as more common conditions, such as stress or peer pressure. Depression, post-traumatic stress disorder, diabetes, disabilities, and special health-care needs are additional examples of issues with which HLC endeavors to help children cope.
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I grew up in a small town on the East Coast. The kids I met in second grade were the ones I stood next to at my high school graduation. The middle school secretary went to our church. I visited my senior English teacher in her home. Everyone seemed to know everyone—it’s the curse and blessing of small towns—and every family seemed to move naturally forward, unseen records flowing to the next school, all our achievements noted as they should be in our little charts. If ever there was a mix-up, surely it was settled by a quick check back in the filing cabinet or a call one street over to the previous school counselor, who had worked there for a hundred years, at least, and knew every student by name and lineage.

My husband, who grew up in a military home and is a soldier himself, experienced a very different school career, one my six-year-old is facing now: the mobile experience. There are transitions issues, records being lost, districts’ rules changing, counselors leaving, tryouts being over, and different shot requirements in all 50 states—all the “what if’s?” that turn into “what nows?” as you navigate through the school system. Oh, ahem, various school systems. For a small-town gal like me, it can be overwhelming, but when you know where to ask for help, it’s also far from impossible.

Recognizing the bevy of unmet needs of military families, the Military Child Education Coalition™ was created in 1998. This 501(c)(3) nonprofit worldwide organization focuses on military-connected and other highly mobile children and the unique challenges that stem from such a lifestyle. The MCEC’s goal is to ensure quality educational opportunities, while including communities: military installations, their supporting schools, concerned organizations, and caring individuals.

Early on, the Military Child Education Coalition incorporated technology into its solutions, which is why workshops and initiatives not included here, these are the materials and information sources designed to help with transitions and other school-related challenges.

http://www.SchoolQuest.org
Official description: SchoolQuest™ provides families who are planning a school move for their child with free, up-to-date critical information about the receiving school and the implications for their child’s academic progress.

In other words: SchoolQuest was created with military children in mind! The searches highlight those school districts closest to active-duty military installations. It personalizes your search by allowing you to create a profile for your child. It even has an online library and transitioning tips for every age.

Insider tip: For students with special needs, in addition to the above information, each district’s special needs coordinator’s contact information is listed, along with a checklist for parents that identifies items, records, and contacts that should be gathered for a smoother transition in both the old and the new locations.

Education Resource Center
Official description: This resource, available on the MCEC’s Web site, provides parents with an opportunity to obtain critical academic information and Web site links for all states as well as the District of Columbia and the
Department of Defense Education Activity (DoDEA).

**In other words:** You can use this site’s map to search by state and find information about school records, counselors, assessments, and school calendars—all properly ordered and easy to review.

**Insider tip:** Search quickly and confidently! Unlike other sites, the MCEC’s Education Resource Center is constantly investigated and updated.

**Aunt Peggie**

**Official description:** Aunt Peggie, one of the MCEC’s valuable researchers, has made it a point to learn about all things military and educational. An “Ask Aunt Peggie” connection can be found on the MCEC Web site as well as within SchoolQuest.

**In other words:** Aunt Peggie is a great resource, and she can answer your questions concerning school moves and transitions. She also has an “FAQ” (Frequently Asked Questions) page that is very helpful.

**Insider tip:** Aunt Peggie is a real person, Peggie Watson. She has been a teacher and administrator, and she is currently a mother, grandmother, and a kind, knowledgeable person who not only wants your questions, but also will work hard to find the answers. Really! So go ahead and e-mail her!

**MCEC Store**

**Official description:** The MCEC’s store has a variety of resources available for purchase.

**In other words:** When I moved my son to Texas last year, we were all set for kindergarten—or so we thought. Turns out, he was missing a shot that was not required in the state from which we transferred. It was one of those times that I thought, “I wish someone would write a book about…” The MCEC has written those books. They have taken those frustrations and made them answers for others. (See the abbreviated list below.)

*Getting Your Ducklings in a Row™: A Guide to Eligibility and Vaccination Requirements for Kindergarten and First Grade Entry*

This is a book that is organized by state and is helpful and easy to use.

*Preparing for the Journey™—Birth Through Grade 2*

This is a great book, filled with practical, inexpensive ideas that families can use to help spark an interest in learning. It is sectioned into age groups for easy reading. It’s an educational handbook every parent should own!

*The Military Parents’ Guide to No Child Left Behind™*

This booklet looks at the No Child Left Behind (NCLB) Act from the perspective of the military child, alerting parents to potential problems they may encounter.

*Growing, Learning, and Understanding™ (GLU™) Kits: Infants Through Early School Age*

There are several of these kits, and they are all wonderful. Each kit contains a workbook filled with useful activities that are based on a series of popular books (included as well). Each kit encourages communication and early literacy. Individual kits center on different themes, from deployment to mathematics. You’ll love the lessons they effortlessly teach, your child will love spending “fun time” with you, and the books themselves will become cherished favorites. Titles include While You Are Away, It’s Okay to Be Different, and Wild About Books. In the fall of 2008, look for Stand Tall and Finding Your Way. These are also great for the preschool classroom.

*Chart Your Course Kit™: Academic Passport, Road Map, and CD The Complete Guide to College Financing and Admissions DVD*

This kit provides practical information for the college-bound student, beginning with sixth graders! It is full of tips and organizational strategies to help students make solid choices about their educational futures.

**Insider tip:** The Military Child Education Coalition prints new books, assembles additional kits, and reviews their information all the time. Check back often to see what new items become available.


**Official description:** The Military Child Education Coalition Web site contains links to different resources for parents, educators, military families, counselors, and other professionals. It recently underwent a complete redesign.

**In other words:** You should check the MCEC Web site for updates on all sorts of useful information.

**Insider tip:** One of my favorite places on the MCEC Web site is something not often publicized. It’s called Reading Corner. You can find it by choosing the “Military” button at the top of the home page (http://www.militarychild.org/military-parent/reading-corner), and then looking at the list of links. It includes recommended Web sites, book lists, downloads, research, and assessments, all about reading and early literacy. There is so much to explore, and all of the information is well researched and useful.

*Celebrating its tenth birthday this year, the Military Child Education Coalition™ (MCEC®) is an organization that continues to grow, form new ideas, and champion the military child. You can join us! Contact the MCEC at [www.MilitaryChild.org](http://www.MilitaryChild.org); Phone: (254) 953-1923, Fax: (254) 953-1925; Military Child Education Coalition, 108 East FM 2410, Suite D, Harker Heights, TX 76548.*

Laura Campbell is a mother and a military wife. She works as the Media Specialist for Public Relations, Marketing, and Project Development at the MCEC, and has also worked as a preschool teacher. Her husband is currently deployed to Iraq.
Many United States Armed Forces servicemembers who are returning home after having served in Operation Enduring Freedom (OEF) or Operation Iraqi Freedom (OIF) are not returning home to a military base, with a military hospital and all of the coordinated care available on a base, but instead to a civilian community, where care might be spread out among various healthcare facilities and organizations. These servicemembers belong to the National Guard and Reserves of the various U.S. Military services. It is simply the inherent nature of the Guard and Reserve structure that there are no central military installations for whom they can identify, a Guardmember or Reservist returns to a civilian community, where they are meant to blend back into a non-military lifestyle—to their jobs, to their families, to the life where they left off. The problem is, in many cases this is not happening. The trauma of extended warfare has caused issues like post-traumatic stress disorder (PTSD), depression, anxiety, and, in some cases, substance abuse. Some servicemembers are returning with physical injuries, including traumatic brain injury (TBI), limb loss, and burns, all of which can lead to psychological distress. Some are having difficulty holding onto jobs that they had handled without a problem before they left. Some are losing their marriages. For some veterans, emotions like anger and fear now color their worldview and their ability to cope or thrive.

Without a comprehensive community system for oversight and care, many of these returning servicemembers are struggling day to day, just to make it through. The struggles are having an impact on their mental and emotional health and their physical recovery, their families, and their employers who are relying on them as a reliable component in their businesses.

A community in southwestern Pennsylvania is attempting to help these returning servicemembers cope and rebuild their lives. The people at the nonprofit Pennsylvania Disabled Veterans Rehabilitation/Vocational Retraining Project (PDVR/VRP) in Johnstown, Pennsylvania are executing a plan to address the unique needs of returning Guardmembers and Reservists. It is an
ambitious and well-planned undertaking and one that gives legs to the idea that we are our brothers’ and sisters’ keepers. This plan is reflected in a “Project Concept” blueprint for action (See Program Concept diagram on the EP Web site’s Military Channel at www.eparent.com/main_channels_military/index.asp). PDVR/VRP believes that if enough people in a community are made aware of the needs of returning servicemembers, and those servicemembers are made aware of the services available in their community, the servicemembers and their families will have access to the quality care, support system, and recovery that they need.

PDVR/VRP’s outreach and services are squarely aimed at helping all veterans and their families. While the supports are critical to aiding returning Guardmembers and Reservists, they are also critical to helping former active-duty veterans, those who are long retired or more recently have left the service.

The program recognizes that there are multiple aspects to a returning servicemember reintegrating back into the community, including the need for help in areas such as physical injury and/or psychological wounds, vocational rehabilitation, transitioning back to civilian employment, and housing. Tom Caulfield, president of PDVR/VRP, emphasizes that many people and organizations in a community are critical to the successful reintegration of veterans, including medical and mental health professionals, rehabilitation technicians, law enforcement officials, educators, veterans’ service organizations, and support groups.

This concept of community participation “has led to over 100 organizations that have given their support” to the endeavors of PDVR/VRP, according to Tom.

To build community awareness, both in the local environs and on a national level, PDVR/VRP held its third annual Community Response Symposium this August, drawing experts from the Departments of Defense and Veterans Affairs as well as local organizations to discuss the needs of veterans and their families and what can be done to support them.

NEXT MONTH: EP will continue its coverage of various entities of PDVR/VRP that are combining resources to aid veterans. EP hopes that this representation of community teamwork might serve as a model for other communities and that communities engaged in the care of their veterans and families might communicate with one another to build the type of infrastructure so critical to veterans’ needs.

Finding and Keeping Employment When the Road Is Long

By Maria Caroff

Sam Taylor’s transition home has posed some challenges. Sam, 26, joined the United States Army eight days after his high school graduation and then spent time in training, graduating from the Army’s Air Assault School. A member of Charlie Company, 1st Battalion, 502nd Infantry Regiment of the 101st Airborne Division, “we went on the initial assault” into Iraq, he says. He was 22 years old at the time. Sam’s tour in Iraq was from March 2003 to February 2004. “I don’t even remember before I was in,” Sam says.

Starting as a private, Sam was promoted to sergeant and served as a squad leader, responsible for himself and seven other Soldiers. Now diagnosed with post-traumatic stress disorder (PTSD), Sam says, “I think that has to do not so much with what I’ve seen as the stress I was put under,” with the responsibility of others’ lives in his hands, at a very young age. Even now, “I worry about the guys 24/7,” he says.

Returning to civilian life is like “being spit back out on Earth after it (the war) chews you up,” he says. “When I first came back, I was having panic attacks,” he said. While he has made progress in his recovery,
there are still challenges. Sam had tried a lot of different jobs on his return. “It’s pretty rough trying to work and trying to maintain some sort of level of awareness in my brain,” he says. Sam describes feeling “fuzziness” in his head. “That’s kind of what I feel like most days,” he says. However, he received help in his job search through Veteran Community Initiatives, Inc. (VCI) and he is able to maintain a job at the Defense and Veterans Brain Injury Center in Johnstown, where he does a variety of jobs in his position of environmental engineer, including public relations, paperwork, and janitorial functions. He plans to eventually begin work as a rehabilitation technician there.

**A Timeless Resource**

**Jason Jeschonek** served in the United States Navy from 1988 to 1993, and after finishing his stint in 1993, “I was having a hard time finding work,” the 38-year-old recalls. He met Tom Caulfield of the then fledgling VCI in 1994. Tom made some recommendations, and Jason received a job where he worked for a number of years, until that particular company closed. Jason again sought VCI’s services and next obtained a job at Atlantic Broadband, where he works today as an account executive. “I love my job,” he says. Over the years, Jason made a point of keeping in touch with Tom. “I let him know how I was doing and what was going on,” he says. Jason was deployed to Saudi Arabia for two months during Operation Desert Storm and counts himself fortunate not to experience any trauma from his time serving.

**Julius Strozak**, 60, a Vietnam-era veteran who served in the United States Army, had worked for the Pennsylvania Electric Company (Penelec) for over 22 years before his position was eliminated during downsizing in 1995. Referred to the Veterans Leadership Program/Veteran Community Initiatives, Julius remembers Tom Caulfield recommending that he take civil service tests to increase his employment opportunities. He had previously taken a couple of the tests, but began to take more. He initially received a temporary eight-month position with the Pennsylvania Department of Transportation (PennDOT), and afterward he interviewed and received a job at Hiram G. Andrews Center in Johnstown, where he worked as a clerk/receptionist in the counseling office from 1997 to June of this year. He is taking a little bit of time off now, but indicates that when he is ready to begin work again, he will go back to Veteran Community Initiatives to see what help they can provide.

**There’s No Place Like Home**

On September 11, 2001, **Kimberly Roberts** was living with her husband in Gettysburg, Pennsylvania, and both were excitedly awaiting the birth of their first child. The phone call from her mother on that day of tragic events brought home to Kim how far away from home she felt under such circumstances and the realization that she wanted to be back home. Home amongst family. Home where she would have a ready-made support system. Home where she could share life’s triumphs and tragedies with the people who mean the most to her.

So she and her husband returned to Johnstown, Pennsylvania, even with the knowledge that Johnstown, like many other Manufacturing Belt communities, had been facing economic challenges for decades. Jobs all too often were scarce, and many people had moved away to settle in more economically thriving communities. Yet the strong support system to which Kim, now 33, returned in 2002 included not only her family but some friends as well. They included Tom Caulfield, VCI’s President and Director, and Marty Kuhar, VCI’s Program Specialist, who were friends of her father, Randy Roberts. All three
had served in Vietnam.

“I definitely was unsure of that job search process,” said Kim, who had majored in psychology in college and indicated that in that field of study, “your path’s not clearly defined.” While in Gettysburg, Kim had worked at a residential treatment facility, providing counseling for various mental health or behavioral problems to girls and young women 6 to 19 years of age. Social services was a field she enjoyed and in which she wanted to continue. “What was really helpful was that Marty sat down and went through the human services organizations here in Johnstown,” she said. Hired in January 2004 as an employment counselor for Pennsylvania Association for Individuals with Disabilities (PAID), Kim was promoted to executive director in September 2005. Kim’s organization works with VCI to help veterans and others find employment. “It was probably one of the best career moves I could have ever made,” she says.

**Veteran Community Initiatives – Resources**

**WHAT DO I NEED TO QUALIFY?**

Veteran Community Initiatives (VCI) provides services to all veterans, including members of Reserve and Guard units. In addition, services are open to the immediate family members of veterans, as well as dislocated workers. In order to qualify for certain of VCI’s services, an applicant must provide proof of their or their immediate family member’s veteran status. VCI accepts DD Form 214 (Department of Defense Certificate of Release or Discharge from Active Duty) and will assist clients with obtaining the form, if necessary.

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**PROGRAMS**

**ALL services are provided free of charge to clients.**

**Vocational Counseling:** VCI assesses skills, abilities, experience, and interests through one-on-one counseling with the client then develops and directs each client through an informal, individual job search plan.

**Outreach:** VCI develops and maintains relationships with the general public, employers, and related service organizations in order to enhance networking opportunities for clients.

**Résumé Preparation:** VCI designs professional, skills, and accomplishment-oriented résumés that are credible and attention gathering.

**Assisted Job Placement/Networking:** VCI assists clients in networking within the employment community to develop job leads and also works closely with area Job Centers, various agencies, and employers for client placements.

**Workshops:** VCI teaches interviewing techniques, job search and networking tactics, cover letters writing, and the basic do’s and don’ts of job searching.

**Informal Referrals:** VCI provides informal referrals to other agencies for clients seeking help to overcome any difficulty (drug & alcohol, psychological, financial) which impedes the employment process.

**Job Fairs:** VCI holds job fairs on a regular basis. Job leads and local contact personnel are available to enhance networking opportunities for our clients.

**Client Thumbnail Sketches:** VCI provides employers with updated background skill sketches, enabling them to match employment needs with a client’s skills and training.

**Library:** VCI has an updated job book of openings, as well as publications and Internet access for job search purposes. A computer/printer is available for clients to create cover letters.

**Job Placement Follow-up:** VCI recognizes the importance of post-placement follow-up. A follow-up discussion with the client can often eliminate potential problems and aid in employee retention at the job site.

**Job Retraining Assistance:** At times VCI has limited job training funding available. If clients meet the criteria, they may qualify for specific funding if it will result in obtaining a job, promotion, or full-time employment from a part-time status.

**Referral Assistance:** For Veterans dealing with Post-Traumatic Stress Disorder (PTSD) and/or Traumatic Brain Injury (TBI), VCI is able to direct clients to specific professional and informal readjustment counseling programs.

**Resources are courtesy of Veteran Community Initiatives, Inc. For more information, contact: Veteran Community Initiatives, Inc., Hiram G. Andrews Center, Wing A, 727 Goucher Street, Johnstown, PA 15905; (814) 255-0355, Fax: (814) 255-0356; VVLP@SURFSHOP.NET, HTTP://WWW.VCIINC.ORG.**
The Family Reunited

Helping Kids with Special Needs Cope with Reintegration

By Ian Shaffer, MD

This is the third of a three-part series from Health Net, Inc. regarding deployment, its effects on children, and some of the steps that parents can take to ease its impact. The series covers possible behaviors and suggested responses during the times of pre-deployment, active duty, and the parent’s return home.

“My dad is in Iraq again. Over the past year, when he gets home it’s been harder and harder to talk with him. We do projects and things together, but he’s often irritable and doesn’t remember things I say.”

—15-year-old son of a servicemember deployed to Iraq

Mom or Dad, after twelve months of combat overseas, is finally coming home! What could be more perfect and easy? In fact, reintegrating a returning servicemember into family life can be quite challenging. For families with children with special needs—kids with certain developmental issues—the experience can be especially trying.

The Honeymoon

Parents who reunite after a time apart may go through a “honeymoon” period when the servicemember first returns. The returning parent comes home to familiar and comfortable surroundings, while the one who stayed behind sees a return to a parenting partnership that will make all domestic duties easier. And, of course, they have each other again.

However, there may be challenges and struggles in the reintegration process. First, the returning parent may not be ready to enter back into family life. The other parent needs to understand that he or she may not get a partner back immediately. Parents should also be aware of how the “honeymoon” affects their children. Most children—especially those who are eight years old or younger and haven’t begun to develop a sense of independence—feel that the separation during deployment was all about them. They will think having the family together again is supposed to make everything better for them. This may be especially true of children who require special attention. What they see in the early days after the return are two adults who are focused on each other and enjoying each other. Children may feel left out and not understand why. They may become resentful or depressed.

The Challenges of Change

After the initial enjoyment of having things back the way they used to be, families may find that things really aren’t the way they used to be. In fact, some may find that things were never the way they imagined, having idealized the past while the servicemember was away. The returning parent was never home all the time.

When a family reunites, what’s most obvious is how much things have changed. The returning parent may see a partner who seems more stressed, more rundown, and less patient. Changes in children may be even greater, especially in younger children and those with special needs. The child who previously made the parent proud by showing courage in overcoming difficulties and developing independence may have regressed. Or the child with whom the parent felt a special bond when they faced that child’s challenges together might seem to have broken that bond, with both individuals needing to recognize that this will need to be rebuilt.

Some behaviors commonly exhibited by children when the parent returns are:
• Seemingly unprovoked hostility toward the returning parent. From the child’s perspective, the logical reasons for this are resentment over being abandoned by the parent or feeling that the parent disrupts a comfortable routine that developed during the absence.

• Shyness or avoidance to the point of treating the returning parent as a stranger. Again, from the child’s perspective there is logic to this. Depending on a child’s age or cognitive development, the parent really may be perceived as a stranger. And, for any child, a parent who returns with physical or emotional injuries may be seen as a different person.

• Hostility toward the parent who has been at home. This may be simple rivalry for the attention of the returning parent.

• Sudden sadness and/or lethargy after the excitement and energy that greeted the return. This may be the natural letdown after the initial glow of the reunion has faded, especially as the child sees that things are not the same as the day before the deployed person left.

• Clinging behavior in an attempt to keep the returnee from leaving again.

Of course, such behaviors may be temporarily reasonable but should change over time. However, if they go on for more than a couple of weeks or at an intensity that interferes with family relationships or prevents family members from functioning, consult your doctor or a therapist.

**Making the Family Whole Again**

Here are things you can do to ease the reunion of your family and make the most of a parent’s return from deployment:

• Use the positive atmosphere of the “honeymoon” not only as a period of enjoyment, but also as a time for the family to get reacquainted. Take note of changes and help your child understand the concept of readjustment. Embrace the idea of reintegration and adjustment and how this will benefit the entire family. Be open and willing to talk about the changes.

• Don’t force things with children. Be available to them and show your willingness to talk, but allow them to come to you. As before, answer questions that are asked. Children at different stages of development will ask for varying amounts of information and will ask questions as they are ready to absorb more.

• Talk to children in age-appropriate and developmentally appropriate terms about your experiences while on deployment. In general, the younger the child, the less specific and the more positive you should try to be.

The return of a parent who is recovering from or adjusting to an injury suffered during deployment can have special significance for a child with special needs. Is there fear that a symbol of strength has been diminished? Or is there a feeling of empathy for and closer identification with the injured parent? What’s certain is that the way the parent deals with his or her own “special need” may profoundly affect the child’s outlook.

The many positives the parent’s return entails are enough to help most families get through the inevitable rough spots they encounter. But some families do struggle. If you do, don’t feel that you’re alone. Enough families have a tough time post-deployment that resources have been created to help. If your family is having trouble readjusting, seek such help. You’ve waited a long time to be reunited; make it worthwhile by meeting the challenges head on.

**Online Resources**

The first two installments of this series—Young Heroes: Preparing Military Children for a Parent’s Deployment (July 2008) and Staying Strong: Coping with Deployment (August 2008) include lists of Web sites for organizations and publications that are helpful for families with children with special needs who are dealing with deployment. Please refer to those articles. Also, the following online articles contain useful information:

- **Military Child Education Coalition**
  How to Prepare Our Children and Stay Involved in Their Education During Deployment  www.militarychild.org/files/pdfs/DeploymentBooklet.pdf

- **National Military Family Association**
  Reunion and Post Deployment: Homecoming Tips, www.nmfa.org/site/PageServer?pagename=reus_deploymentlinks (Information appears close to the bottom of the page.)

- **Department of Defense Deployment**
  Health and Family Readiness Library

Dr. Ian Shaffer is a child psychiatrist and the chief medical officer at MHN (https://www.mhn.com/home.do), the behavioral healthcare subsidiary of Health Net, Inc. (https://www.healthnet.com/portal/member/home.do), serving the needs of 10 million members, including many military personnel and their families.
United States Military Section

News Briefs for Exceptional Families

Marine Veteran Hosts Live Internet Show Profiling the Sacrifices, Courage of U.S. Servicemembers and Their Families

Internet users can catch a glimpse into the daily lives of U.S. servicemembers and their families in a new, exclusively online show called IN THEIR BOOTS (www.intheirboots.com). Hosted by Iraq veteran Jan Bender, the show mixes traditional documentary filmmaking with a new media distribution model. IN THEIR BOOTS is an innovative new series that explores the emotional, psychological, and physical impacts that the wars in Iraq and Afghanistan have on communities here at home.

Every episode of IN THEIR BOOTS is built around an IN THEIR BOOTS "Real Story," a 10-minute, pre-produced documentary told from the perspective of men and women in uniform and their families. The "Real Stories" combine intimate and personal "character-generated" video footage shot by the stories’ participants themselves, with footage shot by the series’ professional production team. The stories stress optimism, the courage of the characters, and the value of the people and organizations that help them on their journey.

Each episode concludes with a moderated forum, broadcast live and hosted by Marine Jan Bender, who served as a combat correspondent/rifleman in Iraq with 3rd Battalion, 1st Marines from 2004 to 2005. Participants in the "Real Story," newsmakers, and experts take part in a discussion on the subjects featured in the episodes. Then, through interactive, new media technology, Bender fields live webcam questions from the viewing audience, allowing viewers to take part in the discussion.

IN THEIR BOOTS is funded by a generous grant from the Iraq Afghanistan Deployment Impact Fund (IADIF). IADIF was established to address the unmet needs of men, women, and families affected by deployment to Iraq and Afghanistan and is administered by the California Community Foundation.

Brave New Foundation is a unique organization that creates media for social justice. The Foundation inspires communities, organizations, and individuals to engage in civic participation, and promotes the democratization of media.

U.S. Department of Labor Initiative: America’s Heroes at Work

The U.S. Department of Labor recently announced a new online resource to help employers in their employment of veterans with traumatic brain injury (TBI) and post-traumatic stress disorder (PTSD), two increasingly common battlefield conditions. The new America’s Heroes at Work Web site (http://www.americasheroesatwork.gov) provides information about TBI and PTSD as well as tools and guidance on how to implement workplace accommodations and other services that benefit affected individuals. In addition, the Web site includes the toll-free phone number of the Job Accommodation Network (http://www.jan.wvu.edu), which employers can call to receive personal assistance relating to job accommodations for veterans with disabilities.

“This America’s Heroes at Work initiative focuses on the employment challenges of returning servicemembers who are living with traumatic brain injury and post-traumatic stress disorder,” said Secretary of Labor Elaine L. Chao. “One of the best ways we can help these courageous men and women and honor their sacrifice is to help them return to full, productive lives through work. Employment can also play a role in their recovery.”

Although their injuries may not be visible, people with TBI or PTSD may face some difficulties—especially with respect to employment. In many cases, a few reasonable workplace supports can help resolve these issues. Through America’s Heroes at Work, employers can leverage a variety of promising practices, such as job coaching and mentoring programs to create a positive, successful workplace experience for disabled veterans and non-veteran employees, such as first responders, who have experienced traumatic events.

America’s Heroes at Work is managed jointly by the Department of Labor’s Office of Disability Employment Policy and the Veterans’ Employment and Training Service, in collaboration with other federal and private agencies engaged in TBI and PTSD programs, including the Department of Defense, the Department of Veterans Affairs, the Department of Health and Human Services, the Department of Education, the Social Security Administration, and the Society for Human Resource Management.

Source: Department of Labor

In EP’s July issue, the article entitled, “Fisher House Homes,” which appeared on page 76, contained two inadvertent errors. In paragraph six, the sentence should have read: Down to the tiniest detail, the building of a Fisher House home is carefully thought out so that military families are served with the greatest sense of compassion and care during a most challenging time. In paragraph seven, the sentence should have read: The homes feature every modification individuals with disabilities need to comfortably move about the home and function with ease, including elevators, power boosters on doors, ground-level laundry facilities, wider hallways, lower beds for easy transfer from wheelchairs, and durable furniture. EP apologizes for these errors, which occurred in EP’s production process.
COVER STORY
Financial Planning: What to Do When Your Child Turns 18

Planning Strategies from Mid-life and Beyond

Seven Wonders of the World of Disabilities

UNITED STATES MILITARY SECTION
Wounded Warriors & Pain Management Issues
Sleep Disturbances and PTSD

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Sleep disturbances are a major symptom of post-traumatic stress disorder (PTSD). In the *DSM-IV-TR* (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision), the official diagnostic manual of the American Psychiatric Association (APA) in the diagnosis of PTSD, the presence of nightmares (recurrent distressing dreams of an event) is part of the *DSM*’s Criterion B (reexperiencing of the traumatic event) and difficulty falling or staying asleep are part of Criterion D (increased arousal)—i.e., sleep disturbances comprise two of the five criteria required for the diagnosis of PTSD.

One or both of these features is experienced in up to 90 percent of patients with PTSD. These symptoms are considered particularly distressing by patients and have a highly negative impact on their quality of life (QOL). Additionally, there is evidence that impaired sleep contributes to physical and mental disorders associated with PTSD and is a contributor to the development and/or is a perpetuator of PTSD itself.

Sleep disturbances also play a role in substance abuse—especially alcohol abuse—as people attempt to self-medicate to avoid the distress associated with disturbed sleep and/or nightmares. Patients also respond to disturbances such as nightmares by engaging in behaviors in which they avoid sleep, resulting in insomnia. These sleep difficulties have a major adverse impact on patients with PTSD. The effective treatment of sleep disturbances is associated with beneficial consequences that go beyond improved sleep and decreased nightmares.

**Seeking Effective Treatments**

A variety of treatments have been tried, and some have shown greater results than others.

Unfortunately, sleep disturbances frequently do not respond to selective serotonin reuptake inhibitors (SSRIs), the major treatment for PTSD. Indeed, SSRIs may, at least initially, make insomnia more severe. The new generation of “atypical antipsychotics” (e.g.: quetiapine, olanzapine, and risperidone) may be helpful but are associated with side effects that include sedation and weight gain. Recently, however, new treatments have been developed that are more effective for sleep disturbances. These new treatments have been developed, in part, because of increased understanding of the pathophysiology (the accompanying functional changes) of PTSD.

**Understanding Sleep**

Sleep is divided into a variety of stages. The major division is that between rapid eye movement (REM) sleep and non-REM sleep. Most, but not all, dreams occur during REM. Additionally, during REM, the body is essentially paralyzed. The paralysis is useful in that it prevents people from acting out their dreams. The brain waves in REM are very rapid and desynchronized. Non-REM sleep is divided into three stages. Here, we look first at the third stage. It is the deepest sleep and is known as slow-wave sleep (SWS), because the brain waves recorded during this type of sleep by electroencephalogram (EEG) are slow. They are also synchronized. It is thought that slow-wave sleep is the major restorative sleep. The amount of this sleep will determine whether you...
feel you have obtained a good night’s rest when you awake in the morning. Stage 1 and 2 sleep is intermediate between REM and slow-wave sleep with respect to rate and degree of synchronization. While the majority of dreaming occurs during REM, it also occurs during other stages, particularly if the sleep is light and the sleeper can be easily awakened.

Understanding PTSD and Sleep
It is thought that PTSD is associated with a failure to process and neutralize frightening memories. This failure allows frightening memories to push in during waking and sleeping hours. Because processing normally occurs during sleep, particularly REM sleep, and nightmares disrupt sleep, a vicious cycle begins, in which the processing of frightening memories is compromised. This has led to the use of a variety of psychotherapies to enhance processing and neutralization of frightening memories to decrease their ability to disturb sleep and to enhance sleep-mediated processing of disturbing thoughts. Alternatively, there are medications that decrease disturbing dreams. The effect of medications on processing frightening memories is unclear, but the two approaches may be complementary since medications may be helpful in breaking the vicious circle noted above.

All Systems Not Go: Some of the Difficulties
Stress in general, and PTSD, in particular, is thought to be associated with activation of the noradrenergic system (NAS). The noradrenergic system consists of the neurotransmitter norepinephrine and its receptors, which are found in the central nervous system and throughout the body—on nerves, blood vessels, and organs, including the heart. There are many types of noradrenergic receptors, alpha (alpha1 and alpha 2) and beta. The noradrenergic system is thought to play a role in the transition from acute stress disorders to chronic stress disorders and to be central to the symptoms in established cases of PTSD. Alpha receptors are believed to have the predominant role in these symptoms, including sleep disruption and intrusions of unwanted and frightening thoughts while patients are awake or asleep. The understanding of the role that the noradrenergic system plays has led to the use of medications that block the noradrenergic system as a way of treating sleep disorders and nightmares.

Evidence for the role that the noradrenergic system plays includes the following: Many of the areas of the brain thought to be associated with PTSD symptoms are heavily stimulated by noradrenergic (NA) neurons and express a high density of noradrenergic receptors. They are very responsive to activation of the system. Furthermore, concentrations of noradrenergic neurons in the cerebrospinal fluid (CSF) are highly correlated with the severity of symptoms of PTSD, and excretion by noradrenergic neurons of Norepinephrine and its metabolites are increased in the urine of patients with PTSD.

Laboratory studies show that increased noradrenergic activity has a variety of bad effects on a person’s REM sleep. These include the diminishing of REM-associated paralysis, leading to increased movements during REM, which may lead to waking up. In addition, shifts from REM to other stages are increased. Thus, noradrenergic system activation is associated with REM fragmentation (waking up throughout the night, reducing the total amount of time spent in the deeper levels of sleep). Poor-quality REM sleep, in addition to leading to awakenings, also prevents a person from processing stressful memories. This leads to waking up more often and decreased processing. In addition, NA stimulation is associated with the lightening of types of sleep other than REM and increased levels of corticotrophin releasing factor (CRF). Corticotrophin releasing factor is a hormone produced by the hypothalamus that leads to anxiety, including an increase in a person’s primitive internal alarm system. Furthermore, it leads to release of Norepinephrine by noradrenergic neurons, which in turn leads to further release of corticotrophin releasing factor, again, increasing a person’s anxiety level.

The Role of Medications
All this suggests that medications that interfere with the noradrenergic system might be useful in PTSD. Clonidine is one such medication. It is an activator (agonist) of the type 2 alpha receptor, a receptor that decreases noradrenergic neuron release of Norepinephrine. Thus, clonidine causes the noradrenerg-
Sleep Disturbances

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Disturbances occurring before the stressor may predict the later occurrence of PTSD. The plausibility of these reports is supported by observations that sleep deprivation is well known to interfere with a person’s ability to cope in general and to impair mood. Furthermore, as discussed, normal sleep, including REM, is thought to play a role in processing memories of trauma, which are central to PTSD. All of these may increase a person’s vulnerability to PTSD. Consistent with this possibility, there are reports that early treatment of sleep disturbances during periods of acute stress may prevent the development of PTSD, and a number of studies have shown that treatments directed at sleep disturbances and nightmares may decrease other symptoms of PTSD. While treatments that focus on traumatic memories may decrease symptoms of PTSD, unless attention is paid to sleep disturbances, patients often continue to suffer from insomnia and nightmares, which, according to these models, may perpetuate PTSD.

The possible interactions of sleep disturbances and PTSD are compatible with several models of the relation of stress, sleep, and PTSD, each of which may hold for different patients: 1) Sleep abnormalities, regardless of cause, predispose one to the development of PTSD after an acute stressor; 2) Sleep abnormalities resulting from acute stressors may cause PTSD—i.e., sleep disturbances mediate the relationship between acute stress and PTSD; and 3) Sleep disturbances and other PTSD symptoms develop in response to the acute stressor, and sleep disturbances may be resistant to standard PTSD therapies that do not explicitly deal with them. If any of these three relationships hold, it is clear that treatments must explicitly focus on sleep disturbances to obtain optimal results with PTSD.

**Fine-Tuning Understanding**

Recent studies have indicated that PTSD is often associated with sleep-disordered breathing. Two explanations for this association have been advanced, both of which are plausible and may co-occur. As has been described, sleep, including REM sleep, is broken up in patients with PTSD. It has been shown in experimental settings that such sleep fragmentation is associated with an increased tendency for airway collapse. While such airway collapses may not be of magnitude to cause sleep apnea (a temporary suspension of breathing occurring repeatedly during sleep), with its easily observable arousals, gasping for breath, snoring, etc., they can cause hypopneas (abnormally slow, shallow breathing), which trigger microarousals that serve to restore sufficient airflow—i.e., hypopneas lead to further sleep fragmentation. This is known as upper airway resistance syndrome (UARS). These apneas or hypopneas have been shown to lead to nightmares or at least to impart negative emotional tones to the dreams associated with them. Thus, it is clear how a vicious cycle could result, leading to both nightmares and fragmented sleep.

Disruptions of other phases of sleep lead to lack of restorative sleep (sleep that leaves a person feeling that he or she has had a good night’s rest). This decrease is often associated with daytime sleepiness and/or a lack of energy. Other signs of sleep-disordered breathing include: morning headaches, dry mouth, nocturia (waking up to urinate), and cognitive-affective disturbances, which include depression, anxiety, attentional problems, and memory disturbances, among others. Since upper airway resistance syndrome may require state-of-the-art technology for its detection, sleep-disordered breathing often remains undetected and hence ignored. Aside from the technical difficulties associated with the detection of subtle forms of sleep-disordered breathing, their neglect in part results from the tendency of both doctors and patients to focus most on the psychological aspects of PTSD as the explanation of symptoms, including sleep disturbances.

It has been proposed that in at least some cases, sleep problems that persist after psychological and/or pharmacological treatments result from sleep-disordered breathing continuing. Indeed, it has been shown that in some cases, treating PTSD by continuous positive airway pressure (CPAP) alone, which is the gold-standard treatment for sleep-disordered breathing, and without any psychological intervention, not only alleviates sleep problems but can also cause a dramatic relief from other PTSD symptoms, underscoring the potential causal or mediating role of sleep problems, including sleep-disordered breathing in the genesis of PTSD. Since many patients with PTSD find that continuous positive airway pressure may produce claustrophobia and anxiety, conservative approaches such as instruction to sleep on the side instead of the back, attention to nasal hygiene, or the use of nasal dilator strips may be used first. The latter techniques clear the nasal passages, thus decreasing airway resistance and, hence, mini-collapses. Periodic limb movements in sleep, which disrupt and fragment sleep are also increased in patients with PTSD, probably due to increased noradrenergic tone.

**Psychological Treatments**

In addition to medication and treatments for underlying sleep-disordered breathing, there are a variety of psychological approaches to the treatment of sleep disturbances. One of these, imagery rehearsal therapy (IRT), focuses on the symptom of disturbing nightmares. In this treatment, patients are taught techniques of imagery and how to apply these to their nightmares. Two
Sleep Disturbances

types of instructions have been employed that are equally effective.

In one of these, patients are asked to remember a nightmare, write it down, and then change the ending in any way they deem helpful and rehearse the new “dream.” This is often done in group sessions. This technique has been shown to have ongoing positive effects on the number of nightmares per week and the number of nights without nightmares. Furthermore, insomnia is often improved because of the decrease in sleep disturbances resulting from nightmares and a decrease in protective behaviors adopted in attempts to ward off nightmares. (These protective behaviors include: delaying bed time, getting out of bed when waking rather than trying to get back to sleep, sleeping with lights on, substance abuse, and others). PTSD symptoms often decrease as sleep improves. Some patients find that imagery rehearsal is stressful and may increase fears. These negative effects may be decreased by first teaching patients how to employ pleasant imagery and having them start with less fear-inducing dreams (e.g., those not dealing explicitly with the traumatic events and limiting imagery rehearsal to one dream per week).

A second form of psychotherapy dealing with sleep issues is Sleep Dynamic Therapy® (SDT), which includes a multitherapeutic focus on sleep issues in addition to imagery rehearsal therapy for nightmares. Sleep Dynamic Therapy consists of six two-hour sessions given weekly in a group format with an emphasis on psychoeducation and sleep-directed cognitive behavioral therapy (CBT). Sleep-directed cognitive behavioral therapy involves identifying stimuli that either interfere with or help with sleep, together with identification and abandonment of maladaptive habits that interfere with sleep. The psychoeducation includes identification of symptoms of sleep problems, including lack of restorative sleep, daytime sleepiness, and frequent awakenings, etc., which are often ignored because of the other obvious symptoms of PTSD. In addition, proper bedtime habits (good sleep hygiene) are taught.

Increasing Understanding

While the importance of nightmares and insomnia as symptoms of PTSD has long been appreciated, it is increasingly becoming apparent that this may be only the tip of the iceberg. Other types of sleep abnormalities such as sleep-disordered breathing and periodic limb movements in sleep are apparently common and may play a role in insomnia or nightmares. Importantly, not only are sleep disturbances major sources of distress for patients with PTSD, but they may play key roles in causing or perpetuating the disorder. They may also contribute to substance abuse, particularly of alcohol. While alcohol may help patients fall sleep, there is a rebound awakening. Furthermore, sleep worsens during withdrawal. These factors lead to increasing amounts of alcohol consumption. Fortunately, there are an increasing number of treatments available for sleep disturbances (e.g., imagery rehearsal therapy, Sleep Dynamic Therapy, pharmacotherapy, and, in some cases, continuous positive airway pressure). Yet in order for these treatments to be effective, the sleep problems must be noted. While it is hoped that clinicians are becoming more aware of the prevalence and importance of sleep disturbances, it behooves the patient to bring them forward if the clinician does not focus on the issue.

Patients’ descriptions of sleep disturbances are the gold standard for their identification. While polysomnography (EEG, eye movement, and muscle activity measurements obtained during sleep) may be helpful in identifying and/or confirming some cases of sleep disturbances, there are many false negatives. This is because sleep laboratories, and even home monitoring, induce feelings of safety in many patients with PTSD. The partner may supply invaluable information regarding sleep-disturbance symptoms.

Determining a Person’s Options

Further studies are required to determine how to optimally use the great variety of treatments now available for sleep disturbances, including nightmares, associated with PTSD. Among the questions requiring answers is this one: Is there one “best” treatment or, as is more likely, are different clinical patterns associated with different responses to a given treatment? Medications may improve sleep and decrease nightmares while psychotherapy may help with the reprocessing of traumatic thoughts. Since at least some good-quality sleep is required for optimal reprocessing, the two techniques are likely complementary. In view of this, should medications and psychological therapies then be used at the same time or in sequence? These and many other questions need to be answered.

Since it is likely that different treatments and/or their combinations may be required for a given patient, patience and persistence will be required while sequential trials are performed. But it is fair to say that this should be done with a spirit of optimism and conviction that an effective treatment regimen will be found. Not only may such treatments alleviate a decreased quality of life for individuals due to sleep disturbances, but they may also improve other PTSD symptoms. •

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“Bloom where you are planted” is sage advice that parents have passed down through the ages to their children. It is especially wise counsel for the military child who faces new environments on a regular basis. But in today’s complicated, fast-moving world, filled with choices, opportunities, and myriad pathways from which students with disabilities may choose after high school, how do military parents— or any parents for that matter—find the optimal post-secondary option for their child? In planting a patch of ground, much thought and cultivation goes into planning the garden before the first seeds are sown. Likewise, early encouragement and forethought given to students, with particular attention paid to mastering the skills of self-determination and self-advocacy, will better position them for success. Being a prepared gardener will help you avoid potential pitfalls and problems in your student’s transition.

As the exceptional student begins to set his or her post-secondary plan, it is essential that the parents shift from the role of “advocate” to the role of “supportive partner and ally.” The student must learn to become his or her own advocate, in order to ensure success at the post-secondary level.

Knowing your child’s particular strengths, identifying appropriate post-secondary options, and understanding the laws affecting your choices can seem daunting. But as any good gardener can tell you, will is the root and knowledge is the stem and leaf. Knowledge about your individual student can first be gained through your child’s input and feedback. Encouraging self-knowledge can result in a refined understanding within your student of his or her unique abilities and skills and the possibilities for action within his or her control—and, ultimately, in an increase in both confidence and competence. Second, as a parent, you know your child’s abilities and preferences best, and this adds a valuable perspective to your bank of information. The development of an individual learning profile, in conjunction with career assessment and vocational evaluation tools (available commercially and through your school system), are other opportunities for targeted information gathering. Last, grow your store of knowledge by digging into your current community, state, and federal networks and associations. The educated gardener knows that information is like fertile soil. If it is not cultivated, nothing can be harvested.

Many laws and regulations govern colleges and universities. In the United States, all institutions of higher learning must adhere to the standards established in the Family Educational Rights and Privacy Act (FERPA). Under the standards of FERPA, colleges and universities communicate directly with the student, treating the student as an adult and protecting his or her privacy. The student must prepare to become his or her own advocate, or grant you, as the parent, access to his or her university records by signing a FERPA waiver. Some colleges and universities will offer a universal FERPA waiver, while others will require the student to authorize release of information each and every time the information is being shared with someone other than the student.

Having prepared the soil and learned all you can about propagation, it is time to assemble your team and tools. Keeping your student as the center of focus, a collaborative support team can be formed to match transition services to the needs of your military child. Along with the student and parents, this collective group may include special and general education teachers, counselors, vocational education counselors and case managers, special education coordinators, career technical education teachers, administrators, transition specialists, and service providers. The cooperative gardener will find many hands make light work when they have gathered their interdisciplinary team with access to the best practices and current resources.

Under the Americans with Disabilities Act (ADA) of 1990, all colleges and universities are required to provide proper accommodations to the exceptional student. Cultivating a relationship with the Dean of
Students office or the Student Services staff is an important first step when assembling your team and tools. The Dean of Students office will have a staff member who works as a liaison and advocate on behalf of exceptional students; however, your student must self-identify and file all of the necessary documentation. Building this relationship early is advised. If possible, meet with someone in the Dean of Students office during your initial campus visit or orientation session, and continue to cultivate that relationship as your student progresses through the college experience. Be sure that your student understands what documentation must be provided in order to receive necessary accommodations. Be aware: The documentation requirements may differ from one state to another, so be sure to work very closely with the Dean of Students liaison.

Whether your student is choosing college or a career/technical education as his or her post-secondary aspiration, designing and following a landscape map is critical to successful transition. Plot the long- and short-range goals, ambitions, and needs (including financial, transportation, housing, medical, accessibility, family support, and community services) of your student within the broad categories of career/vocation, education, independent living, and leisure, to chart your specific pathway to a favorable outcome. Keeping this timeline and set of steps front and center as your blueprint for success will enable you as the planning gardener to better guide the transition progress.

Colleges and universities offer a multitude of planning tools in order to ensure timely completion of undergraduate coursework. Academic advisors will work with the student to create a plan of study or a “four-year plan” to map each semester’s courses. The student, academic advisor, and parents should refer to this course plan at least once a semester, prior to course registration, in order to track the student’s progression toward graduation.

Changes in the weather and soil conditions can drastically affect the best intentions of any gardener, so regular review and revision of your military student’s transition plan and position is necessary. Tracking your child’s progress—beginning with the first Individualized Education Program (IEP) meeting through the post-secondary option identification and beyond—as well as recurring communication allows everyone involved in the transition activity to stay connected and relevant, and better able to address and overcome barriers and challenges as they are confronted. For the gardener, without constant watchful care, a garden—any garden—rapidly returns to the state of the uncultivated countryside around it.

It is important that your family recognizes the transition you will experience as your student prepares to enroll in a post-secondary institution. Your family must communicate openly about each member’s expectations during this transition period. Student and parents should discuss academic and social expectations as well as family expectations. With a good plan and the proper support, your student and family will quickly adapt and begin to flourish.

As we encourage and inspire our students with disabilities to realize their objectives after high school, the common goal of a meaningful life is our desire for all students and should be our shared purpose. Throughout this article, assisting the student with disabilities in their post-secondary transition has been compared to conceiving, planning, and minding a garden. In the end, both endeavors are an exercise in optimism—sometimes it is a triumph of hope over experience. Whether the result is a horticultural masterpiece, or only a modest vegetable patch, it is based on the expectation of a glorious outcome. This hope for the future is at the heart of all gardening.


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As more and more severely wounded servicemembers return from the wars in Iraq and Afghanistan, the challenge of caring for these individuals and their families has become increasingly taxing for the existing Department of Defense (DoD) and Department of Veterans Affairs (VA) healthcare systems. As the VA struggles to accommodate the increased demand for services, patients are increasingly being referred to civilian practices. Additionally, many servicemembers are National Guardmembers and Reservists, who are not eligible for care within these military and veterans healthcare systems and will have to return to their civilian healthcare providers. Providing the vital medical and mental healthcare needed for all those affected by military service is greatly challenging the existing healthcare resources in our country.

With the higher survival rates of wounded from the current conflicts, many individuals are seeking treatment for profoundly complex physical and mental health injuries that have not been dealt with before.

Since the beginning of these wars, over 1.5 million servicemembers have been deployed, and over 33,000 have been severely wounded, suffering battlefield injuries that in previous wars and conflicts would most likely have been fatal. However, because of improvements in battlefield medicine, body armor, and medical evacuation, these wounded warriors are surviving. But many will face lifetime challenges, including chronic pain due to the complexity and severity of their wounds. Injuries from improvised explosive devices (IEDs) are causing traumatic brain injury (TBI), traumatic amputation (the loss of a body part that occurs as the result of an accident or trauma), multiple fractures, shrapnel wounds, and post-traumatic stress disorder (PTSD).

These injuries often leave the wounded with lifelong consequences, including chronic, disabling pain and the resulting impact on their ability to perform daily activities that were once taken for granted. These injuries can profoundly impact the overall quality of life for an individual and his or her family system. Many times, these individuals are young adults with young families, whose lives are now changed and challenged as they struggle to redefine roles, expectations, and financial responsibilities. These issues are further compounded as the individuals and caregivers try to obtain effective pain management, with the comprehensive, integrated options that are necessary for optimal treatment. The wounded, their families, and their caregivers will require information, resources, and the support of their communities to ensure that these individuals have the necessary means to improve pain care and function and to regain a maximum quality of life after surviving such complex and severe injuries.

Right now, when soldiers are wounded in combat, the options for pain management are limited. Morphine is often the only choice available until the individual can be stabilized for transport to Landstuhl Regional Medical Center in Germany or to another facility. When untreated or undertreated, acute pain or pain resulting from a wound can often predispose a person to developing chronic pain later. Improvements in options available to wounded servicemembers could help to deter the development of chronic pain.

Once servicemembers who have experienced battlefield wounds are stabilized in Germany, transport is arranged to one of the medical facilities within the DoD, where experts in combat trauma are available to provide continued care and rehabilitation. These facilities include: Walter Reed Army Medical Center, in Washington, DC; National Naval Medical Center, in Bethesda, MD (also known as the Bethesda Naval
American Pain Foundation
A united voice of hope and power over pain.

Hospital; and Brooke Army Medical Center, at Fort Sam Houston, in San Antonio, TX.

Once this initial care is completed, if servicemembers remain on active duty they will continue their care with- in the DoD healthcare system. If they are medically retired and discharged from active duty, care is trans- ferred to the VA healthcare system. Currently, there are about 150 VA facilities and about 800 outpatient clinics available to provide service. However, additional resources will be needed due to the number of severely wounded adding to the already increasing demands from an aging veterans population. Current data from non-severely injured servicemembers from Operation Iraqi Freedom (OIF) and Operation Enduring Freedom (OEF) registering for VA care indicate that pain problems will be among the most common complaints for all returning servicemembers, and that pain prevalence may surpass rates observed following the Persian Gulf War. Wounded servicemembers returning from Iraq and Afghanistan are expected to overwhelm pain clinics.

Many servicemembers are not eligible for care within these systems and so must find care within the civilian healthcare system where oftentimes the severity of the wounds suffered and the complicating comorbid condi- tions (e.g., chronic pain and PTSD) are unfamiliar to civilian providers. Additionally, many local community hos- ptals and healthcare centers are currently operating at maximum capacity, making an increase in demand for services difficult to meet. The constrained availability of providers who specialize in pain management and can provide comprehensive care is increasingly problematic.

Because so many civilian contractors have provided services in Iraq and Afghanistan, contracting companies are also finding that some of their employees are experi- encing the same severity of wounds as military per- sonnel. These individuals are not eligible for care within the DoD or the VA healthcare systems and will need to rely on resources within their communities to ensure management of chronic pain in addition to the other care needed for their wounds to heal.

Due to the extent of their injuries, pain is often the pri- mary diagnosis for severely wounded servicemembers. It requires readily available, effective options to decrease their pain and improve their function and quality of life. When pain is not effectively controlled, the individual is affected physically, psychosocially, spiritually, and fre- quently economically, due to loss of income.

Unfortunately, many wounded within the active-duty and veteran communities with chronic pain are uncom- fortable acknowledging and accepting their condition and will delay seeking treatment for chronic pain. They may feel there is a stigma attached to talking about pain, where it has at times been perceived as a weakness or an inability to perform their job. Many times, their wounds are not physically visible, leaving the wounded feeling embarrassed about discussing or communicating with their healthcare provider regarding pain. Yet untreated pain can be debilitating, draining, and depressing for the individual, leaving him or her feeling isolated, irritable, and overwhelmed. Caring for the needs of family mem- bers, including spouses and children, requires energy and resources that their bodies frequently simply do not have as they attempt to cope with daily, unrelenting pain.

Active-duty servicemembers and veterans have a high incidence of psychological distress and other medical comorbidities, including PTSD, depression, substance abuse, and suicide. (A comorbid condition is one that exists simultaneously with another medical condition.) Chronic pain often goes hand in hand with PTSD and depression. Left untreated, these conditions can be over- whelming to the individual. Encouraging those who are wounded and suffering from chronic pain to seek care is only the first step. There also must be resources available within all of the healthcare systems and the communities who care for the wounded to provide consistent, effective, readily available options for pain treatment and care.

Untreated or undertreated pain can impact individu- als, family members, and caregivers as they struggle to cope with the burdens of military separation and subsequent war-related stress as well as these painful, debili- tating injuries. Spouses are often the first to open lines of communication regarding how pain affects their loved one and their ability to perform activities and enjoy life. Unfortunately, they are also often the ones who suffer along with the person in pain. Family mem- bers, including children, will often have to perform jobs or tasks that the wounded are no longer able to perform, because they are just too painful. Physical disability may also prevent them from performing extra activities they once enjoyed. Family resources may be stretched beyond current capabilities, physically and financially, increasing the stress levels for spouses and children. Divorce rates have increased among returning veterans, and this is affecting children. Teachers, clergy, and other community service groups will see an increase in mem- bers who are affected by chronic pain.

Communities must rally around their war-wounded. As indi- viduals and families struggle to adjust to the effects of having
suffered combat wounds and the ongoing pain that so often accompanies them, treatment options need to be developed and made available so that the cascade of detrimental effects from untreated or undertreated pain is lessened or eliminated.

This means that all healthcare systems need to be proactive in educating the professionals who will care for these wounded warriors about the most effective options for treating the complexity and severity of their pain. There also must be resources for providing improvement in access to care, and a decrease in wait times within the DoD, VA, and community healthcare systems.

Research on acute and chronic pain care needs to be supported to explore the most effective methods of managing pain, given the unique combat injuries suffered today. Education and support for the individual, his or her spouse, and other family members, including children and caregivers, need to be made available so that they understand the most effective way to communicate with their healthcare provider, advocate for the care they need and deserve, and reduce their sense of isolation.

Communities need to raise awareness of the impact of untreated and undertreated pain and enact legislation to support programs and facilities to ensure that resources and support are available to active-duty and other military servicemembers, to veterans, and to civilians who have suffered painful injury during combat as well as all of those within their circle of care.

For additional information, resources, online support and discussions, and ways to become involved with current legislation to support those who experience ongoing pain, and their families and caregivers, please contact the American Pain Foundation at http://www.painfoundation.org, or at: 201 North Charles Street, Suite 710, Baltimore, MD 21201-4111; 1-888-615-7246; info@painfoundation.org.

Founded in 1997, the American Pain Foundation (APF) is an independent, nonprofit 501(c)3 organization serving people with pain through information, advocacy, and support. APF’s mission is to improve the quality of life of people with pain by raising public awareness, providing practical information, promoting research, and advocating to remove barriers and increase access to effective pain management. •

Brenda Murdough, MSN, RN-BC currently serves as the American Pain Foundation’s coordinator of the Military/Veterans Initiative where she advocates for pain management needs of veterans and military personnel, their family members, and caregivers. Brenda has a Master of Science degree in nursing and is board certified in pain management.

Thank You to Our Veterans and to Those Currently Serving

Veterans Day is Tuesday, November 11

On this Veterans Day, November 11, 2008, EP would like to thank all of the men and women who have served and who are currently serving in the United States Military and in Homeland Security. We thank you, servicemen and servicewomen, wives and husbands, sons and daughters. We thank you, mothers and fathers, grandmothers and grandfathers, aunts and uncles, girlfriends and boyfriends, cherished friends, all who love someone who has served or who is currently serving. We know that each of you is affected by the way of life and uncertainty that is unique to military service. We appreciate your courage, commitment, and your daily sacrifices. We offer you our heartfelt wishes for your daily care and protection.

May you all be safe and prosperous.
R&R — Return and Reunion

By Jodi O’Donnell-Ames

In the September edition of Exceptional Parent magazine, I wrote the article, “Coming Home Different.” That particular article was geared toward teens of returning soldiers, suggesting tips to make the transition easier for you, your parents, and your family. Amid my suggestions, I promised that I would be back with a second article. Here, in “R&R — Return and Reunion,” I again concentrate on YOU and YOUR specific needs, this time when reuniting with your parent.

While conducting my research for R&R, I found out both good and bad news. Which would you like first? Good! The good news is that I had plenty of materials to leaf through regarding this topic. (challenges experienced by teens of deployed and returning soldiers). This fact means two things: 1) that many of us recognize that children and teens, in addition to adults, feel the effects of war and 2) that there are available resources to help and support you and your family during this adjustment process. That’s all good to know. So, what’s the bad news (not really bad, just a fact)? The challenge is not easy, right? Well, not everything is just perfect, right? While you’re not the “littlest” members, I would like to do the same for you. I’m not as cute as Elmo, but I believe that teens of servicemen and servicewomen should be acknowledged for their roles as military family members. It is not an easy role, and I commend you for facing the challenge and doing your best.

With that in mind, let’s get back to your needs. Your parent was deployed, you impatiently awaited their return, now he or she is home and everything is well. You may have matured during that routine of deployment, and now you must switch gears once again. The reality is that your parent probably changed during deployment and that you probably have, too. You may have changed physically (gotten taller, stronger), and you most likely changed emotionally as well. You may have matured during that time, out of necessity, and become more independent. Your mom or dad remaining at home with you needed additional help, so being a young adult, you chipped in. In addition to the normal teen issues, you had to deal with a teenage “tour of duty,” and it wasn’t easy. Below are some ideas to help you cope with your new challenge — return and reunion.

Expressing Your Needs

There are many things that you need in order to be at your best (no, not a Wii™—sorry). Your immediate needs are shelter, food, love, and good health. Adding to the list, positive communication, and good relationships and experiences would be nice. I am confident that your family provides your basic needs, so you are already ahead of the game. Let’s concentrate on the additional needs during this reunion period.

I’m certain that you have expectations for your family once a tour is over. Unless your parents are mind readers, there’s only one way for them to understand those expectations — tell them! It’s usually extremely easy to talk to your friends. As a matter of fact, you’re doing it all the time. Through texting, phoning, and instant messaging, you and your friends maintain a close relationship and are in the know. You know who likes whom, who is sad today, who might be relocating next year. All this information provides topics for discussion.

Keeping an open line of communication with a parent or adult is typically not so easy. As a matter of fact, you might get aggravated when an adult asks personal questions or even not-so-personal questions. When parents and adults ask questions, it may seem like they’re prying. But they could just be excited about YOUR interests. Regardless, it’s important to keep the lines of communication open. And, the topic doesn’t always have to be about you! You can ask about their day, job, or hobbies, also.

When you are ready to approach your parent or parents about your needs during the adjustment period, timing is everything. Choose a quiet time and a place free of distractions. Turn off your cell phone, the television, and any other form of distracting communication. Rely on the old-fashioned, dependable means — verbal dialogue.
Remember to be honest but not disrespectful. When something is offensive, it may not be what is said but rather how it’s said. Parents, like teens, can be sensitive to negative language. Avoid yelling or being sarcastic when addressing a parent or adult. Try not to play the blame game. Use the word “I” instead of “you.” For example, instead of saying, “You have been gone for so long, and now you never make time for me because you’re always busy playing golf,” try saying, “My tee shot got rusty while you were gone—I was wondering if you could help me get a few extra yards out of my swing?” Now the conversation is in the parent’s favor. You are letting your parent know that you missed him or her. You were honest, but not disrespectful, in your communication. This makes the dialogue more of a conversation and less of a confrontation. And if all else fails, text them!

**Reaching Out, Reaching High**

Relationships are very important to your well-being. As a teen, you need ample time with your family, but you also need independent and alone time with your friends. You depend less and less on your parents every day and are formulating patterns for your own adulthood. Now that a parent is back, you may have more freedom to explore your interests and skills.

There are thousands of teens who are in your same situation. You can read about their experiences on the Web sites listed in the accompanying sidebar. Don’t be afraid to try another teen’s successful approach. Remember the adage by Charles Caleb Colton, “Imitation is the sincerest form of flattery.”

**Hanging Out With Hobbies**

Just because it’s not cool to be within five feet of your parents publicly doesn’t mean that you don’t need them or want to be with them. Unless they’re psychic, your parents might not know that you’re disappointed when they rekindle their relationship and leave you home to babysit your younger siblings. If time with one parent or both would make you happy, speak up! Quality time is an important part of the reunion. Believe me, when any one of my teens asks me to do something, I jump on the chance to bond.

Now is an ideal time to start a hobby with your parent. Find a common interest and sign up for a class or just dabble at home at your leisure. You and your parent will have fun and plenty to talk about while gaining skills. It’s a wonderful opportunity to get reacquainted. Hey, and you could always work on that rusty tee shot!

You, too, are an important member of the military serving our country. Read the Military Child Bill of Rights (http://www.nmfa.org) and celebrate your job well done. And remember that Hope Loves Company!

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By Jodi O’Donnell-Ames

**Helpful Web Sites**

- [http://www.armyfrg.org](http://www.armyfrg.org) (Family Readiness Group (FRG))
  
  Once there, go to Featured Links and click on MyArmyLifeToo. Read about the many wonderful services that are offered to help you with deployment and reunion. Under the Top Links column, I got to read about Operation Military Kids—“the U.S. Army’s collaborative effort with America’s communities to support children and youth impacted by deployment.” Cool stuff happening to help you cope! You can also read about how other teens cope with deployment and return.

  
  This is a Web site created just for teens. It also contains links for children and tweens, too, so tell your siblings. It is provided and maintained by the Family Readiness Group (FRG) and can be reached via the FRG home page.

- [http://www.ourmilitarykids.org](http://www.ourmilitarykids.org)
  
  I always ask my teens, does your fun always have to deplete my wallet? Well, if you like to have fun and don’t have the financial freedom to always do so, this Web site demands your attention. According to the Our Military Kids nonprofit organization, children need “comfort, stability, routine, and fun.” I second that. For this precise reason, Linda Davidson and Gail Kruzel founded Our Military Kids in 2004. Their goal is to grant fun opportunities to school-aged children of National Guard and Military Reserve servicemembers. Our Military Kids provides grants (quickly, too!) for sports, fine arts, tutoring, and even space camp and driver’s education training. When you contact them, they’ll thank you for your service as a military child or teen. Go for it! (Call 866-691-6654)

- [http://www.nmfa.org](http://www.nmfa.org)
  
  Having fun is important. Did you know that there’s a camp just for you? It’s called Operation Purple Camp. (Look for the link in the box on the righthand side of the National Military Family Association home page.) Yes, this summer has passed, but you can start planning for next year’s fun (there’s an application posted online). In the summer of 2008, there were 100 weeks of camp held in 62 locations in 37 states and territories. The camp is free and is a weeklong overnight camp. It is open only to military families. All week long, you’ll have fun while learning ways to deal with war-related stress. The best part is that your experience will be similar to that of the other teens you will meet.

  
  The AAP Military Youth Deployment Support Web site has been designed by the American Academy of Pediatrics to support military youth and their families. This site includes excellent links, one of which is http://www.nmfa.org and...
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*May you all be safe and prosperous.*
Strategies to Help Children with Special Needs Enjoy Successful Community Outings

UNITED STATES MILITARY SECTION

Strategies to Help Children with Special Needs Enjoy Successful Community Outings

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Our son Broden was diagnosed with autism in May of this year. My husband and I have been in the process of coping with our son’s diagnosis. We have been trying to stay afloat, facing the steep learning curve of interpreting and understanding TRICARE regulations, Applied Behavior Analysis (ABA), and biomedical options. We have also wanted to ensure that our older son, Hayden, knows he is just as important to us as ever. It has been a bumpy road, but we have already learned quite a bit along the way. My husband and I want to share our ideas so that other parents can use this information to their benefit if their child should receive a diagnosis similar to Broden’s.

The most frustrating thing for us has been a consistent lack of communication among medical agencies and providers. It seemed that if we went to one provider for assistance, they were unable to provide us with a solid answer on where to go next. They either said, “We can’t help you. Go back to your family physician,” or “We are not allowed to give you our opinion. Go back to your family physician.” Our family physician would scratch her head and then send out a few more referrals to other providers to see if they could pinpoint a diagnosis for Broden. There was no smooth communication system that helped us as parents to receive a timely diagnosis for our son. In our experience, even after receiving the diagnosis of autism, a lack of good communication among the medical teams and the therapy providers continues.

After analyzing our family’s experience—from the time we thought something was wrong with Broden, to the time of diagnosis—we decided there were certain things we wanted parents to know if they think their child could have severe delays or have autism:

- Understand the milestones of your child’s development.
- Be proactive in seeking medical care for your child.
- Know what to do if you receive a diagnosis of autism.
- Take care of each other.

**Understanding Your Child’s Development**

It is important for parents to understand their child’s development. Well-baby checkups are important to ensure your child is meeting all of the critical mile-
stones in his or her life, but every physician is different. In my experience with both of my boys, we sometimes saw a more “strict” pediatrician or a pediatrician that said, “Oh, let’s just see what happens.” I realized that with Broden, it was up to me as the parent to say, “No ... let’s not wait to see what happens. Who do I make an appointment with to see if I should be concerned about my son’s development?”

When we went to our son’s developmental pediatric appointment, the developmental pediatrician told me his motor skills were delayed. She pointed to his chart firmly, and said, “This is not normal.” I told her I had taken Broden to every well-baby checkup that was required. How did he fall through the cracks? Again, I realized it was up to me. In the future, it was going to have to be my job to ensure that I was knowledgeable about my son’s milestones, because I could not assume that the pediatrician will be as proactive as I need him or her to be. I am learning to always ask questions. If your doctor seems annoyed with your questions, then find another doctor who will not be.

Being Proactive

Once I realized that my son had delays and that he needed to be seen by a developmental pediatric team, I knew it was up to me to ensure that he was seen as soon as possible. I was shocked to find out that there was a six-month to one-year wait for children to be seen.

After I went to my physician to get a referral, I didn’t call just one hospital to make an appointment, I called many. In the beginning, they did not allow me to talk to someone on the phone. I had to leave a detailed message about my son, and then they would call me back. I realized that this was going to be a long process. I couldn’t just call and get an appointment like I would call a hair salon to get my hair cut. It took days for these medical centers to call me back and to answer my questions.

The first question I would ask was, “How long is the wait?” I would then ask, “Do you take TRICARE?” and then, lastly, “Can I get on a cancellation list?” After I had talked with them, they would mail me a long, detailed packet of information I needed to fill out about Broden. Then, I had to send it back. After reviewing the information packet, they would call me with an appointment. As they would tell me the process, I would look at the calendar. I felt this imaginary clock in my head just ticking. As his mother, I felt a sense of urgency. The longer the wait, the longer this clock would tick. In my mind, time was starting to run out. He had just turned two years old. We needed to find out what was going on. I was struggling to find someone who answered the phone to have the same urgency in his or her voice that I had for my son. This made me very angry.

Eventually, my son was able to get in to see the developmental team early, because we were on the cancellation list. I can’t stress to parents enough that something as simple as asking to be on a cancellation list can make such a difference.

Another way to be proactive is to research and network with other parents. I started to research autism the day I suspected this could be Broden’s diagnosis. I tried to learn as much as I could, including information about therapies that were successful in helping children with autism. One of the best things I have done is to talk about it. At times, people do not want to talk about what is going on in their lives. If parents feel this way, they should consciously work on discussing this with others. The more friends who know about your child, the more opportunities there are to meet other families who are going through similar experiences.

A good friend of mine introduced me to someone she knew in her neighborhood whose son has autism. Once I started talking with her, I felt so much more empowered. I could relate to her, and she gave me lots of practical information on how to help Broden. She then introduced me to another person who also had a son diagnosed with autism but whose son’s diagnosis was eventually dropped. Finally, I could see a child who was diagnosed with autism at two years of age, yet at five years of age showed no signs of autism. What a privilege it was to meet him. I knew there was hope. I got this hope from networking with families and conducting research. The more I knew, the better I could help my son.

What to Do Once You Receive the Diagnosis

Once you get the diagnosis of autism, you are the advocate. You have no choice, because you do not have a doctor to provide you with a recovery plan, and there is no medical protocol. Most doctors will tell you there is no cure for autism, but if you see a DAN!™ (Defeat
Autism Now) doctor and an ABA therapist, you will hear there is hope for your child.

You will need to start doing research on Board Certified Behavior Analysts (BCBAs) in your area. You’ll need to ask yourself if a clinic or a home-based program is best for your family. A home-based program involves tutors coming to your home to work with your child, but at times, you may be responsible for hiring those tutors. The tutors will be trained by the Board Certified Behavior Analyst. If you take your child to a clinic, the Board Certified Behavior Analyst will have tutors that he or she trains to work with your child at the clinic. There are pros and cons to each program. It is up to you to choose a program that is best for you and your child.

You do not need to wait for the final TRICARE referral letter to schedule an appointment or to call and talk with BCBAs in your area. Research Applied Behavior Analysis programs and see if they take TRICARE. At times, there is such a long wait to get your child into an ABA program, the referral will be through before your child can be seen. You can always work with TRICARE to get the referral changed to another ABA therapist if the situation changes. Remember, you can cancel the appointment if a referral is not approved.

Once you get the diagnosis, enroll your child in the Exceptional Family Member Program (EFMP) and TRICARE’s Extended Care Health Option (ECHO). There is an outdated stigma that Soldiers who have a family member enrolled in EFMP will experience adverse effects on their career progression. This is a myth. The truth is that the Army will recognize your child’s needs and assign your spouse to a place that will benefit your child. Your goal should be to enroll in these programs so that the Army can be in a position to help you and your family.

Begin researching Defeat Autism Now doctors. These doctors are supported through TRICARE Prime and Standard, not ECHO. The referral process is through your TRICARE primary care manager. The benefit of a DAN doctor is that he or she will treat the cause of your child’s autistic tendencies, not the symptoms. In Broden’s case, our DAN doctor discovered he was allergic to many foods and severely allergic to many molds. Changing his diet and moving into a home without mold issues proved remarkable for him. Broden’s level of alertness, his weight, and his responsiveness to therapy all increased with the introduction of a gluten-free, casein-free diet, along with supplements. Broden started sleeping through the night. That meant that Hayden and I could sleep through the night, too.

**Taking Care of Each Other**

The best advice we received from other parents was to remember that the process is a marathon and not a sprint. As a couple, each of you will handle the diagnosis and prognosis in a different way. Our advice is to capitalize on each other’s strengths. Every person in your family can contribute to your child with autism. In our family, Mark’s strengths were dealing with Army regulations, bureaucracy, and TRICARE. My strengths were researching autism therapy, holistic approaches, and restricted dietary applications. Later, I started to study ABA therapy and to watch Broden’s tutors very closely, in order to augment what Broden was receiving at the clinic. I wanted to ensure that Broden was continuing his therapy outside of the clinic. Hayden, our four-year-old, was incorporated into Broden’s therapy, due to his wonderful outgoing personality and his desire to connect with his brother. Hayden has always had a gift of persistent engagement and would encourage Broden to interact with him. Our extended family has been very supportive, and we found this really makes a difference in our journey. Our advice is to educate your entire family so that they understand the trials you are facing as a family. The more they know about your situation, the more creative ways they may find to help you.

Though our family is just beginning our journey, we have learned so much in the last six months. The diagnosis of your child may seem frustrating and heartbreaking, but in many ways, it also opens many doors for you and your child. There is an incredible community of parents who are willing to share their ideas and insights. DAN doctors and BCBAs truly believe in treating your child as a whole person and will quickly become an important part of your life. Even though it has been difficult and frustrating at times while helping our son Broden, we have realized that it has brought us closer as a family. One of the most important lessons I have learned is to not sweat the small stuff. Take one day at a time. We’ll eventually get to where we want to be. •

Shelly and Mark Huhtanen have been married for six years. Mark has twelve years in military service and is a Major in the United States Army. He has a Master’s Degree from Webster’s University and is currently attending the School of Advanced Military Studies at Fort Leavenworth, Kansas. Shelly has a Master’s Degree in Professional Communication from the University of Alaska. She is currently a stay-at-home mom, caring for their two boys, Hayden, who is four years old, and Broden, who is two years old.
My name is Mirna Moreno, and I am the proud mother of fraternal twin boys. Six weeks into my pregnancy, my husband Stephen and I found out we were having twins, and I'll never forget the look on his face when the doctor gave us the news. We were both so happy with the idea of finally becoming parents for the first time. I was on bed rest at 32 weeks and was fortunate enough to carry my babies for 38 weeks. I had several ultrasounds, and everything checked out okay according to my doctor. We didn't have a clue that one of our sons would be born with a bilateral cleft lip and complete cleft palate.

On May 18, 2005, I gave birth to my baby boys. Orlando weighed 7 pounds and Santiago weighed 5 pounds, 10 ounces. I remember hearing my doctor say, “He has a cleft lip,” but I did not know what she was talking about. A few moments after they were born, my husband Stephen brought them to my side, and with teary eyes, he told me, “He is still so beautiful.” Santiago was taken to the neonatal intensive care unit (NICU) and stayed there until a specialist came to the hospital to make a mouthpiece for him to be able to eat without the feeding tube. In the meantime, my husband and I would visit him every chance we had, but I spent most of the time crying and blaming myself for what had happened to my son. Relatives and friends who came to see us at the hospital gave us words of hope that everything would be fine and that I shouldn’t worry too much, but nothing would comfort me at this point.

Once Santiago came home, he had a hard time eating, and he slept most of the time. We tried everything to get him to eat, but after missing a few feedings, we decided to take him to the hospital. I was advised to stay overnight in his hospital room with him. A nurse sat with me and taught me how to feed my baby. After two days, I felt confident enough to feed him on my own, but he was still having trouble keeping his formula down. There were several choking episodes when formula gushed out of his nose and mouth at the same time.

I went back to work when the boys were only six weeks old. My maternity leave had begun when I was put on bed rest at 32 weeks. My maternity leave had begun when I was put on bed rest at 32 weeks. We found ourselves in a financial crisis, due to my being out on maternity leave for three months with no pay. Santiago’s surgery was coming up soon. My dear friends from work put together a bake sale and raised enough money for my family in order for Santiago to have his first surgery. Their donations also covered the monthly orthodontist visits he required to have his nose/mouthpiece adjusted. There are too many people to name, but you know who you are, and we will forever be indebted to you. I like to call these friends, “Santi’s Angels.”

Santiago had his hard palate surgery at Texas Children’s Hospital in Houston, when he was only three months old. He didn’t eat for the first two days after the surgery, but I had been told that might happen. We used a syringe to feed him but that didn’t go so well when I tried it. My sister Celina became a pro at using those syringes, so she fed him most of the time after his surgeries. After his hard palate surgery, he made a full recovery after a few days, and he gained all his weight back.

At six months, Santiago had his lip repaired and a set of ear tubes put in. His ear, nose, and throat specialist (ENT) told us he had a lot of fluid buildup, but everything turned out okay, and his hearing improved dramatically. I was shocked when I saw him right after his surgery. His facial features had changed so much that he looked like a different child to me. I think what scared me the most was when I saw blood coming out

The Moreno Family (l to r): Santiago, Stephen, Mirna, and Orlando.
of his ears, nose, and mouth. His face was very swollen, and he wouldn’t stop crying. Once he was taken to his room, we tried to feed him, but he wouldn’t sit still long enough to get a drink. Once he calmed down, we tried it again, and he was able to drink just a few ounces. Just a few days later, he was able to eat and drink as he usually did, which made me breathe a sigh of relief.

At nine months, Santiago had his soft palate repaired, but this time it didn’t go as well as the previous two surgeries. Once he was taken to his room, we tried to feed him, and he started to choke. It took us a few tries to get him to drink for the first time. He stayed in the hospital, and Stephen’s parents were kind enough to stay with him overnight. Three days after the surgery, I noticed he was still bleeding and would not stop crying, even after I gave him his medications. I rushed him to the emergency room because the stitches had come apart, but we were told there was nothing they could do. We would have to wait a few weeks and see what damage had been done. The stitches coming apart left a small hole in his soft palate, which makes his speech sound nasally, but we were told that another surgery would take care of that issue. Just a few days after this incident, he was able to eat and drink, with the occasional sneeze, which brings food out of his nose. But he just wipes it off and goes about his way.

The small hole in his soft palate doesn’t bother him one bit. Santiago’s pediatrician has requested a referral for Santiago to see the plastic surgeon who initially did all his surgeries. He has an appointment at the beginning of December to have another assessment, and chances are he will have another surgery. The upcoming surgery will require the soft palate to be opened all the way to be able to stretch some of the tissue and bring it together. I was told the surgery is very delicate, and I am praying to God that everything turns out okay. This surgery is one of the many he will require until he is an adult. As the years go by, adjustments will have to be made to fit his facial features.

Now that my husband is in the United States Army, our medical bills have lowered dramatically. Since the twins were born before Stephen joined the Army, we were not aware that they were covered by his insurance, and I continued coverage on my insurance, which made it difficult financially. We were not told about our medical benefits, and we continued to struggle by having co-payments every time Santiago went to his pediatrician and the specialists he was required to see.

Stephen enlisted in the Army in August 2007. We were enrolled in TRICARE in early 2008. Being covered by TRICARE has been a blessing. We have the Standard plan, which allows my boys to see their pediatrician and specialists at no cost for each visit, as long as we stay within the network.

Stephen, a Private First Class (PFC), has not been deployed yet, and that has made it easier on our family as far as moral support goes. He is scheduled to deploy in October 2009, which for now makes it easier for us to attend Santiago’s scheduled doctor appointments.

Santiago has had four surgeries since his birth. The last one consisted of a new set of ear tubes in November 2007. A follow-up hearing test and checkup confirmed everything was okay.

Once we moved to Fort Stewart, I went to a Newcomers’ Orientation and found out that my son should have been enrolled in the Exceptional Family Member Program (EFMP). The program benefits include respite care and family meetings with other members for support. The people in charge of this program have been very helpful and attentive to our needs. I feel good knowing I can find someone to talk to and someone who can relate to the everyday issues of having a special child in our lives.

Santiago has a slight speech problem at the moment. His words sound nasally, but that is due to the small hole in his soft palate. I am told that once he has the surgery to close the hole, his speech will improve, and he might not need speech therapy. My other son, Orlando, is developing slurred speech, but his pediatrician is not too concerned because he thinks Orlando is just copying Santiago. The pediatrician is convinced that once they are in prekindergarten, Orlando’s speech will improve when he is around other kids.

If someone had told me when Santiago was a toddler that he would be doing this well, I would have never believed it. My heart just melts when I see him smile because he reminds me of what pure love is. We all have had our share of tears, but I believe things will soon be better. I am lucky enough to have a husband who is strong enough for the both of us; otherwise, I don’t think I would make it. I also believe that God chooses special babies for going into special families for a reason. Santiago is a happy child, loves the outdoors, plays well with his brother as well as the other kids, and has a very loving quality about him.

I have been able to find awesome doctors to look after the well-being of my children, and I would like to thank all the doctors, nurses, and friends who have been involved in the care of my child. May God bless you. I would also like to give a special thanks to all my family for being so supportive and always having a shoulder for me to cry on.

Mirna Moreno was born and raised in San Salvador, El Salvador, until the age of eight, then moved with her family to Houston, Texas. She is currently working toward a Bachelor’s degree in Criminal Justice. Her husband, Stephen, is a Private First Class in the United States Army. He is scheduled to be deployed in October 2009. Mirna and Stephen have been married for six years and live with their fraternal twin boys, Santiago and Orlando, in Georgia.
Strategies to Help Children with Special Needs Enjoy Successful Community Outings

By Alan Harchik, PhD, BCBA, and Patricia Ladew

Even the most uneventful days at home can be challenging for families who have a child with an autism spectrum disorder (ASD) or another developmental disability. The challenges multiply when parents or caregivers take the child to a dentist or doctor’s appointment, the grocery store, or on another outing into the community. For military families, periodic relocations often require frequent readjustments to unfamiliar people and routines and to new and different community settings.

“It’s tough, because we move every couple of years,” says Xiomara Grant, who lives in Austell, GA, with her husband, David, a Major in the Army, and their 7-year-old son, David Jr., who was diagnosed with autism when he was 18 months old. Before moving to Georgia, the Grants lived in Kansas and New York.

For Xiomara and David, taking young David out into the community for medical and dental appointments, haircuts, and shopping trips can be difficult. “When we’re headed for the dentist, David knows, and he doesn’t like it,” Xiomara says. “He gets scared and cries.” David has good reason for not liking the dentist. He has had to be sedated and strapped into the dentist’s chair for dental procedures. “I don’t take him to the barbershop anymore because he always cries there, too,” adds Xiomara. “I cut his hair myself.”

Seemingly routine activities such as medical and dental office appointments, haircuts, and shopping trips can be difficult. “When we’re headed for the dentist, David knows, and he doesn’t like it,” Xiomara says. “He gets scared and cries.” David has good reason for not liking the dentist. He has had to be sedated and strapped into the dentist’s chair for dental procedures. “I don’t take him to the barbershop anymore because he always cries there, too,” adds Xiomara. “I cut his hair myself.”

Making Choices That Make Sense

Given the chaos and crowds of a mall during the holidays, Xiomara is making smart choices about which outings make sense for David.

But if families avoid regular appointments and community outings because of a child’s negative responses, that child may learn to use problem behaviors to escape these situations. More importantly, the child will not have the opportunity to learn new skills and integrate successfully into his or her community and family life.

David and Xiomara have worked hard to understand young David’s needs, create routines, and teach him useful skills. Their goal is for David to have positive experiences in the community and be exposed to people and places in much the same way a typical child would be.

Professionals at May Institute, a national network of educational, rehabilitative, and behavioral health services for individuals with special needs, have had great success with a number of research-based methods that can help parents like Xiomara and David make their child’s community experiences good ones.

Creating Successful Outings

One method that helps create more successful outings is desensitization. It means gradually exposing the child to a situation or setting that is problematic.
Before You Head Out...

A little advance planning goes a long way toward ensuring successful community outings for children with special needs. Behavior specialists at May Institute offer parents the following tips:

- Teach the child about the situation in advance of the visit. Parents or caregivers might make a book with photos of someone the child knows going through all of the steps of the activity in the actual setting, including receiving the treat at the end of the activity. An alternative would be to make a video for the child to watch.
- Create a simulated, pretend situation before the actual outing. Research suggests that if the situation is made realistic, it can result in improved behavior in the real setting. Simulation allows for many more practice opportunities before the actual outing.
- Gradually expose the child to a situation or setting that is problematic (also known as desensitization). Over time, the child will usually become more comfortable in that situation or setting.
- Make changes to the environment to make it feel more comfortable or safe for the child.

When planning a community outing, make certain all the steps have been practiced.

Success At the Supermarket

David and his parents have also enjoyed more successful trips to the supermarket lately, thanks in part to some new strategies they have learned from David’s behavior analyst, Meghan Holligan-Whitney, BCABA (Board Certified Associate Behavior Analyst), who works out of May Institute’s Atlanta office.

“David was having severe elopement issues, meaning he would run away from his parents when he was out in public,” says Meghan. “He loves puzzles, so I take a puzzle with me when I take David to the grocery store. For every 30 seconds he stays with me and doesn’t leave my side, I give him a puzzle piece, which he puts in a little bucket. At the end of our shopping trip, we go to the car, and he gets to put his puzzle together. That’s his reward.”

Using this technique, Meghan has helped David learn to stay by her side. “His elopement episodes have gone from eight per store visit to one,” she says. Now she’s working with David’s parents to help them implement this successful method.

Meghan also encouraged David to get young David more involved in the process of grocery shopping. It’s a suggestion that has worked well. “I have him hold the basket if it’s not too heavy,” says David. “And, after we check out, I let him carry one of the bags back to the car. That makes him feel good because he’s part of the process. He’s a big help.”

Planning, Practice, and Praise

For most children, learning “supermarket skills” should begin with practice settings at home or in school before moving on to a small grocery or convenience store. The child should be able to follow a number of basic instructions such as “come here,” “stop,” “hold my hand,” and “wait in line with me” in a more controlled environment before visiting a larger supermarket.

“There are a lot of stimuli in a supermarket, so it’s important to plan ahead to ensure success,” advises Jack Stokes, MSEd, BCBA (Board Certified Behavior Analyst), Director of Residential Services for May Institute in Randolph, Massachusetts. Jack and his staff work with the students in their care on developing the skills that will help them to take successful trips to the supermarket. He recommends the following:

- Set a time limit for your outing.
- Be sure you know where the bathroom and all the exits are located before you take your child to the store.
- Pick a time when the store is not likely to be crowded.
- Have activities and small rewards or “reinforcers” with you.

“When thinking about rewards, remember to use verbal praise and to be very specific,” Jack advises. “Don’t just tell your child he or she is being...
‘good.’ Say, ‘I like how patiently you are waiting in line.’ It’s a good rule of thumb to reinforce good behavior every 30 to 40 seconds with specific verbal praise.”

Addressing Problem Behaviors
Developing a plan to address problem behaviors that may happen during an outing is also important, according to Jack. “Things happen,” he says. “You won’t always be 100 percent successful. You need to plan ahead so you can quickly and safely get your child out of the supermarket if you need to. Be prepared to abandon a cart of groceries and walk out of the store if your child is out of control.”

Once the child masters some basic skills, the supermarket experience will be much more positive. Then, he or she can learn more advanced skills such as making and using a shopping list, locating one or more items from the list, pushing the cart appropriately, asking for help from a store employee, and mastering counting and other money skills.

Planning, practice, and praise pay off. After a child has developed a new set of skills, he or she will be able to use those skills in a variety of new situations and settings.

Reaping the Rewards
David and Xiomara Grant have witnessed firsthand that ongoing and intensive support can help a child with special needs make great strides. With some pride, David recounts a recent visit to the home of his boss.

“My son had never been there before, and he wanted to explore,” he said. “So my boss walked David upstairs and downstairs so David could satisfy his curiosity.”

“He didn’t run around,” David continued. “He just wanted to explore the house. It was a totally new place with new people. He didn’t cause any disruption. It was a fine night out with people he had never met before in a location he had never been before.”

Creating Happier Holidays
The holiday season can be a joyful time—a time for getting together with friends and family, exchanging visits and gifts, enjoying fabulous feasts, and attending parties. Changes in routine, numerous social obligations, and unrealistic expectations can also make it a stressful time, especially for families who have children with special needs.

In the midst of so much activity and change, parents should make consistency a priority. They should make it clear to their child that even though this is an exciting time and regular routines are changing, they expect him or her to continue to use clear communication and work on activities of daily living such as dressing and eating. Likewise, family members should be consistent in their responses to problem behaviors.

It is best to try to intervene early, before a behavior problem escalates, and also to try to use positive rewards for following instructions and other desirable behaviors. Have plenty of the child’s favorite items, such as preferred foods, toys, and DVDs available to reinforce good behavior. Some other things to consider around the holiday season include:

- **Routines.** Holidays often require changes in daily and weekly schedules. Schools have days off, after-school activities may be altered or canceled, and new or temporary activities might be added. Parents and caregivers can address these changes with children by using picture schedules throughout the day or week, and by including lots of positive preferred activities and rewards on a regular basis.

- **Shopping.** If your child accompanies you to the mall, supermarket, or department store, try to go early in the day or during the midweek when it is likely to be less crowded. To ensure greater success, plan shorter trips. Be sure to use small rewards during and after a successful trip.

- **Family gatherings.** Getting together for family gatherings can present some of the most stressful challenges of the season. You can prepare in a number of ways. Get out photos from previous gatherings and talk with your child about the names of people who will be attending this year’s get-together. If you will be going to someone else’s home, you may be able to get photos of the house and guests beforehand.

Work on social greetings and conversation skills at home, depending upon your child’s verbal ability. Bring along favorite videos and toys to make the experience as positive as possible. Find out if there is a quiet area in the home you will be visiting where you can take your child if necessary.

You can try to find out about details of the gathering that are important to your child, such as the seating plans for the table, the planned menu, and if there will be any dogs or cats in the home. For some children, it is better to bring along their favorite food and/or to eat at home before heading out. In many cases, it is better to get to the gathering early because it is easier for the child to be there first, before many of the guests arrive. Make family and friends aware of what to expect from your child, both positive and challenging. This can be done by telephone, via e-mail, or with a short note.

- **Travel.** Many children with autism and other developmental disabilities enjoy riding in the car. Most families have determined the best way to travel by car, including what to bring along and how often to stop. Airline travel, however, can be particularly difficult. Some parents have found it helpful to contact the airline a few weeks prior to the flight to find out about special boarding procedures for families with children with disabilities or other assistance that can be provided.

Teaching a child the necessary skills to navigate new and challenging situations outside the home will help that child be more independent, happier, and better able to function in the world. With careful planning and a lot of patience and love, community outings can be enjoyable for you and your child.

Alan Harchik, PhD, BCBA, is May Institute’s Senior Vice President of Educational Services. Dr. Harchik oversees the operation and management of the Institute’s private schools for children and adolescents with autism and other developmental disabilities, as well as its school for students with brain injury. Dr. Harchik is a licensed psychologist, a board certified behavior analyst, and a certified teacher of children with moderate and severe special needs. For the past three years, Dr. Harchik has written monthly, autism-focused columns for newspapers in Massachusetts.

Patricia Ladew is a senior writer for May Institute’s Office of Communications. She has specialized in healthcare writing for the past 20 years.
In communities nationwide, Easter Seals is helping to meet the needs of America’s military servicemembers and veterans with disabilities and their families in the face of a growing crisis.

With thousands of servicemembers and veterans returning home from Iraq and Afghanistan—often with profound physical and mental healthcare needs—gaps and barriers to vital services are preventing many from fully participating in family and community life.

“They are struggling,” says Doug Carmon, assistant vice president of Easter Seals’ Military and Veterans Initiative.

Over the past five years, 1.64 million servicemembers have been deployed to Iraq and Afghanistan. In all, there are 24.5 million veterans nationwide. During any given month, 700,000 are unemployed and nearly 200,000 are chronically homeless.

The challenges are far-reaching. Longer, more frequent deployments have impacted entire families. Younger servicemembers are returning with wounds not seen in the past, as battlefield technology and medical advances make it possible for more to survive severe amputations, burns, and traumatic brain injury (TBI) that would have proven fatal in years past. Meanwhile, many are living with post-traumatic stress disorder (PTSD). At the same time, older veterans face issues related to aging.

As the nation’s largest nonprofit provider of services to individuals with disabilities and their families, Easter Seals already is providing multiple services to servicemembers, veterans, and their families, including: job training and employment, medical rehabilitation, adult day services, mental health services, transportation, therapeutic camping and recreation, respite and caregiver services, and accessibility solutions and technology for home, work, and independent living. Additionally, as the leading provider of autism services in the country, Easter Seals offers a wide variety of treatments for children and adults living with autism—from early intervention and inclusive child care to school support and transition-to-work programs. But, says Carmon, “There’s a need and a desire to do more.”

Easter Seals’ Military and Veterans Initiative
Partnering with the Departments of Defense (DoD) and Veterans Affairs (VA) and collaborating at the national, state, and local levels, Easter Seals is reaching out to more servicemembers and veterans by designing new programs to augment those provided by existing military and veterans systems of care and support.

For example, Easter Seals New Hampshire, in collaboration with federal, state, and local resources, is connecting servicemembers and their families to services that meet their medical, social, emotional, and financial needs during deployment, upon returning home, and throughout
the process of community reintegration by actively engaging military families well before deployments occur and needs arise.

Easter Seals Iowa is providing veterans and their families with in-home assistance, including vocational rehabilitation assessments, recommendations for home modification and accessibility, Web-based community engagement, and traumatic brain injury rehabilitation.

Carmon says such collaboration is key. “It’s really beyond one organization,” he says. “No one entity can do it all. We have to take what we do best, put forth those practices, and work together.”

Kristen Barnfield is Senior Director of Public Relations at Easter Seals. Kim MacGregor is a freelance/disabilities writer whom Easter Seals has worked with for more than 10 years. They have a combined 25-plus years’ experience in writing about disabilities, including the many children, adults, and families living with autism or those struggling to connect back to their community after military deployment and a newly acquired disability, as well as other healthcare topics.

Helping the Briggs Family

On April 16, 2005, a rocket-propelled grenade was launched into a military operating base in Ramadi, Iraq. The grenade landed about 10 feet from Army Sergeant Bob Briggs.

Bob lost his right eye. He also sustained a traumatic brain injury (TBI) and lost the ability to move his left arm, hand, and leg. With his wife, Michelle, by his side, the father of two has faced multiple surgeries, medical rehabilitation, and adjustment to civilian life while living with a newly acquired disability.

For Bob, having a TBI means mood changes, difficulty with short- and long-term memory, and trouble processing written or oral communication. To help improve his mental skills, Bob has been using a therapeutic cognitive rehabilitation computer program provided through Easter Seals’ Veterans with TBI Pilot Project.

Bob also faces the challenge of having limited mobility. Prior to deployment, he was a highway equipment operator for the State of Iowa. Today, he helps operate the family’s home-based pet boarding and grooming business with the aid of an all-terrain vehicle (ATV) provided by the U.S. Department of Veterans Affairs’ Vocational Rehabilitation & Employment program.

Chuck Larson, Easter Seals Iowa rural rehabilitation specialist, helped Bob select the ATV and get comfortable using it around his property. In less than a year, Bob has made great strides.

“It’s a medically therapeutic activity for him to use the ATV,” Larson says. “I see it all the time—assistive technology can help someone look beyond their disability and feel more a part of their family and community.”

Initially, Bob had trouble getting in and out of the ATV. Now he uses it to cut brush, clear the driveway during the winter, move heavy objects, and even bond with his son and daughter.

“Our kids can feel like Daddy is getting closer to being better when he takes them for a ride, and they laugh and have fun together,” says Michelle. “The best part is that he gets to run a piece of equipment…it gives Bob a sense of his prior self before being injured.”

Bob says, “Easter Seals is doing a great thing stepping in and helping. They’ve done an excellent job for me. I feel like they’ve gone above and beyond.”

Easter Seals has teamed up with the National Military Family Association to host the Operation Purple® Summer Camp Program to provide camping experiences for children of deployed parents at five Easter Seals affiliate sites as well as Operation Purple Healing Adventures for servicemembers with disabilities and their families at Easter Seals Camp ASCCA in Alabama (Alabama’s Special Camp for Children and Adults).

Here, a boy participates in a log crossing.
Welcome to a new section of Exceptional Parent Magazine (EP). This is the first of 12 monthly installments from EP under a United States Army Co-Operative Research Agreement entitled the Exceptional Family Transitional Training Program (EFTT). The spirit of the agreement is a true collaborative effort of civilian and military partnership working to improve the quality of life for families caring for individuals with special needs.

At the core of this program is the recognized need - expressed by several high-ranking General Staff Officers - that in today's military, unit readiness entails more than just preparing our men and women for war. Unit readiness also involves recognizing that at least one member out of every infantry squad may be caring for someone with special needs in his or her household. Accordingly, leaders need to be sensitive to this. The EFTT program is intended to provide education and resources to those military families caring for loved ones with special needs, thereby giving our men and women in the field comfort knowing that their sons, daughters or loved ones at home are receiving the best possible care. The impact on morale, retention and efficiency of the unit will be markedly improved as additional stresses will have been lessened.

The primary objective of the program is to develop and deliver an integrated special needs educational curriculum/program involving electronic web and print-based mediums. This program builds upon EP’s existing work with the Army, Marine Corps and Navy Exceptional Family Member Programs (EFMP) within the military special needs community and integrates EP’s acknowledged leadership in this arena in the civilian sector. The rationale for this program is the existing need to provide healthcare professionals and family caregivers with access to peer-reviewed, best practices education through which the quality and standards-of-care for the individual with special needs can be maintained and improved and unit readiness augmented and enhanced. A secondary but important objective is to insure that what is offered has applicability and is in the public good.

"Community Of One, From Our Families…To Your Families" calls for the inclusion of a special military section in EP Magazine and on the EP website (which receives over 2.0 million visits per month) written by veterans with disabilities from the EFMP community dealing with issues faced by military families, i.e., transitioning from one military installation to another with a family member or child with medical or educational special needs. It is not uncommon for a military family to have more than one family member with special needs. Oftentimes the family arrives at a new location with no other support and the stress of possible frequent deployments. The key to a successful transition is the EFMP manager. This individual is responsible for assessing housing and community support needs while linking parents to special education school officials, health care providers and family caregivers at both the losing or gaining commands. The linking of the EFMP manager and the Soldier who is caring for a family member with special needs provides a viable connection, one that has the potential to help that Soldier have a successful tour of duty in his or her unit.

This special military insert, “Community Of One, From Our Families…To Your Families,” offers the Soldier, Commander, EFMP manager, health care professional and family caregiver a rich opportunity for community resources. This empowers the Soldier to use the resources to care for his or her family member with special needs. Products and services featured in EP Magazine can benefit families who may not have access to this information. Similarly, civilian families will come to know and appreciate the challenges faced by military families and hopefully a dialogue will be established through EP’s Search and Respond section, a mainstay of this award winning publication for 36 years. This section provides an opportunity for families to reach out to each other, share ideas and experiences and break down barriers brought on by the emotional strains of those caring for family members with special needs.

Thank you,

Kerry Dauphinee
Military Managing Editor
PUTTING THE PIECES TOGETHER

Parents and families have identified that obtaining information about their child’s rights and entitlements is their primary need when they face the challenge of obtaining appropriate services for their child. Assuring appropriate services for and protecting the rights of your child can be very difficult. Even though there are many experts on various service issues, there is only one ongoing “expert” about your child—and that is you, the parent. The fact is that no one else is as interested in these issues as you are.

Parents are expected to give legal consent to their child’s service providers and to sign release forms permitting a multitude of others to access records they themselves may not be permitted to see. Withholding information from a parent makes the parent feel helpless and powerless, intimidated and in awe of the providers. But this practice on the part of the “experts” is no longer acceptable in today’s consumer-oriented society.

Parents must educate themselves if they are going to be able to maximize their time, effort, resources, and knowledge to the benefit of their children. You need to arm yourself with information and skills to do the best job you can for your child. You must be assertive in finding and using available resources.

You can tap many resources to help you better understand your child’s rights and needs. Consumer-based advocacy organizations are an excellent source for information and educational materials that may enhance your understanding. Think of these resources as tools you use to solve the problems you and your child face. There also are many books and materials now available to parents that explain broad subjects like medical needs and treatment, special education and accessing community services and resources, or give detailed information about specific needs, services, or conditions.

Your effort as a parent to educate yourself helps you form a strong base from which you can reach out to grab and pull out the nuggets of information that become key to putting it all together for your child and for your family. When parents educate themselves, they become better able to interact with and to educate those who work with and around their children and their families. You will feel more self-assured about your expertise and preparation and service providers, sensing your confidence, will take you more seriously.

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TUBE FEEDING

Part 1: Transition Plateaus

Part 2: Turn Those Tube Feedings Into Mealtimes

Plus: EP launches Community of One
From Our Families…To Your Families—An exclusive new feature for military families with special needs
Community of One
From Our Families...To Your Families
Community Of One

From Our Families…To Your Families

Today we live in a world that is exceptional in many ways. “Change is inherent in all things,” counseled Plato, “change is constant…which can lead us to empowerment.” Over the next few pages Exceptional Parent Magazine (EP) is offering you an insight, a glimpse if you will, into how the military works with Soldiers, families, health care professionals, educators, and care providers in the special needs community. In the shifting sands of our global and personal worlds, exceptional parents are often the first to embrace Plato’s advice and allow change and unforeseen occurrence to move them to powerful action.

We invite you, military and civilian families and professionals, to come along on the journey with Community of One, From Our Families…To Your Families. It is a true collaboration of families, health care professionals, educators, and care providers in the civilian and military community. Historically, both communities have been working alongside and towards the same goals: to inform, educate, advocate and treat families with special needs challenges. We are in a unique situation at this juncture because we can now bring the best practices of both communities together; we can enhance the quality of life for our loved ones and provide quality training for our families, health care professionals, educators, and care providers. And this can be accomplished in a “Community Of One.”

In the past, medical and educational professionals did not consider parents to be part of the team in coordinating care for their loved ones with special needs. People with special needs were often institutionalized in the belief that professional “experts” could provide better care than parents. Over the years the U.S. military has been known for “taking care of their own,” and this spirit needs to be enhanced. EP has established significant relationships with every major professional medical society and consumer advocacy organization whose focus is the care and support of people with special needs. These relationships are at the core of EP’s ability to deliver “Information that Matters from People Who Care.” EP products and services will benefit both civilian and military families, providing all a greater voice and increased understanding.

Leo Rosten wrote, “I cannot believe that the purpose of life is to be happy. I think the purpose of life is to be useful, to be responsible, to be compassionate. It is, above all, to matter, to count, to stand for something, to have made some difference that you have lived at all.” If you are the parent of an exceptional child, it is our sincere wish that the resources in this insert will arm you with information that will be “useful”, that will “matter” and “count”. If you are a professional working with these families, it is our hope that your philosophy echoes that of Leo Rosten: that you feel your purpose in life is to be useful, to be responsible and to have the passion and compassion to make changes in the lives of families caring for members with special needs.

Please join us now as we begin this incredible journey through the pages of EP. While, as Plato observed, change is inevitable, families must, can, and do rise to meet the challenges of caring for someone with a disability. Families need not do it alone, however. Support, knowledge and resources can certainly make the load lighter and empower you to move forward undaunted. And that’s why we’re here—as a community of one.

With my best regards,

Kerry Dauphinee
Kerry C. Dauphinee*
Military Managing Editor
Who is STOMP?

By Luz Adriana Martinez

The Specialized Training of Military Parents, better known by many as STOMP, is a federally funded Parent Training and Information (PTI) center established to assist military families who have children with specialized education or health needs. STOMP exists to empower military parents, individuals with disabilities, and service providers with knowledge, skills, and resources so that they might access services to create a collaborative environment for family and professional partnerships without regard to geographic location.

Heather Hebdon founded STOMP in 1985. Heather is the spouse of a retired Soldier. She and her husband are parents to three young adults with different disabilities and two beautiful grandchildren, one of them with a disability. When Heather started STOMP, it was because she saw a need for her own family and many other families like hers. "When we were moving from Hawaii to Washington, it would have been fantastic to have someone to connect my family with the resources available in the installation where we were moving," says Heather. She goes on to say: "The vision for STOMP was to establish an organization that would provide support to military families of children with special educational and medical needs, as well as military and/or civilian professionals who work with them. "To this day no other organization has the array of services or training activities established to work with Exceptional Family Member Program (EFMP) family members. STOMP is a project of the Washington PAVE Organization and is funded through a grant from the U.S. Department of Education.

The staff members of the STOMP Project are parents of children who have disabilities. They have experience in raising their children in military communities and traveling with their sponsors to different locations. This makes the staff and the program uniquely qualified to support military parents who themselves have children with special needs.

Valerie Patterson is in the East Coast office. Valerie is the spouse of an active duty Soldier assigned to Fort Bragg. They are the parents of five beautiful children ranging in ages from eleven to nineteen. Of these, four have special needs. The East Coast region includes: North Carolina, South Carolina, Georgia, Florida, Mississippi, Arkansas, Alabama, Louisiana, and Tennessee. This is a total of 50 active duty military installations. Valerie has been with STOMP for three years. "I want families to know that we understand what they go through because we experience the same challenges. I want parents to know that they are not alone. I still have trials and tribulations with my own kids’ Individualized Education Plans (IEPs). As much as I would like to say that we don’t have any problems, we do." Valerie goes on to say: "I wish I could say that we have the perfect IEPs; there are no perfect IEPs because our children change and develop. The IEP is set up so that we can change it according to their growth, and if we see no growth, we can change the IEP to meet their needs."

Adriana Martinez is in the Central office. Adriana has been with STOMP since 1991 when she first attended the Parent Professional Teams Workshop and became a volunteer for STOMP. In 2001 she started working for STOMP as a Parent Education Coordinator and currently is the Assistant Program Director. Adriana and her military husband have two children, the oldest of which has Down syndrome, diabetes, and other medical needs. The Central region includes: Nevada, Utah, Colorado, Nebraska, Kansas, Missouri, Arizona, New Mexico, Texas, and Oklahoma, a total of 41 active duty installations.

Beautiful Tacoma, WA is the location of the STOMP headquarters. Working out of this office are Heather Hebdon, STOMP’s founder mentioned earlier, and Karen Elliott. Karen and her husband are the proud parents of two beautiful girls. Both of their girls are enrolled in the EFMP program, the youngest with more significant needs. "I found STOMP while preparing for a Permanent Change of Station (PCS) to Germany. I attended a workshop at Fort Huachuca with Adriana Martinez, and during the introductions, I told Adriana that one of these days I would have her job. I now do." Karen has had some great experiences as a military spouse but in her eyes “finding STOMP was as if I had found my home.” She goes on to say, “This is the place where everyone speaks and understands the same military and special needs acronyms. I left that workshop
Who is STOMP?

with my STOMP binder and finally understood what I had to do at my daughters’ next IEP meeting.”

The Headquarters office offers its services, not only to the rest of the country, but also to all the military installations overseas. This is what makes STOMP, truly, a global program.

Among the services that STOMP provides are workshops and materials on:
• How to work with the educational planning team to get services for your child who has a disability;
• How to access resources in both current duty stations and future duty assignments so that the child can begin receiving services quickly when the family transfers;
• How to make informed decisions with respect to overseas assignments and/or services within the Department of Defense Dependent Schools (DODDS) overseas and Domestic Dependant Elementary & Secondary Schools (DDESS) within the United States;
• Working effectively with military systems like TRICARE, Extended Care Health Option (ECHO) and the Exceptional Family Member Program (EFMP) for a particular branch of service;
• How to access educational and medical records and develop a comprehensive home file.

In addition to this, STOMP offers a variety of services though the Internet. The STOMP website can be found at www.stompproject.org, and one can always send an email to stomp@washingtonpave.com. In addition to this, STOMP offers two email based discussion lists to further connect parents and professionals across the globe. The STOMP listserv exists to enable military families worldwide to stay informed and connected and to learn from each other. It provides them with the necessary knowledge, skills, and resources to access services and feel confident in their role as their child’s best advocate. To subscribe, send an email to STOMP-subscribe@topica.com. The second list is called TRI-FAT. The TRICARE Funding Autism Treatment list exists to enable families attempting to obtain funding through TRICARE for a variety of autism treatments (including but not limited to Applied Behavior Analysis, supplements, AIT, etc.) to connect with each other, sharing information and support. To subscribe to the lists, parents and professionals can send an email to TRI-FAT-subscribe@topica.com

Every year STOMP invites teams from installations to form teams of three, consisting of a military parent, a military professional, and a member of the State’s Parent Training and Information centers. This is a four and a half day training established to strengthen teams so that they can return to their installations and assist families who have individuals with disabilities. “This is part of the dream for STOMP,” says Heather, “to have a STOMP volunteer in every installation so that when a family is moving to that location, the Parent Professional Team Volunteer (PPTVN) will be there as a local resource providing them information before the family arrives at the new installation.” There are currently PPTVN’s in twenty-five states and overseas in Kaiserslautern and Mannheim, Germany and in Yongsan, Korea.

Additionally, STOMP provides materials to parents and other interested individuals about:
• A variety of disabilities;
• P.L. 108-446 Individuals with Disabilities Education Act (IDEA);
• Section 504 of the Rehabilitation Act;
• Department of Defense Instruction 1342.12 Provision of Early Intervention and Special Education Services to Eligible DOD Dependents in Overseas Areas.

Most of these materials can be downloaded from the STOMP website free of charge.

With the changing environment of the military because of the war effort, it is important that families feel they have a source of information, support, and resources. While there may be resources within the community or schools, not all of them are aware of the unique difficulties that arise when your spouse is deployed. Because of personal experience, the STOMP staff understands these issues. They have faced the challenges that many families face when they are, not only working to secure effective services for the family member with disabilities, but also dealing with the realities of having family members deployed in high-risk areas. This provides a unique perspective that families appreciate when addressing concerns regarding services for the family member.

For more information on what is available in the installation you will be PCSing to, refer to How To Attend A STOMP Workshop. For a one-on-one consultation or to attend PPTW as part of a team, call any of the STOMP offices. The staff will be more than happy to assist you with your mission to be the best advocate you can be for your child.
Greetings from
The Military Child Education Coalition™

The Military Child Education Coalition™ is excited to partner with Exceptional Parent Magazine for this new effort to serve families who have children with special needs.

About MCEC™
The Military Child Education Coalition™ or MCEC™ is a private non-profit 501(c)(3) organization focused on the academic and school-related needs of all United States military-connected children. Addressing the transition and other educational challenges faced by the military child, MCEC™ serves as an incubator of innovative approaches, a conduit of promising practices, and an information source for organizations, educators, and parents. Toward this end, MCEC™ performs research, develops resources, sponsors professional institutes, conducts conferences, and publishes information for all constituencies.

About Military-connected Children
Serving alongside the members of our nation’s military are more than 1.8 million military-connected children. Because of their parents’ commitment to serve our country, the lives of these children are full of the excitement and challenges of frequent transitions, the possibility of a service member’s deployment and its concomitant separation, and many other cultural and circumstantial differences that make their childhoods distinctive. In their own way, each of these children is also serving our country.

Military-connected children face unique challenges. Military children typically move between six to nine times from the time they start kindergarten to their senior year in high school; this transition rate is three times more frequent than that of their civilian counterparts. Each move can create academic, social, and emotional challenges for the transitioning child, particularly if the relocation is to a new state or country. With military members and their families located all over the world, this happens often.

Moving is always a challenging event, but for families with a child with special needs, an additional layer of complexity is involved. With 13% of military children identified with a special need, a large number of families are faced with the task of understanding new or different state rules regarding special education, the possible need to have their child reassessed to allow access to needed programs and services, and adjustment issues as routines are changed each time they move.

Other issues inherent to military life, including the likely deployment of a parent, which separates a child from his or her family member, and concern for a service member parent’s safety, also add to concerns faced by military-connected children and their families. MCEC™ encourages and supports parents to serve as their child’s first teacher and best advocate through a series of programs, including MCEC™’s Growing, Learning, and Understanding (GLU): Making Meaning through Early Literacy™ initiative. This initiative helps parents promote literacy and discuss hard topics through children’s books and guided resources.

Students with learning challenges and those with extraordinary ability require tailored academic services and settings to address their needs fully and to provide them with the necessary opportunities to reach their full potential. Maintaining continuity and predictability for children and families while also achieving this needed flexibility can be complicated. MCEC™ has developed a series of trainings, called the Special Education Leaders Institute™, to help leaders in the education and military communities understand the issues and develop ways to support military-connected, special needs students.

Future columns will discuss specific programs and services MCEC™ offers to support families and educate school and military personnel regarding the unique issues faced by military families who have a child with special needs, including the Special Education Leaders Institute™ and Growing, Learning, and Understanding (GLU): Making Meaning through Early Literacy™ initiative. For more information, please contact Stephanie Surles, MCEC™’s Research and Development Officer, at stephanie.surles@militarychild.org or visit MCEC™’s website at www.militarychild.org. •
MilitaryHOMEFRONT: Your Source for Official Quality Of Life Information and Resources For The Military Community!

For TROOPS & FAMILIES:
Life in the military is both challenging and exciting! On MilitaryHOMEFRONT you can access information ranging from how to find commissaries and exchanges to how to get help for loved ones injured in combat. Here you find resources to support:

- Parenting
- Eldercare
- Deployment
- Legal and Personal Finances
- Casualty Assistance
- Transition and Employment
- Relocation
- Special Needs

For SERVICE PROVIDERS:
MilitaryHOMEFRONT provides a wealth of information to service providers who support the military community. The information ensures that service providers have access to the most current resources to include:

- Department of Defense policy
- Legislation
- Management Guides
- Tool Kits
- Promotional Materials
- Program Directories

For LEADERSHIP:
MilitaryHOMEFRONT is an excellent source of information for military leaders. A variety of topics and resources can be found to include:

- Commander’s Guides
- Early Bird News Digest
- Military Knowledge Online
- Legislation and Policy
- Casualty Support

MilitaryINSTALLATION Directories: These directories allow you to locate programs and activities on military installations worldwide.

The MilitaryHOMEFRONT Troops & Families section has a dedicated Special Needs area that has a wealth of information and resources for military families with special needs and includes information on Education, Medical Care, as well as Legal and Financial Services. A description of the personnel and assignment functions of the Exceptional Family Member Program as well as pertinent regulations, forms, and points of contact are included.

FAMILY CONNECTIONS FORUM: Military families with special needs can use this forum to connect with other military families and find out about resources at other duty station locations or ask general disability-related questions.

FAMILY SUPPORT: Find who provides family support services and where. Learn about enrolling your special needs child in child care and learn about respite care and other available resources.

TOOL BOX: The Tool Box is a valuable component of MilitaryHOMEFRONT. It contains tools that will help a family organize their medical and educational information, find helpful toll free numbers and access benefit checklists. The Tool Box also includes links to locators to find respite care, eldercare agencies, Social Security Administration offices, and more. Also included in the Tool Box area is the Department of Defense (DoD) Special Needs Parent Tool Kit. The Tool Kit contains 110 pages of comprehensive information and tools geared toward helping military families with special needs children navigate the maze of medical and special education services, community supports, and benefits and entitlements. Each module contains valuable resources and important facts; record keeping tools and sample letters have also been incorporated. The Tool Kit is divided into six colorful modules that can be easily downloaded and printed or saved on to a CD.

Visit MilitaryHOMEFRONT’s special needs section today to connect to the military special needs community!

The website is www.militaryhomefront.dod.mil/efm•
EP Position Paper on The Dignity of Life

TEENS AND SEIZURES
When Medicines Don’t Work—Devices and Diet

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Community of One
From Our Families…To Your Families—An exclusive new feature for military families with special needs

Center For the Intrepid Opens In Style
Community of One

From Our Families...To Your Families
United States Military Section

Center for the Intrepid Opens In Style
Two Fisher Houses poised to meet family’s needs

By Elaine Wilson, Fort Sam Houston Public Information Office

Thanks to the generosity of 600,000 Americans, wounded warriors now have a $50 million state-of-the-art physical rehabilitation facility. The Center for the Intrepid, designed for service members wounded in operations Iraqi Freedom and Enduring Freedom, recently opened at Fort Sam Houston along with two new Fisher Houses during a ceremony that included speeches from Chairman of the Joint Chiefs of Staff, Marine Gen. Peter Pace, and Deputy Secretary of Defense, Gordon England. R. James Nicholson, secretary of the Department of Veterans Affairs, also spoke at the ceremony. “There are those who speak about (wounded warriors) today—‘He lost an arm. He lost a leg. She lost her sight.’ I object,” Pace told the injured troops in attendance. “You gave an arm, you gave a leg, you gave your sight as gifts to your nation that we might live in freedom.” The $50 million center was built entirely from private donations through the Intrepid Fallen Heroes Fund, which provides assistance to the nation’s military heroes injured in the performance of duty and to their families.

“This is a red-letter day for this country and for the 600,000 Americans who have contributed a dollar, some more than a million dollars, to make sure our young men and women who have given so much to this country are aware the American people care about them,” said Arnold Fisher, chairman of the Intrepid Fallen Heroes Fund. “They are our national treasure.”

Dozens of wounded warriors joined more than 3,000 guests at the grand opening. The guest list included Senators Hillary Clinton and John McCain, country music band Big & Rich, Rosie O’Donnell, Michelle Pfeiffer, producer David E. Kelley and top military leaders from all branches of service. Rock music star John Mellencamp performed during the ceremony. Although the audience was packed with the top military leaders and Hollywood celebrities, the wounded warriors received the longest round of applause, along with a standing ovation. “It’s amazing, truly amazing. It really shows the American people care,” said wounded warrior, Staff Sgt. Daniel Barnes, a bilateral amputee.

The four-story, 60,000-square-foot center was designed for wounded warriors like Barnes. Equipped with the latest rehabilitation technology, it is a potential
athlete's dream. The facility includes an indoor running track, firing range, pool, two-story climbing wall, prosthetic center, and a computer-assisted rehabilitation environment, known as CAREN. This rehab environment comprises a dome with a 4-meter platform and screen, simulating for the user everything from a stroll down a city sidewalk to a day on the lake. It allows patients to improve their gait and balancing.
center for the intrepid

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skills. The unit is one of nine in the world and the only one in the United States. “What you see before you is a monument built by the contributions of 600,000 Americans,” Fisher said. “This is a monument to not only the men and women and their families who will come here but a monument to the generosity of our citizens and their love for those who serve.” The center will initially cater to amputees and burn patients injured in the Global War on Terrorism but is hoped to expand to encompass retirees, family members, and veterans.

“This is my son’s (Ken Fisher) and my commitment and our mission,” Fisher said. “We’ll continue this as long as it’s necessary. Our only wish is that a place like this will someday become a garage.” The two new Fisher Houses, located nearby the Center For the Intrepid, bring the on-post total to four. Fisher Houses serve as a home away from home for families of patients receiving medical care at major military and Veterans Affairs medical centers. The 21-room homes are built in the newer Fisher House style, a sprawling 16,800 square foot dwelling, as opposed to the older models that are just over 5,000 square feet.

Families will be able to live in comfort and style as they care for their loved ones in homes that more closely resemble a Malibu mansion than temporary military housing. Each home has a kitchen even Martha Stewart would love, a formal dining room, several sitting rooms and elegant bedrooms equipped with DVD/VCR systems and flat-screen TVs. “What a privilege it is to render assistance to military families,” said Ken Fisher, chairman of the Fisher House Foundation. Gen. Pace echoed the sentiment. “Thank you to the families – families of the fallen, families of the wounded; you sacrifice in ways that people who have not walked in your shoes can only imagine. When we are wounded, you are there to help put us back together. Those of you who are family members of fallen and of wounded have served this country as well as anyone who has ever worn the uniform.” •

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The First Awards Ceremony at the Center For The Intrepid

Master Sergeant Daniel Robles Is Honored With A Purple Heart and Bronze Star ★
By Elaine Wilson, Fort Sam Houston Public Information Office

With the star-studded grand opening just a day away, Army Vice Chief of Staff, Gen. Richard A. Cody, officiated over the first awards ceremony at the Center for the Intrepid (CFI). The official dedication of the $50 million, state-of-the-art rehabilitation center for wounded warriors was slated to draw a crowd of 3,000, along with a slew of celebrities and politicians, to include Senators Hillary Clinton and John McCain, and entertainers Michelle Pfeiffer, John Mellencamp, and Rosie O’Donnell.

On this day, however, Cody’s focus was not on the grand opening of the CFI or the celebrity cast but on Master Sergeant Daniel Robles who was being honored with a Purple Heart and Bronze Star in the lobby of the new center. “We have a warrior ethos in the Army that Master Sergeant Robles has lived up to all of his career and certainly on that day in April 2006 in Baghdad, when he was serving as an Non-Commissioned Officer (NCO) leading Soldiers, when he was injured,” the general said.

Robles, a mortar platoon sergeant, was injured April 8, 2006 while on a patrol in southern Baghdad. He was riding in the lead vehicle of a convoy when it hit an improvised explosive device (IED). Robles was riddled with shrapnel and lost both of his legs below the knee as a result of the explosion. “Since then he’s been going back and living that ethos of mission first, never accepting defeat, never quitting and never leaving a fallen comrade,” Cody said.

That same mission applies to the Center for the Intrepid, Cody said. The center was made possible through private donations and the commitment of Arnold and Ken Fisher, a father-son team who head up the Intrepid Fallen Heroes Fund and the Fisher House Foundation. Both the Intrepid Fallen Heroes Fund and the Fisher House Foundation are members of the Defense Department’s America Supports You program, that works to highlight ways in which Americans support U.S. troops, veterans, and their families. “Mission first is getting Soldiers like Master Sergeant Robles back on their feet: never quitting is his job; never accepting defeat is our job to help him; and never leaving a fallen comrade is what the Fisher House Foundation and the CFI Foundation [have done, as well as] all of those great Americans who have donated their dollars and their hearts to let our Soldiers know that if you are wounded on the battlefield, we will stay with you,” Cody said. Despite his injuries, Robles stood to receive his Bronze Star and Purple Heart, which Cody called a “badge of honor.” Cody also commented, “I hate giving out Purple Hearts, but I’m also proud to give out Purple Hearts because I know the pain and suffering that not only the Soldier goes through, but also his family, in helping him in coming back, never quitting, and giving him back his life.”

Cody said that regardless of their injuries, many of the Soldiers he meets profess their love of this country and the Army. “Most of them say, ‘General, can we stay in? I have so much to offer,’” he said. The general said Robles asked him the same question. Cody gave his answer at the awards ceremony. “You have my commitment as vice chief of staff of the Army,” he said. “We’ll keep you in the Army as long as you want to stay.” Robles, who has 17 years already under his belt, said he’s excited he will be able to complete a 20-year career. “It’s pretty amazing,” he said. “[Cody] even gave me his card. I couldn’t ask to be in a better place coming to Fort Sam Houston and Brooke Army Medical Center,” Robles said. “I can only imagine what will be accomplished once this place is fully open. Tomorrow is a big day for Fort Sam and all of the services.”

Along with the Center for the Intrepid, two new Fisher Houses opened Monday at Fort Sam Houston. The 21-room houses, which resemble an upscale hotel, provide a home away from home for families of wounded warriors. “People ask me why we do what we do,” said Ken Fisher, chairman and CEO of the Fisher House Foundation. “Look to my left,” he said, referring to Robles. “Can you imagine this sergeant going through his rehab and not having his family with him? This is exactly why we do what we do.”

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Home Away From Home

Fisher Houses bring military families together

By Elaine Wilson, Fort Sam Houston Public Information Office

Specialist Eric Gonzales was on patrol in Iraq when he saw the first improvised explosive device (IED). He backed away from the IED, not realizing a second one lay just inches from his feet. When it exploded, the shrapnel pierced the infantryman’s lower body, some flying into his face. In the two years since his injury, Gonzales’ battle has switched from fighting the enemy to fighting to regain his life. His myriad medical issues—damaged knee and shoulder, memory loss, hearing loss, arthritis, back injury, infections—eventually landed the Louisiana National Guardsman at Brooke Army Medical Center (BAMC) in October 2006.

Eight hours away in Alexandria, La., Gonzales’ girlfriend, Misty, constantly worried about Eric. She worried he wouldn’t be able to remember his medical appointments, ask his doctors the right questions, or pay his bills. But neither could afford to shell out the hundreds of dollars needed for a hotel or the long, weekly drives to San Antonio so they could be together. Then a friend told them about the Fisher House program, which provides military families a place to stay while their loved one recovers from an injury or illness. Just before Christmas, Misty moved into the Fisher House, down the street from BAMC.

Although still battling for his health, Eric credits his ongoing strength to Misty and his newfound happiness to the Fisher House. “She moved here, and we just got married January 3 by the justice of the peace downtown,” he said. “The Fisher House brought us together.”

“I’m here. He’s getting better,” said Misty, who also brought their four-year-old daughter, Cameron. “He knows I’m OK, too. He doesn’t have to worry about me either anymore. If it wasn’t for the Fisher House, I’d still be at home worrying about him.”

With the surge of war-wounded over the past few years, Misty represents a growing population of family members who are moving near major military medical centers to be with their loved ones, many facing lengthy recoveries. Most would not be able to afford a long-term stay without the help of the Fisher House program.

Founded in 1990, the Fisher House program serves more than 8,500 families annually and has provided more than two million days of lodging to family members since the program started, according to the program’s Web site. The low-cost temporary housing has saved families more than $60 million in lodging costs, plus savings on subsistence and transportation costs. On post, Fisher Houses 1 and 2 opened in 1992, pre-dating the construction of the new BAMC building. The eight-room, 5,000-plus-square-foot homes were planned with family in mind and come complete with several common areas, a big kitchen, and plenty of comfy couches and chairs. “These Fisher
Houses were built for a short stay, but with the war, the families are staying anywhere from forty-five days to two years,” said Russell Fritz, assistant Fisher House manager. “But with limited space, one of the hardest things I have to do is tell someone there aren’t any rooms available.”

The new Fisher Houses are sure to remedy that problem. The two, 21-room homes, projected to open in late February, will comfortably accommodate an additional 42 families. The homes are a sprawling, 16,800 square feet and are decorated with the finest linens, furniture, and home décor, all courtesy of donations made through the Fisher House Foundation. Like the older homes, the new houses have sitting and dining areas and a large kitchen. However, the newer homes are also compliant with the Americans with Disabilities Act, making them better able to accommodate wounded service members.

“Our Soldiers will not only feel more comfortable but will be able to be an integral part of the family again—allowing them to help with laundry, make dinner, take care of their kids, as well as being able to take care of themselves,” said Inge Godfrey, Fisher House manager.

While the new Fisher Houses are decked out in the latest in technology and design, the most valuable feature in the homes is one without a price tag—the families. “What’s wonderful about the Fisher House program is it offers a home away from home for families as well as fellowship during their
stay,” Fritz said. “Families have a tendency to bond. They cook for one another, care for each other’s kids, and those with cars provide transportation to those without.”

“They also help each other through an emotionally challenging time,” he said. “Family members may come back from the hospital depressed because their Soldier had a setback. The residents here can most times relate and can help relieve stress by listening to what happened and then share their experiences.”

“It helps to be in a family environment with other kids,” said Air Force Master Sgt. Shawn Roberts, who has lived in the Fisher House with his four-year-old granddaughter, Navaeh, since October 11th. His wife, Jacki, is being treated for cervical cancer at BAMC. “We watch each other’s children. Cook together. It’s a great support system.” Roberts’ friend, Staff Sgt. Robert Hardwick, a chaplain’s assistant at Fort Hood, Texas, went from referring people to the Fisher House to checking in himself. Diagnosed with prostate cancer, Hardwick has been staying at the Fisher House while he undergoes chemotherapy and radiation at BAMC. “I could sit in my room and be depressed about my cancer. But here, everyone has their own story. We can relate to each other,” he said. “Being here has helped me tremendously. It’s a close-knit family.” Fritz said that the relationships formed between residents far exceed their stay.

“When a former resident got married, people traveled to Illinois from Texas and Washington to be there. We’ve even had weddings at the Fisher House,” Fritz said. “Inge arranged for food, flowers, and the guests. The only setback was the groom was an inpatient. The hospital commander arranged for an ambulance and it drove up here with cans tied to it for the newlyweds.”

Inge said that it was the least she could do. “My position gives me the advantage to give directly to the men and women who serve in our military the best of care while they reside at the Fisher Houses,” she said. “I am filled with passion for these families and feel so fortunate to be a part of the Fisher Houses families, taking care of those who serve.”

With so much to offer families, Fritz said he is always surprised when people say they never heard of the Fisher Houses. “People come to us after living out of pocket for weeks or months and are near a financial breaking point because they didn’t know we were here,” Fritz said. “If people are unable to donate, then they can help by spreading the word.” Fritz said the Fisher Houses are also always in need of supplies, but the best bet is to call ahead to find out the current needs. A gift of money is also welcome since the Fisher Houses run 100 percent through donations.

For more information about the Fisher Houses at Fort Sam Houston, call 210-916-6000. For information on the Fisher House Foundation, visit http://www.fisherhouse.org.
The Military Child Education Coalition™’s Special Education Leadership Institute™

The Military Child Education Coalition™, or MCEC™, is a non-profit organization focused on the academic and school-related needs of all United States military-connected children. One of the main methods used by MCEC™ to address the issues faced by military families and their children is professional development opportunities.

MCEC™ offers a variety of training sessions to help parents, educators, military leaders, and others concerned with the well being of military-connected children learn more. One of these offerings, the Special Education Leaders Institute™, was designed to help leaders in both the education and military communities understand the concerns of military-connected special needs students and develop ways to support them during transitions.

The Special Education Leaders Institute™, or SELI™, is currently conducted in two phases. The first phase covers basic information about military life; challenges for transitioning students with special needs; navigating different program and Individual Education Plan requirements; the responsibilities that sending and receiving schools have toward transitioning students; informing, involving, and supporting parents; improving systems of communication; and utilizing MCEC™’s Interactive Counseling Centers™, which provide secure video conferencing and document sharing.

The second phase of SELI™ covers advanced resources like technical support for school districts, military communities, and families; information on the social and emotional needs of military families; details on family support systems; understanding and celebrating military culture; and Exceptional Family Member Program issues and accommodations.

Both continuing education units and graduate credit are available for those completing the SELI™ training.

Currently, 222 individuals have completed one or both phases of the institute offered in the United States and Europe since SELI™ was first offered in 2004. Additional trainings are and can be scheduled around the world. To learn more about SELI™, visit http://www.militarychild.org/SpecialEdu.asp. To register for a scheduled training, please see http://www.militarychild.org/SELIform.asp.

It is important that students with learning challenges and those who have extraordinary abilities receive tailored academic services and settings to ensure their educational needs are addressed fully. The ability to adapt to students’ needs also provides opportunities for the students to reach their full potential. Since communities also have to be predictable and stable for families, the delicate balancing of these two approaches is important. SELI™ provides communities with information to better understand the various issues faced by military families who have a child with special needs and have access to the tools for creating workable solutions within their area.

For more information, please contact Stephanie Surles, MCEC™’s Research and Development Officer, at stephanie.surles@militarychild.org or visit MCEC™’s website at www.militarychild.org.
In 2004, the Individuals with Disabilities Education Act (IDEA) was reauthorized by Congress. This law has been in effect since 1975 and has undergone many changes. Some of the changes have been considered positive by families, while others have been considered less than positive. The Reauthorization in 2004 made some sweeping changes that have had a direct impact on families who are not as likely to stay in one school district or State. For military families, these changes can cause both challenges and a sense of assurance when making a move.

The IDEA was established to provide a Free and Appropriate Public Education (FAPE) for all eligible students. Each State is responsible for developing eligibility criteria consistent with the intent of the law. This means that they will decide the types of evaluations that will be accepted to determine eligibility, criteria for meeting eligibility, and other important factors. The federal government has given no specific eligibility criteria with the exception of developmental delays and a process for learning disabilities. Each State is required to ensure that the process they use is consistent with the federal law. The IDEA has always been based on six basic principles:

• the right to a free and appropriate public education (FAPE);
• the right to appropriate evaluations;
• the right to an Individual Education Program (IEP);
• the right to be educated in the Least Restrictive Environment (LRE);
• the right to parent and student participation; and
• the right to procedural due process.

For military families moving from one duty station to another, the challenge of insuring the services necessary for their child can be daunting. The IDEA 2004 includes language to help families as they transition to the new duty station when their child has an IEP. With the reauthorization, the new State or school district is required to accept the child’s current IEP and implement the services to the extent appropriate until such time as they have reviewed records, done any needed evaluations, and then determined the student eligible, or ineligible, under the State’s provisions for education of students with disabilities. Families need to provide the school with the most current IEP and any supporting evaluations. This means it is critical for the family to have a current home file that includes all of this information.

Students with learning disabilities, behavioral/emotional disabilities, communication disorders and other challenges, who do not have significant cognitive delays, would not be required to have these benchmarks in their IEP. The Federal law only requires the school district to develop “measurable annual goals.”

While it may appear simple and straightforward, the language of the IDEA 2004 does not ensure the family that the program the child was receiving in the previous duty station will be the same as the one provided at the new location. Terminology is different from location to location, eligibility requirements may be different, programs may not be the same, and even the provision of related services may be different from one location to another.

While the IDEA regulations came out on August 14, 2006, States are still in the process of developing their
State regulations or policies for the implementation of these regulations. The States may implement the federal regulations in their entirety, or they can add language or protections that are State-based. The Federal law needs to be considered as the foundation upon which the State regulations will be built. Some of the most challenging areas of the new IDEA with which States are currently struggling include:

1) The exclusion of short-term objectives for students who are not being assessed to alternate standards—The IDEA only requires short-term objectives or benchmarks for students whose disabilities are so significant that they will not be assessed to the same high standard as other students with disabilities or their non-disabled peers. Students with learning disabilities, behavioral/emotional disabilities, communication disorders and other challenges, who do not have significant cognitive delays, would not be required to have these benchmarks in their IEP. The Federal law only requires the school district to develop “measurable annual goals.” Benchmarks or short-term objectives have been an easy way for parents and teachers to determine if the child is making progress toward the annual goal and to report on that progress on an ongoing basis. Without the short-term objectives or goals, families and schools will need to determine how best to measure progress and report on that progress. The challenge for families, who move from a State or Department of Defense Education Activity (DoDEA) where short-term objectives or benchmarks are going to be continued as a State or Department of Defense (DoD) policy to a State that will not require these, is implementing the IEP as written, measuring progress, and determining whether the goals are clear enough to actually be measurable.

2) The provision that transition services must begin by the student’s 16th birthday—Prior reauthorizations of the IDEA had transition services beginning at age 14. This transition planning was to include course of study, consideration of post-school options, and, where appropriate, independent living skills. With the reauthorization, the language was changed to say that the IEP in place when the student turns 16 must have transition goals as a part of the IEP. The transition plan must include post-school outcomes, linkages with outside services to assist in the transition, and the functional aspects of the student’s needs and goals. For families coming from a State or system where transition goals were developed and implemented at age 14, to a State where they have changed the language to 16, families and districts will need to reconcile how they will implement the goals and if there is still a need for transition goals before removing them from the student’s IEP.

3) The use of “research-based” programs—For many years, students with disabilities did not have access to the curriculum used by their peers. Teachers developed strategies and programs to address the student’s individual learning style and needs. With the alignment of the IDEA with the No Child Left Behind Act (NCLB), there is now a requirement that goals and objectives be based on “research-based” strategies. This means that the curriculum and strategies that are to be included in the IEP and student’s program must have demonstrated proof of the effectiveness of the methods being proposed. The challenge lies in where the research originates and what access the different states and programs have to this research. Children with autism, and the use of different curriculum to meet their needs, are a prime example of the challenge a State or District might face. In some States, Applied Behavioral Analysis (ABA) is an integral part of the program, while in other locations ABA is not provided in the schools. Some programs utilize the Picture Exchange System (PEC) for communication, while others use technology or sign language or a combination of strategies. While all of these may be research-based, they may not be provided with the same level of intensity or even in the same way from one location to another.

4) The use of “Responsiveness-to-Intervention” (RTI) for determination of eligibility as a student with a learning disability—As stated earlier, each state establishes its own criteria for eligibility. The Federal Government, however, identified a process for determining if a student had a learning disability. This process utilized an equation that looked at the student’s level of expectation (what he or she should be able to do) based on IQ, and the student’s level of performance (how he or she was actually performing in academic areas). The

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Know what is happening in your child’s program: what curriculum is being used, how goals are being implemented, and how support services and technology are being used. These are questions about which you need to have knowledge.

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IDEA for Military Families

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expectation was that if there were a large enough difference between what you would expect the child to be able to do and what the child was actually able to do, then there was a learning disability. This methodology has been utilized since 1975. However, it causes a student to have to fail before they can receive services. With the reauthorization, local school districts can now use RTI to determine if a student has a learning disability. This protocol looks at the student’s access to research-based strategies and the level of intensity of the child’s access to the strategies. The school system can increase the level of intensity to the research-based standards to see if improvement occurs. If, even with this more intense support, a student is not showing success, the school district could refer the child for special education support, even if there weren’t a large difference between the child’s level of expectation and level of performance. The research has demonstrated that this method of support has effectively addressed the needs of many learners and, therefore, made it less likely that they will need special education services. While this methodology has been highly supported by the Reauthorization of IDEA, it has been left up to the local school districts to decide if they will use RTI to determine eligibility. For military families, this may pose a significant challenge. For instance, what happens to a child who moves from a school district where he or she received RTI and needed the additional assistance of an IEP to a school district that does not recognize RTI as a method for determining eligibility? Because this is a local decision, students who move from a community-based school district into another school district either on the installation or elsewhere in the same state may find themselves having to go through the eligibility process once again to prove the child has needs.

While these issues may appear to be a challenge, there are ways families can minimize the potential fallout. The following strategies have proven effective for other families and are worth considering as you contemplate how you might want to proceed.

• Stay involved. Know what is happening in your child’s program: what curriculum is being used, how goals are being implemented, and how support services and technology are being used. These are questions about which you need to have knowledge.

• Be sure your IEP is clear and that all related services, assistive technology support, and accommodations are listed. Just because services are provided for all children at one location does not necessarily mean it is something that will automatically happen at the next duty station.

• Connect with other families, both at your current duty station and at your future duty station, and, when you are going to move (Permanent Change of Station—PCS), make contact with families and get their input into how things work.

• Stay involved with email lists or bulletin boards for military families. This will help you stay abreast of the different issues you might face, whether they are educational, TRICARE, or even EFMP issues. Military OneSource, Military Home Front, STOMP, and the Military Child Education Coalition (MCEC) all have information on resources and services.

• Make connections early with the EFMP staff at Army Community Services (ACS) so that they can assist you with potential challenges and help link you with resources within your local community. They are also a great resource for information and support when you get ready to PCS. They can forward information, with your permission, to the EFMP at your new duty station. However, don’t leave it all up to the EFMP Manager—get points of contact yourself and follow up.

• Connect with the school liaison office and local school districts. Send your child’s IEP out ahead of your move, so that the new location is aware of the services your child is receiving. It is also a good idea to give them consent to talk with the current school district to get clarification as they plan for your child’s arrival.

• Learn your rights and responsibilities. The law is only as good as the paper it is written on if you don’t understand it. Major challenges occur, not because the system is broken, but because of misunderstandings and communication breakdowns. When you understand your rights and use them as a tool, not as a weapon, it is far more likely that the services needed by your child will be provided.

• Finally, remember that services don’t have to be called the same thing, or even look exactly the same, to be effective. Be open and willing to consider options and discuss your concerns and ideas openly with the school.

IDEA provides promises and commitments, but to make it complete, parents need to understand their role and act as the advocates for their children. Remember, no matter how effective a program is, how good a teacher is, or how well your child used a specific technique or service, you can’t pack all of these services to take with you. So, remain involved and stay aware. You are the only consistent piece in your child’s educational career.
Effective Transition Planning for Learners with Autism

Easter Seals Therapeutic Day School of Chicago

Stress Management When All You Need Is Rest

NMEDA Quality Assurance Program

Wheelchair Transportation Safety Series Part 1

SEIZURES AND TEENS Maximizing Health and Safety

Community of One From Our Families…To Your Families

Tips for Preparing for Upcoming School Transitions

One for Autism

Fort Lewis EFMP

Autism Awareness Month

Cover Story An Interview With Vanessa Williams on Her Special Olympics Involvement and Her Movie, My Brother
Community of One

From Our Families…To Your Families

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Fort Lewis Exceptional Family Member Program (EFMP)

By Heather Hebdon

Located in the shadow of Mt. Rainier, Fort Lewis is the home of the highest per capita exceptional family member population in the Army. Ideally located on the Northwest coast of Washington State, Fort Lewis is home to the Strykers and First Brigade. Every Military Occupational Specialty (MOS) can be found on the installation. Combined with its close proximity to McChord Air Force Base, the installation is ideally suited to meet the needs of the military family.

With the large Exceptional Family Member Program (EFMP), Fort Lewis has developed a unique partnership to meet the needs of families. Fort Lewis established a contract with Washington PAVE, a statewide disability organization, to provide the services of an EFMP Coordinator at Army Community Service (ACS). It soon became apparent that with the needs of the families, more support was needed. To address this need, the Fort Lewis ACS Director designated a full-time staff person as the EFMP Manager to work in concert with the EFMP Coordinator. This dynamic team has become the model of efficiency and support upon which families can depend.

Within the community surrounding Fort Lewis, families will find a variety of resources and services. The installation is surrounded by 13 school districts of varying sizes and scopes. Tacoma School District is the second largest school district in Washington State, while Fife School District is one of the smallest. Clover Park School District, which is the school district that provides services to families living on the installation, has a special education population of approximately 1,500 students from pre-school to high school. Almost 50 percent are military affiliated children. “The military has both a positive impact and is also challenging for the district,” comments Mrs. Ann Almlie, Director of Special Education Services in the district. “There are a really high number of children with autism so we are working with the autism program at the University of Washington and developing innovative and exciting programs to meet the needs of our students.”

Mrs. Almlie also emphasized the positive role the soldiers have. “It is a wonderful experience working with the soldiers.” She also recognized the challenges with deploying soldiers, stating, “Many of our staff members are married to military personnel and the impact on moves in the middle of the year is greater. When their spouses are deployed, many of them choose to go back home so we have worked to ensure we have a good pool of quality staff available to address these situations.”

Mrs. Almlie stated that the district has established strong programs to work with students with disabilities. “The only population of students that we contract out is students who are deaf.” She pointed out that so much more is possible because of the relationship with the Fort Lewis EFMP and PAVE to help parents become involved within the community. She said that these connections have greatly enhanced the district’s ability to support families. She indicated that these programs have helped families understand the differences they encounter in Washington State. “The one thing parents are not used to is that they may not live on post and be in Clover Park School District. EFMP has helped get information to us early. If we get the records soon enough, we can work
with the families regarding appropriate placement in our district or another in the area, before they even get to Fort Lewis. Getting the records early is critical.”

Adults with disabilities have found support and resources for many of their needs through the network of support available through TACID (Tacoma Area Coalition for Individuals with Disabilities), the Division of Developmental Disabilities (DDD), and the Division of Vocational Rehabilitation (DVR). TACID programs include both social and work-related support. The challenge, however, is the long waiting lists for resources for adults. This can leave the families with a sense of frustration. The EFMP staff has developed close contacts with the various community resources to keep them aware of the families and to ensure that they stay current regarding these potential difficulties.

Known for the community supports available for individuals with disabilities, Pierce County has become a location where families look to retire. The resources have been diminishing, and families now find themselves turning to the EFMP for far more than they might have in the past. Families work with Mary Herrera, the EFMP Manager, and Nancy Dozier, the EFMP Coordinator. “The families and professional staff are very comfortable working with both of us,” stated Mary. “We work as a tandem team to ensure that families can get the support they need.” Nancy added, “We try to keep each other really aware of the various requests. We work together with the families and do a lot of brainstorming.”

The EFMP has worked hard to get programs and supports in place. They have monthly support group meetings open to all families as well as a quarterly support group specifically established for families with members who have autism. “We do a monthly newsletter, offer recreational activities, and have a terrific annual family camp in conjunction with Camp Prime Time up in the Cascade Mountains,” stated Nancy. Mary also emphasized that they have the newsletter on a number of installation websites, as well as having a regular EFMP piece in the ACS newsletter. “We try to find as many ways as possible to get information to our soldiers,” stated Mary.

Both of these dynamic ladies emphasized that they couldn’t do it without the collaboration among the various programs and resources on the installation. “There are no turf issues. We are all working together to help the families,” stated Mary. “We have good links with Child Youth Services, Army Public Health Nursing, Madigan EFMP, and the School Liaison Office,” Nancy said. “They are involved and willing to work together to help our families. It is really terrific.”

Both Mary and Nancy commented on their concern for the families with the ongoing high level of deployment. “Some of the moms have disappeared who were active last year. They’ve lost their gusto. It is just too much for them. They need 100 percent of what they have to take care of their families,” Nancy stated. Fort Lewis is hoping to be one of the Army installations that will be receiving an influx of funding to give these families a break by providing aid for respite care. Additionally, Washington PAVE has acquired funding that the EFMP will use to enhance recreational opportunities for the support groups.

Mary stated, “We really love working with the families. We may not have all the answers, but we will turn over every rock to find information.” They both emphasized that they love it when families who have learned about a resource or program come back and tell them about it so they can share it with other families. “Knowledge is power, and we love to empower them,” Nancy said.
Something powerful is at work in an unassuming building in the south central section of the Lone Star state: It is a formula for success. Will it revolutionize thinking, like that famous formula E=mc^2. It has the potential—if its significance is recognized. The formula consists of multiple parts—there are significant pieces that, if present, should nearly guarantee success and, if absent, could make it nearly impossible to achieve.

The formula: Passion + Hope + Support + Faith + Opportunity + Belief + Teamwork = Success. Seven pillars on which to hang your hat. Einstein’s formula is known as the theory of relativity. We’ll call ours the theory of connectivity—connectedness to each element in the formula and to positive outcomes.

So now you need proof. And I say, “Olga and ‘One for Autism,’ in San Antonio, Texas.”

To meet Olga Vasquez-Silva is to encounter someone who is alive with the strength and evidence of her convictions. To further understand Olga is to meet her husband, that piece in a picture puzzle that simply goes “click.” To even further appreciate the tapestry of Olga is to learn that she and her husband have four children (Ryan, five; Anthony, three; Jacob, one; and Natalia, two months) and that her parents are living in the family’s home. And, finally, to fully round out your understanding of Olga, you must hear the parents of children who attend One for Autism and who swear by Olga’s methods and her outcomes, but most of all by her heart.

One for Autism is a thriving and ever-growing facility for children with autism and other developmental delays. One for Autism, Inc., umbrellas One for Autism Academy, which offers a classroom setting, as well as One for Autism Center, which provides one-on-one comprehensive therapies, including behavioral therapy, occupational therapy and speech therapy. This creates a “one-stop” opportunity for families seeking care for their children. Even now, expansion is under way to include older children and adults in an additional center, which will be known as the Youth and Adult Treatment Center.
Olga currently oversees about 180 children with autism and developmental delays between the One for Autism facility and private consulting. There are about 45 children at One for Autism Center right now. “Fifteen of them are typically developing, so we have an inclusive setting here in the classrooms,” says Olga. The youngest child is 23-months-old while the oldest is 10-years-old. “And we do provide all the realms that you can imagine that an autistic child needs,” she said, “from play therapy, music therapy, music class, behavioral therapy, occupational therapy, speech therapy, and we work as a team. We have a combination of about 19 staff, and we have about nine consultants that come in every week to work with our children.”

A “typical” child is considered to be one without developmental delays. “I used to say ‘normal developing,’” Olga reveals, “and one of the doctors said, ‘Tell Olga to start saying ‘typical,’” so then I started saying ‘typical.’ You raise a lot of questions with the word “normal,” says Olga.

Olga’s children are some of the typical children blended in to the mosaic of One for Autism. Olga relates that she sees how her son Ryan is learning from this experience. She describes an outing to McDonald’s in which Ryan told her that he thought another little boy had autism. Ryan said, “I’m going to go ask him if he wants to play.” And he did. They played as any two children would play, engaged and having fun. Ryan, at age five, through regular contact, has developed the perception to recognize another child’s special needs.

The new One for Autism Youth and Adult Treatment Center will make a difference for children currently with Olga. “I don’t want them to age out (become too old for services), I want them to have a continuum. I want the parents to know also that there’s support when they get older, when we have to teach them job skills…We need a job coach? We’ll have one. We need placement? And we’ll go and do that. The way I see it is that we’re going to just have more support throughout their lifetime, throughout the kids’ and the parents’ (lifetime). It’s so important.”

While Olga plans to build the new center gradually by starting with smaller numbers of students then adding on, her vision stretches to the horizon. “You know, everybody’s asking… when are you going to say ‘no,’ when are you going to say ‘I don’t know how to work with a person that’s 40, that’s older than me’?” Her response? “If we can help him, hey, let’s see what we can do for him. If the man or the woman is too severe or we can’t work with them…,” Olga pauses. “There’s no such thing as you can’t work with somebody; it’s the effort you put in it,” she says. Even now, Olga is consulting with a 30-year-old and a 40-year-old.

The new Youth and Adult Treatment Center will offer a school setting for grades four through 12 and will include children ages 10 to 21. Olga plans a fully accredited school. She notes that some children come to One for Autism for the first time at 10 to 12 years of age. At that point, different skill sets are required. “So it’s another ballgame with the older ones,” she says. When the new center site became available, it didn’t take long to recognize that this would be a place for her older kids. The current waiting list for the new center stands at about 30.

Additional services will also be integrated at the Youth and Adult Treatment Center, Olga says. “We’re going to be able to provide added service such as art therapy… We’re going to individualize all the curriculum specials, like music and art and all that good stuff. What we’re looking at is that every child is going to be exposed to it.” Research has shown that people with autism tend to naturally excel at music and art.

Every sound formula has been tested to see whether it stands up to the rigors of observation. What about this one, this “formula for success”? At One for Autism, success is evident in children’s improved behaviors and increasing social, academic, and life skills as well as in the resulting word-of-mouth praise that adds more names to the waiting list. Karen and Daniel Giorgi,
whose three children with autism attend the center, echo one another in praise for Olga’s commitment to children. Daniel, a chaplain at Randolph Air Force Base, describes her as “down to earth,” and Karen notes that she has “a heart as big as Texas.”

What about the integrity of the formula’s separate elements? There are positive signs.

**Evidence of Olga’s Passion.** Scheduled for a Cesarean section at 6:30 a.m. with her fourth child, Olga was at One for Autism at 8:00 a.m. the morning prior to the surgery and remained until 6:00 p.m. in the evening to greet the children’s parents and take care of staff. Right after she had a C-section with her third child, she called in payroll. “I couldn’t even feel my legs yet. And my husband’s like, ‘Look at you,’ and he took a picture of me calling payroll in. I said, ‘I have to take care of my staff.’ And he’s like, ‘I’m not going to say anything,’” she said with a laugh. “It’s just a commitment—you don’t let me down, I’m not going to let you down … staff-wise and children-wise.”

**Witness of Hope.** Olga notes that some people come in to One for Autism and tell her what their child cannot do. “To me, right when they say, ‘You can’t,’ [I’ll] say, ‘Well, let’s try. Let’s see what he can do.’” While she makes no promises, she shares her experiences of progress with children, what she has seen happen, so the parents know. “Hope is good,” she says.

**Confirmation of Support.** It is hard to imagine the level of success that One for Autism has achieved without Michael, Olga’s husband. Devoted and proud, he spends much of his time on unglamorous but necessary logistics like business administration and maintenance, allowing Olga to focus on the care and progress of the children. He recognizes Olga’s vision and gives himself over to his part in the mission of achieving it. His insurance business is stable enough that he is able to leave daily functioning to a capable secretary, while he pours himself into One for Autism. “My husband has been just an angel in this,” says Olga, through stress and pregnancy and all that has had to be dealt with. “He helps me so much,” says Olga. “If I have a conference, he’s the one who doesn’t even ask me, ‘Well, do you want to go?’ He knows I will go, and he knows that he needs to stay with the kids. So sometimes he’ll (say), ‘What are your plans for the weekend?’ I say, ‘Well, I have to go to a meeting, a two-hour meeting.’ Okay, so then he’ll make plans after that because he knows he’s the one that has to be with the kids while I go.” At bath time each night, Michael bathes the boys while Olga prepares their clothing and gets them dressed. Mealtime is a matter of communication, with the couple teaming up to decide who does what for each young child. Michael and Olga have been married for six years.

**Testimony to Faith.** “Of course, I thank God every day that it (the success of the program) happens. If you do good, good things happen,” Olga says, with conviction. Olga says that she grew up hearing a phrase from her mother, one that her mother says to this day: Si Dios quiere—If God permits. “And I say it sometimes with my families that speak Spanish,” she says.

**Indication of Opportunity.** Olga’s families are devoted to her and to her work. The mother of one of her kids called Olga about the opportunity for a building that was available. That building, with another, smaller separate building and play area, will become the new Youth and Adult Treatment Center.

**Verification of Belief.** Olga recalls that she was optimistic as a child. While there have been struggles since the center opened, with finances and doing all
the work necessary to meet licensing requirements, her philosophy is, "If you're not doing anything wrong, then no wrong should come to you, so things come together." Things always seem to work out for financing or permits, even if it is at the last minute. "But you have to get away from the, oh, "I'm in it for the money" stuff like that. You have to be in it for the heart. You have to be in it to make a change in these children. And to help the parents believe that there is hope, that we have to be in it to make a change in these children. And stuff like that. You have to be in it for the heart. You have to get away from the, oh, "I'm in it for the money"

Proof of Teamwork. "You know, everybody says, 'It's Olga's school, it's Olga's school,' " Olga reflects, "but it takes a team to get to what I do. I will take the time to talk to (staff). I will take my time because if it weren't for them, it wouldn't be the way it is now... it shows not just a commitment to me, but it shows a commitment to my kids. It shows a commitment to those kids that need us. It works like a family." Olga has been willing to take a paycheck cut to hire valuable staff.

Trained as a behavioral therapist and consultant with an M.A. in Special Education, Olga uses Applied Behavior Analysis (ABA) at One for Autism. The beauty of ABA is that not only can staff note qualitative changes in the children but quantitative ones as well. ABA, or discrete trial format, has been shown to be a highly effective tool in the treatment of autism spectrum disorders. ABA uses observation to help track and modify behavior to increase social, academic, and other life skills.

At One for Autism, an instructional binder is created for each child, with the specific skills to be worked on with the child. Each therapist who works with the child tallies the number of successful completions of a particular behavior or skill. For example, if staff is working with a child on eye contact, the therapist will give a directive to the child designed for establishing eye contact. When the drill is complete, the therapist will tally the positive responses to eye contact. If a child makes eye contact five out of ten times, this is a measurable result that can be compared with ongoing progress in the child's responses and behaviors. Instructions are consistent. "We don't change it around because it's not good for them until we get to the point where we're generalizing these skills."

Olga notes that they try to address criticisms of ABA as a therapy. "One of the main criticisms of ABA is that the kids get too dependent; they become robots. So in order to prove that they don't become robots... you need to find a point where you're able to generalize. If he can do it with her (and) he can do it with him, then we've got generalization. He talks different than her, and he has a different personality than she does, so these kids are generalizing, so that means they're learning." When children reach an 80 percent response level across three separate therapists on a skill, "then we're ready to move this drill up," she says, increasing the difficulty level.

One for Autism utilizes a daily communication log with parents. "They know every hour what the kids did, what they ate for lunch, who they worked with and if they received speech, OT or ABA, and the therapist writes a note to them," with details, says Olga.

Olga notes that ABA works with autism and other disabilities "for the type of treatment that we do, which is all one-on-one, retraining the brain. That's what we do. We retrain the brain to focus, to listen, to provide more concrete examples for our kids, who are very, very visual learners."

Challenges are addressed. "As behavioralists, if they're not participating, it's probably a behavior that's interrupting them. So we need to know how to handle that." Variables like seizures, medication disruptions, and other factors can affect a child's ability to focus on the task at hand. For these situations, staff is encouraged to stop drills and build rapport with the child. Different therapists rotate work with the children, which allows for score comparisons and building reliability in the way therapy is administered and its outcomes.

Part of the interactive approach at One for Autism is that each child's instructional binder does not merely reside at One for Autism. The binder is available to parents on weekends, for their review of their child's progress and for feedback between parents and One for Autism staff. Parents can use the binder information to work on generalizing their child's behavior to other settings. This regular communication does not leave progress to mystery but to informed communication. Parents will even report that they take the binder on an outing to the park, because they want to continue the progress that they are so excited to see in their child. Olga does encourage break time. If parents would like staff to work on a particular skill that they think their

Variables like seizures, medication disruptions, and other factors can affect a child's ability to focus on the task at hand.
child is ready to learn, such as tying shoes, One for Autism is receptive to working on that, within the structure of discrete trial format that they use.

While the limited number of physicians available to diagnose children with autism or other developmental delays can mean placement on a waiting list until they can be seen, Olga is able to begin treatment prior to that first physician visit. She is certified in Autistic Diagnostic Observation Schedule (ADOS), Module 1, and can administer this exam. Without the supervision of a physician she says, “Of course, I can’t do the diagnosis, but I can treat.” Familiar signs that can signal autism are children walking on their toes, self-stimulation behaviors, and being non-verbal. “By the time they get to that doctor, I have data to tell her this is what he’s done, this is how he’s developing, this is his mastery level, what else do we need to do for him?” Efforts can be focused. “We can target the behaviors and decrease the behaviors or get rid of them. Then the opportunities for learning come about because you’ve gotten rid of the behaviors that interrupt learning.”

“The younger you start, the more successes you will see,” says Olga. “The more hours they get seen a week, the faster we see progress because they build from that mastery level.” Drills are done in areas such as gross motor imitation and verbal imitation, and fine motor, oral motor, and verbal receptive skills. The results tracked in each child’s binder include the number of responses to the number of prompts in a drill as well as at-a-glance grids that readily reveal a child’s ongoing progress. One of the advantages to One for Autism is that for the children who attend other schools during the daytime and come to One for Autism for therapies afterward, they do not miss out on regular classroom time by being taken from the classroom for therapy sessions.

When a parent asked Olga about the teacher turnover rate at One for Autism, Olga was able to tell her that she has employees who have been with her since she turned her home’s garage into a therapy setting. It is a two-way loyalty. Olga offers mentorship opportunities for her staff. She’ll pay for staff working on their ABA certification and cover the cost of books because she was there at one time and knows what it was like. She does this “because of their commitment with me and because they want to study what we do. To me, it’s heads up, I’ll help you with your books if I can.” In the end, the children benefit. She will purchase furniture at auctions, knowing that the money saved can then be used for additional therapy hours or other needs for the children.

Meeting the needs of the children means meeting the needs of parents and the whole family. The bilingual One for Autism is a valuable resource for Spanish-speaking families, providing a comfort zone in that arena. Because One for Autism has been approved for the U.S. Military’s TRICARE Extended Care Health Option (ECHO) program, military families are eligible to receive services there. Olga describes a family who had relocated from Puerto Rico to San Antonio. The parents have triplets: one son with autism, another son with a speech delay and a daughter who is typically developing. In January, the father was deployed to Iraq for one year. The children’s mother primarily speaks Spanish, and the family’s first interview at One for Autism was conducted in Spanish. With her husband gone, she can continue ongoing dialogue about her children with Spanish-speaking staff, who can help make her feel more welcome and can address her needs. Prior to the triplet’s father’s departure to Iraq, the family had moved closer to One for Autism to make life a little simpler. Olga indicates that she has committed herself to sending their father videotape updates so that he can see his children’s progress in therapies.

The Beginning

A nursing student at University of the Incarnate Word in San Antonio, Olga had started working some rotation units in various hospital departments, including oncology and pediatrics. One day, she returned to the neonatal intensive care unit where she had worked the previous day and inquired about one of the babies who “was” absent from its earlier spot. She thought the child had been moved upstairs to another floor. Then she was told that the baby had passed away. Olga notes that she gets attached to people she encounters. “This was not for me. Experiencing death and being able to accept it was something that I wasn’t prepared for.” Olga dropped out of the nursing program. She went to the job bank at the school to check out job postings. She found a listing indicating that a mother was looking for somebody to help with her son with autism—no experience necessary. At the time, Olga was unfa-
miliar with autism. She attended the interview and was offered the job while there. “So right after that happened, I went home and I researched autism, because I did not know what autism was. As I researched it, it was really interesting and of course with autism, children will be able to get treatment.” Olga eventually graduated with a Bachelor of Arts degree in psychology and a minor in biology as well, due to all of her nursing classes.

The family that Olga worked with was addressing their child’s treatment needs by bringing in a consultant from UCLA who trained Olga and four other therapists who worked with their child. This was Olga’s first exposure to discrete trials, the applied behavior analysis (ABA) approach. “I learned a lot from him, and I just found it so rewarding to see this child from Point A to Point D within weeks.” The consultant set up a 30- to 40-hour per week program of therapies for the three-year-old child. The consultant would come every three months on a weekend and spend two days training the therapists. The therapists were videotaped as part of training. New goals were set each time. “So we could see what was coming up with him, and we would drive to get him to that point, so by the time the consultant came again we already had all these skills that he had given us beforehand.” This child is now 12 years old, and Olga will still do consultations with him as necessary. She had worked intensively with him for the first three or four years.

“And within that time working with him, he actually inspired me to go get my master’s in special education, because I was noticing that a lot of the skills that we were working on were academic-, educational-based, and in order for me to advocate for him in a meeting or for me to know where we were going, I thought it would be essential that I needed to go and further my education in the educational aspect of it. But, of course, the psychology helped me with the disability in itself.”

Eventually, another family requested that Olga provide consulting services, then another. She did this for about seven years, traveling to people’s homes. “Then I got married. I got my master’s. We bought a house.” Soon, the expectant couple’s garage was transformed into two therapy rooms and a waiting area. Each therapy room has a two-way mirror for parents to observe the progress of therapy with their child. The clientele list began to grow. “I happened to consult a child whose father owned a daycare.” Eight hundred square feet of space was available at this site, he indicated, if she were interested. Olga decided that she wanted to start implementing education with the therapies. In August 2004, she began a half-day program at the site, with six children. By December, the number had doubled to 12 and by the end of the summer the center had reached its full capacity under licensing regulations at 20 children. A parent of one of her children told her they were going to look for a place for her because they wanted the school to grow. One Friday, the parent called to say she had found something, and Olga followed up that day to find out more about it. On Saturday, she and her husband looked at the building, and on Sunday, they signed a contract. “Essentially, it was our place by Monday.”

**The Future**

Growth is a pervasive theme. “I want to get my Ph.D. in clinical psychology,” Olga notes. “I love school.” She recognizes “that what I do is something that not everybody could do.” But if a plan is made to pursue this work, “if you don’t have a commitment and the heart, it’s not going to work,” says Olga. “You fail the children first before you fail yourself. I know what I need to do now. I know my purpose as my career, as growth to myself, what I love to do. And this is what I love to do.”

Like Einstein’s theory of relativity, this formula for success with its interconnected elements is both simple and complex. It is the beauty and the challenge of it. It makes logical sense but requires dedication and determination to master its separate elements. Then there’s the payoff. Olga knows.

“And just the reward at the end of the tunnel: to see these kids go potty and get rid of the pull-ups, to see these kids eat with a fork instead of their hands, to see these kids say a word where they never talked, I mean that’s just…it’s unbelievable and to think that you had something to do with it, even more. The way I see it with me is that, what am I going to change today, what good am I going to do today, even if it’s something very small.” Or large.

Next month, we’ll talk in-depth with some families whose children attend One for Autism.
United States Military Section

The Face of the Exceptional Family Member Program (EFMP)

Families at Fort Lewis

By Heather Hebdon

I recently had the opportunity to talk with three of the Exceptional Family Member Program (EFMP) families at Fort Lewis. They represent the broad spectrum of families on the installation who are dealing with deployments, resource needs, and everyday life as parents of children with disabilities. Fort Lewis has the highest per capita EFMP enrollment in the Army. This has brought about many challenges and unique experiences for the families here. These stories tell a little about the challenges the families face and the opportunities available out there.

The Klatik Family Story

Entering the modest home of Marcie Klatik, I was immediately struck by the bustling joy of four girls sitting together playing. The children range in age from 12 years to 2 years. The youngest two, Adriana and Juliana, have Down syndrome. Marcie has her hands full with a pre-teen, a child with ADHD, and the twins. She also has the worry associated with a spouse being deployed to Iraq. “This is his second tour, so we have kind of gotten used to his being gone,” Marcie said.

She has the role of mom, dad, taxi driver, and therapist. She is quick to point out that her girls are very important to her. “The one challenge I have is the lack of anyone to stay with the girls. I have no respite, so the only time I really get out is when we have therapy or when I go to the Down syndrome support group.” This isn’t really a break, she explains, as the twins are always with her. This has made her husband’s absence more intense without any means to get away and not worry about the girls and their needs.

Marcie commented that she has a full day, everyday and that by the end of the day she is ready to rest. To get through the day, she has learned coping strategies. “I have gotten myself into the mindset of single parent. It’s a survival mode. I’m getting ready for the next day
and planning.” This is when, many times, her husband contacts her wanting to hear how things are going and connect. “We have access through Internet and phone, but it isn’t the same as his being here,” she explained. “When he calls, I am so busy, I can’t stay on the phone as long as I know we would both like.”

The twins were born two years ago. Marcie, her husband, and the two older girls were stationed at Fort Huachuca, Arizona when she learned that she was pregnant and expecting twins. “We didn’t know the girls had Down syndrome until they were born. I moved back to Washington State where I had some support because my husband was being sent to Germany,” Marcie explains. “We decided to have me at home until the babies were born.” He came home for their delivery. After the delivery, he went to pick up the girls from school. “While he was out, the doctor broke the news to me that the twins both appeared to have Down’s. I couldn’t even speak. When my husband came in, I had to have them tell him because I couldn’t stop crying to let him know.” This was the beginning of the many new responsibilities the family would face.

Shortly after the girls were born, Marcie’s husband was compassionately reassigned from Germany to Fort Lewis. He was at Fort Lewis for less than two months before being deployed the first time to Iraq. Marcie found support in her connections with Specialized Training of Military Parents (STOMP) and the Fort Lewis EFMP. She began meeting with the Pierce County Parent Support Group and has become an active support parent to other families. “One thing I can be thankful for are the good doctors I’ve found,” Marcie explains. “They know how little time I have, so when I go in with the twins, they are willing to hear about any other concerns I have about the other girls.”

The twins are basically quite healthy according to Marcie. They have had few colds, and the only real challenge they have is the small hole Juliana has in her heart. This is expected to be repaired in September. Marcie shared how well the twins are doing. They receive early intervention services and therapy. Adriana is beginning to babble. “They have over 20 different sign language signs,” Marcie stated. Adriana, who is more gregarious, is quick with the signs, sometimes giving more of an approximation than a real demonstration of the sign she is trying to use. Juliana, on the other hand, is very specific in her signing. “She sat and observed the world for a long time before she started using her signs. She is really precise,” stated Marcie, as she demonstrated how Juliana signs “more” and “all done.”

Marcie explained that the twins have really helped her and their sisters grow. “When you are younger, you look at disabilities. You might have made fun of those with disabilities. You might have looked at them and thought they had to do something wrong to be like that. There is nothing wrong with someone because they have differences. Because of the twins, I evaluate how I look at people. I’m far more open and accept people for who they are. It has really helped. I’m thankful that it has given the older girls an open heart and mind. It has kept them from judging what someone can or cannot do.”

This writer would add that the attitude of the girls is reflective of the way their mother approaches her challenges. Regarding the situation she is in with her husband’s absence and the girl’s needs, Marcie states, “I’m going to make their lives as fulfilling as possible. If you throw something at me, I’m going to make it work.” Marcie has done exactly that. She has identified the challenges, recognized her own needs, and been open to helping others. In doing so, she has made it a better place not only for herself but her children and others as well.

The Strickland Family Story
Entering the quarters of the Strickland family, I was immediately greeted by Madison, a lovely little girl with
blond hair and a twinkle in her eye. “She rules the roost,” her mother, Angie, stated. Madison is an only child. She was born at 25 weeks, weighing 2lbs and 3oz. “She was pretty sick at first,” her mother explained. “When she was only two weeks old, she developed some significant problems that required surgery where they removed part of her intestines,” Angie noted.

Madison has cerebral palsy (CP). It affects her speech and ability to walk, but she is an endearing and bright little girl with much to say and a will to be heard.

Angie explained that her husband had been in the service and had then gotten out. “He was in the North Carolina National Guard when he was sent to Iraq the first time. While he was there, we were able to get the things Madison needed. When he returned, we realized he needed to go active duty.” Specialist Strickland has been to Iraq two times and is scheduled to deploy again this spring. The family arrived at Fort Lewis in May of last year and must now decide whether Angie and Madison will stay on at Fort Lewis or return to their home of record in North Carolina. Angie explained that the decision is really hard. Madison gets four hours of nursing a day, four days a week. She has a feeding tube and many health issues. “It takes two people, at times, to care for all of her needs,” explained Angie. “If I go home, I’ll only get about two hours a day of service, but I would have my parents to help.” Madison also gets a great deal of therapy and support at Fort Lewis. Angie commented that when they were in North Carolina, she had to travel to Chapel Hill for much of Madison’s care. “That is a one-and-a-half to two-hour drive,” she commented. “Here, everything is only five minutes away.”

Madison attends school at Evergreen Elementary at the Fort Lewis installation. Angie commented that when they were in North Carolina, Madison was the only child in a wheelchair. “When she went to Evergreen, she saw all the children in wheelchairs. It was pretty cool.” She is in a class with other little girls and has developed some terrific friendships. Madison doesn’t have effec-
Angie also noted the support she has gotten from the support group on Fort Lewis.

Angie indicated that she doesn’t go out a lot. “Madison’s needs are really extensive,” she explained, “but I have gone to the Christmas party and other activities.” She notes that these have meant a lot to her and Madison.

Angie has also made connections with a lot of other families who have children with disabilities on Post. “There are lots of families,” she stated. She told of an experience in which she was assisted by another parent and how much it helped. “We all work together,” she said.

The Brown Family Story

Valentine’s Day balloons were being bounced around by Larson, Ashley and Major Don Brown’s youngest son, as Ashley and I started our talk. Larson is a beautiful, blond-haired eighteen-month-old. He and his brother Bowen (also known as “Bo”) are full of energy and laughter. The balloons were a treat that had come home with the shopping. Ashley explained that they had been something the boys really wanted. “I was trying to get things done and they were really demanding. I thought ‘whatever makes them happy,’ so we can get this over with,” stated Ashley, the demure, dark-haired mother of these two little pistols. “There has been some adjustment we have had to go through,” Ashley explained. Major Brown had been home a few weeks before the interview but had returned to Iraq. “I knew it was going to be difficult, but I didn’t know how hard it would be on the boys,” Ashley stated.

Ashley shared that Bowen was their first child. “It took us a year to get pregnant, so we were really excited. I started noticing differences when he was about 10 months old,” Ashley explained. “I had this feeling something was wrong. I told the doctor, and I’ll never forget what he said. He told me I was being a neurotic mother.” Ashley indicated that she became more concerned when Bowen wasn’t doing things like the other babies his age were doing. “He wouldn’t say, ‘bye-bye,’ or other things that we saw in other children.” Eventually, the Browns were able to get a referral for an Early Intervention speech therapy evaluation from their physician at Fort Leavenworth, Kansas. “When she came out to see us she said, ‘I have serious concerns about your son. This is not a language delay. That was when she started to help us get some answers,” Ashley stated. The Early Intervention speech therapist made a referral to a developmental pediatrician. “At Fort Leavenworth, they have a contract with the developmental pediatricians, and they actually come to your home,” explained Ashley. “The referral was made when Bo was 20 months old, and the developmental pediatrician came to our home when he was 23 months old,” she stated. “He knew we were getting ready to PCS and that Don would be going to Iraq as soon as we got settled at Fort Lewis. We had done a lot of research on the Internet and knew that he was going to tell us Bo had autism, so when he got there, we told him we were pretty sure that it was autism and that we wanted to spend the time talking about what to do. He spent about 10 minutes with Bo then confirmed our fears. He gave us a paper with the diagnosis written on it and told us to get services as soon as we got to Fort Lewis,” Ashley explained. She went on to state, “You know, I knew what he was going to tell us, but when he said autism, I completely lost it. The rest of the conversation was a blur.”

Relocating to Fort Lewis was a challenge for the Browns. Major Brown had been in school and was specifically requested for the assignment to Iraq. “We left Fort Leavenworth 14 days after getting Bo’s diagnosis. We got to Fort Lewis, and within 30 days. Don was on his way to Iraq. I didn’t know a soul here, and I had Bo and a six-month-old (Larson).” Ashley indicated that she had to connect with the resources and learn what was available. “That’s when I met Nancy, the EFMP Coordinator out at Army Community Service (ACS),” she said. “I thought I was functioning well and that I was emotionally capable, and I was. But now, when I look back on it, I realize what a wreck I was.”

Ashley stated that the deployment had some impacts that they had not expected. “Since Don left so soon
Exceptional Family Member Program

After the diagnosis, he didn’t really get the chance to grieve. So when he came back, he not only had to go through the re-entry, but at the same time, he had to go through the grief of the diagnosis.” Ashley indicated that Don came home and had to learn new parenting techniques because they were working on getting Bo to communicate. “He was trying to learn all these techniques when we were just beginning to work with Bo and we were getting a lot of negative behaviors because of his need to communicate,” Ashley explained.

When asked what has helped her family through the challenges of two deployments to Iraq in less than three years, she stated, “The military community is so close-knit. The majority of our neighborhood is either deployed or getting ready to be deployed. We know what it’s like for each other. I couldn’t have done it without the military wives.” She explained that when she first got to Fort Lewis and her husband had deployed for his first tour in Iraq, she had been concerned about her family being different and having to seek assistance from strangers but that having the military support made all of the difference.

Ashley also stated that having specialized groups to learn from is critical. She shared how the EFMP group had been of assistance and spoke of her connection with the University of Washington autism program. “Bo was lucky because he got intense, early intervention services. Many of the kids with autism don’t get that level of therapy early-on.” She went on to explain, “When you move somewhere, you always hope you will move where a child has already been diagnosed and the services have been established, so you can work easier.”

Ashley indicated that when her husband returns from this tour to Iraq, they will learn whether they will be remaining at Fort Lewis for a time or if they will be moving before the end of next year. “I’ve already got Bo’s name on waiting lists in five different states in case we move because there are such long waiting lists,” Ashley noted. These are all things that weigh heavily on her mind. She also stated, “The hardest part of this is not having him (Don) here. I can’t just call him to get his opinion or help. I don’t have him to ask those questions. I can only talk to him one time a week for 10 minutes, so I don’t want to inundate him with negatives. It’s kind of a Pollyanna approach,” she explained, because she is trying to shield him from the problems.

“Don’t get me wrong, it does slip sometimes,” she stated, “but I try to not have him worry about things. This puts a lot on me.”

Ashley noted that the biggest challenges she thinks families face when they are in the military is the lack of extended family to help when there are challenges. “With other families, you have your parents or other family to help if you need a break,” she explained. “When you are in the military, you have to look for resources. Finding childcare for Bo and Larson has been difficult. Finding a care provider has been hard. When they hear that Bo has autism, they become fearful and think of the worst case. It can be really challenging when your spouse is fighting for our country and dealing with his family and their needs. We need support from the civilian community to survive deployments,” Ashley stated. “As a military spouse, I worry about my husband. I really appreciate when the support is there.”

Ashley finished by saying, “We move frequently, sometimes as often as every two years, but the friendships you have can’t be found anywhere else like they are in the military.” It is clear that such support has been the anchor that has held things together for the Brown family. While the divorce rate for families who have children with autism is 80 percent, and the divorce rate for officers returning from Iraq is close to 50 percent, the Brown family shows a resiliency that comes from facing the challenges and finding the solutions that work best for them.

The Klatik, Strickland, and Brown families have learned to utilize available resources to meet the challenges they face. EFMP services are one supportive component that these resourceful parents have found to meet their families’ needs.

When they hear that Bo has autism, they become fearful and think of the worst case. It can be really challenging when your spouse is fighting for our country and dealing with his family and their needs.
The Military Child Education Coalition’s™

Tips for Preparing for Upcoming School Transitions

By Stephanie Surles

The Month of the Military Child is not only a good time to celebrate your child, it is also a good reminder to prepare for the end of the current school year and a great beginning for the next year. Between moving and transitioning to the next level, there is a good chance your child may be in a new school next year. Transitioning schools can be a challenge for children and parents alike; a new school can mean many more changes for a family with a child with special needs. You may have to contend with new state rules regarding special education. Your child may need to be reassessed by his or her new school and may face adjustment issues as routines are changed. And you may have to find a new network of support for both you and your child. Make sure everyone starts off on a good foot by preparing for transitions now.

Start early. As soon as your child may be in a new school, start preparing. The more time you have to plan, the more likely things are going to be in order. Of course, you may not have much warning about an upcoming move, so it is a good idea to try to keep things organized at all times, just in case.

Organize your records. Make sure you have current copies of important documents, including:
- Any school records (assessments, grades, learning plans, portfolios, documentation of meetings, etc.)
- Records from your child’s doctor (vaccination records, general medical records, and any other information)
- Records from other professionals working with your child (counselors, therapists, and other specialists)

Have at least TWO copies of everything. Talk to school officials, in both schools if possible, about transferring records directly from one school to the next. If the schools have one of MCEC’s™ Interactive Counseling Centers™, records can be transferred through the ICCs™. Make sure to carry at least one copy of your child’s records with you so your child’s education is not held up if the moving company misplaces boxes.

Update your child’s information. Check on your child’s learning plan, school assessment records, and vaccination records. Is it time to renew an Individualized Education Program (IEP) or get a booster shot? If so, do this now. If your child is due for a renewed IEP before classes begin in the new school, talk with your current school officials about reschedul-
ing meetings to start as soon as possible. It’s much easier and more effective to carry a brand new IEP with you (even if the new school feels the need to do its own) than an old one.

**Get letters of introduction from professionals working with your child.** Your goal is to have the transition go as smoothly as possible for your child. This is easier if new teachers, counselors, or therapists receive clear information from the professionals who already know your child. The new professionals may want to conduct their own assessments, but the additional information will help them get to know your child faster, which will smooth the transition for your child.

**Make your own record.** No, we aren’t advocating that you try out for *American Idol* (although if it is your dream, go for it!). We want you to track your interactions with your child’s school and medical personnel. Designate a location, such as a special notebook or your planner, and keep your own notes. For example, when you request school records, record who you asked, when you asked, exactly which records you asked for, and what you were told. Be sure to document important phone numbers and details about the people with whom you have spoken as well as what they told you. Given the intricacy of these issues, different people may tell you different things. You want to be able to say, “Mrs. Smith said XYZ on this date.” Keeping track of these details may seem unnecessary, but the more information you have on hand, the more control you have.

**Research local rules.** Rules and regulations may be very different when you move to a new state or country. Before you move, learn all you can about the policies and procedures that will affect your child. Figure out which offices you’ll be dealing with and contact them. Establish a connection with the people you’ll be working with once you arrive and talk to them about the process of getting needed services for your child. You can find links to the state agencies that handle special needs issues by visiting the “State Resources” page at www.nichcy.org. Learn more about special education through DoDEA schools at http://www.dodea.edu/instruction/curriculum/special_ed/index.htm.

**Learn about your new district and school.** As soon as you know where you’ll be living, contact the school district and school officials to learn more about their process: How do they require records to be transferred? Do they only accept records directly from a school or are hand carried records OK? Can you begin establishing your child’s local education plan before you arrive? How quickly will special services be provided to your child? For more information on schools, including contact names and information, visit MCEC’s™ SchoolQuest™ at www.schoolquest.org.

**Talk with other parents.** Visit the “State Resources” page at www.nichcy.org or talk with Specialized Training of Military Parents (STOMP) to find information on parent groups in your new location. Connecting with other parents who have been through the transition process can help you gather information on the tips and tricks that work best. They can tell you who to talk to when you are in a hurry, questions you need to ask, what can stall progress, and how to work around roadblocks. Plus, you’ll get access to a great source of personal support.
Cover Story
PA Department of Education and Vemics
An Interview with Dr. Gerald L. Zahorchak

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Assistance Animals and Special Pets

Research Frontiers: Understanding Science, Unlocking Potential
A new column from the Kennedy Krieger Institute

www.eparent.com
At right: Roland Paquette and his service dog, Rainbow, with Sheila O'Brien, Executive Director of NEADS, a non-profit organization established in 1976 to train and provide rescued dogs and donated puppies to assist people who are deaf or physically disabled in leading more independent lives.

Community of One
From Our Families...To Your Families

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Dear Military Families,

As the former Exceptional Family Member Program (EFMP) Manager, Army Community Service at Fort Sam Houston, Texas, I found STOMP listservs to be a very practical and informative way for military families to stay connected and to find out the latest medical and educational information about special needs, including resources for transitioning families. The STOMP listservs became a tool that I could depend on to help the families I served.

Today, the listservs remain an outstanding resource for parents to engage with other parents who have children with special needs. STOMP listservs are a comprehensive place that parents can go to ask other parents questions and to address concerns—visitors to the listservs know that other parents have traveled down the same path that they are preparing to journey. STOMP is always searching for new resources for parents and professionals, recognizing that when everyone works together as a TEAM, the child wins.

With Best Regards,

Kerry C. Dauphine
Kerry C. Dauphineè
Military Managing Editor

STOMP has two very active listservs

**Tri-FAT Listserv**
The TRICARE Family and Autism Treatment (Tri-FAT) listserv is for families who have children with autism. The listserv members share ideas, resources, and vital information on everything from Applied Behavior Analysis (ABA) therapy to TRICARE.

If you have questions, concerns, or useful information about your experience as an exceptional family, come and share your experiences online with a network of other STOMP families and professionals. To join the Tri-FAT listserv, please send a blank email to: Tri-FAT-subscribe@topica.com

To join the STOMP listserv, please send a blank email to: STOMP-subscribe@topica.com. To join either Tri-FAT or STOMP: Contact the STOMP staff directly at 1-800-5PARENT v/tty, STOMP@washingtonpave.com, www.stompproject.org.
When people see the term "military-connected child," they often think of the Active Duty forces. However, approximately 650,000 of the 1.8 million military-connected children have parents who serve in the National Guard or Reserves. What are the National Guard and Reserves, and how are they different from the Active Duty forces? And what do these differences mean for children with special needs?

The five branches of the military—Army, Navy, Marine Corps, Air Force, and Coast Guard—all have Active Duty service members, the men and women who serve in full-time positions. The military also has a Reserve Component comprised of Reservists and National Guard members. Each branch has a Reserve force. Typically, Reservists serve part-time, unless activated for full-time duty.

The Army and Air Force both have National Guard forces as well. During times of peace, the National Guard is under the command of each state’s governor through The Adjutant General or TAG for that state. However, these forces can also be called on by the President for federal missions. In those cases, they are activated and placed under command of the Department of Defense (U.S. Department of Defense, “DoD 101: An Introductory Review of the Department of Defense).

Active Duty and Reserve Component service is often very similar for service members, but there are significant differences for their families. Active Duty families often live on or near military installations (a base, post, or camp), are in contact with other military families, are typically more accustomed to the military lifestyle, and live daily with the possibility of reassignment or deployment. The communities in which they live are also more familiar with the military lifestyle and issues that military families and their children face.

National Guard and Reserves families, however, often live very civilian lifestyles. Many do not live near a military installation and are not able to connect as easily with other military families or the programs and services designed to support them, such as the Exceptional Family Member program designed to serve families with children who have special needs. Some Active Duty members are also considered "geographically isolated" from an installation due to assignments in recruiting, ROTC programs, with National Guard or Reserve units, or other special assignments. The communities in which these Reserve Component and geographically isolated Active Duty families live often have little or no significant and permanent military presence. In practical terms, this means community leaders and members are less familiar with the day-to-day events affecting these military families and the issues their children face. The disruptions in schedules and routines caused by deployment or reunion may not be understood by those serving children with special needs.
Many children of National Guard and Reserves members had limited experience or understanding of their parent’s commitment to the United States Military prior to September 11, 2001. However, the Global War on Terror has necessitated an increased activation of National Guard and Reserves members. The United States is currently experiencing the largest call-up of the National Guard and Reserves since World War II (Statement of The Military Coalition before the Subcommittee on Personnel, House Committee on Armed Services. March 16, 2005). In February of 2007, almost 84,000 National Guard and Reserves members were mobilized. Up to 40 percent of the total U.S. forces serving in Iraq and Afghanistan are personnel of the National Guard and Reserves. This has required these children to become accustomed to the deployments and separations that previously have been more common to the Active Duty experience.

The bottom line is that military children are in almost every community in America. Dealing with a high volume of relocations and separations, some families have the support of carefully designed services available through military installations. Others, however, are not located near these supports and need a system of state and local policies that benefit military children. Military-connected children need support no matter where they live. For National Guard and Reserve families with children who have special needs, the support of educators and community members is crucial.
Since the military requires its members to be mobile, every military family would benefit from developing a portable home file for each family member. Home files are records that you compile to provide a method for keeping critical information in a central, accessible location. They offer a record of everything from immunizations to correspondence, to critical data needed for entrance into a variety of services and programs. A working home file will naturally grow in conjunction with the evolving needs and issues of the family member.

A home file for a child with disabilities or special needs can simplify the process of seeking new services. Preparation of a home file will help with activities such as your child’s medical appointments, meetings for his or her Individualized Education Program (IEP), evaluations, and transitions. In cases involving due process, home files can save valuable time and money.

What records should be in a home file? A home file should include, at a minimum:

- Birth certificate
- Social Security card
- Current photo
- Immunization records
- Additional relevant medical records
- School records

When a child has a disability or special needs, additional information is critical to have on hand. It is then recommended that a file be expanded to include:

- Academic achievement reports
  - Tests
  - Report cards
  - Transcripts
- Psychological evaluations
- Physical Therapy (PT), Occupational Therapy (OT), and Speech Therapy/Language evaluations
- Current and past IEPs
- Behavioral/Social evaluations
- Vocational evaluations
  - Interests
  - Skills
  - Aptitudes
- Disciplinary records (including behavioral assessments)
- Samples of the child’s work and accomplishments
- Communication logs
- Correspondence
- Non-academic activities in which the child is involved, such as:
  - Scouts
  - Therapeutic recreation
  - Religious programs
  - Additional relevant non-academic activities
- Videos of your child in school settings and at home

An exciting new system that has been developed to assist military families with record keeping is available at the Specialized Training of Military Parents (STOMP) website, www.stompproject.org. This system, known as the Special Care Organizational Record (SCOR), is a comprehensive home file for medical issues, produced by the Department of Defense (DoD) and TRICARE Management Agency (TMA). This helpful record was derived from efforts at the Center for Children with Special Needs and the Washington State Department of Health’s Children with Special Health Care Needs Program. SCOR can be downloaded in Word format to allow parents to modify the record according to their child’s particular needs. It can be filled in online and saved to a Word file that can then be updated as necessary.

Methods for storing a home file will vary. Think about creating a mobile home file in a binder or portable file box that will reflect the needs of a particular appointment or meeting. Some of the records will be used more than others. When you anticipate that you will need to share part of your file with a professional, give them a copy, but *never your original.* It
is so reassuring to walk into a meeting or appointment knowing that you are as prepared as possible. Professionals love it when parents have information at hand. Instant access to information helps to create a partnering relationship from the start.

**How do I obtain copies of medical records?**

Oftentimes, families have assumed that they can acquire their medical records and hand carry them to the next installation. They are concerned about the records being lost or information being incomplete. Since the records belong to the military, families do not have the right to take them from the facility. However, they do have the right to obtain a complete copy of the record. To obtain a copy of a military medical record, the sponsor or family member needs to go to the Correspondence Section of the Military Treatment Facility (MTF) and file a request for copies. If the request is because of a Permanent Change of Station (PCS) or due to Estimated Time of Separation (ETS), the sponsor needs to take a copy of those orders to obtain a free copy of any family member’s records, including those of a child with special needs. It is also important to have a valid power of attorney if the service member themselves is unable to make the request for copies. Since hand carrying of records is no longer allowed, copies of PCS orders will help the MTF forward the child’s records correctly to the next duty station. When filling out the request, be sure to ask for test results, radiology files, and inpatient and outpatient records from each clinic where the family member has been seen. Most radiology films are digitized now, but if the child has any traditional films, make sure to request copies of those as well. Remember, even though the record is about your child, it belongs to the MTF.

To obtain copies of medical records from civilian providers and institutions, check with each organization’s records department. Be sure to obtain a copy of any request form required. Proper documentation, signed by the parent, will give new providers the correct information regarding where they can request the child’s records as well as evidence of the parents’ permission for release of those records. Again, it is important to note that the record belongs to the civilian provider.

**How do I obtain copies of school records?**

The Individuals with Disabilities Education Act (IDEA) guarantees our right as parents or guardians to have access to our child’s educational records. Parents have a right to records that are directly related to their child and are maintained by an educational agency or institution or by a party acting for the agency or institution. It is recommended that a written request for a copy of the child’s records be addressed to the special education director of the current or past school district. In this letter, be sure to request “any and all records in any form and in all locations.” This phrasing makes it clear that it is expected that the parent will receive copies of any type of record the child may have: discipline folders, psychological reports, health files, grade reports, any records in a cumulative file, tape recordings, microfilm, computer files/diskes, and videotapes. If the information stored concerns the child and is kept by an educational agency, it qualifies as an educational record. This includes information forwarded from any medical facilities. The Health Insurance Portability and Accountability Act of 1996 (HIPAA) requirements do not apply to school districts. Only the Family Educational Rights and Privacy Act of 1974 (FERPA) requirements apply.

FERPA protects parents’ rights to access records, protects the privacy of those records, and is applicable to both civilian and Department of Defense Education Activity (DoDEA) schools. When a parent requests to see or obtain copies of records, the school district has 45 days to provide access. It is important to note that if a meeting regarding the IEP or a hearing related to the identification, evaluation, or placement of the child is scheduled, the school district is required to provide access to those records before the meeting. The school district is allowed to charge a reasonable fee for making the copies, but is not allowed to charge for the staff time it takes to make the copies. Additionally, a fee cannot be charged if it would “effectively prevent” the parent from accessing the records. Parents have the right to see the records and to take notes from them even if the school refuses to make copies. If a parent or eligible student is not able to effectively review the records, the school “shall provide them with a copy of the requested records or make other arrangements for them to review or inspect the records.” Should a parent feel they have been denied access to or correction of a child’s records, or if a release of information without parental consent occurred, a written complaint can be sent to:

- Family Educational Rights and Privacy Act (FERPA) Office
  U.S. Department of Education
  400 Maryland Avenue SW
  Washington, D.C. 20202

Or, if the child is in a DoD school:

- Department of Defense Education Activity (DoDEA)
  4040 North Fairfax Drive
  Arlington, VA 22203-1635
When should a review of records occur? Every family needs to consider what works best for them. However, it is recommended that families review records at least annually, and it is suggested that they be reviewed prior to any and all meetings, when considering requesting a hearing or mediation, or when preparing to PCS/ETS. Each review is a great opportunity to update the child’s home file with the most current information. Parents and students can review all information directly related to the student. However, schools can refuse parental access to “personal notes.” Personal notes are defined as notes that a school official makes for his or her own use and are not shared with anyone else. While viewing the records, the parents are not allowed to change or remove anything from the record. To note portions of the record they have reviewed, they are allowed to make a small mark in the corner of the pages of the record.

What is annual notice with regard to records? At the beginning of each year, school districts are required to provide families with notice regarding what information is considered directory information, and under what circumstances a district can release records without parental consent. The annual notice also informs parents or eligible students (those who have reached the age of 18 or age of majority) of the right to inspect records, the procedures for requesting amendments, and policies with regard to disclosure of the contents of records to school officials. The notice of, and consent to, the release of directory information is frequently given within the student handbook. Directory information includes student name, student home address, course of study, and awards and honors. Directory information does not include student records of discipline, grades, special education services, or medical information. FERPA requires that students who are disabled, and parents, must be effectively notified of the annual notice.

What if there is an error in the records? While reviewing records, families may find information they believe to be inaccurate, misleading, or that denies them the right to privacy. If such a situation arises, a request for the correction of that information in the child’s record should be made. The request should be in writing and should be addressed to the special education director or supervisor of the district. If the request to correct the record is refused, parents have the right to request a hearing. If the results of the hearing do not resolve the issue, parents may place a written statement in the record. If the record is forwarded or shared with any other agency or person, this written statement must be attached to the record in question.

Who has outside access to records? Families are assured privacy of their child’s record. However, at times there are limited exceptions to this rule. Schools are allowed to release directory information without specific parental consent if annual notice has been provided, and the parent has not specifically denied that release in writing. Schools can also release records to police or juvenile authorities if there is any legal action being considered against the child. This release is to ensure that the child’s disability is considered as a factor in the determination of any actions taken. The school district must maintain records of requests for access to and disclosure of personally identifiable information from educational records.

Can school records be destroyed? Families may not be aware that districts have a requirement to maintain educational records for a period of time, after which they can destroy the records. Schools cannot destroy records after a request for access has been made. But remember that destruction of records can occur during “normal course of business.” The school district must attempt to notify parents and eligible students of the planned destruction of records and allow them the opportunity to obtain those records instead of having them destroyed. If families do not respond to the “reasonable” attempt to notify them, then the records can and will be destroyed by the district.

For more information on home files and records, go to the STOMP Web site at stompproject.org, click on the Publications link, and scroll down to the Home File/Records link. Click on this link for a Home Files & Records packet.

There is additional help and advice for home files and records through Military HOMEFRONT, Military OneSource, SCOR, State Parent Training and Information Centers (PTIs), STOMP, TMA, TRICARE, and local and national disability organizations. Look around in that pile of papers that seems to constantly grow, and make a start on your child’s and other family members’ home files.

Visit these valuable Web sites:
Military HOMEFRONT – www.militaryhomefront.dod.mil
Military OneSource – www.militaryonesource.com
SCOR – www.tricare.mil/specialneeds
State PTIs – www.taalliance.org
STOMP – www.stompproject.org
TRICARE – www.tricare.osd.mil
Universal Design

Making Education Accessible to All Students

By Heather M. Hebdon

The term universal design has been used in the field of construction and building for many years. It has only recently been applied in the educational arena, where by definition it is “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design.” Universal design is considered a “best practice.”

So how does universal design work best for the education of students with disabilities? Consider for a moment a classroom setting where all students are participating in a lesson and discussion on geography. Would a student with sensory or cognitive disabilities be at a disadvantage? In many classrooms, yes. However, when universal design is incorporated into the curriculum, the teacher begins to try additional creative ways to bring the information to life for students. He or she might use assistive technology to help develop a three-dimensional picture of the terrain being studied. The instructor might use recorded text or have a student read parts of the text and then discuss how the content applies to the lesson. When universal design is applied, it opens the opportunity for all students to gain information. It is not always easy, but it can, and should, be done.

Some Department of Defense schools as well as numerous Department of Education schools on military installations include enhancement of geography, reading, and math lessons. Some states that have effectively incorporated universal design into their curriculum include Colorado, North Carolina, and parts of Texas.

A program funded by the United States Department of Education has developed a Web-based clearinghouse on universal design, emphasizing that for universal design to be effective, certain principles need to be followed. These principles have been correlated to the word “design” itself:

- **DEMOGRAPHICS** – Ensure that it accommodates many individuals’ abilities and characteristics.
- **ECONOMY** – Make it available and affordable.
- **Senses** – Allow the user to access information through several senses (e.g. sight, sound, touch).
- **INTUITIVE** – Make it easy to understand.
- **GENERATIONAL** – Design it to serve people of all ages.
- **NAVIGATION** – Design it to reduce physical and intellectual barriers.

Universal design is an important component in developing strategies and techniques for identifying and circumventing barriers in existing curriculum materials and delivery methods, according to Kathy Powers of the Maine Consumer Information and Technology Training Exchange (Maine CITE), a project of the Maine Department of Education.

“Using technology to increase the accessibility of the curriculum itself shifts the responsibility for change from the individual to the learning environment,” states Powers. “The ultimate goal of these efforts is the creation of accessible, inclusionary classrooms. If we are going to include all students in standards-based reform, an understanding of universal design concepts must be part of this professional development.”

While technology is not a requirement of universal design, it makes the creation and use of universally designed curriculum much faster and easier. It also allows teachers to adapt curriculum more easily to meet a wide range of student needs. Over the past few years, there has been a concerted effort in special education to promote curricular materials with built-in adaptations that are flexible and customizable, particularly in digital media.

Curricular design should incorporate certain prerequisites of learning:
- Information must be accessible.
- Support must be available for the development of skills.
- The learner must perceive the learning to be important.

These prerequisites should be built into the curriculum by:
- Providing multiple representations of the information being presented.
- Providing multiple or modifiable means of expression and control.
- Providing multiple or modifiable means of motivating and engaging students.

Universal design has the potential to change the learning experience for students with disabilities, helping them to more creatively interact with teachers and other students and to better achieve their educational goals.

To learn more about universal design in education, visit the following websites:
- www.cec.sped.org
- www.ed.gov
- www.maine.gov/education/speced
Community colleges offer a variety of programs of study. Program options include completion of the Associate of Arts and Associate of Science degrees. Acquisition of these degrees includes completion of the first two years toward a bachelor’s degree for professions such as education, pre-law, business, biology, etc. In addition, other programs of study include training options through the Associate of Applied Science and Certificate programs. These program options typically include “hands-on” instruction, with the majority of coursework designed to provide the student with applicable skills to enter the workforce. They were designed to address the needs of employers by developing a workforce to meet employment vacancy demands. Through the community college, the workforce training program options provide an opportunity to pursue affordable career training. In addition, students pursuing certificate programs will find that the majority require fewer courses than the associate’s degree to complete program requirements.

Some of the best educational support services for students with disabilities can be experienced through the community college. The goal of academic support is to assist students in working around their disability by teaching them compensatory skills and assigning instructional accommodations to level the academic playing field. This provides the student with the opportunity to learn the material and to express their knowledge without interference from the disability. The process of receiving educational support services begins with a student “self-identifying” himself or herself to educational support staff as an individual with a disability.

The level of educational support received is based on the severity of the disability and the student’s ability to benefit from the prescribed accommodations. Therefore, those with the most severe disabilities do not necessarily receive the most accommodations. The determination of support begins by reviewing documentation describing the diagnosis and disability, as well as information provided through clinical interview with education support staff. It is important that documentation of disability be as recent as possible. Each college sets its own guidelines regarding the timeframe...
in which documentation will be considered acceptable. A general rule of thumb is five years for learning disabilities, two years for Attention Deficit Hyperactivity Disorder (ADHD), and one year or less for any type of mental illness or medical condition. The documentation should include: current diagnosis, current functional impact on learning, and recommended accommodations. Acceptable forms of documentation include but are not limited to:

- Special education testing from your school district
- Test results from a psychologist, neurologist, or psychiatrist
- A letter from a physician qualified to make the diagnosis
- Test results from any branch of the military

It is imperative that each student consult with educational support staff on their respective campus to determine what forms of documentation are acceptable.

**Admissions Process**

One of the first opportunities to receive assistance is during the admissions process. Admission into the community college system is simple and easy. Most community college admissions are based on an open enrollment system, indicating that admission is based solely on completion of a high school diploma or a GED. There is no other eligibility requirement such as minimum ACT or SAT scores, class rank, an essay describing future career goals, admissions interview, or documentation of community volunteer activities, all of which are typically required as part of the admissions process at four-year colleges and universities. The admissions process usually consists of completion of pertinent contact information (e.g. address, phone number, Social Security number, etc.) and a student data form indicating course of study. Despite the ease of the admissions process, it is strongly recommended that students with a disability contact the educational support office in order to improve understanding of program offerings before selecting a major course of study.

**Placement Test**

Once the admission application is completed, the next step in the process is completion of a placement test. The placement test is not a pass/fail test and does not determine eligibility to attend college; remember the “open enrollment” concept described earlier. The purpose of the placement test is to determine appropriate skill level within the areas of reading, writing, and mathematics. The results are used by academic advisors during course registration. Because the outcome determines course placement, it is in each student’s best interest to perform his or her best on the assessment. For students with disabilities, this usually trans-
lates into utilizing eligible accommodations in order to perform their best. As with all prescribed accommodations, they will be based on the student’s disability and level of need. Placement test accommodations may include but are not limited to extended test time; testing in a quiet, non-distracting location; use of a reader; use of alternative forms of the placement test. The results of the placement test are usually provided to the student immediately.

**Course Registration**
Following the placement test, the next step in the registration process is for the student to see an academic advisor for course registration. The student with disabilities should seek advisement through the educational support office. Academic counseling is available to students without disabilities through the general counseling office. Although a student with a disability is not prohibited from seeking advisement through the general counseling office, there is no guarantee the advisor will be knowledgeable about disabilities and be able to offer the best advice.

During the course registration process, the disabilities specialist will discuss the student’s placement test results and recommend course selection. Students with disabilities should consider pursuing a part-time course load, especially for their first couple of semesters. This will allow them to adjust to the course requirements without jeopardizing their grade point average.

In some cases, students will prefer to be classified as full-time in order to continue to be eligible to receive health insurance coverage through their parents’ policy. Part-time students should inquire with the educational support staff to determine if they qualify to be considered a “full-time” student at less than a full-time course load. If approved, these arrangements would be carried out through the Registrar’s Office.

**Other Items to Remember**
Other important topics of discussion during the registration process include: the student’s academic strengths and weaknesses; how the disability fits into the picture; the best time of day for classes (e.g.: taking courses that begin at 8:00 a.m. versus late morning); and the number of days per week the class will meet (i.e. a course that meets more frequently during the week means less new material to be covered in each session).

**Instructional Accommodations**
Once courses have been selected, the final process is to develop instructional accommodations. These accommodations will be based on the student’s disability, level of need, and the student’s ability to benefit from the accommodations. Accommodations may include:
- Books on tape
- Note-taking assistance
- Use of calculator
- Use of a “fact” sheet
- Extended test time
- Testing in a quiet, non-distracting location
- A reader for exams

The student’s input will usually be included in the development of the accommodations. It is important for the student to disclose to educational support staff what has worked in the past and what has not. Each accommodation prescribed should be explained to the student so that they have an understanding of how the accommodation will be carried out. This not only facilitates student follow-through, it also empowers the student to provide an explanation to faculty, if necessary.

The method used to inform faculty about each student’s accommodations varies by campus. In some cases, the students are asked to hand carry the accommodations form to each of their instructors and discuss their needs. In other cases, the information is forwarded from the educational support office to each instructor via campus mail. Students should inquire about the method of choice on their respective campus.

As an individual with a disability you can prepare for the college experience by:
- Registering for classes early. Do not wait until the last minute.
- Seeking out assistance from educational support staff.
- Understanding your particular disability and learning style(s).
- Knowing your academic strengths & weaknesses.
- Being prepared to discuss your needs with faculty and educational support staff.

A community college can provide just the right springboard a student with disabilities needs to enter the workforce or to prepare themselves for additional schooling. Knowledge and use of available accommodations can ease the academic experience and enhance opportunities for success.

Larry Rodriguez is a counselor and instructor at Palo Alto College in San Antonio, Texas.
Military Editorial Team (MET)
Invitation to Readers

MET’s goal is to have only the most current and accurate information available for you, your family, professionals, and caregivers.

Leo Rosten wrote:
“I cannot believe that the purpose of life is to be happy. I think the purpose of life is to be useful, to be responsible, to be compassionate. It is, above all, to matter: to count; to stand for something, to have made some difference that you have lived at all.” If you are the parent or loved one of an exceptional child or family member, it is our sincere wish that the resources in this insert will arm you with information that will be “useful,” that will “matter” and “count.” If you are a professional working with these families, it is our hope that your philosophy echoes that of Leo Rosten: that you feel your purpose in life is to be useful, to be responsible and to have the passion and compassion to make changes in the lives of families caring for members with special needs.

We enjoy reading your stories, and hearing about your successes in the military and civilian community as you find ways to overcome the unique challenges you face on a daily basis. We like first hand experiences and pictures. If you are willing to share your thoughts in an article, please contact me so I can send you a copy of the Exceptional Parent magazine guide for authors and photograph release. I look forward to hearing from you in the near future. Please e-mail atkdauphinee@eparent.com.

With Best Regards,

Kerry Dauphinee

Kerry C. Dauphinee
Military Managing Editor
Exceptional Parent magazine
With the conflicts in Iraq and Afghanistan and the increased deployment of service members into harm’s way, it is important to consider the impact on the family left behind. It can be difficult for any military family, but when a parent deploys, special consideration needs to be given to provide essential support for the family of a child with a disability or special needs. Families have found a number of effective strategies that can decrease the level of anxiety and increase the level of normalcy during deployments. This will provide the parent who remains at home with some stability and comfort in knowing that their child can cope with the situation.

Teach your children the geography of where the deploying parent is being stationed. You can use pictures, create a mobile, or provide information in very general terms (i.e., indicating that there is water, mountains, sand, etc.) so that your child has an idea of what the place
looks like where Mom or Dad is going. This alleviates the fear that they are somewhere that is non-existent to the child. This can be accomplished by a simple craft that the whole family can do before the parent leaves. A flat map of the world, glue, marker, pictures of the equipment used by the parent in the service, as well as pictures of an airplane, other family members who live in different parts of the country or world and the deploying parent, will help to make a big picture of where Mom or Dad is in relationship to their home, grandparents’ homes, etc. Glue the pictures on the appropriate locations on the map. Be sure to include a picture of your home. If you can get pictures from your relatives of their homes to go with their picture, include them. When your spouse gets to the new location, have them send a picture back, with the background of the new location. With computer technology, this can happen shortly after the parent arrives. This will allow your child to realize that Mom or Dad isn’t still in the air flying, or off somewhere in the field, but is actually located at the new place you identified on your map. Join the location of home to the location of the deployment with a dotted line. Do the same with the other pictures. This will help with conversations about Mom or Dad’s location and why the deployed parent is not coming home at night. They can see there is some distance between your home and other family members’ homes as well as where the parent is located.

It is important to help your child understand the length of time that your spouse will be gone. If your child does not understand when the parent is coming home, he or she could come to the conclusion that the parent is not coming home at all. Visual ways of helping him or her understand time and space can include using construction paper and developing a chain (one link for each day until the parent comes home). At the end of each day, tear off one of the links of the chain. If you learn your spouse’s deployment is going to be extended, just add links to the end of the chain. You can discuss why these are being added. Your child can help add them. One parent devised a daily calendar to help her child. She writes, “We purchased a cork bulletin board, divided it into seven sections, and with acrylic paints, painted each section a different color. We assigned each section a day of the week. We pinned pictures of daily activities to each section. Then we made a construction paper chain which we color coordinated with the bulletin board. The chain represents the days that the parent will be gone on deployment, so the chain needs to be the length of the deployment. We attached the chain in swags going around the room. It was quite impressive and a tremendous help. It gave our child a visual on the length of time Dad would be gone. Even children, like my special needs son who does not have a concept of yesterday, today or tomorrow, can be able to understand how long their parent is going to be gone.”

Other parents use their refrigerators, have a memory wall with pictures of birthdays, holidays and special events, or devise clocks to help provide a visual of the time between when Dad or Mom leaves and when they will be returning. The more you can do to provide a picture of when, where, and for how long the family will be together again.

Even with the most well-planned system in place, you may face difficulties. Your child will have some emotional reactions to his or her parent being gone. The way you react to situations will help guide your child through their own emotional responses. Experts say that there is at least a four-week adjustment period when the deploying parent leaves and when they return. Both sides of the deployment can be stressful. Preparation for the departure as well as the return of the parent can help to alleviate these difficulties. When you are taking care of yourself and fulfilling the needs of your children, you may find you have not only the respect and control of your children, but they also display a greater sense of relief that things are really okay, even with the other parent gone. Be consistent, stable,
and spend special time with each child. Remember, when the family environment is stable, then you can concentrate on other matters such as helping each other with the emotional hardship of missing a spouse or parent.

Another aspect to consider in helping your child through deployment is how to keep the deployed parent a part of the daily things you do. You can help your child feel closer to the missing parent by making a video of the parent. Consider making multiple copies of it so that if they play the video over and over again, it won’t wear out before Mom or Dad comes home. Have your spouse read one of your child’s favorite books into a tape recorder. This way, you can sit with your child, turn on the tape, and hear the story read by the missing parent. Additionally, in many of the deployment locations, there is the capability of doing a live link via the Internet. These can be scheduled so that you and your child can talk to Mom or Dad and see her or him over the computer. There are also systems at many of the family service centers that can provide this support.

Creating a picture book of the deploying parent or providing your child with one of Mom or Dad’s work shirts or outfits to sleep with may also help. They could wear it or wrap a stuffed toy in it. This gives them a sense of Mom or Dad being right there with them. And don’t forget to include your spouse in decisions about your child. Many schools are now setting up Individualized Education Programs (IEP) meetings with a conference call capacity to the parent who is deployed so that he or she can give input into the IEP for their child. Share pictures and videotaped assemblies, recreational activities, and daily activities. Have your child send kisses through the mail or over the Internet. These can be a specific symbol or picture that you scan or mail to the other parent. This helps your child know that Dad or Mom knows they care.

It is especially critical to remember that, as the parent remaining behind, you have to take care of yourself. Your children are more likely to adapt to the dynamic changes in the family when you are both physically and mentally healthy. One way to maintain health is to establish a routine of exercise. This means getting out of the house and doing something like walking, swimming, going to the gym, or working in your yard or garden. Regular exercise as well as eating healthily will keep you on top of things more easily. When your health is poor, you are more susceptible to infections, colds, and viruses. Staying healthy makes it easier to deal with the expanded demands on your day and on your emotions. Take time to do things without the children. This may be a challenge, particularly trying to find someone to stay with your child with special needs, but it is essential for both you and your child to have those breaks. Go out to lunch while he or she is in school, go to the library or a movie, or even window shopping. Finding time for yourself will help you keep a better perspective on what is happening. Make use of all available state services. Contact your local departments and offices that provide services for developmental disabilities and mental health needs. See if you can get respite care or a Medicaid waiver to help with your child. Use any hours you are provided. Find a care provider you can trust before the deployment, so you are not searching for someone when you are more stressed. This will enable you to discuss ideas, become confident in the way the provider works, and build a relationship with your care provider before your spouse is absent. Try to get on the support agencies’ calling lists, ask to receive their newsletters, and attend their social events. If there is not a system at your installation, perhaps you could start one. Find emotional support to cope with tough times.

We know we may all face some form of deployment or separation while our family is in the military. Making the deployment easier will help both you and your child with special needs. If you find yourself having difficulties, be sure to talk with someone. There are always those who can help. Use your resources and take care of yourself. If you take care of yourself, keep informed, and involve your children in the separation process, the deployment will not be devastating for you or your child, but an experience that will create new skills for your child and new insights for you.
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Cover Story
Challenger Little League
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Bonus Supplement
The Consumer’s Guide to Mobility Equipment Dealers
At right: Roland Paquette and his service dog, Rainbow, with Sheila O'Brien, Executive Director of NEADS, a non-profit organization established in 1976 to train and provide rescued dogs and donated puppies to assist people who are deaf or physically disabled in leading more independent lives.

Community of One
From Our Families...To Your Families

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I remember attending my first civilian support group meeting as a parent of a toddler who had just been diagnosed with autism. My Marine Corps spouse was stationed at Camp Lejeune, North Carolina. In those days, autism was only known by the majority of the population as that unique and rare disability that the actor Dustin Hoffman had portrayed as character Raymond Babbitt, an autistic savant, in the movie *Rain Man*.

I left the support group that night crying because I felt so alone and confused. The other parents in the group had older children. They were discussing transition issues, guardianship and special needs trusts, when all I wanted was family survival strategies. I had lots of questions, such as: How can I accept the diagnosis and cope with feelings of denial? How can I stop my son from injuring himself and screaming? When will I get some sleep?

A few months later, my husband, Bruce, received Permanent Change of Station (PCS) orders to Parris Island near Beaufort, South Carolina. We previously had been stationed on Parris Island as Marines. We were familiar with the local area, but we knew nothing about special education services. We chose to live on the installation because there was a Department of Defense school.

Our family immediately established an excellent relationship with the special education teachers and director as well as with the Marine Corps Air Station Beaufort Exceptional Family Member Program (EFMP) Coordinator. We worked together to create the Laurel Bay Support Group for Parents with Special Needs Children. Our support group met monthly for five years. Families benefited from free childcare, guest speakers every other month, and family fun events.

My husband and I never considered ourselves experts. The support group was a journey that we embarked on with other parents. All of us were searching for survival strategies, a few helpful resources, and the trust and companionship of others who could relate to our life as parents of a child with a disability and a military family living a mobile lifestyle. Occasionally, we addressed systemic issues, but that was not the primary reason for meeting or our mission. Throughout the years, we learned a few things about establishing and maintaining a support group, which we would like to share with you. Here are some tips to help you establish your own support group for military families with special needs.

**Identify the Need**

“Identify the need” simply means finding out if there are enough interested families in your military community who want to meet. Here are just a few resources in your local community you can contact to identify the need:

- Each military Service’s EFMP point of contact: The Army and Marine Corps installation EFMP Managers and Coordinators are located at your local family service center and can provide you with the approximate number of families enrolled in the program at your location. Visit the MilitaryHOMEFRONT Troops & Families Special Needs section [http://www.military-homefront.dod.mil/efm](http://www.military-homefront.dod.mil/efm) to learn more about each of the Services’ EFMPs.
- Your local community Early Intervention Program: If there is a Department of Defense school on your installation, you can reach out to the Educational and Developmental Intervention Services (EDIS) program located at your local Military Treatment Facility, which provides early intervention.
- Child Development Center(s)
• Special Education Teachers or Directors
• School Liaison Office
• Military Treatment Facilities’ Pediatrics Departments
• New Parent Support Program

You can use the Department of Defense MilitaryINSTALLATIONS directory http://www.militaryinstallations.dod.mil/ to locate points of contact for the programs listed above.

Logistics

To establish a support group, you should decide where to meet, list necessary equipment and supplies, organize contact information, coordinate childcare options for families, and make arrangements for refreshments.

• Support Group Location – Collaborate with the organizations listed above and ask if they have a room and tables and chairs you can use (at no cost!) for monthly meetings. If finding a location is problematic, contact your local Command and ask if you can use the family service center or another space on the installation to meet. Using your home should be your last option; however, some groups do work well when parents agree to have the meetings in their homes during designated months.

• Equipment and Supplies – You will need some basic administrative supplies, such as notebooks to keep track of your group contacts, organization contacts, and discussion topics. You should document systemic issues as well as expenses you incur and donations you receive. Some guest speakers may ask if you have a laptop computer and a projector and screen they can use for their presentations. It is okay to ask guest speakers to bring handouts instead, or you can coordinate with your local family service center or other organization to get the audiovisual equipment for your group meeting.

• Contact Information – Save time and money by asking new members to the group to provide you with their email address so that you can contact them to notify them about group meeting dates and special events, instead of calling each member on the phone.

• Childcare – Proving childcare during meetings is central to the success of your support group, especially if the family’s service member is deployed or has other duties. The Child Development Center (CDC) may provide care if the minimum number of children attending is met. Get in touch with your local Chaplain, Officer Wives Club, Enlisted Wives Club, or other groups because they may have philanthropy funds to help pay for childcare expenses for families who may not be able to afford the hourly rates. Remind families that if they have respite care services they can use some of their respite care hours to attend support group meetings. If CDC providers are not available, consider a childcare co-op for group meetings; instead of one monthly meeting, consider having two and dividing childcare responsibilities among the parents.

• Refreshments – An excellent way to get parents to commit to attending a meeting is by asking them to bring refreshments such as soda, cookies, or a cake. Be aware that providing drinks and snacks can become expensive as your group grows, so asking other parents to contribute is advisable but certainly not a group necessity.

Marketing

Marketing can be challenging without funds and support from local organizations. I was fortunate to have a close friend who was a graphic designer for a local printer. She donated her time to design a logo for our group and print flyers. Now, with computer software and a little skill, you can easily design your own flyers and print them from the comfort of your own home.

Sharing marketing responsibilities with the other parents in the group is important because they may be aware of funding sources and have valuable distribution ideas. Also, reach out to the organizations listed and ask if they would be willing to photocopy your flyers or brochures. Place them in strategic locations where families with special needs can easily see them. One of the best places to put a flyer is in a doctor’s office or waiting area. We also found that more families attended meetings when the school placed flyers into each child’s backpack and the EFMP sent the flyer as an attachment via email to the Commands and enrolled families.

Funding Support

Our group received funding support from the local Officer Wives Club. We used those funds to purchase refreshments for family events and pay for lifeguard(s) when we had pool parties. If you have established a group in partnership with any Department of Defense program, they cannot donate or solicit funds from other organizations for your group. Speak to your installation Public Affairs Officer (PAO) before you plan any fundraising events on the installation for your support group.

Community Outreach

Partnering with civilian organizations for special events has many benefits, including enhancing your event...
Support Groups

attendance. I do recommend that you ask families and service providers to register to attend an event you are hosting when a speaker has to travel from outside of your local area to speak at your event, so that you have an estimate of the number of attendees. There is nothing more embarrassing than asking a guest speaker to come to speak to your group when no one attends. Of course, low attendance due to an unforeseeable event such as severe weather is understandable.

You can also gather a lot of valuable resources for your group by reaching out to community disability organizations. Speaking to them helps expand their awareness about the military special needs community.

New Parents
Always remember to spend additional time speaking with parents who have just received a new diagnosis and are looking for support. The following resources will help:

• The Department of Defense Special Needs Parent Tool Kit is an excellent resource for new families. You can download a copy onto a CD to give to families or direct them to the Department of Defense MilitaryHOMEFRONT Web site, where they can access the Tool Kit at http://www.militaryhomefront.dod.mil/efm (Select ToolBox).

• Develop and distribute an information package with valuable local resources for new families joining your group. Local organizations are always willing to provide their program brochures and other information to be given out in packages for new families. Be sure to update your information package regularly.

• Refer families to military and community programs that can help them support their family member with special needs.

• Refer families to reliable and official sources of information online, such as the Army Web site, http://www.myarmylifetoo.com/, a valuable source of official Army information for families with special needs.

Establishing Ground Rules for Meetings
Every group needs ground rules. Here are a few ground rules that helped us keep our group a place where families could find support:

• Confidentiality is important. Group discussions should be respected and kept within the group.

• Avoid making judgments or expressing opinions about methods or treatments. It is acceptable to bring information to the group, but do not expect group members to agree with you.

• Every group member should have the opportunity to share information or express feelings. You would not want to be interrupted, so do not interrupt others.

• End meetings at a reasonable time.

• Systemic issues that are identified within the group should be well documented and agreed upon as a group before presenting them to the responsible authority, such as a school board.

Group Goals
As your group begins to meet on a regular basis, you may want to periodically address the purpose of the group. Ask group members if they are ready to tackle issues families have on the installation or other concerns. There are some military installation family service centers that have committees that meet monthly or quarterly to address military family quality-of-life concerns. Ask your family center director or EFMP Manager or Coordinator for general committee meeting details and tell them you would be interested in speaking to the committee(s) about your support group.

Today, families have the Internet to connect with other families with special needs. Specialized Training of Military Parents (STOMP) http://www.stompproject.org/ has an excellent online listserv that has been a valuable resource for families for several years. MilitaryHOMEFRONT has a Special Needs electronic bulletin board style forum and installation forums http://www.militaryhomefront.dod.mil/forum for military families with special needs to communicate with each other. However, there is no online group or listserv that I have found that can replace the personal touch of a local military support group for families with special needs.

My family has transitioned from the new family that was searching for survival strategies to an empowered and educated family of advocates now searching for transition and employment resources. Our needs have certainly changed, but I would not be surprised if you came across us at your local support group as we search for a place to connect with military parents with special needs teenagers and adults with special needs.

Isabel Hodge is a Marine Corps veteran and has been living the Marine Corps military lifestyle as a military spouse for 19 years. In addition to being a parent and highly effective advocate, Isabel has worked as an installation-level EFMP Coordinator and at Marine Corps Headquarters as an EFMP Support Coordinator for four years. Today, Isabel works as a content analyst for the Department of Defense Military Community and Family Policy Program Support Group.
We are the Johnson family: parents Andy, 37, and Cindy, 38, and daughters, Amanda, 16, Shelbie, 12, and Alexis, 5. Andy and I are both in the United States Air Force (USAF). Over the last 19 years, we have served in various assignments around the United States and overseas, including deployments and Temporary Duty Assignments (TDYs) for mission support and training. I would like to share with you how the USAF helped our military family continue our careers and care for our three daughters at the same time, including our youngest, Alexis, with special needs.

My first duty assignment was at RAF Alconbury, United Kingdom (RAF stands for the Royal Air Force, the air force branch of the British Armed Forces), where I spent two exciting years traveling. My next assignment was at Hurlburt Field, Florida, where I experienced a desert deployment and entered the wonderful world of motherhood. Amanda was born on April 10, 1991.

The next three years were spent at Sheppard Air Force Base (AFB), Texas, where Shelbie was born on September 7, 1994. The next assignment was at Tyndall AFB, Florida for 18 months. The most exciting tour was one that Andy and I were able to share at MacDill AFB, Florida where Andy and I became Paratroopers with the Joint Communications Support Element. We thoroughly enjoyed our assignment, jumping out of planes with the airborne unit and even got to make two jumps together. In our minds, we were ready for anything the world brought our way. Little did we know what was ahead of us and the new challenges we would face during our next tour of duty.

In 1999, while I was assigned to the Defense Supply Center Philadelphia (DSCP) and Andy was stationed an hour away in New Jersey at McGuire AFB, we found out I was pregnant. We were thrilled. At the time, Andy had orders to Korea for a one-year tour, and I had orders to Germany for a three-year tour. Our plan was that shortly after our baby was born, the girls and I would move to Germany, and Andy would join us following his tour in Korea. We were excited about spending time in Germany with our new baby and our two older daughters! Because Andy and I had been stationed in Europe when we were younger, we were looking forward to traveling and sharing the experiences with our daughters. I prayed all the time that our family would be blessed with good health and safety until we were together again in Germany.

Alexis Marie Johnson, our third baby girl, was born on April 25, 2002. I started to become concerned when she was three- to four-months-old, because she still was not lifting her head or moving around. She was like a noodle. I grew more concerned when she reached six months and still was not able to do these things. By her six-month well-baby appointment, the doctor became worried and referred us to a specialist. The appointments with specialists have not stopped since.
I struggled through those first three months of doctor visits; I was scared I was going to lose my baby girl. I saw so many sick children at every appointment. I became terrified every time the phone rang, thinking it was a doctor with bad news. My girlfriends accompanied me for support to all of Alexis's appointments. I never knew what type of news I would receive.

On January 29, 2003, my birthday, I met with a geneticist at Children's Hospital of Philadelphia (CHOP) and was given Alexis's diagnosis of IsoDicentric 15–idic(15) (a chromosome abnormality in which a child is born with extra genetic material from chromosome 15). After the geneticist patiently explained the diagnosis and symptoms, my only reaction as I handed my daughter over to my girlfriend was to hug the doctor and tell her "Thank you." I was hugging her because she had told me that what Alexis had was not terminal.

I think the hardest part of the situation for me was that my husband was gone, and I had no family around. Yet I am grateful for the support given to me back then by my older daughters and girlfriends. We were entering a whole new world, the world of special needs.

We learned that people with chromosome 15q duplications are frequently affected by developmental disabilities. (See sidebar on facing page.)

The Air Force (AF) had always impressed me with how they helped individuals and families whenever possible. With my personal experience, I can verify the AF went out of their way to care for our family, with no hindrance to its mission. When Alexis was diagnosed, the AF sent Andy home at his six-month mark in Korea. With her diagnosis, I was scared and confused. I wanted to stay home with her every day. I was ready to separate from the military. We reached a point where we felt alone; we could not think beyond ourselves and what we needed to do from that day forward for our family. Our supervisors, who were wonderful Airmen, fathers, and mentors, spent lengthy time with us, discussing our situation and possibilities. They assisted us in laying out options for our continued AF careers while caring for our daughter with special needs. These men melted my heart with their understanding and sympathy for our situation. They agreed to help us as much as possible in hopes of ensuring we completed our tours and were able to honorably retire with 20 years of service.

Our assignment to Germany was immediately canceled upon Alexis’s diagnosis, because no one really knew what we faced and what type of medical facilities she would need. Andy was given a Permanent Change of Station (PCS) assignment to return to McGuire AFB. He worked nights for a year while he kept Alexis home during the day, allowing her to stay healthy and attend her weekly occupational therapy (OT), physical therapy (PT), and speech therapy appointments. The New Jersey Early Intervention Program was fabulous in offering Alexis professional, caring experts who came into our home to provide her with the therapy she needed. Fortunately, I was able to attend her hospital appointments and most of her therapy sessions. We kept this schedule until her second birthday.

The AF allowed me to PCS from DSCP to McGuire AFB with my husband until a training position with limited deployments and TDYs opened at Fort Dix, New Jersey, located next to McGuire AFB. The Air Force generously moved me to fill the two-year controlled tour. After my two years at Fort Dix, I was promoted out of the position but was blessed to return to McGuire AFB as Director of Education, Noncommissioned Officer Academy. I have served in this position over the last year and will remain in it until my retirement this summer. Andy moved from McGuire AFB to the United States Air Force Expeditionary Center at Fort Dix in a controlled tour/training slot where he will also remain until his retirement this summer. Thankfully, many individuals with impact on our careers agreed this location met the medical and school facilities/program needs for Alexis's challenges, and they gave us the opportunity to remain here to meet our family needs. It has been difficult for us to change jobs so often, but it has been well worth it for the stability and support we have received. Our tours of duty continue to let us give back to the AF as it continues to give to us.

We always felt that we were in a perfect place for Alexis; New Jersey has a lot of support for people with special needs. We are seen regularly at CHOP and yearly at Bethesda Naval Hospital. We think the world of our physicians. Alexis attends Burlington County Special Services School District (BCSSSD), a special needs school for children ages 3 through 21. She is in a full-day, year-round preschool class for children with disabilities. Her teachers, Ms. Clark, Ms. Pat, and Ms. Donna, are some of the most amazing people we have met. I pray that all children with special needs are cared for, motivated, and challenged the way Alexis is by her teachers and her classmates.

Alexis receives PT, OT, and speech therapies two times each week and attends aqua therapy once per week. She takes the school bus to and from school every day and loves the ride. Her bus driver, Mr. George, is a pleasure to see every morning, and he provides us comfort in putting her on the bus each day. Alexis also attends the McGuire AFB Child Development Center (CDC) for two hours after school each day. The ladies in her room, Sue, Tina, Vielka, Arden, Brandi, and Midallia are outstanding and
What is Isodicentric Chromosome 15?

Isodicentric chromosome 15 is the scientific name for a specific type of chromosome abnormality. Individuals with isodicentric chromosome 15, or ‘idic(15),’ have 47 chromosomes instead of the typical 46 chromosomes. Occasionally, a person may have two extra idic(15) pieces (48 chromosomes) or three extra idic(15) pieces (49 chromosomes) in all or some of their cells. When the extra genetic material comes from the paternal chromosome, a child may have normal development. However, when the duplicated material comes from the maternal chromosome, developmental problems are often the result. Most commonly, the region called 15q11-q13 is the portion of chromosome 15 duplicated. Individuals with idic(15) usually have a total of four copies of this chromosome 15 region, instead of the typical two copies (one copy each on the maternal and paternal chromosomes and two copies on the idic(15)).

Some children and adults with idic(15) are said to have mosaicism, meaning that their extra 15th chromosome is present in some, but not all, of their body cells. Mosaicism occurs by chance in this and many other chromosomal disorders.

What is interstitial duplication chromosome 15?

People born without an extra chromosome but who have a segment of duplicated material within chromosome 15 are said to have an interstitial duplication chromosome 15 (int dup(15)). Most often this is the same section (15q11-13) that makes up the extra chromosome in idic(15). For this reason, people with interstitial duplications of 15q and those with idic(15) share similar characteristics. For both conditions, there is a wide range of severity from one person to the next; as a group however, people with interstitial duplication 15 tend to have milder symptoms than those with idic(15).

How often do duplications of chromosome 15 occur?

Researchers think that approximately 1 in 8,000 babies are born with an extra chromosome that came from chromosome 15. The most common type of marker chromosome 15 is very small and does not cause any problems. We don’t know the frequency of the larger ones that cause the symptoms seen in idic(15) and int dup(15), but one researcher estimates they occur in about 1 in 15,000 – 20,000 births. Generally, people do not have family members with the chromosome abnormality. The idic(15) usually forms by chance in one person in the family. Children with idic(15) are born to parents of every socioeconomic, racial, and ethnic background. There is no known link between idic(15) and environmental or lifestyle factors. In other words, there is nothing that parents did before or during pregnancy to cause their child to be born with idic(15).

How are duplications of chromosome 15 diagnosed?

The diagnosis of idic(15) is made through a blood test called a chromosome study, with FISH (Fluorescence In Situ Hybridization) confirming the diagnosis by distinguishing idic(15) from other supernumerary marker chromosomes. Interstitial duplications of chromosome 15 can be more difficult to detect on routine chromosome analysis but are clearly identifiable using a 15q FISH study. Families should always discuss the results of chromosome and FISH studies with a genetic counselor or other genetics professional to ensure accurate interpretation. Additionally, studies on all family members can be done to answer questions regarding recurrence can be explored with the genetic counselor or other genetics professional.

What problems are caused by duplications of chromosome 15?

Since chromosomes carry genes that determine how our bodies grow and develop, having extra chromosomal material can alter a person’s physical and mental development. Unlike many other chromosomal syndromes, there are few characteristic physical findings associated with idic(15) and int dup(15). There is also a wide range of severity, so that two children with the same chromosome pattern may be very different in terms of their abilities. In general, the following features are found in most people with idic(15) and int dup(15), to varying degrees:

- Poor muscle tone (hypotonia), particularly in babies, with delayed milestones (although the vast majority will walk independently)
- Cognitive disabilities/learning disabilities
- Autism spectrum disorders
- Seizure disorders
- Speech/Language delay
- Sensory processing disorders
- Attention Deficit Disorders (ADD/ADHD)
- Anxiety disorders
- Small size for age
- Minor unusual physical features, including wide-spaced eyes with skin folds at the inner corners (epicanthal folds); noticeable unfolding of the edge of the ears; short, upturned nose with a low or flattened nasal bridge; and full lips

As with any chromosomal syndrome, there can be differences in the way children’s, hearts, kidneys, or other body organs are formed. Parents should check with their genetics specialist for specific recommendations regarding medical evaluations.

At the present time, there is no specific treatment that can undo the genetic pattern seen in people with idic(15) or int dup(15). Although the fundamental genetic differences cannot be reversed, children and adults have been known to benefit from some of the following:

- Early intervention (speech, physical, occupational, and sensory integration therapies)
- Ongoing special education
- Total communication systems (a combination of speech, sign, gestures, and picture exchange)
- Behavioral strategies
- Sensory integration strategies
- Medical management of symptoms
- Vocational training

Isodicentric Chromosome 15 and Autism

For more than twelve years, scientists have noticed that some individuals with autism also have idic(15). In fact, idic(15) is the most frequently identified chromosome problem in individuals with autism. (A chromosome anomaly involves extra or missing chromosomal material, not changes within the genes, such as Fragile X syndrome). There are now over 20 reports in the literature of individuals with both autism and idic(15). The frequency of these reports suggests that the co-occurrence of autism and idic(15) is not by chance. There may be a gene or genes in the 15q11-q13 region that is/are related to the development of autism in some individuals.

Genetic research studies of individuals without chromosome anomalies also support this idea that an autism-related gene may be present in 15q11-q13. Specifically, research studies found that certain DNA markers from the 15q11-q13 region were found more often in individuals with autism than in individuals without autism. Although this does not mean that DNA markers are too small to be genes, they suggest that researchers may be getting close to finding an autism gene in this region. Researchers are currently focusing on genes in this region called the GABA receptor genes, known as GABRB3, GABRA5, and GABRG3. They are good candidates for being related to autism, not just because of their location, but also because of their function. The GABA genes make proteins that carry messages between nerve cells. Several studies have found associations between GABRB3 and autism (Buxbaum et al., 2002; Shao et al., 2002; Cook et al., 1998), but further study is needed.

Isodicentric Chromosome 15 and Seizures

Seizures represent an important medical feature of idic(15) syndrome. Over half of people with idic(15) will have at least one seizure. The vast majority of those will experience their first seizure before age five. In a survey of 90 parents of children with idic(15), the following preliminary picture of the relationship of idic(15) to seizures emerged:

- 54 percent of the group surveyed had experienced at least one seizure. Age of onset of the first seizure ranged from birth through eighteen years, with a mean age of 2.9 years.
- 55 percent of those with seizures had onset by one year of age, with 92 percent having onset prior to age five.
- Parents reported multiple seizure types in their children, including generalized tonic clonic (18 percent), absence (12 percent), and myoclonic seizures (11 percent). Sixteen percent of the group, accounting for 29 percent of those with seizures, had a history of infantile spasms. Many children experienced more than one seizure type, and several had severe, intractable epilepsy.

When surveyed about the impact of the child’s seizures on his/her quality of life and functioning, 51 percent of parents reported a minor impact, 16 percent a moderate impact, and 33 percent a major impact.

Abnormal GABA receptor gene expression is a likely contributor to seizures in people with idic(15). Additional studies are needed to further characterize seizures in idic(15) and to study the effectiveness of medications which influence the brain’s GABA receptor system.

Information on Isodicentric Chromosome 15 is courtesy of IDEAS (Isodicentric Chromosome 15 Exchange, Advocacy & Support), a nonprofit corporation and support group with over three hundred families from around the world affiliated with its efforts. IDEAS is an entirely volunteer-run organization supported by grants, donations, and many hours of volunteer effort. For more information, visit www.idic15.org.

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as well. The ratio of caregivers to children in her classroom was changed to allow more one-on-one time with her. Every day, Mr. Willie from the CDC meets Alexis to get her off her school bus and walk her down to her room. Although Alexis is nonverbal, she will let you know what she wants and who she wants to be with. Mr. Willie is the only person she wants getting her off the bus each day. It’s so cute!

Earlier, I mentioned that one hardship we faced was not having the extra support and assistance associated with having family around. Another hardship are the TDYs that take us away from home. Fortunately, we have never experienced simultaneous TDY assignments, but even a single TDY assignment creates an increased burden. Since Alexis’s birth, I have experienced more assignments than Andy. A couple of them have been for months in duration. I am very proud of my husband. He never complains but instead presses forward and does everything he can to care for the girls. It’s very difficult, because Amanda and Shelbie are very active in their school and sports activities. Amanda is president of her class and on the honor roll. She participates in varsity soccer, lacrosse, winter track, and cross country, and is also a member of many committees. Shelbie takes modeling/acting classes; participates in soccer, basketball, and softball; and is on the yearbook committee. What makes it more difficult is that Alexis is becoming harder to take out and about so we can’t do some activities with her. We adjust and accept that one of us will remain home with her when needed. We still do the majority of activities as a family, but we have to plan more and be cautious of the surroundings. My friends have been super over the years in understanding and helping us drive our older girls around when my friends’ kids are involved in the same activities. Our friends, Nina and Kathy, ensured Shelbie could stay involved in all her school activities and sports.

Alexis is globally delayed (with a variety of developmental delays, including mental, physical, and communication) to around the twelve-month level. She is autistic, cognitively delayed, and nonverbal; she has epilepsy, low muscle tone (which requires leg braces), and episodes of shuddering attacks. She is the cutest, happiest little girl I think I have ever been around. She is a gift from God. Our Christian faith has kept our family together and helps us each day to continue in what we pray is God’s will.

Alexis attends the Special Olympics Young Athletes™ program where activities are led by Natalie. She takes horseback riding at Rein Dancer Therapeutic Riding Center (funded by the Air Warriors Courage Foundation), with Pam and Steffi, and she just enrolled with our local Challenger Baseball team, coached by Mike. We consider ourselves blessed to have just started 15 hours a month of Applied Behavior Analysis (ABA) with Linda from the Lovaas Institute.

Our family is part of the most amazing support group—IDEAS (Isodicentric 15 Exchange, Advocacy & Support; http://www.idic15.org/). The parents of children with idic(15) are a true blessing. They are strong, funny, and very supportive. Nicole Cleary, a parent of a child with idic(15) and the Executive Director of IDEAS, as well as my personal hero, commits her time and energy to bringing us together and keeping us informed. IDEAS holds international conferences every two years. Our family has attended the last two, and we are looking forward to attending the one this June in Boston, Massachusetts. While attending the last two conferences, I found peace and comfort in being around so many special children and their parents and siblings. During the three-day event, everyone is smiling and just happy to be healthy and together. Because of my daughter’s special needs, I joined a community of understanding, loving friends whom I feel blessed to have met. We are united in such an incredible way.

The United States Air Force has been amazing for our family. My grandfather, Colonel Carl Peterson, retired from the Army; my father, Senior Master Sergeant (SMSgt) Ed Thomas, retired from the Air Force; and Andy and I will retire this summer after proudly serving for 20 years. We are humbled to serve in a great military and for a great nation. We are very blessed to receive the good care we need in order to raise our daughter with special needs.

We would like to personally thank Colonel Robert E. DeGraphenreid, Lieutenant Colonel Anthony V. DiMarco, Captain Douglas M. Blough, Chief Master Sgt Timothy Daigle, Chief Master Sgt William Rener, Chief Master Sgt Edwin Ayers, Chief Master Sgt Richard P. Price, Sr., and Chief Master Sgt Warren L. Wofford. The actions of these men had a significant impact on how we have handled having a child with special needs. They kept our family together and helped us to make sure that we could take care of each other.

Cindy Johnson is a Senior Master Sergeant (SMSgt) and her husband Andy is a Master Sergeant (MSgt) in the United States Air Force. Both Cindy and Andy will retire this summer, each with 20 years of service.
Dear Military Families:

We here at EP are very excited about some new features and upcoming educational highlights that we hope will help make a big difference for you!

First, have you had the opportunity to check out the re-designed and expanded EP Web site? Check it out at www.eparent.com. Take a moment and see what we’re doing to make it even better than ever. Especially exciting for the Military Editorial Team is the introduction of the Military Channel. Visit this Channel often for important stories about what is happening in your world—from valuable Military resources to can’t-miss community connections that should help you find the best care for your child or other loved one with special needs. In addition to the Military Channel, the EP Web site offers information regarding financial planning, technology, sports and recreation, and so much more. There is the always-popular Search & Respond feature, where you get to share ideas and ask questions of other people. Blogs lend additional insight into others’ experiences. Browse the EP Bookstore, where you will find a collection of over 2,000 books about disabilities and special needs to offer you support and direction.

How would you like to find out more about pressing issues for your family or other families that you care about and have the opportunity to ask questions of world-renowned professionals in the disabilities area? EP is offering an opportunity for just that, and you can participate from the comfort of your own home or installation! We’re thrilled to announce the presentation of six free educational, online seminars in upcoming months. Unique to these seminars is the method of their delivery to you. You can join a group at your installation to view these together, live and online, via a system known as Vemics (Visually Enhanced Multi-Point Interactive Communications System), or you can view them in the comfort of your home, using your computer, and viewing streaming video. You will save on the cost of transportation to a seminar site as well as on hotel and dining expenses. Even better, you’ll immediately have an opportunity to discuss the issues with your family and friends who attend or who view it with you. Can’t make the actual presentation on-line? You can register to view it after the presentation as an archive file. Below is a sneak peak of this upcoming series with tentative months the seminars will take place. For more information on this upcoming series, visit www.epliveonline.org in the coming months for full seminar details.

COMING SOON
SIX LIVE, ONLINE, INTERACTIVE, SEMINARS LED BY EXPERTS IN THE FIELD OF DISABILITIES
HELP YOURSELF…HELP YOUR FAMILY…HELP A FRIEND
Tune in and learn the latest information regarding:
• Respite Care (Tentative Month: July)
• Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder (ADD/ADHD): Diagnosis, Treatment and Management in Children and Adults (Parts I & II) (Tentative month: August)
• Autism Spectrum Disorders in Children and Adults (Parts I & II) (Tentative month: September)
• Asthma and Air Flow Obstruction (Tentative month: November)

We’d love to have your company as we kick off these educational opportunities for enhancing the lives of those with special needs and all who care about and for them. See you soon!

With Best Regards,

Kerry Clayton Dauphinee
Military Managing Editor
Exceptional Parent Magazine
Finding our way anywhere in life

is easier when we have the proper directions to navigate there. This is especially true when we face out-of-the-ordinary situations where we require extra energy and commitment to understand our circumstances, gather our resources, determine potential outcomes, and fulfill our goals.

Families with a member or members with disabilities or special needs know that parent handbooks for the typical child can only take them so far, if they can be used at all. Where do you turn then? The Internet has become a lifeline for researching a variety of symptoms, diagnoses, and available interventions. The ability to connect with other parents on a similar journey can help to lighten the load and provide support for a challenging undertaking.

Still, as the Special Need Parent Tool Kit, a publication of the Department of Defense (DoD), notes, “Many parents wish their children came with instruction booklets. For parents of a specially challenged child, this feeling may be magnified.”

The DoD has done a fine job of creating its own type of instruction booklet, with its Special Needs Parent Tool Kit, by providing vital information in one place for consolidated, easy, and quick reference. This topnotch tool kit for military families who have a child with disabilities or special needs is a comprehensive resource. Available as a PDF file, it runs a gamut of topics to help ease the load and provide support for a challenging undertaking.

Topics in the tool kit include: 1) the discovery that your child has a disability; 2) the emotional impact of diagnosis; 3) early interventions; 4) education options; 5) health benefits; 6) families in transition; 7) advocating for your child; 8) resources and support; and 9) records and tools.

The tool kit is visually appealing. It is colorful and organized with an attractive layout and polished, professional look. Organized into self-contained modules, it flows as a single document and handily cross-references its other modules. It has a table of contents and pertinent breakout quotes, as well as letter templates for requesting important items such as: 1) a school evaluation; 2) an independent educational evaluation; and 3) school records.

It includes information about an Individualized Education Program (IEP), including how to organize an IEP notebook and background information on Section 504 of the Rehabilitation Act, which educates parents about their options beyond the parameters of the Individuals with Disabilities Education Act (IDEA).

Among many valuable insights, the Tool Kit offers information to parents regarding what their emotional responses might be in learning that their child has a delay or disability, responses that are similar to those defined by Dr. Elisabeth Kübler-Ross to describe people dealing with impending death. This does a great service for parents by informing them that their emotional responses are a natural process and by validating their feelings regarding this unexpected turn in their lives.

Facing a diagnosis and shift in vision for your child, a situation for which most parents are unprepared, can be not only emotionally daunting, but practically overwhelming as well. The beauty of the Tool Kit is that at any time from birth to adulthood, a parent can turn to the reference for guidance and strong encouragement regarding their rights, options, and resources. As the Tool Kit notes, “Parents are natural advocates for their children.” In turn, the Tool Kit is an advocate for parents and caregivers.

Valuable tips include: 1) the information that “a key component to effective advocacy is record keeping.”; 2) letting parents know that they should attend meetings about their child with a family member or friend who can provide moral support; 3) homework helpful hints; 4) legal resources; 5) medical resources; 6) financial aid resources; 7) safety; 8) disaster preparedness; 9) caring for an adult child with special needs noting that parents have a right to receive copies of evaluation results and notice regarding aspects of programs for their child; and 10) availability of military, as well as federal, state, and community resources.

The DoD has pooled this information in one handy tool kit, yet its benefits should not be limited to military families. Anyone can, and should, take advantage of this great resource.

While it is impossible to write the perfect manual that covers everything that could possibly come a parent’s way, this DoD resource does an excellent job of putting power in the hands of parents and providing them with a guide and support to navigating and negotiating their child’s best and brightest future.

To download the Special Needs Parent Tool Kit, visit http://www.militaryhomefront.dod .mil/efm. Select ToolBox.
Deployment is one of those dreaded things in military life. Your spouse looks at it as the opportunity to do his/her job as it was intended—in a combat zone. I don’t think any spouse looks forward to being away from family; it just seems that they crave the ability to put all of the training they have worked on to practical use. I think deployment falls into many unpleasant categories but at the same time allows us to find new skills and determination we didn’t know we had.

Just like the stages of grief we experience and re-experience with a child with disabilities, deployment could be viewed as having stages, too. Preparing yourself with resources can be a great place to identify the feelings your family is experiencing. How you will act on the information you gain will be one way to gauge your progress before, during, and after the deployment. Just because something is in your “deployment file” doesn’t mean it will be at the top of the stack when you need it. Surrounding yourself with information is great so long as you allow yourself to use the information. People with similar situations or experiences are a great source of comfort and information.

Don’t be afraid to respond to a kind word or deed. I will never forget the sweet, elderly woman who saw me at church with my two girls, stopped to give me a hug, and commented, “I remember what it is like to be home with the children while my husband was deployed. Always pray for your husband and the children will be more secure when they see you do this.” The struggles we face now may be more intense, but common ground can be found in the strangest places. At Ft. Lewis there is a bridge where every Saturday and Sunday people of all walks of life can be found holding flags and banners as they wave to anyone who goes over or under the bridge. There have been many times when knowing that these people stand and support us in the sun or the rain has given the girls and me an extra boost to get through the day. Sometimes people will notice the Department of Defense (DoD) sticker on the front window of my car and stop to express thanks.
for what our spouses and families deal with. One eventful trip to Target included my youngest “cleaning the floor” while throwing a fit. While I did get stares, I also had the pleasure of a kind person who said, “Thank goodness she is well cared for enough to throw a fit and miss her Daddy!” When someone from my church family asks how they can help, I had to learn how to respond with something besides, “Oh, I’m fine.” It is liberating to allow yourself to say, “I need my lawn mowed. Do you know anyone who can fix a bicycle tire? How do you take a light bulb out of a socket when the bulb has broken?”

Respite care—these are two wonderful words that I truly gained an understanding of during deployment. Many installations are increasing the availability of hourly care at no cost to families who have a deployed parent. Take advantage of this! The value of taking the time to just “be” cannot be stated enough! I have found it is worth the aggravation of schlepping the kids to the Child Development Center (CDC) so that I can blaze through the commissary alone. I like to be with people, but it can also be very, very rewarding to sit in a movie by yourself with no one asking you to open their candy, ask a question, or make an escape from the theater! There have been times that I have hired a babysitter or exchanged with a friend just so I could take a nap. Respite care allowed me to view myself as a valuable member of the military community and a gosh-darn good Mom of a child with disabilities, too!

Sometimes I felt like I needed someone to give me permission to seek help, cry, or just enjoy a bag of Hershey’s Kisses. Consider permission to be granted. When we seek healthy outlets for our stress, we are better parents, our children are happier, and our spouse is less stressed while away. I have heard the previous statement so many times that it seems almost trite. The thing is, it may be trite, but it is true!

Karen Elliott is a military wife of 15 years and EFMP. She and her husband have two wonderful children, who are both EFMP. Karen feels that her position with Specialized Training of Military Parents (STOMP) enables her to return the favor to all of the people who have cared enough to guide and support her family as her needed advocacy skills develop.

Valerie Patterson is the Parent Education Coordinator for the East Coast Office. She has been part of the STOMP staff since November 2003. Valerie is a proud Army wife and the mother of five beautiful children, four of whom are enrolled in EFMP.
Exceptional Parent

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COVER STORY
The Gordon Family's Accessible Home

Family Finances: Staying Afloat in Rough Seas

Seizures and Teens Stress, Sleep, and Seizures

United States Military Section

Community of One
From Our Families... To Your Families

ECHO – The Extended Care Health Option

MCEC™'s Growing, Learning, and Understanding (GLU™) Program

WHEELCHAIR TRANSPORTATION SAFETY SERIES
Riding to School in a Wheelchair

www.eparent.com
The Military Child Education Coalition™ (MCEC™) has created a series of programs to encourage and support parents serving as their child’s first teacher and best advocate. One such program is the initiative Growing, Learning, and Understanding (GLU™): Making Meaning through Early Literacy™. This initiative was designed to develop early literacy skills in children from birth through second grade.

GLU™ helps children make meaning of the world around them through the use of kits covering a range of themes and literacies. Each GLU™ kit is a theme-based set of resources, which includes activities and information sheets centered around a book or other resource. Suggested age ranges are noted for each kit and individual activity, with modifications listed for many activities so adults can easily find ways to best meet the interests and skills of their child. Modifications are also included for children with special needs so all children are able to benefit from these resources.

GLU™’s themes cover various aspects of literacy, from language acquisition and reading to art and mathematics skills. The activities were thoroughly researched and designed with the developmental needs of young children in mind. All GLU™ kits are built around carefully chosen resources that parents and childcare providers can expand upon, adapt to the needs of their own children, and use over and over again as children continue to grow and learn.

Parents and care providers are encouraged to utilize careful observation and understanding of their own children, as well as research and information regarding the development of young children, as they explore the kits, use the activities, read the books, and, most of all, have fun learning together!

Current kits include the It’s Okay to Be Different kit, which nurtures self-esteem and builds children’s acceptance of their own individuality and the differences they see in others; the Wild About Books kit, which was developed to nurture children’s early passion for learning, instills in them a strong love of literature and reading and helps guarantee their success in school and in life; and the Textures and Treasures kit, which was designed for infants and toddlers and with an understanding of the vital importance of sensory exposure to early brain development.

GLU™ kits are available to parents, educators, and anyone else who is working with young children. For an overview of the GLU™ kits and their contents or to purchase a GLU™ kit, please visit: http://www.easycart.net/MilitaryChildEducationCoalition/Educational_Resources.html.

Annual Conference
Each summer, the Military Child Education Coalition™ hosts its annual conference, which includes information for parents, educators, and other adults who care about military children. This year’s conference will be held July 11-13 in Kansas City, Missouri.
City, Missouri. For more information, please see the conference details below or visit http://www.militarychild.org/KansasCity.asp/.

MCEC™ is a non-profit organization focused on the academic and school-related needs of all United States military-connected children. MCEC™ believes strongly that parents are the first and best advocates for their child. For more information, please contact Stephanie Surles, MCEC™’s Director of Research and Product Development, at stephanie.surles@militarychild.org or visit MCEC™’s Web site at www.militarychild.org.

Stephanie Surles, JD, MPA, is Director of Research and Product Development at MCEC.
United States Military Section

Dear Military Families,

On Thursday, June 14, 2007 as I was preparing dinner, I happened to have on The Oprah Winfrey Show. The last segment of the show caught my ears, eyes, and heart. What I witnessed was one of the most inspirational stories I have seen and heard in my life. It was as though Dick and Rick Hoyt were physically in my living room, sharing Rick’s story from exclusion to inclusion that he achieved through determination, commitment, and the unconditional love of his family.

In 1962, Rick was born into the Hoyt family. He came into the world as a special gift to Dick and Judy Hoyt. See, Rick – due to complications from his birth—was diagnosed early in life as having spastic quadriplegia with cerebral palsy and later was determined to be nonverbal. The Hoyt family immediately chose a journey of inclusion that at the time was not heard of or practiced.

Dick and Rick have achieved more together as a father and son than one could ever wish, hope, or dream. What they have achieved over the years is so comprehensive that I can only scratch the surface here. What I would like to do is invite you to visit www.teamhoyt.com to witness for yourselves this remarkable father-and-son journey.

Kahlil Gibran, author of The Prophet, wrote in Spiritual Sayings of Kahlil Gibran, “To understand the heart and mind of a person, look not at what he has achieved, but at what he aspires to do.”

Kahlil came into this world long before Dick and Rick. I can only imagine that when he wrote the words above, he was thinking of people much like Dick and Rick. The essence of what Kahlil wrote was that it is not what people like Dick and Rick have achieved throughout their lives, but it is Rick’s aspirations that have given life to him and to Dick and to thousands of people around the world.

We have so much to be thankful for; each day invites us to look at ourselves and challenge ourselves to look at what we can do, not what we cannot do. We all have aspirations in our lives, and it is people like Rick and Dick that can be our teachers, if we are willing to accept the challenge.

Dick and Judy Hoyt epitomize Community of One—From Our Families...To Your Families. They could have chosen exclusion during the 1960s for their son Rick, but they chose inclusion instead. Both Dick and Judy’s aspirations for Rick were far more important than what anyone at the time could have imagined.

Of special note, Dick served his country for over thirty-five years and recently retired from the Air National Guard.

Hoping that you and your families find the reward in your aspirations.

With Best Regards,

Kerry C. Dauphineè
Military Managing Editor
Are you struggling with caring for a family member with physical or mental disabilities and wondering how to tap into more resources and pay for additional quality care? If so, ECHO is just a call away.

The Extended Care Health Option (ECHO) is a supplemental portion of the TRICARE military health program, available to active duty family members (ADFMs) who qualify based on specific physical and mental disabilities. The program provides financial assistance to qualified beneficiaries and offers an integrated set of services and supplies beyond the basic TRICARE program.

The ECHO program evolved from previous government programs designed to assist those with special needs. In 1966, Congress passed the Military Medical Benefits Amendments, which established the Program for the Handicapped, originally developed to provide financial assistance to ADFMs with serious disabilities. This program was replaced with the Program for Persons with Disabilities (PFPWD) in 1997. In 2001, the Department of Defense (DoD) worked through the National Defense Authorization Act to establish the current program known as the Extended Care Health Option (ECHO), which was implemented on September 1, 2005.

As a result, some benefits previously available only under PFPWD are now available under the basic TRICARE program, allowing more TRICARE beneficiaries to access those services, while enhancing services available to ECHO-eligible beneficiaries.

What follows are questions and answers about the ECHO program, to help parents and professionals navigate the program.

Who is eligible for ECHO?

ADFMs are eligible for the ECHO program when they have one or more of the following qualifying conditions:

- A serious physical disability that may include infantile cerebral palsy, spina bifida, loss of vision or loss of hearing
- Moderate or severe mental retardation
- Any physiological disorder, condition, or anatomical loss affecting one or more body systems, which has lasted, or with reasonable certainty, is expected to last
for a minimum of twelve contiguous months and which precludes the person with the disorder, condition, or anatomical loss from unaided performance of a major life activity

- Beneficiaries less than three years of age with a developmental delay equivalent to two standard deviations below the mean in adaptive, cognitive, or language function; Down syndrome or fetal alcohol syndrome
- An extraordinary physical or psychological condition of such complexity that the beneficiary is homebound
- A diagnosis of a neuromuscular developmental condition or other condition in an infant or toddler that is expected to precede a diagnosis of moderate or severe mental retardation or a serious physical disability
- Multiple disabilities, which may qualify if there are two or more disabilities affecting separate body systems

ECHO benefits are available to family members of a deceased active duty sponsor until midnight of the beneficiary’s twenty-first birthday, as long as the sponsor was eligible at the time of death.

ADFMs can also access ECHO benefits under the Transitional Assistance Management Program (TAMP). Please visit www.tricare.mil for more information about TAMP.

Who is not eligible for ECHO?
Retirees and their family members, as well as North Atlantic Treaty Organisation (NATO) family members, are not eligible for ECHO benefits.

How do qualifying beneficiaries register for ECHO?
To begin the registration process, beneficiaries must enroll in the Exceptional Family Member Program (EFMP). This program was established through the Department of Defense (DoD) and is a mandatory enrollment program for active duty personnel who have a family member(s) with special needs.

When military service members are considered for assignment to an installation within the United States, EFMP enrollment is used to determine whether needed services, such as specialized pediatric care, are available through the military health system at the proposed location. This program provides a single point of contact that facilitates a family’s relocation. The program ensures that they are stationed in a geographical area where their family members can receive the services they need.

Although some programs may have a different name, each uniformed service branch – Army, Air Force, Navy, Marine Corps, Coast Guard, and National Guard and Reserve – has an EFMP.

The EFMP:
- Identifies family members with special medical and/or educational needs.
- Documents the services they require.
- Considers those special needs during the personnel assignment process (especially when approving family members for accompanied travel to overseas locations).
• Involves the personnel and medical commands and the educational system.

How do beneficiaries enroll in the EFMP?
To enroll in the EFMP, beneficiaries should complete the demographics/certification sections of the required forms, DD Forms 2792 (medical services) and 2792-1 or CG 5494 (special education/early intervention summary). The provider must complete and sign the medical summary section. These forms may be obtained at a local recruiting office, through a TRICARE Service Center, online at www.militaryhomefront.dod.mil, or at a Military Treatment Facility (MTF) EFMP office.

Beneficiaries will need to submit the EFMP forms to the appropriate EFMP manager. Enrollment in this program is required for most beneficiaries prior to requesting ECHO services; however, enrollment will be waived for those branches of service, such as the National Oceanic & Atmospheric Administration (NOAA) and Public Health Service (PHS), which do not have an EFMP.

Additional information about the EFMP can be found at www.militaryhomefront.dod.mil/efm (Select Exceptional Family Member) or by speaking to a Special Needs Coordinator at an MTF.

Who can beneficiaries contact if they have questions regarding the EFMP?
For more information about the EFMP, beneficiaries may visit www.militaryhomefront.dod.mil/efm, visit the TRICARE Service Center, or speak to a Special Needs Coordinator at an MTF.

What do beneficiaries need to do after they register in the EFMP?
Once beneficiaries have registered with the EFMP, they must register with the regional managed care support contractor having jurisdiction where they reside.

Beneficiaries must provide the regional contractor with documentation of an active duty sponsor, qualifying condition, and enrollment in the EFMP, from their sponsor’s branch of service. Upon completion of registration and approval, the beneficiary’s Defense Enrollment Eligibility Reporting System (DEERS) record will be updated to indicate that he or she is eligible for ECHO benefits.

Can beneficiaries receive ECHO services prior to completing the ECHO registration process?
To avoid delaying receipt of ECHO services while completing the ECHO registration process, the regional managed care support contractor or TRICARE Overseas Program Regional Director may grant ECHO-eligible beneficiaries a provisional eligibility status for a period of not more than ninety days, during which ECHO benefits will be authorized and payable. This provisional status is only granted once the EFMP manager has accepted the EFMP paperwork for enrollment and has forwarded it for processing.

Is there any cost related to ECHO registration?
TRICARE does not charge a fee for registering in ECHO; however, the sponsor/beneficiary may incur costs associated with the determination of ECHO eligibility. For example, the sponsor of a TRICARE Standard or Extra beneficiary may be required to obtain diagnostic services to verify an ECHO qualifying condition. The sponsor/beneficiary is liable for all relevant TRICARE Standard or Extra cost-shares associated with the receipt of those services. These cost-shares are not reimbursable under ECHO.

The PFPWD program had a maximum monthly benefit of $1000. Is the benefit the same under ECHO?
With ECHO, the monthly benefit has increased from $1,000 to $2,500 per beneficiary, regardless of the number of family members with the same sponsor receiving ECHO benefits.

What are the costs associated with ECHO benefits?
TRICARE ECHO beneficiaries are eligible for $2,500 of ECHO services per calendar month, with a monthly cost-share based on the sponsor’s pay grade.

How are beneficiaries notified when they are registered for ECHO?
The regional managed care support contractor or TRI-
CARE Overseas Program Regional Director will provide the sponsor/beneficiary with written notification of his or her eligibility determination and the information that the beneficiary is registered in ECHO. Generally, the beneficiary is eligible to receive ECHO benefits as of the date of registration.

**What services are provided through the ECHO program that are not available through the basic TRICARE program?**

The following benefits are exclusive to the ECHO program. Beneficiaries enrolled in TRICARE Prime who receive ECHO benefits must comply with all requirements of TRICARE Prime, such as using a primary care manager for routine care and obtaining referrals for specialty care.

- Medical and rehabilitative services
- Training on the use of assistive technology devices for parents and siblings, when required as an integral part of the management of the qualifying condition and vocation training
- Special education—Applied Behavior Analysis (ABA) Therapy
- Payable services, which include periodic evaluation of the beneficiary, development of a treatment plan, and training of individuals to provide services in accordance with the treatment plan
- Institutional care when a residential environment is required due to the severity of the qualifying condition
- Transportation under certain circumstances to and from ECHO-authorized services. The reimbursed amount for the use of a privately owned vehicle is limited to the Federal government employee mileage reimbursement rate in effect on the trip date.
- Assistive services, such as those from a qualified interpreter or translator
- Durable equipment (DE), including adaptation and maintenance. DE is a device or apparatus that does not qualify as durable medical equipment (DME) under the TRICARE Basic program, but is essential to the elimination or reduction of functional loss resulting from, or the disabling effects of, a qualifying condition. DE can only be covered under the ECHO program with an appropriate diagnosis and need.
- Expanded in-home medical services through TRICARE ECHO Home Health Care (EHHC). EHHC provides care for beneficiaries who need services from a licensed person such as an LVN/LPN or RN. The services they need from a licensed person are more frequent, often more than one to two times an hour. An example of this type of care is the suctioning of a tracheotomy tube.
- In-home respite care services (short-term care for a beneficiary that provides relief to full-time caregivers)
- ECHO respite care—16 hours per month when receiving other authorized ECHO benefits
- TRICARE EHHC respite care—up to 40 hours per week (eight hours per day, five days per week) for those who qualify
- Beneficiaries eligible for EHHC respite may need care that occurs frequently (more than two times in an eight-hour period), but does not require a licensed person to perform the care, or care that does not require direct supervision of a licensed person to perform. An example of that type of care is suctioning the mouth, or giving medication or formula through a feeding tube.

*Note: Only one of the above respite care benefits can be used in a calendar month. They cannot be used together.*

**Is custodial care covered under ECHO?**

Custodial care, which is defined as room and board and assistance with daily living activities provided in a nursing home, is not included under ECHO; however,
services provided in support of daily living activities may be cost-shared when they are provided through the EHHC benefit.

What respite care options are available through ECHO?
ECHO provides two respite care programs. The first benefit, ECHO Respite, allows registered beneficiaries a maximum of sixteen hours of respite care from a TRICARE Certified Home Health Agency care provider to manage a beneficiary’s required skilled and non-skilled services in the absence of the primary caregiver.

Beneficiaries are eligible for this care during any calendar month in which they also receive any other ECHO-authorized benefit. For example, a beneficiary who is receiving a prorated authorization for durable equipment for three months is also eligible to receive ECHO respite care benefits during the same three months.

The second benefit is known as EHHC Respite or the Sleep Benefit, which allows qualified beneficiaries up to forty hours per week (eight hours per day, five days per week) of respite care. To qualify for this service, the beneficiary must have frequent, required interventions more than two times during the eight-hour period the primary caregiver would normally be sleeping.

Beneficiaries may not use both forms of respite care within the same calendar month.

Is the cost for ECHO respite care included in the $2,500 benefit limit?
Yes, the available sixteen hours per calendar month of ECHO respite care is included in the $2,500 benefit limit.

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<td>E-8, O-2</td>
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<td>E-9, W-1, W-2, O-3</td>
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The sponsor/beneficiary is responsible for the appropriate amount shown in the above table, in addition to any amount in excess of the government’s maximum monthly coverage for any benefits received in a month, including the ninety-day provisional period extended to the beneficiary.

The sponsor/beneficiary cost-shares under ECHO are in addition to those incurred for services and items received through TRICARE Prime, Extra and Standard options.

The sponsor/beneficiary cost-shares under ECHO do not apply toward the catastrophic cap in the basic TRICARE program or the EHHC fiscal year benefit cap.

ECHO at Work – Helping Families with Children with Special Needs

ECHO provides durable equipment benefits
A six-year-old child with cerebral palsy required specialty durable equipment not covered under the TRICARE Basic program; unfortunately, the child was not enrolled in ECHO. The provider’s initial request was denied under basic benefits. As a result, the ECHO coordinator was notified, who determined the beneficiary was eligible for ECHO, and the requested equipment was then covered. The coordinator contacted the beneficiary’s parent to inform her of the benefits for which her child qualified under the ECHO program. As a result, the beneficiary was successfully enrolled and obtained the required equipment, which decreased the effects of her disability and increased her mobility.

EHHC respite care reduces the day-to-day challenges for caregivers
A set of triplets was born prematurely at twenty-four weeks. All three babies required ventilation support and care in a pediatric rehabilitation facility for several months. The first of the triplets was sent home with intermittent nursing care, followed by the other two triplets, who were approved for EHHC respite care.

The ECHO case manager negotiated for an RN to provide respite services for the two triplets with the greatest needs, and will continue to monitor and evaluate the progress of the triplets and request additional services if needed.

ECHO provides continuity of care
A family living in the Walter Reed area was receiving forty hours of respite care per week to assist with their child’s care. The child’s father was transferred to Camp Lejeune, in North Carolina. To provide the family with continuity of care, the EHHC case managers from the Walter Reed and Camp Lejeune areas coordinated to make sure all authorizations and MTF referrals were completed. The family deeply appreciated the transparency of care during the transition, and the case manager continues to communicate with the family to ensure that all their needs are met.
What is the difference between ECHO Home Health Care (EHHC) and EHHC respite care?

- The EHHC benefit provides medically necessary skilled services by a licensed professional to eligible homebound beneficiaries whose needs exceed the limits of the Home Health Agency-Prospective Payment System (HHA-PPS) as described in the TRICARE Reimbursement Manual (TRM). Also included in the EHHC is respite care under certain circumstances.

- EHHC respite care services are provided to eligible beneficiaries who require frequent interventions (defined below). Beneficiaries may receive eight hours of respite care services five days per calendar week. The respite care services will relieve the primary caregiver(s) of the responsibility of providing such services, in order to allow them the opportunity to rest or sleep.

**Frequent Interventions:** For a homebound ECHO-eligible beneficiary, frequent interventions refer to services, as included in the beneficiary’s plan of care, which are required more than two times during the eight-hour period the primary caregiver(s) would normally be sleeping. These services consist of skilled services that can be performed safely and effectively by the average non-medical primary caregiver(s) without direct supervision of a healthcare provider after such individual(s) have been trained by appropriate medical personnel.

What is the difference between durable medical equipment (DME) and durable equipment (DE)?

Durable medical equipment is defined as equipment that:

- Can withstand repeated use
- Is primarily and customarily used to serve a medical purpose
- Generally is not useful to an individual in the absence of an illness or injury

_Durable equipment_ is a device or apparatus that does not qualify as durable medical equipment under the basic TRICARE program but is essential to minimize functional loss or disabling effects resulting from a qualifying condition. DE can only be covered under the ECHO program with an appropriate diagnosis and need.

Examples of DE are special computer peripheral devices (keyboard, mouse, etc.) or software that makes a computer functional to an ECHO beneficiary with a qualifying condition that would otherwise limit or prohibit the beneficiary’s ability to use the computer; or an electrical/mechanical lifting device that raises an ECHO beneficiary in a wheelchair from ground level to first floor level of the beneficiary’s residence.

Is durable medical equipment covered under ECHO?

DME, defined as medically necessary equipment primarily used for medical purposes, is not covered under the ECHO program. DME is covered under the basic TRICARE program and requires a prior authorization. Durable equipment that does not qualify as DME may be available for beneficiaries registered in ECHO, providing there is a need. DE also requires prior authorization.

What is the Custodial Care Transition Program (CCTP)?

The National Defense Authorization Act for fiscal year 2002, Section 701, changed the definition of custodial care. Custodial care is no longer defined by the condition of the beneficiary but by the type of services being rendered. The CCTP was created as an interim strategy to provide all medically necessary skilled care to beneficiaries receiving custodial care prior to the custodial care definition change and up to the implementation of new sub-acute programs.

Upon implementation, CCTP beneficiaries will be transitioned into the new programs as medically appropriate. Included in the new sub-acute programs is the transition of the PFPWD to the ECHO program. As PFPWD/ECHO benefits are only available to family members of active duty sponsors, retirees and their family members currently in CCTP will continue to receive the same level of services through CCTP, as long as they are medically necessary.

How will the CCTP coverage transfer over to the EHHC benefit?

For ADFMs who are receiving home healthcare services under the CCTP, EHHC will replace CCTP as a means of providing intensive home healthcare services. For ADFMs needing part-time or intermittent home health services (thirty-five hours or fewer each week, and respite care not provided), the TRICARE Home Health Agency-Prospective Payment System (TRICARE HHA-PPS) is available as part of the basic TRICARE program.

ADFMs who are receiving medically necessary in-home skilled services through the CCTP at the start of healthcare delivery are eligible to continue receiving those skilled services in-home through the CCTP, pending meeting the following conditions:

- Healthcare delivery began under the new TRICARE contracts in each former region, under the previous...
managed care support contracts.
• The beneficiary requires in-home skilled services beyond the limits of the Home Health Agency-Prospective Payment System.

Retirees and their family members currently in CCTP will not transfer to EHHC benefits. They will continue to receive the same level of services through CCTP, as long as the services are medically necessary. •

Jolene Neff is a Case Management Supervisor for Health Net Federal Services, the government operations division of Health Net. She has more than 10 years experience in the medical field and has worked with special needs families for the past three years.

As the managed care support contractor for the TRICARE North Region, Health Net provides healthcare services to over three million uniformed services beneficiaries, active and retired, and their families. Health Net has a long history of providing cost-effective and quality managed health-care programs for government agencies, including the Department of Defense and Veterans Affairs.

Regional Contractors

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

Illinois, Indiana, Iowa, Kentucky, Maryland (excluding the National Capital area), (Rock Island Arsenal area), Michigan, Missouri (St. Louis area), Ohio, the western portion of Pennsylvania, Tennessee (Fort Campbell area), West Virginia, and Wisconsin: Marilyn Ault—800-977-7910, Ext. 62038

North Carolina and Virginia (excluding the National Capital area): Elaine Abrams—800-977-7531, Ext. 64735

Delaware, District of Columbia, Maryland (National Capital area), the southern portion of Pennsylvania, and Virginia (National Capital area): Jolene Neff—800-977-7961, Ext. 55840 or Addie Simpson—800-977-7635, Ext. 63239

Connecticut, Maine, Massachusetts, New Hampshire, New Jersey, New York, the eastern and northern portions of Pennsylvania, Rhode Island, and Vermont: Rita Uhren—800-977-7961, Ext. 55806

Humana Military
South Region and Overseas
www.humanamilitary.com
1-800-444-5445

Southeast (Augusta) Market – Florida (excluding the Panhandle), Georgia, and South Carolina – 800-447-6072

For additional information about the ECHO program, please refer to the TRICARE Extended Care Health Option brochure available on Health Net’s Web site, at http://www.healthnetfederalservices.com, or at a TRICARE Service Center, or refer to the following resources:

DoD Information
www.militaryhomefront.dod.mil

Click on Troops and Families, then Special Needs/EFMP. The Special Needs Parent Tool Kit will provide a great deal of detailed information.

Additional Resources

TRICARE
http://www.tricare.mil

ECHO Program through TRICARE
http://www.tricare.mil/echo/default.cfm

Military OneSource
www.militaryonesource.com
CONUS 1-800-342-9647
OCONUS 800-3429-6477

Specialized Training of Military Parents (STOMP)
http://www.stompproject.org
An Interview with

Dr. Rebecca Posante

Interview conducted by Isabel Hodge

Isabel Hodge, a content analyst for the Department of Defense Military Community and Family Policy Program Support Group, recently had the opportunity to interview Dr. Rebecca Posante for Exceptional Parent magazine. Dr. Posante is the Department of Defense’s Program Manager for Special Needs. Dr. Posante took the time to describe a variety of helpful and exciting online support services for military families, including MilitaryHOMEFRONT, MilitaryINSTALLATIONS and Plan My Move.

EP: What do you see as the biggest challenge for military families who have a child with special needs?

Dr. Rebecca Posante: In my opinion, the biggest challenge, besides the obvious of coping with the challenges of taking care of a family member with special needs, is the frequency with which military families relocate. On the average, a military family moves every two to three years. For a family with a special needs member, this means a family must identify and evaluate services at each new location. Families need very specific information. They need to know what they currently receive, from which agency, what qualifies them for the services, and how to access them at the new location. It can be very challenging.

EP: Are there any DoD (Department of Defense) resources that help families sort this out?

DRP: Fortunately, that answer is, “Yes!” One that immediately comes to my mind is a site launched three years ago, the Department of Defense’s MilitaryHOMEFRONT (http://www.militaryhomefront.dod.mil). It provides reliable, up-to-date, quality-of-life information for all servicemembers, their families, their leaders, and the staff who support them. Before that site was launched, I had a Web site specifically for military families with special needs called EFMConnections. We integrated the information from that site into MilitaryHOMEFRONT.

EP: Can you give examples of what information is available on MilitaryHOMEFRONT for Army families with special needs?

DRP: The MilitaryHOMEFRONT site is organized into three tabs (Troops and Families, Leadership, and Service Providers). Within the Troops & Families tab, the Special
Needs/EFMP module has excellent general and military service-specific information on special needs – for all age groups, including information on early intervention services, special education, and transition planning. This section provides information on the Exceptional Family Member Program (EFMP) for each of the Services, including the standardized forms, policies, and points of contact. The State Resources section provides families with links to valuable state Web sites such as the Early Intervention and Head Start programs and state Medicaid Web sites. Additionally, there are more than 25 Frequently Asked Questions. The Tool Box section is the central location for special needs contacts, tool kits, service locators, and directories.

We developed a DoD Special Needs Parent Tool Kit that can also be found on MilitaryHOMEFRONT in the Tool Box section. The Tool Kit provides families with an overview of many types of services and recommendations for organizing information.

My personal favorite features on MilitaryHOMEFRONT are the Family Connections forum and the Family Stories. We wanted to develop an online community where military families could connect with each other—one of the best ways that families learn about programs and services. The Family Connections forum has a general electronic bulletin board where families can post questions and responses or just share resources and other information. The forum also has installation-specific bulletin boards that have proven to be most beneficial for those families who are relocating to a new duty station and want to find out more about services in that area.

EP: It’s that time of year when many military families are moving. What kind of information do you have for them?

DRP: I’m so glad you asked this question! Just recently, MilitaryHOMEFRONT launched two new applications directed at helping military families before, during, and after a move. The first, MilitaryINSTALLATIONS, allows families to identify points of contact for approximately 55 programs and organizations, both military and civilian, on 250 U.S. military installations worldwide. For example, let’s say you are an Army family relocating to Fort Bragg, and you want the contact information for the Fort Bragg EFMP Coordinator. The directory will generate not only the point of contact for the EFMP Office on Fort Bragg, but will also generate a map with directions. The map also allows you to plot points of interest. Additionally, through MilitaryINSTALLATIONS, families can learn about the programs available to them on the installation, from schools to childcare to finding a job.

EP: MilitaryINSTALLATIONS certainly sounds like a useful tool for military families. What is Plan My Move?

DRP: Plan My Move (http://www.planmymove.mhf.dod.mil) uses the information available through MilitaryINSTALLATIONS but packages it in a series of planning tools. By entering the family’s current location, their new location, and their departure date, Plan My Move generates installation overviews, a three-month planning calendar, valuable travel and arrival checklists, as well as important points of contact and family program information. There are many ways families with special needs can use the Plan My Move application. For example, they can develop their own relocation budget and use school comparison tools to assess demographic data, including school location and distance from nearby installations, total enrollment and ethnic percentiles, and test scores. We have added items to the three-month calendar, the TO DO lists, and the checklists that are specific to families with special needs. As an example, the calendar reminds families to hand-carry their Individualized Education Programs (IEPs) to the next school, as well as to check on SSI (Supplemental Security Income) eligibility at the next location.

EP: Technology never ceases to amaze me! Is there anything else you would like to share with Army families with special needs?

DRP: Certainly! MilitaryHOMEFRONT publishes a monthly special needs newsletter to families who subscribe. We also disseminate information in the What’s New and Special Needs Events features. Anything that we learn about goes onto the site (special events, new Web site features, and important DoD and government announcements that may impact military families with special needs). To subscribe to the MilitaryHOMEFRONT Special Needs newsletter, visit http://www.militaryhomefront.dod.mil, and click on the SUBSCRIBE box on the left.

We have been fortunate to receive a number of accolades for the MilitaryHOMEFRONT site. I want to express the Defense Department’s appreciation for all of the resources and recommendations sent by family members to the Web site each day. If you have a resource you think will benefit military families with special needs, simply use Feedback at the top of every page on the Web site to share information with our content development team.
United States Military Section

Community of One
From Our Families... To Your Families

Finding Their Way: Faith and Fortitude Lift Family of Five

Adult Transitioning for the Military Child with Special Needs

COVER STORY
Dr. Leila Daughtry-Denmark
A Life of Service to Children

What is Celiac Disease?

Newborn Screening Update

Preventive Health Screening for Adults with Disabilities

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Community of One
From Our Families...To Your Families
Finding Their Way:
Faith and Fortitude Lift Family of Five

By Maria Caroff

was a puzzle with their second child, then the surprise diagnosis. The last diagnosis came before their youngest child was one-year-old. The lack of attachment and bonding to mother and father was a heartbreaker for both parents.

And now—beautiful music. Perhaps, at the moment, this isn’t the type of music that floats like a whisper from a flute or slides like a sigh from a violin. Instead, it is an alternative beautiful music—the instruments clashing and clambering over one another, some notes pitched high, many held for multiple beats with no clear-cut sign of when this particular piece of music will reach its climax and finale.

All is as it should be in the household of the Giorgis. The source of the sounds is Daniel and Karen’s two youngest children, Angelina and Jonathan, as they play with one another, shouting, laughing, and tumbling about.

Like all great music, this music has a story to tell.

The excitement and loving interaction between Angelina and Jonathan illustrates how far the children have come in their short lives, since Karen and Daniel received the children’s diagnoses of autism. Angelina, six, Jonathan, four, and older brother Elijah, eight, have all three made tremendous progress in a variety of ways.

Karen, a stay-at-home mom, and Daniel, a chaplain at Randolph Air Force Base in Universal City, near San Antonio, Texas, recall the course of their journey.

When Elijah was one-year-old, Karen says, Daniel felt that something wasn’t right. He thought Elijah might have mental retardation. “He was just so different,” Karen says. “He would flap his hands, he wouldn’t look at you, he couldn’t say anything, he wouldn’t imitate you. We didn’t even know about autism.” Autism was not mentioned by professionals they saw, Karen says, although she had asked about his speech delay. “I just was a doting Mom. I thought, oh, he’s just different. He’s cute. And then not having had any other kids, I thought well maybe kids go through stages. And then he would get hurt, and you wouldn’t even know it. People were like objects to him. He would just push them aside or walk into them, just like they were a toy.
or something, move them away. And so the kids would cry. And then I’d try to tell him, ‘No, don’t do that.’ You know, other kids would look at me, but he wouldn’t. So then I would leave because I’d be so frustrated, like why can’t we stay and play like other people. What’s wrong? And I was just like, oh, I don’t know what it is, maybe it’s me. And then when she was born…”

Angelina was uncharacteristic, too. “But it was in a kind of a different way, like more of a quiet way in that she was so particular, like she wouldn’t eat unless you fed her from the, I think it was her right side, and you had to hold her facing the right way. When she slept, she wanted to be in her snuggle wrapped up to here or else she wouldn’t sleep. And then he (Jonathan) had his oddities about sleeping, and I was like, motherhood shouldn’t be this hard.”

**Diagnosis**

The family moved back to the United States from Regina, Saskatchewan, Canada, where Daniel had been attending seminary. A friend who was a special education teacher talked with Karen about Elijah saying, “There’s something not right. You really need to get your son checked.” Karen notes, “I was glad” when she said it. Another friend told Karen that she thought Elijah might have autism. Information downloaded from the Internet revealed possibilities of lifelong disabilities, a group home, institutionalization. “And it was like someone punched me,” Karen says. “I was so devastated, so then I just started to pray. I was like God, I can’t do this. This is so horrible.”

A few minutes after Karen explains this, Angelina pipes up, “Why did you get smacked?”

Her mother answers, “I didn’t get smacked. I just felt like it.”

“Oooh. Then I’ll pray for you,” Angelina says fervently. “Dear Jesus, please make Mommy’s smack feel better, in Jesus’s name. Amen.”

The first diagnosis for Elijah came from a neurologist in New Hampshire, where the family was living while Daniel was in the Air Force Reserve. Elijah was also diagnosed with obsessive-compulsive disorder (OCD). The neurologist prescribed Clonidine and recommended that the family look for a group home for Elijah. Elijah’s parents sought a second opinion from Dr. Margaret Bauman, a top autism researcher at Ladders Clinic in Wellesley, Massachusetts. Dr. Bauman confirmed the diagnosis of autism but offered other avenues of treatment, including the recommendation of biomedical intervention to help with gastrointestinal issues as well as Applied Behavior Analysis (ABA). Due to financial constraints, some of these interventions would be undertaken later.

Because the standard procedure at Ladders Clinic was to evaluate siblings, Angelina was also evaluated. (Jonathan had not yet been born.) Karen was told, “Your daughter has autism, too.”

“And I was like, ‘What?’ It didn’t occur to me, because she was so different from him. I thought autism was him. But looking back…” Karen describes Angelina as having been in her own world. “You’d have to call her name a bunch of times. She wouldn’t look at you. She didn’t interact with anybody. She couldn’t imitate. She had no joint attention (in which a person is able to coordinate attention to an event or object with another individual). And so then I was, like, ‘Oh, no.’ So then I started praying even harder.”

Karen would stay up all night long sometimes, reading research about autism, trying to discover whatever might help her children. “I always hated science,” she says with a laugh. But much of the material was scientific, and she read it.

By the time Jonathan was born, Karen recognized the now familiar signs. “He wouldn’t look at me, just like the other two.” He would look past her. He wouldn’t breastfeed. It had been her dream to breastfeed her children, Karen says, and she had had a lactation con-
sultant from La Leche League come to her home. It was to no avail. “All of them were really averse to breast-feeding,” she says of the children. “They couldn’t even put their lips on me.” Because of what she had learned with Elijah and Angelina, Jonathan was diagnosed early and intervention for him began when he was eight- to nine-months-old.

Foods and Supplements
As Karen began to talk with others and others reached out to her, she gained valuable information. Coming home from the hospital after a C-section with Jonathan, she immediately began Elijah and Angelina on a gluten- and casein-free regimen, feeling that there was “no time to waste.” She also included digestive enzymes and probiotics, previously recommended to her. Karen continued to give the children other vitamins and items they had been taking, such as B12 and cod liver oil.

Four months after she began the gluten- and casein-free diet, “when everything came out of their systems,” Elijah and Angelina both began to talk, she says. They began to learn shapes and “started telling me colors and letters. It was just amazing.” They started doing better in their therapies, too, Karen notes. Significantly, Elijah started to calm down. He “got a lot better,” says Karen.

A couple of years later, when the family arrived in San Antonio and Daniel went from part-time work in the Reserve to full-time active duty, with the advantage of increased pay and TRICARE (military healthcare services) benefits that covered therapies, Karen began giving the children supplements known as glyconutrients and phytometrics. A nurse had read an article in the newspaper about the family and had contacted Karen suggesting that she try these. It was the third recommendation Karen had received for the glyconutrients and phytometrics, and she decided to try them. The nurse, Debra, became a friend and continues to offer guidance and emotional support.

The diet and supplements had helped a lot of their physical issues, Karen says. The addition of the glyconutrients and phytometrics brought bigger and faster results, she recalls. “They started passing PT (physical therapy) goals and OT (occupational therapy) goals like crazy,” as well as ABA goals, she says. Their awareness and understanding improved as though a “fog” had been lifted. “That’s when their improvement went from a little bit to like that,” she gestures. The children began to learn much more rapidly, requiring only one repetition versus repeated repetitions they had previously required for learning. Karen saw a significant difference in the drawings that Elijah likes to make, as they evolved from scribbles to recognizable
shapes. Elijah is now able to make detailed drawings.

Finding the right foods was challenging and time consuming. Angelina did not eat solid foods until she was two-years-old. The children were given rice milk, coconut milk, and potato milk in place of dairy products. These days, Angelina and Jonathan are both now able to eat both gluten and dairy products, and Elijah drinks rice milk. Karen tries to feed the children as much organic food as possible, free of pesticides, additives, and dyes.

Karen’s day begins at 4:30 or 5:00 a.m., when she prepares the children’s supplements, crushing some of them to make them easier to take, then chasing the kids around, if necessary, to give them to them, she laughingly says. She prepares a hot breakfast for the children’s rising at 5:30 or 6:00 a.m. and continues getting ready for the rest of the day with school and therapy schedules.

The children are in bed by 7:00 p.m., and Karen describes herself as being “comatose” and in bed by 9:00 p.m.

Therapies and Services
Karen and Daniel are pleased with their current home, in San Antonio, Texas, having lived in Regina, in New Hampshire, Florida, Las Vegas and Carson City, Nevada, and Abilene, Texas. They are happy with the services they have at One for Autism in San Antonio, where all of their therapies are available in one location, a far cry from traveling from location to location to receive therapies as Karen had done in the past.

Karen had encountered trouble receiving the school services she needed for Elijah in one of the places where they had lived. He was not making the progress she felt that he should be making, and therapy was only provided in a group setting, not one-on-one. In this public school setting, where Karen felt that staff did not know what to do with kids with autism, Elijah displayed a lot of anger, throwing desks, hitting people, and crying. Staff would make him sit and write and would not let him go out for recess. This did not seem to alter the behaviors. Back then, he also used to run into his mother, knocking the wind out of her. Karen sees a big change now as Elijah receives more individualized attention and therapies.

When Daniel received orders to Abilene, the family became eligible for TRICARE benefits and ECHO (Extended Care Health Option) and for coverage of ABA, which they began once they reached San Antonio.

All of the children currently receive speech, OT, and ABA therapies, and Elijah also receives RDI® (Relationship Development Intervention®) therapy. They all were doing well enough to stop physical therapy.

Interaction and Achievement
It’s amazing to see Angelina and Jonathan build a fort together, where before one child would be “over here” and the other “over there,” Karen notes. Angelina gets top marks in school. The kids love to learn. And “they retain things—not an autistic trait,” says Karen. Jonathan began reading when he was three-years-old.

Angelina attends school at their church for a half day, Monday through Friday. Attendance is free. She had previously attended a public school, for a full day, but there were 22 children in the classroom. She would return home ashen, says her mother. The classroom at church has 11 students, the teacher, and a teacher’s aide, and Angelina is thriving.

In the church classroom, Angelina is “learning how to be kind to others...how to treat others, how you want to be treated...and that you’re not first–you’re important, but you’re not first.” It had been a “huge thing” to take Angelina out of a school children with autism and place her in a typical environment, says Karen. But she is flourishing.

These days, Elijah is more attuned to others. He’ll say, “Oh, sorry,” if he accidentally hurts someone. He’ll initiate play with other children and join in play. Because he is still making progress with his speech, Karen will sometimes help out, letting other children know, “He learns differently than you do, but he wants to be your friend,” and typically children will say, “Oh, okay,” and play.

Jonathan’s speech is better now, says Karen, and his coordination has improved from the days when he used to frequently fall over things. He rides a bike with training wheels, and he and Elijah interact like brothers more now, wrestling one another. He continues to interact very well with Angelina.

The whole family is now able to go to a movie, something they had been unable to do before.

Faith and Support
How do Karen and Daniel handle the magnitude of caring for three children with autism? With reliance on one another and their faith. “I couldn’t do this by myself. There’s no way. No way,” says Karen. “He’s [Daniel’s] my biggest cheerleader. I cry on his shoulders. And then he just encourages me, and says, ‘We’ve come this far, you can do it. You’re doing such a good job.’” Daniel describes himself as Karen’s “biggest fan.” “He’s my fuel,” says Karen. As one would expect from a chaplain, he’ll say, ‘You can do all things through Christ who strengthens you.’ And I’ll say, ‘Really? I guess you’re right.’”
Probiotics

Marily from the foods that contain them. People who believe in the effectiveness of probiotics is another choice families sometimes make.

Supplementation with items such as glyconutrients, phytonutrients, and/or probiotics is another choice families sometimes make.

Phytonutrients

Glyconutrients (glyco—sugar, nutrient—source of nourishment) refers to eight sugars (saccharides). Glycoproteins are sugar molecules attached to protein molecules. They help cells within the body to communicate with each other. People who believe in the efficacy of glyconutrients maintain that the average diet lacks sufficient nutrition and that glyconutrients help to form the necessary and important glycoproteins essential for good health.

Animal studies do indicate possible health benefits from supplementation with glyconutrients, but there is insufficient research to support this assertion for humans. The lack of sufficient research makes it difficult to establish benefits as well as risks, and supplements are not regulated by the Food and Drug Administration. With the lack of research, the medical community at this juncture is for the most part not endorsing these products.

This is where families often make a decision based upon trusted friends or other sources when attempting to move forward with the best care they can gather for their child. People relay experiences with these products in which they describe significant improvement in physical and behavioral health, as well as in mental clarity. This is powerful anecdotal information, especially when it comes to caring for your child.

Phytonutrients

Phytonutrients (phyto—plant) or phytochemicals are organic components of plants, and are found in fruits, vegetables, legumes, nuts, grains, and teas. As a result of a variety of scientific studies, they are recognized by the mainstream medical community as being beneficial to human health. Some of these phytochemicals appear to protect humans against heart disease and certain cancers, as well as age-related macular degeneration. Phytonutrients are believed to enhance cell-to-cell communication, act as antioxidants, repair DNA damage caused by smoking, and enhance immune response, among other benefits. Phytonutrients include carotenoids (the red, orange, and yellow pigments found in fruits and vegetables) and flavonoids, among other classes. Flavonoids are also found in fruits and vegetables, as well as soybeans. Multiple studies appear to substantiate the claim of phytonutrients for good health. Advocates recommend obtaining the benefits of phytonutrients primarily from the foods that contain them. People who believe in the effectiveness of supplements may make a choice to use phytonutrient supplements.

Probiotics

Probiotics are foods or supplements that contain “good” bacteria found normally in the body. It is believed that these microorganisms may aid digestion and help to protect against some bacteria that is harmful. Considerable research is being done with probiotics, with an eye toward determining whether they can, when taken as food or supplements, help to treat or prevent illness such as diarrhea after treatment with antibiotics, vaginal yeast infections, and other ailments. Probiotics currently being studied include lactobacillus acidophilus, bifidobacterium, enterococcus, and Saccharomyces boulardii. The medical community is interested in the potential of these microorganisms for providing another avenue to good health.

When it comes to your family’s health, it’s a personal choice. Consulting with professionals, gathering information from other trusted and reliable sources, considering safety, discussing your options, and establishing your goals all will help you to move toward a decision that works best for you and your family. It is crucial that parents share with physicians all supplements that are being used to prevent unintended interactions with prescribed medications. This way, a team approach can help to ensure safety and optimal benefit of treatments. Ongoing diligence, research, and attention to the effects of your choices should help to move you in the healthy direction you seek for your family.

At the same time, Daniel says, “There are times when we just kind of need to be quiet…or just totally frustrated and we need to work through that.”

The experience is hard—physically, emotionally, financially, and spiritually, says Karen. “It’s overwhelming. You don’t get enough sleep. You don’t eat right. If I didn’t have God in my life to help me. … His hand has been in this the whole way.” Karen and Daniel both note that people have been brought into their lives just when they needed them.

Daniel recalls that they had lived right across the street from the lead commander, Colonel (now Brigadier General) Jonathan George, when they were at Dyess Air Force Base in Abilene. “He saw our family,” says Daniel. “He saw how we interacted. He was a real proponent for us.” He brought all of the commanders together to discuss the family’s situation. “He called them all together because he realized here was a need that wasn’t being met.” Colonel Schuyler Geller, the medical group commander, “really went to bat for us,” too, Daniel says. Colonel Geller, whom Daniel describes as “brilliant,” started making phone calls. “His compassion is just as big as his brain,” he says.

As for the myriad challenges, Daniel says, “What are we going to do? Stop? What happens if you stop?” It’s about the children’s future. “We can’t just give up and say check us into a mental institution.” Yet, “there are times when you feel like you’re at your wit’s end,” he says. “Like road kill,” Karen chimes in. “And the car comes back over you again,” she laughs. But “throughout the New Testament,” says Daniel, “it says that Jesus had compassion on them. We spend a lot of time on intervention. We certainly don’t neglect what’s the source of the healing and the strength. God uses doctors. God uses One for Autism. Ultimately, we credit Him. God has given me a new ministry. People come to me, and I am able to encourage them because of what we’re doing.” Daniel notes that he has had strong support from his base leadership and from his fellow chaplains.

“It hurts!” Daniel admits, “but it’s for the benefit of others, and it’s for the glory of God.” There is precedent for what Karen and Daniel face, the chaplain notes, citing a passage from scripture regarding receiving and giving comfort. He gets his Bible and reads: “Blessed be the God and Father of our Lord Jesus Christ, the Father of mercies and God of all comfort, who comforts us in all our tribulation, that we may be able to comfort those who are in any trouble, with the comfort with which we ourselves are comforted by God. For as the sufferings of Christ abound in us, so our consolation also abounds through Christ. Now if we are afflicted, it
is for your consolation and salvation, which is effective for enduring the same suffering which we also suffer. For if we are comforted, it is for your consolation and salvation. And our hope for you is steadfast, because we know that as you are partakers of the suffering, so also you will partake of the consolation."

Thus Daniel and Karen pass on the comfort they have been given. So many moms spent hours with her from the beginning, sharing, and saying to call this person or call that person, says Karen. And you learn it’s “just what you do. You reach back and help other people,” and let them know that there is hope.

The family attends church twice each week, and Karen sees the benefit for the children in the support they receive from other church members and from what they are being taught.

What They’ve Learned
“It’s easier to see the grace when it’s quiet,” Daniel says. “When you’re going through it, you wonder when it’s going to stop.” Sometimes the expression ‘God won’t give you more than you can handle’ sounds trite, he says, “but at the end of the day we’re still alive, and we’re still standing.”

Sometimes, when the family is in public, Karen and Daniel can feel discouraged. As they see other children, they sometimes feel, “We still have so far to go,” says Karen. But “when you’re looking at that, you’re forgetting how far you’ve come.”

As they continue their efforts and interventions for their children and see the results, “it’s like peeling the layers back on the autism to find the person underneath,” Karen says. What has she found? “They’re beautiful people.”

Deliberate Choices
The children get along well. “They don’t fight,” says Karen. She and Daniel are judicious about what they allow the children to watch on television and on videotape. They typically choose educational or Christian programs and some mainstream programs. The children don’t see people hurting each other, says Karen, and they don’t see children acting out. They watch educational and musical videos. They don’t watch scary things. They’re watching videos that “build up family and build up Mom and Dad–Mom and Dad aren’t stupid,” she says. “So they’re very good kids. They have so much catching up to do that I want all their time to be effective,” she says.

Choosing a certain type of care for the children is deliberate, and sacrifices do need to be made. The family does not go on vacations. All the money goes to supplements, says Karen. “It takes a lot, because kids with autism are really sick.” Also sacrificed are coffees, movies, dinners. It’s all about our kids, Karen notes, about their future.

Family time, says Daniel, involves devotions and reading the Bible together. “We sing; we pray,” he says.

Karen and Daniel feel good about the children’s attendance at One for Autism, a center for children with autism and other developmental delays (see the April 2007 issue of EP for a story on One for Autism). All of their therapies are centered there, and they have the benefit of interacting with both typical and non-typical children.

The Future
Given to ready smiles and laughter, Karen is devoted to a full spectrum of care for her children. “I just have my eyes on full recovery,” says Karen. “I’m not going to settle for anything less.”

Both Karen and Daniel demonstrate strong dedication and hopes for the future of their children. They’ve traveled an arduous path, but the children’s progress is obvious in their behaviors and interactions both within the family and outside of it.

So, listen. There is more music just waiting to be heard. And look. There is more artistry, waiting to be revealed.
Transition is a dynamic lifelong process that seeks to meet individual needs as a person with disabilities moves from childhood to adulthood. Per laws in most states, once an individual becomes 18 years of age that person is considered an adult regardless of the level of his or her disability. Initiating planning for adult living activities and financial support is crucial while the child is still a minor. This article discusses a strategy developed by the Naval Medical Center Portsmouth Neurodevelopmental Pediatric Department to address transition for military children with disabilities and other special needs. It provides an overview of unique military considerations, including: continuing TRICARE benefits, Exceptional Family Member Program (EFMP) eligibility after age 18, and respite benefits through Extended Health Care Option (ECHO). It discusses legal, financial, academic/lifestyle, community resources, and self-advocacy considerations. It concludes with lessons learned from information obtained from special needs families and unprecedented quarterly transition forums.

United States military members risk their lives all over the globe defending America’s freedoms. The military prepares and requires members to be mission ready. Mission readiness entails long work hours, frequent assignments away from home and family, and the need to be ready for deployment at any moment, particularly in support of the global war on terror. Combining military requirements with responsibilities of family life and the added time and attention required to parent a child with disabilities can be complex. Data gathered from the headquarters offices of the Military’s Exceptional Family Member Programs (EFMPs) reflect that there are an estimated 91,204 active duty sponsors (military service personnel) who have a family member with special medical or educational needs. Children with disabilities or with chronic conditions generally require more frequent utilization of healthcare and related services than children in general. For the military family with a child with disabilities, early attention to transition planning for the child’s lifelong quality of life can prove invaluable.

Transition can be defined as an individualized and coordinated lifelong process focused on improving the personal, interpersonal, and functional circumstances and achievements of an individual with disabilities as that person progresses from one life passage to another. It takes into account one’s strengths, abilities, skills, potential, needs, interests, preferences, and personal and occupational goals. The American Academy of Pediatrics notes that for those with disabilities or special healthcare needs, healthcare transition is a dynamic process (American Academy of Pediatrics, 2003). The goal is to maximize lifelong functioning and potential through the provision of high-quality, developmentally appropriate healthcare services that continue uninterrupted throughout the lifespan.

Considerations for the Military Child with Special Needs
Transitioning to Adulthood

By Glenda Lewis-Fleming
National laws provide protection for persons with disabilities. The Americans with Disabilities Act (ADA), the nation’s first comprehensive civil rights law for people with disabilities, provided protections against discrimination for people with disabilities. The ADA ensures equal opportunity in employment, state, and local government services and programs, places of public accommodations, public and private transportation, and telecommunications. The Individuals with Disabilities Education Act (IDEA), the nation’s special education law, provides transition planning for students with disabilities. IDEA requires that, to the extent possible, children with disabilities be entitled to the same educational experience as their non-disabled peers. The 2004 amendments to this federal statute required appropriate transition goals in the Individualized Education Program (IEP) beginning not later than the first IEP, to be in effect when the child is 16 and updated annually thereafter. The federal No Child Left Behind (NCLB) Act of 2001 also affects the education of children with disabilities and special needs. Section 504 of the Rehabilitation Act emphasizes that “no otherwise qualified individual with a disability in the United States, as defined in section 7(20), shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance or under any program or activity conducted by any Executive agency or by the United States Postal Service.” The Department of Defense (DoD) has policies and instructions (DoDD 1020.1 and DoDI 1342.12) that include information to families and professionals regarding nondiscrimination of individuals with disabilities as well as available education and services.

From a healthcare perspective, Healthy People 2010 established the goal that all young people with special healthcare needs receive the services needed to make necessary transitions to all aspects of adult life, including healthcare, work, and independent living. Healthy People is a national, 10-year plan intended to guide federal, state, local, private, and community health promotion and wellness activities and policies to improve the health of Americans.

Naval Medical Center Portsmouth Neurodevelopmental Pediatric Department

The Neurodevelopmental Pediatric Department at Naval Medical Center Portsmouth provides comprehensive services for infants and children who have disabilities and/or complex medical needs. Conditions include but are not limited to: autism spectrum disorders, learning disabilities, attention deficit hyperactivity disorder (ADHD), developmental delays, cerebral palsy, or other neuromotor delays. The department’s overall goal is to assist military children with special needs reach their optimal level of quality of life and promote self-esteem and independence, as well as minimize health consequences when the military beneficiary fails to meet developmental milestones. Staff includes: three neurodevelopmental pediatricians, an occupational therapist, a physical therapist, a clinical psychologist, two speech therapists, hospital corpsmen, an office manager and assistant, a management analyst, and a volunteer educational consultant. The developmental pediatricians, with special training in diagnosing children with different developmental patterns, conduct a thorough evaluation of the child’s health and development, known as the neurodevelopmental assessment. Children are followed long-term.
and provided with comprehensive lifestyle counseling regarding education, socialization, family involvement, and healthcare specific to their developmental and chronological age.

In 2005, the Neurodevelopmental Pediatric Department providers received numerous inquiries from families concerning preparations and planning as their children transition into adulthood, which resulted in an increased emphasis on transitional issues and transitional planning. The department conducted a comprehensive literature review and contacted local, state, and federal agencies to obtain insights and guidance on how best to fully address the issue of transition. From this review of literature and networking, the department developed a two-page flyer entitled, “Information at Your Fingertips: Consideration for the Military Special Needs Child Transitioning to Adulthood.” Parents were provided this document as initial information regarding their beneficiary with special needs transitioning into adulthood. In January 2006, the first Special Needs Transition Forum was established in response to transition-related inquiries the Department continued to receive from parents.

Design and Implementation of the Special Needs Transition Forum

The Neurodevelopmental Pediatric Department at Naval Medical Center Portsmouth maintains a data-base of beneficiaries served. The TRICARE Defense Enrollment Eligibility Reporting System (DEERS), a computerized database of military sponsors, families, and others worldwide who are entitled under the law to TRICARE benefits, was checked to determine local eligibility of potential beneficiaries. Invitations were mailed to eligible families. Subject matter experts from applicable military and community agencies were invited to serve as speakers. Approximately 70 persons were in attendance at the first forum, which exceeded staff expectations. The forum was rated by attendees as highly successful. A second forum was hosted in May 2006. The second forum was modified to include: families of children with disabilities, regardless of age; more agency participation; and a parents’ panel. A single-parent military officer shared his journey and lessons learned in working with his child with disabilities on the path to adulthood. Utilizing feedback from both forums’ attendees, the department designed a template and established quarterly forums. Specific topics were identified as key issues for every forum. An overview of prioritized topics is presented below.

Military Health Benefits: Continuation of TRICARE

TRICARE is the health benefit program for all seven uniformed services: the Navy, Marine Corps, Army, Air Force, Coast Guard, Public Health Service, and the National Oceanic and Atmospheric Administration. Unmarried children up to age 21 (including stepchildren who are adopted by the sponsor) are covered by TRICARE, even if the spouse gets divorced or remarried. A child age 21 or older may be covered if he or she has severe disabilities and the condition existed prior to the child’s 21st birthday—or, if the condition occurred between the ages of 21 and 23 while the child was enrolled in a full-time course of study in an approved institution of higher learning and is, or was at the time of the sponsor’s death, dependent on the sponsor for more than one-half of his or her support. A child may also be covered up to the 23rd birthday if he or she is in school full-time. In order for the child to continue benefits, every year the sponsor must ensure that the special needs family member is listed in DEERS as being eligible for military healthcare ben-
To extend military ID card privileges for unmarried children with disabilities who are over age 21, sponsors should contact their appropriate Services personnel command:

- **Navy families**, contact the Navy Personnel Command (PERS-312D) at (901) 874-3360 or DSN 882-3360.
- **Air Force families**, contact the local servicing Military Personnel Flight Customer Service Section.
- **Army families**, contact the Defense Finance and Accounting Office at (317) 510-2774 or DSN 699-2774.
- **Coast Guard families**, contact the Family Resource Specialist or Family Advocacy Specialist at the local Integrated Support Command (ISC).
- **Marine Corps families**, contact Headquarters U.S. Marine Corps, Manpower and Reserve Affairs (MRP-1) at (703) 784-9529 or DSN 278-9529.

For additional information, see the TRICARE Handbook, www.tricare.osd.mil, or contact the Managed Care Support Contractor (MCSC) for your region. If the individual with disabilities or other special needs no longer qualifies for TRICARE benefits, they should contact the local Social Security Administration Office or Human/Social Services Department for assistance from federal and state programs such as Social Security and Medicaid.

**Continuation of Exceptional Family Member Program (EFMP) Eligibility**

Each uniformed service has an EFMP or Special Needs Program – a mandatory enrollment program for active duty service members (ADSMs) who have a family member with chronic medical, behavioral health, and/or special educational needs. The objective of the EFMP is to assess, document, and code the special education and medical needs of eligible family members. Assessing the family member's needs during the assignment process is aimed at ensuring optimum use of Permanent Change of Station (PCS) moves by taking into consideration the needs of the military, the service member's career needs, and the special needs of the family. As long as the need exists and the sponsor remains on active duty, the special needs member continues to be eligible for EFMP. For more information about the EFMP, visit the MilitaryHOMEFRONT Web site at http://www.militaryhomefront.dod.mil.

**The TRICARE Extended Care Health Option (ECHO) and Respite**

ECHO is a supplemental program to the TRICARE Basic Program. TRICARE ECHO requires all eligible beneficiaries to enroll in their Service-specific EFMP and to register with their regional Managed Care Support Contractor to obtain ECHO benefit authorization. ECHO is available only to eligible active duty family members. Qualifying conditions include moderate or severe mental retardation, a serious physical disability, or an extraordinary physical or psychological condition of such complexity that the beneficiary is homebound. ECHO provides additional financial resources for an integrated set of services and supplies designed to assist in the reduction of the disabling effects of the beneficiary's condition. The program offers two types of respite care benefits: 1) Respite Care – 16 hours per month when the beneficiary is receiving other authorized ECHO benefits; and 2) ECHO Home Health Care (EHHC) Respite care, which may provide up to 40 hours per week (eight hours per day, five days per week) if the beneficiary is homebound.

Respite refers to care provided to the patient in order that his or her family may take a break from the daily routine of caregiving. Providing a break in the daily routine may help caregivers to relax for a while and come back revitalized and better able to care for their family member [GAO/HRD-90-125, September 1990]. The National Information Center for Children and Youth with Disabilities (1998) refers to respite as “a gift of time” and notes that respite can provide the child opportunities to build new relationships and move toward independence. A Web site that identifies potential respite resources in every state is available at http://www.respitelocator.org/index.htm. The Community Services Board in each city may serve as a resource for added information about respite services available within a particular locality.

**Legal Considerations**

Attorneys with the Naval Legal Service Offices conducted the legal considerations session at the Special Needs Transition Forum. Prominent issues discussed were guardianship and special needs trust. The attorneys emphasized that when a child with disabilities reaches the age of majority (which in most cases is the age of 18 but may vary from state to state), the child’s parents do not automatically remain their child’s guardian. Regardless of the severity of a person’s disability, at the age of majority, all people – including those with cognitive, intellectual, and developmental disabilities – legally become adults. Many adults with disabilities do not require a guardian. Many people with varying degrees of intellectual or physical disabil-
Transitioning

ities can manage their own affairs with informal assistance and guidance from family and friends. For others, the degree of impairment makes consideration of formal guardianship essential. Guardianship is a judicial determination made in a court of law and is a serious matter because it is viewed as a limitation of a person’s independence and rights. Experts on guardianship report that it is an avenue to pursue if the person’s parents, doctor, teachers, psychologist, and other appropriate caregivers or service providers agree that the individual is incapable of making informed decisions without appropriate guidance and information. When deemed necessary, the guardianship process should be initiated several months prior to the 18th birthday. Every state has its own specific laws on guardianship, and it is essential that families become aware of the specific requirements of the state in which they reside. To begin guardianship proceedings, a Petition for Guardianship must be filed with the court in the county in which the individual lives. If the individual lives in a residential school, it can also be filed in the county in which the parents live. Depending upon issues that arise, this process may take months to complete.

Another vital legal issue for discussion is the consideration of establishing a special needs trust. A special or supplementary needs trust offers families a reliable way of safeguarding their child’s eligibility for benefits, while also providing for additional needs not covered by the government. The parent(s) must select a trustee to manage the trust. A special needs trust enables the trustee to pay for everything from personal needs to recreational activities to technology to help the child navigate through his or her world. Rather than the special needs individual receiving direct bequests, the trust serves as the recipient of all inheritances or gifts. Grandparents, other relatives, and friends planning to leave a gift or bequest to the special needs child may best assist by directing the gift/bequest to the special needs trust. A trustee and a guardian are not one and the same. Trustees oversee trusts; guardians or conservators handle personal and legal affairs. It is imperative that the parent work with a qualified lawyer in setting up the child’s special needs trust. Some advocates have recommended that parents not have the child with a disability as the beneficiary of their insurance policies or hold excessive cash (over $2,000) in his or her own name. Military Survivor Benefit Plan (SBP) annuities; Servicemen’s Group Life Insurance (SGLI); Dependency and Indemnity Compensation (DIC); and death gratuity payments can have an impact on community, state, and federal benefits that may be available to surviving children with disabilities. An experienced planning advisor may be needed to balance adequate provisions for the person with a disability and the rest of the family. Laws concerning guardianships and estates vary from state to state. Service-specific military legal services departments may be able to provide the military family with guidance and direction. When consulting an attorney, it is advisable for families to seek an attorney with expertise in disability laws and special needs issues.

Financial Considerations

Parents/advocates must be aware that there is a multitude of programs designed to provide financial support for individuals with disabilities. “Deciphering government disability benefits is like trying to untangle an enormous knot. To uncover what you may or may not qualify for, you will have to persevere and call on all your patience” (With Open Arms, 2002). Government benefit programs include: Medicaid, Medicaid Waiver Programs, Medicare, Title V – Children with Special Health Care Needs (CSHCN), state-mandated insurance.
programs, and non-medical benefits from Social Security available to children with disabilities, including Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI). Every state administers its own Medicaid programs and varying levels of uniformity exist from state to state as well as from locality to locality. Special needs families must apply and qualify for benefits in the state where the special needs member resides. It may be beneficial for families leaving the military before retirement (and without health insurance) to contact the State Children’s Health Insurance Programs (SCHIP) for information on benefits for minor children.

SSI is a federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help people who are aged, blind, or who have disabilities who have little or no income. It provides cash to meet basic needs for food, clothing, and shelter. SSI benefits are not based on an individual’s prior work or a family member’s prior work. SSI benefits are available to children with disabilities under age 18 whose disability is expected to last more than 12 months or result in death and whose parents’ income and resources are limited. When the child with special needs has been denied SSI and the child is unable to work due to his or her disability, reapplication for SSI should occur as soon as he or she turns 18. A child with disabilities may qualify to receive SSDI benefits based on a parent’s entitlement. SSDI benefits can continue into adulthood if the child has a qualifying disability that began prior to the age of 22. Visit http://www.ssa.gov or contact your local Social Security Office for further details about SSI or SSDI.

Active duty families currently receiving SSI or other Social Security Administration (SSA)-sponsored assistance that are scheduled to transfer duty stations to another state are encouraged to contact the SSA before transferring, in order to maintain continuity. At age of majority or after Social Security benefits are awarded, the individual with disabilities may want to consider applying for Section 8 Housing, administered through the local housing authority. Depending upon state and locality, there can be a long waiting period for Section 8 Housing of up to two years or more.

**Academic/Lifestyle Considerations**

A 2002 Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs emphasized that the goal of transition in healthcare for young adults with special healthcare needs is to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate healthcare services that continue uninterrupted as the individual moves from adolescence to adulthood (PEDIATRICS, 2002). Successful transitioning occurs through careful planning, making sure that the child is equipped with the right tools and skills to make a smooth transition, and ensuring that the child’s needs will be met. Academically, transition is a continuous process, beginning from the time a child enters school. Each student requires different types of support to realize his or her dreams for the future. IDEA entitles students with disabilities to a free, appropriate public education through age 21. A cornerstone in the education of every child with a disability is the IEP. A 2004 amendment to IDEA mandates that consideration of postsecondary goals and transition services be addressed in the IEP not later than the first IEP to be in effect when the child turns sixteen, or younger if determined appropriate by the IEP team, and evolve with each ensuing year until the student leaves school. During the child’s school years, the legal rights offered by IDEA are guaranteed. Typically, once a child graduates from high school, the state no longer assumes educational responsibility for that student. Services in college and universities are available only under the ADA and Section 504 of the Rehabilitation Act. Thus, upon leaving high school, it is the student’s responsibility to ask for accommodations and other needed support services.

The Department of Rehabilitative Services partners with the public and private sectors to advocate and provide quality services that empower individuals with disabilities to maximize their employment, independence, and full inclusion into society. Counselors provide services related to students with disabilities transitioning from high school to adult life. Each state has vocational rehabilitation services offices and disabilities offices that may provide comprehensive job training and employment services. If the student is not already enrolled in vocational education, the parent or guardian should contact the school’s IEP Manager or Transition Coordinator/Liaison to explore available options at least one year prior to high school graduation. In Virginia, the Woodrow Wilson Rehabilitation Center in Fishersville offers integrated medical and vocational rehabilitation services addressing a diverse range of services designed to improve independence and employability to people with disabilities. This campus houses a vocational school and medical rehabilitation units.
Helpful Web Sites

Web sites are not all-inclusive and are provided as a guide only.

- [http://www.militaryonesource.com](http://www.militaryonesource.com)—Military OneSource provides service and support 24/7 for military families across the globe.
- [http://www.militaryhomefront.dod.mil](http://www.militaryhomefront.dod.mil)—MilitaryHOMEFRONT is the official Department of Defense Web site designed to help military eligible beneficiaries, their families, and service providers with information on services and resources for military families.
- [http://www.usdoj.gov/crt/ada/adahom1.htm](http://www.usdoj.gov/crt/ada/adahom1.htm)—The U.S. Department of Justice/Americans with Disabilities Act (ADA) home page. It contains many links and resources to information for those seeking data on how to enforce the ADA.
- [www.militarychild.org](http://www.militarychild.org)—The Military Child Education Coalition™ (MCEC™) is a 501(c)(3) non-profit, worldwide organization that identifies the challenges that face the highly mobile military child, increases awareness of these challenges in military and educational communities, and initiates and implements programs to meet the challenges.
- [http://www.stompproject.org](http://www.stompproject.org)—Specialized Training of Military Parents (STOMP) is the National Parent Training and Information Center for military families.
- [www.nefe.org](http://www.nefe.org)—The National Endowment for Financial Education (NEFE) is an independent, non-profit foundation committed to educating Americans about personal finance and empowering them to make positive, sound decisions to reach financial goals.
- [http://www.ncil.org](http://www.ncil.org)—The National Council on Independent Living (NCIL) is an organization that advocates for services and rights for people with disabilities and provides information on independent living, including links to local Centers for Independent Living.
- [http://www.ucp.org](http://www.ucp.org)—United Cerebral Palsy (UCP) is a national organization with a nationwide network of affiliates committed to change and progress for people with cerebral palsy and other disabilities.
- [http://www.guardianship.org](http://www.guardianship.org)—The National Guardianship Association provides information on guardianship.

Community Resources

Networking and remaining aware of community resources is essential in serving and advocating for those with disabilities and other special needs. The plurality of issues associated with disabilities and special needs invites comprehensive interventions incorporating local, state, and national resources. Numerous researchers have discussed social supports as important to buffering the effects of stress on a family with a child with a disability (Fallon and Russo, 2003). Military families with special needs children have reported that such supports can be challenging to locate at new duty stations. Combined with the extraordinary requirements of military life and the expectation that active duty members be mission ready at all times, families who have children with special needs can become overwhelmed with the responsibilities of caring for their child. Community resources are continuously changing and/or modifying service delivery. One resource support for military families is MilitaryHOMEFRONT, an official DoD Web site designed to help military eligible beneficiaries, their families, and service providers with information on services and resources. This resource and others that special needs families have shared as helpful are listed with their Web sites as a sidebar to this article.

Self-Advocacy

A July 2006 U.S. Census Report indicates that 18 percent of the U.S. population, or 51.2 million people, have some level of disability. Educational specialists, healthcare professionals, and case managers can assist an individual with disabilities and/or that person’s family with advocating for the child’s needs in such areas as occupational, speech, and/or physical therapy, academic concerns, and/or recreational services, etc. It is important to recognize that self-advocacy is a critical skill for higher functioning individuals with disabilities. Providing tools and strategies that help people to learn their rights, how to speak up, how to objectively listen to and evaluate information, and how to ask for accommodations and communicate needs is priceless. How effective one is as an advocate is largely determined by the degree of objectivity one can bring to a situation. At the same time, personification of disability issues can result in a raising of public awareness.
Hence, persons with disabilities may serve as advocates on a global level. Their role in informing and educating the general public about rights, needs, and issues regarding people with disabilities is essential. Further, they may be instrumental in informing and educating lawmakers and public policymakers regarding the needs of people with disabilities and in providing decision makers with information about policies that impact persons with disabilities.

In the Hampton Road, Virginia area, the ENDependence Center of Northern Virginia, Inc. is a local example of an agency that provides multifocal services to people with disabilities. The ENDependence Center is a non-residential, community-based resource and advocacy agency managed by and for people with disabilities. Designed to assist persons with disabilities to lead independent, productive lives, it promotes an independent living philosophy and equal access for all people with disabilities. Staff from this agency are included as forum speakers to increase awareness of agency services and provide information on positive life changes in housing, employment, and community involvement.

**Transition Forum Lessons Learned and Tips From Families**

Seven primary lessons have been learned from discussions with parents of children with special needs and from information gleaned from presentations at the quarterly forums.

Families with a child with disabilities must at a minimum familiarize themselves with the ADA, Section 504 of the Rehabilitation Act, and the IDEA. They should know and understand the protections these laws do and do not provide.

Experts in the field of disabilities note that a primary concern of families with children with disabilities is the person’s quality of life throughout their lifespan. Military families must begin to address the transition process before the family member with special needs reaches the age of adulthood. Families should seek legal assistance from those who are experienced in disability laws and special needs issues.

Military Treatment Facilities (MTFs) and providers can promote continuity during periods of transition. Parents of children with special healthcare needs expect advice from their pediatricians on transition concerns and regarding when and how to transfer to the care of another medical provider. As their child ages out of the pediatric healthcare system, families need to be assisted in obtaining a transfer to appropriate healthcare. When possible, physicians with expertise in adult medicine and experience with adults with disabilities should be identified as the new Primary Care Managers (PCMs). Physician-to-physician communication may be the better strategy in this area of care coordination. A written summary of pertinent medical history, surgeries, therapies, medications, and immunizations also facilitates successful transition and is a key step in care coordination.

The family must keep documentation. Maintain a paper trail by documenting all contacts made on behalf of the person with disabilities. Note date, time, name of person spoken to, and a brief summary of the contact. Keep copies of medical/treatment reports, surgeries, lists of medications, EFMP applications, IEPs, etc. Keep all documentation together in a binder in a safe location.

Communication is an essential ingredient of healthy relationships and a critical skill set for families in general. Facing the daily challenges and responsibilities of caring for a family member with disabilities, combined with the military requirements of being mission ready, primary caregivers may devote less attention to their spouse, other children, or personal healthcare.
Transitioning

This can have negative consequences on the entire family. It is important for family members, particularly spouses, to reserve time together for expressing thoughts and feelings, including discussions on transition concerns. Good communication involves making a commitment to talk to each other often, even if by e-mail or phone calls. Finding the delicate balance between caring for the family member with disabilities and the needs of the entire family can ultimately enhance the whole family.

The advocacy role as described by many forum participants is an essential component in transition planning for a family with a child with disabilities. The parents and child must understand the child’s disability, help the child to understand how it impacts him or her, and seek out understanding support systems. This may require support and assistance from professionals, family members, and others with disabilities. A myriad of professional organizations exist that offer this type of support. Frequently, a resource may be the more informal support system of families with children who share the same or similar disabilities. These families may be a valuable source of information about available programs, services, and benefits. Equally important, they can provide a powerful source of emotional support by sharing specific strategies that they have used to balance the various needs of individual family members.

Caught up in the difficulties of balancing work, family, and military obligations, and the needs of a child with disabilities, it is easy to lose sight of blessings that develop from the child with special needs. Be sure to stop and reflect on the positive aspects of the child and learn to identify and build upon the child’s strengths. Remember to recognize and celebrate the family member with special needs.

Conclusion

Transition is a lifelong process. Early initiation of transition planning is critical to enhancing the quality of life for the individual with disabilities throughout his or her lifespan. Services that are needed to assist the individual with special needs transition from childhood to adulthood can range from informational to intensive. The level of services is defined by the amount of support and intervention a parent and/or child requires. Neurodevelopmental departments and military providers can assist the active duty family to explore transition issues. The MTF can also be an added source of support for the child with special needs and the family by working to promote a seamless system of care that is coordinated, developmentally appropriate, psychosocially sound, and comprehensive to help with transitions. The goal of this effort is to create a win-win situation for all involved. The child with special needs is assisted with a smooth transition. The sponsor is provided the essential support he or she requires to meet the needs of his or her family. The knowledge that these responsibilities are met and their families at home are cared for can provide peace of mind wherever sponsors are assigned, whether at home or deployed in support of combat operations defending the needs of the country.

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United States Military Section

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In 1999, Hurricane Floyd prompted former Governor Jim Hodges to issue a mandatory evacuation for residents of Beaufort County, South Carolina. My family evacuated a few hours prior to the mandatory evacuation being announced and avoided one of the worst traffic jams in U.S. history. We made the decision to leave early because we knew our son who has autism could not tolerate sitting for hours in traffic.

Earlier, in 1993, Marine Corps Base Camp Pendleton experienced heavy rains, and extensive flooding occurred along the Santa Margarita River. Our base housing area was cut off from the main portion of the base because the bridge was under water.

On June 28, 1991, I was nine months pregnant when a 5.8 magnitude earthquake shook the San Gabriel Mountains and reached as far as Camp Pendleton.

I was a young Corporal in Okinawa, Japan when the building shook, forcing me to the floor. The air conditioning vent fell from the ceiling and rendered my Second Lieutenant unconscious.

In retrospect, these events are just some of the highlights of our 21-year military adventure together. Each event was a valuable learning experience. Is my family a magnet for natural disasters? No, we’re not. I tell people who ask that particular question that the joy of coastal living also comes with some unfortunate risks. If you live in any of those areas for any given amount of time you’re bound to experience powerful weather that will impact your lives. The key to successful coastal living is to be prepared. The same statement could be made by families living in the Central Plains and Midwest or those living in northern states where pipes freeze and roads are blocked by several feet of snow—the simplest and smartest thing is to always be prepared.

The Atlantic hurricane season officially began on June 1. If you haven’t already noticed, tropical storms have already impacted the eastern shores. Violent storms and tornadoes have struck several Midwestern towns, have destroyed lives, and caused millions of dollars in damage. I believe it is safe to say that many of the people affected by those storms are saying today that they never thought it could happen to them. The big question is – are you prepared to support your family member(s) with special needs if it happened to you?

Prior to 9/11, information specific to those with special needs was scarce. Lessons learned from past events have pushed local and state governments and the military to do more to help citizens with special needs take additional steps to prepare and protect themselves.

While much of the information in this article focuses primarily on hurricane preparedness, it can also be used for emergency preparedness for other types of disasters. The idea is to not only help service providers develop their own plan for supporting military families with special needs, but also help families create their own disaster preparedness plan.

Military Installations Help Families Prepare
If you reside on a coastal installation such as Camp Pendleton, California; Camp Lejeune, North Carolina; or in Norfolk, Virginia, take the time to attend the local hurricane preparedness briefings that are typically
held at the beginning of hurricane season. The briefings are often repeated if there is a high probability that the installation may be impacted by a hurricane. These types of briefings are the best avenue for your family to obtain preparation tips, important contact information, and to get updates on the status of the installation if the base sustains damage. After a disaster, you might not be permitted to return to your home right away if the damage is significant.

If there is an official mandatory evacuation issued, you must leave immediately. You may be reimbursed for evacuation expenses if you reside on a military installation. By attending installation briefings, you can also learn about reimbursement entitlements.

Marine Corps Recruit Depot Parris Island has gone one step further in keeping families informed and has posted excellent information on their installation Web site (http://www.mcrdpi.usmc.mil/newsinfo/hurricane/index.htm), such as: The Hurricane Survival Guide, Hurricane Preparedness Brief, and helpful resources such as links to the South Carolina Emergency Management Division and the American Red Cross Hurricane Preparation Manual.

**Official Unit Volunteers**

Don’t forget your unit spouse volunteer networks such as the Army Family Team Building Program, Navy Ombudsman and Marine Corps Key Volunteer. These organizations serve as the official link between the Command and families. Your unit or command may use their appointed volunteers to contact you. You should contact them if you have questions or need assistance. Make sure your command-appointed volunteer has your contact information so they can reach you if you evacuate.

**Service Providers Can Help Families Prepare**

There are many professionals within the military and local communities who have the ability to assist military families in developing their personal disaster preparedness plan. Service providers should take the time to visit their designated local community and installation emergency shelters. The Americans with Disabilities Act (ADA) requires that all public evacuation shelters be accessible to people with disabilities. The Department of Justice has published An ADA Guide for Local Governments: Making Community Emergency Preparedness and Response Programs Accessible to People with Disabilities (http://www.ada.gov/emergencyprep.htm). Share this valuable ADA guide with people responsible for the shelters in your area. Distribute preparation tips, resources, or other information to families by using your program’s Web site, newsletters, or other publications.

**Military Community Support for Families**

Listed below you will find some military community resources that you can connect with to get resources and assistance with developing your disaster preparedness plan:
Disaster Planning

Exceptional Family Member Program (EFMP) Managers and Coordinators – The Army and Marine Corps family centers are staffed with EFMP personnel that can provide you with local and state disaster preparedness resources as well as connect you with local support groups or families that may want to partner and evacuate together.

Personal Financial Management Personnel – Planning for a disaster or evacuation also means setting aside easily accessible funds to cover possible lodging expenses, hurricane preparedness supplies, and other items. Your local family center has Personal Financial Readiness personnel that can help you create your financial plan for disaster preparedness.

Tip: Military Aid Societies such as the Navy-Marine Corps Relief Society, Army Emergency Relief, and Air Force Aid Society can provide funding assistance if needed.

New Parent Support Program Personnel – The New Parent Support Program (NPSP) is a voluntary home visitation program for parents expecting a baby and for parents of children up to three years of age. Talk to an NPSP staff member about any concerns you might have, including on topics such as emergency preparedness or support resources.

Military Treatment Facility Primary Care Managers – If you have a family member who has significant medical needs or is receiving hospice care services, coordinate their care and support with their medical case manager, primary care manager (PCM), or the hospice program’s clinical service coordinator. Arrange special emergency transportation to a hospital or other designated facility in advance. Ask for a point of contact for your family member’s PCM in the event you have to evacuate and the receiving medical facility needs to communicate with the PCM. Ensure your contact information is available to your PCM.

Installation Housing Managers – Try to make arrangements for your home to receive a generator in advance if you have a family member who requires electricity for vital medical support equipment to run. If generators are not available, then speak to your family member’s medical case manager or primary care manager about other support options. Remember, climatically controlled environments are very important for people with ectodermal dysplasia or other conditions that may affect a person’s ability to control their body’s temperature.

Call your local installation housing office for instructions on how to prepare your home. Leave a telephone number where the housing office can reach you if you
evacuate. Don’t forget to share your evacuation plans and contact information with your extended family members, your neighbors, and your friends!

Points of contacts (POC) for all of the programs listed above can be found by linking to the DoD’s MilitaryINSTALLATIONS directories and looking up installations and their directories of services (http://www.militaryinstallations.dod.mil).

Emergency Response Personnel (Fire Departments, Military Police) – Inform emergency response personnel if you have oxygen tanks and other potentially hazardous equipment in your home. Tell emergency dispatchers well in advance about any hazardous equipment in your home. Always make sure your family member is carrying some form of identification with them. Medical jewelry or sewn-in information inside shirt collars is probably the best identification method caregivers use when the family member has difficulty communicating. Talk to your family member about how to identify firefighters and police officers. Teach them to memorize important contact information and to provide that information to responders. Schedule a visit to your local police department or military police and get to know the emergency response personnel that regularly patrol your housing area. The DoD Web site MilitaryHOMEFRONT has emergency communications resources (http://www.militaryhomefront.dod.mil/efm – Click on Resources).

Plan Together as a Family

Deployed Spouse – Make sharing your evacuation plans a part of your deployment readiness plan. Before your spouse deploys, tell him or her where you will evacuate and provide contact information at that destination. Remember to notify your spouse’s command if your evacuation plan changes!

Helping Children Cope – Hurricane season can be a particularly stressful time for children. Limit the time you spend watching and listening to the news and weather updates. Include your children in preparations by giving them items to place in the disaster preparedness kit and helping them prepare their own special kit (e.g.: snacks, games, books, their own personal flashlight, etc.). Try to maintain the routines and schedules that your family may have, such as meal times and bedtimes. It can be difficult to tell how stress affects an adult or child with special needs who cannot communicate easily. Be aware of subtle clues such as difficulty sleeping, crying, headaches, loss of appetite, etc. The Federal Emergency Management Agency (FEMA) has developed a fun Web site, just for children, to educate them about hurricanes (http://www.fema.gov/kids/hurr.htm).

Use the Buddy System – Coordinate with other military families with special needs and plan your evacuation together. It is always safer to travel with others. I often traveled with neighbors and friends who were also evacuating. (My spouse was the base Telephone Officer and had to stay on the installation to keep communication lines open. Their spouses were pilots who had to fly the jets out of the area to prevent damage. They could not evacuate with us.) We made

“Over 200,000 people with chronic medical conditions, displaced by the storm and isolated by the flooding, found themselves without access to their usual medications and sources of medical care.”

–The Federal Response To Hurricane Katrina: Lessons Learned

www.eparent.com/EP MAGAZINE • September 2007 87
Disaster Planning

our hotel reservations early because we knew we could always cancel them later if we didn’t need them. We used radios to communicate with each other because cell phones are not always reliable. (Tip: Always have coins or a calling card available to make telephone calls!) Having another family to partner with is especially important when a family member is deployed and you are left to handle everything on your own. There is a great sense of security in just knowing you are traveling with someone you trust and who will help you if you run into problems such as your vehicle breaking down or getting a flat tire.

Relocating To or Out of an Affected Area – Yes, it does happen. Mandatory evacuations due to Hurricane Katrina forced military families to evacuate the New Orleans area to safe havens. Household goods are better left in storage facilities until after the storm. Contact the nearest Personal Property Office or Transportation Office if you have questions about household goods or medical equipment that was shipped with your household goods.

Preparing Above and Beyond the Basic Disaster Kit
Any major Internet search engine will deliver hundreds of basic disaster preparedness lists in response to a search using the terms emergency, disaster preparedness, or hurricane preparedness. Make time to determine what your family member with special needs may need in the event of major power loss, evacuation and/or disaster. Here are just a few questions to ask yourself:
• What are your plans if you have no electricity or water for several weeks? How will you operate equipment that runs on electricity, such as pumps and monitors? How will you keep medication and/or special food refrigerated?
• How will you prepare your food if you don’t have electricity or gas to cook it?
• Do you have enough food to last at least two weeks?
• What will you do if you lose access to potable water?
• Where will you stay if there is a mandatory evacuation?
• How will you store items that need to be refrigerated during your evacuation?
• What can you take with you to the evacuation shelter?
• Do you have enough space in your vehicle to carry all the items you will need?

Your Disaster Preparedness Kit Should Include:
• Military and DEERS ID Cards! (You will need them to access medical care.)
• Credit and/or debit cards and cash
• Telephones (not wireless) that plug into the wall and will work when phone lines are not damaged. These types of telephones do not require household current to operate. The U.S. Coast Guard recommends that you try using text messaging if you cannot make calls with your cellular phone.
• Prescription and non-prescription medications – Have at least a two-week supply and discuss your prescription medication needs with your PCM. What would happen if you lost your medication or if you ran short and needed more?
• Medical Alert IDs
• Important documents – medical records, wills, insurance paperwork, Individualized Education Program (IEP), Individualized Family Service Plan (IFSP), etc. Store them in a secure, waterproof container that can be easily carried.
• First aid supplies
• Lots of extra batteries for assistive technology, battery-powered fans, flashlights, radios, etc. Rotate your batteries regularly to ensure you always have fresh batteries.
• Special foods, supplements, bibs, and special eating utensils and support
• Manual Hoyer Lift, if needed
• Sanitation and hygiene items
• Extra towels, washcloths, and flat bedsheets
• Small- and large-sized garbage bags
• Plastic containers or waterproof bags to protect medical equipment and smaller items
• Power converters – Most power converters will plug into a vehicle’s cigarette lighter or power outlets. They can provide power to a variety of items, including augmentative communication devices. You may need to have extra power outlets installed in your vehicle, depending upon your needs. Small, portable refrigerators are excellent for storing medications, and some can be plugged into vehicle power outlets.
• Special Care Organizational Record (SCOR) – This is a tool developed by TRICARE to help you track your family member’s medical care, support, and other needs (http://www.tricare.mil/OCMO/download/SCOR.doc). Use the SCOR to provide written instructions on how to care for your family member with special needs in the event you or other caregivers in your family are not available.
• Remember to think about what could happen if you or your spouse are taken ill or are injured. Will someone know how to care for your child’s medical needs?

Transportation
Having reliable transportation is vital for your family’s safety during an evacuation. At a minimum, check your tires, your spare tire(s), and the date of your last oil change when the season begins and prior to an evacuation, if possible. Check to be sure your air conditioning system is working. Heat stroke is a serious concern for family members with special medical needs when stuck in traffic in summertime temperatures with no air conditioning in the vehicle. Contact your spouse’s unit or family center if you do not have a vehicle to use to evacuate and have no other means of transportation out of the area. Be sure they know your needs so they can plan transportation in advance of an evacuation.

Emergency Shelters
Service animals – Most emergency evacuation shelters will only allow service animals (ADA requirement). Don’t forget to hand-carry your animal’s license, ID tags, vaccination records, water, medications, and food.

Food – Take your own non-perishable food. Find out in advance if the shelter to which you plan to evacuate has working refrigerators or coolers to store medications.

Bedding – Don’t forget to take special support cushions. Futons are wonderful when cot availability is sparse and not appropriate for support.

Sanitation & hygiene – Take plenty of diapers and wipes. Remember, there will be long lines to get into the restrooms!

Immune-compromised individuals – Take your own face masks and lots of antibacterial wipes. Talk to the shelter staff to see if they have a separate area for people with special medical needs.

Disaster Recovery
Judging when the best time is to return home can be difficult. Call friends from your neighborhood to see if they have visited the area to assess the damage. Be prepared to live for several weeks without power or potable water if you are allowed to return to your home.

About Mold and Fungi – Infants and elderly family members, immune-compromised individuals and those with allergies or asthma and other respiratory problems should stay away from fungi and mold-exposed buildings until the mold has been eradicated. The Occupational and Safety Health Administration (http://www.osha.gov/oshDoc/data_Hurricane_Facts/mold_fact.pdf) has published fact sheets about mold: how to recognize mold, its health effects, and clean-up tips.

Military families are used to packing up household goods and necessities and adapting to new environments because of our transitory lifestyle. We are also skilled at finding resources and getting connected to services immediately. Start today by pulling together the items you will need in the event of an emergency or disaster. Use the resources provided here to educate yourself about disaster preparedness. Be a military family: prepared and ready.

Additional Resources
Military OneSource – Call Military OneSource (1-800-342-9647) and ask for disaster preparedness resources and a list of national motel and hotel toll-free numbers (http://www.militaryonesource.com).

DisabilityInfo.gov – This official government Web site provides access to disability-related information and programs available across the government on numerous subjects, including emergency preparedness (http://www.disabilityinfo.gov).

National Organization on Disability (N.O.D.) – N.O.D. has an Interactive Map of Disability & Emergency Preparedness Resources (http://www.nod.org/EPIResources/interactive_map.html)

PandemicFlu.gov – This official government Web site provides detailed information on how families can prepare for a pandemic-level disease outbreak (http://www.pandemicflu.gov/plan/individual/index.html).

Guidance for Navy and Marine Corps Personnel Recovering from a Hurricane Disaster – This resource provides information for those who are recovering from a hurricane or flood disaster (http://www.safetycenter.navy.mil/seasonal/disaster.pdf).

Joint Federal Travel Regulations (JFTR) – This regulation contains guidance for military members who may have entitlements related to evacuations (See Chapter 6, Part B). The JFTR can be found at https://secureapp2.hqda.pentagon.mil/perdiem/trvlregs.html.

Isabel Hodge is a Marine Corps veteran and has been living the Marine Corps military lifestyle as a military spouse for nineteen years. In addition to being a parent and advocate, Isabel has worked as an installation-level EFMP Coordinator and at Marine Corps Headquarters as an EFMP Support Coordinator for four years. Today, Isabel works as a content analyst for the Department of Defense Military Community and Family Policy Program Support Group.
Fort Sam Houston Employs Team Effort to Accomplish Army Medical Action Plan

By Phil Reidinger, Fort Sam Houston Public Affairs Officer

The United States Department of the Army implemented a five-phase Army Medical Action Plan (AMAP) this year to improve medical care, services, and transition for wounded Soldiers and their families. The Army achieved success in the first phase of the plan by establishing a list of 10 Quick Wins (See sidebar on page 92) and creating special Warrior Transition Units to care for Soldiers. Phase I was led by Brigadier General Michael Tucker, Deputy Commanding General of the North Atlantic Regional Medical Command and Walter Reed Army Medical Center. Fort Sam Houston is one example of many Army installations that are carrying out a successful AMAP.

“The Army Medical Action Plan at Fort Sam Houston rocks!” That is the message delivered to the Brooke Army Medical Center (BAMC) and Fort Sam Houston community on a marquee located at the installation entrance at the BAMC exit, off I-35.

The message by Brigadier General (Brig. Gen.) James K. Gilman, Great Plains Regional Medical Command and BAMC commanding general is a pledge that Soldiers returning from fighting the battles of war will not have to fight a bureaucracy to obtain healthcare and other services during their recovery at BAMC and their transition afterward.

During a meeting on July 6, with Brig. Gen. Gilman, Colonel (Col.) Wendy Martinson, U.S. Army Garrison (USAG) Commander, and post Army Medical Action Plan (AMAP) planners, Fort Sam Houston’s installation Commander Major General (Maj. Gen.) Russell J. Czerw explained the command’s focus, stating, “Executing the Army Medical Action Plan is a team effort on Fort Sam Houston. We are working with the Installation Management Command and the Medical Command to provide installation resources and services to Warriors in Transition and their Families. We understand, and we are committed as a team with Brooke Army Medical Center, to a plan of action that provides each Soldier and Family member the care, dignity, compassion and respect they rightfully earned.”

On May 15, Gen. Richard A. Cody, Army Vice Chief of Staff, approved the definition for Warrior in Transition as “An Active Component or Reserve Component Soldier who meets the qualifications of Medical Hold, Medical Holdover...
or Active Duty Medical Extension. It also includes Active Component Soldiers who require a Medical Evaluation Board or have complex medical needs requiring greater than 6 months of treatment. Warriors in Transition do not include Initial Entry Training, Advanced Individual Training, or One Station Unit Training Soldiers except in extraordinary circumstances. Exceptions to this definition must be approved by the local military treatment facility and unit commanders.”

Gen. Cody also decided two AMAP areas of responsibility:

- Army Medical Command (MEDCOM) will maintain Command and Control for all Medical Hold and Medical Holdover Soldiers.
- Army Installation Management Command (IMCOM) will maintain Command and Control for all Soldier and Family Assistance Centers except at Walter Reed Army Medical Center.

As part of its AMAP, the Army established 10 Quick Wins (See sidebar) for Phase I of five scheduled phases. The Quick Wins were defined as “any change in process or service in delivering healthcare to Warriors in Transition the Army can implement by June 15, 2007.” When Phase I was complete (April 28-June 15), the Army had achieved its Phase I goals.

According to Col. (Dr.) Barry Sheridan, director of BAMC Healthcare Operations, “We have addressed the Quick Wins at BAMC. We have created a Warrior Transition Unit (WTU) at BAMC to incorporate all the Warriors in Transition. The staffing of these WTUs will be filled with Army assets. We will incorporate the triad of squad leader, case managers, and Primary Care Managers.”

Sheridan also noted that monthly Town Hall meetings are conducted to identify problems and areas of needed improvement for Warriors and their families. Commanders and staff from the Medical Treatment Facility (MTF), the WTU, and the Garrison attend. Escorts now meet families at the airport and bring them to the MTF to meet their Warrior.

Sheridan said that a Soldier and Family Assistance Center is being established to provide administrative and financial assistance; to aid with coordinating government entitlements, benefits, and services; and to provide information and assistance in obtaining non-governmental benefits and services. BAMC already provides facilities in the hospital for Veterans Health Administration (VHA) and Veterans Benefits Administration (VBA) liaisons.

In regard to the Army’s AMAP Quick Wins, Col. David Baker, BAMC Troop Commander, noted that visitors inspecting BAMC commented that BAMC was already setting the standard. “BAMC was already picking up Soldiers at the airport and taking them to their rooms. Caseworkers were already assigned to the Wounded Warriors,” he said. BAMC had accountability of the Soldiers through command formations, to get them out of bed, check profiles, and follow up on Soldiers who weren’t getting out of bed, he indicated. “BAMC is at the tweaking stage of AMAP, because we already set the
10 Quick Wins

Goals in Phase I of the Army Medical Action Plan
Approved by Army Chief of Staff General George Casey, Jr.

(The Army defined Quick Wins, included in Phase I of the AMAP, as “any change in process or service in delivering health care to Warriors in Transition the Army can implement by June 15, 2007.” The Army met this deadline for achieving its Phase I goals.)

Establish Command and Control. Previously, wounded and ill Soldiers undergoing prolonged evaluation and treatment (termed Warriors in Transition) were segregated by Reserve or Active Component into separate companies that fell under different commands with varying leader to lead ratios, disparate resourcing, and often disparate billeting and support structures. The disparities favored Reserve Component Soldiers in some locations and Active Component Soldiers at others. The Army values the service of all Soldiers regardless of component. The Army Medical Command has new unified companies (Warrior Transition Units) providing leadership and support at a ratio of one squad leader to every 12 Warriors in Transition.

Institutionalize the Structure. Previously, the companies supporting Warriors in Transition were not formally manned. Each location was left to devise a method of manning these units by diverting personnel from other duties. In addition the baseline manning document of the medical treatment facility was not adjusted to account for increased workload with increasing numbers of Warriors in Transition. A formal manning document now exists that authorizes personnel to provide leadership, clinical oversight and coordination, administrative and financial support at a strength based on the size of the population supported. At the heart of this structure is the triad of the squad leader, the primary care manager, and a nurse case manager to provide a synergistic level of support incorporating leadership, medical oversight, and medical coordination and management.

Prioritize Mission Support & Create Ownership. Army leadership has directed the senior commanders on Army installations to make Warrior in Transition facilities and furnishings top priorities for repairs and improvements. In addition, they are to conduct monthly Town Hall meetings to identify problems and areas of needed improvement for Warriors and their Families. Commanders and staff from the medical treatment facility, Warrior Transition Unit, and Garrison must attend.

Flex Housing Policies. Policies now allow for single Soldier patient attendee support to receive military or guest house lodging in the same manner that family members of married Soldiers have been authorized. Warriors in Transition are now considered on par with key and essential personnel for military housing vacancies.

Focus on Family Support. Previously, Families arriving at Medical Treatment Facilities in support of a wounded or ill Warrior received varying levels of support. The Army recognizes the importance of supportive Families. Best Practices were institutionalized across the Army. Escorts now meet Families at airports and bring them to the Medical Treatment Facility to meet their Warrior. Soldier and Family Assistance Centers are being established to provide administrative and financial assistance; assist with coordinating government entitlements, benefits, and services; and provide information and assistance in obtaining non-governmental benefits and services. A Soldier and Family Hero Handbook will be distributed to all Soldiers and Families as a further aid. Formal Family Support Groups are being established.

standard. BAMC is not coming up with new things to do; we are tweaking certain things to make them better for the Wounded Warriors,” he said. Some of the adjustments Baker describes include keyless entries for the burn center patients, because they cannot open the doors; automatic flushers for the toilets; establishing a Family Readiness Group for the Wounded Warriors; continuing to evaluate patients negotiating one or more wheelchairs down a sidewalk; and adding 168 employees to the staff.

“Consolidating a Soldier and Family Assistance Center into a one-stop shop will make it easier for the Wounded Warrior to get around. Anything that the Wounded Warrior needs will be in this unit. AMAP is a good thing for BAMC and good for the Soldiers and their families. As General Gilman says, the key to success is to never stop listening,” Baker emphasized.

MEDCOM has created the MyMEB (My Medical Evaluation Board) Web site on the Army Knowledge Online Web page, allowing Warriors to go online and access the status of their MEB. In addition, a physician dedicated to assisting Soldiers with the MEB process is being assigned for every 200 Soldiers involved in the process.

To further assist Soldiers in expediting the MEB process, MEDCOM is implementing new access to care standards for Warriors in Transition. MEDCOM has trained ombudsmen to permit the identification and resolution of problems at the earliest opportunity.

The Army leadership has directed the senior commanders on Army installations to make Warrior in Transition facilities and furnishings top priorities for repairs and improvements. Fort Sam Houston Garrison Commander Col. Martinson directed the re-opening of the BAMC ID Card office on July 10 in the basement of BAMC, specifically for Wounded Warriors and their
with the support of a full-time Family Readiness Support Assistant. The Medical Command has trained ombudsmen to permit the identification and resolution of problems at the earliest opportunity. Consolidated policy is being developed to facilitate processes that support Warriors in Transition and their families.

**Develop Training & Doctrine.** Previously cadre and staff in the companies supporting wounded and ill Soldiers received no formal training and no formalized standard operating procedures existed. The Army has developed standard operating procedures for the newly established Warrior Transition Units (WTUs), focusing on the mission of these units—i.e., to set the conditions to facilitate the Warrior to duty, or to facilitate the transition to active citizenship. Orientation programs for new WTU commanders and cadre have been developed and the first formal course will be held June 25-26, 007. The Medical Command has increased its training programs in the identification and treatment of Post Traumatic Stress Disorder with special focus on Social Work personnel, WTU nurse case managers, and psychiatric nurse practitioners. The Army leadership has established a Post Traumatic Stress Disorder and Traumatic Brain Injury awareness chain teaching program for all commanders and Soldiers.

**Create Full Patient Visibility.** In previous wars, commanders often found it difficult to locate Soldiers after they were evacuated from the battlefield. The Medical Command has greatly improved the ability to provide feedback to commanders through the Joint Patient Tracking Application and is now further improving the reach-back with a letter directly to the Soldier’s commander with instructions on how to contact the Soldier and how to submit awards and evaluation reports for battlefield service. The Medical Command has established policy for reception of Soldier-patients arriving by commercial or private transportation. The Army recognizes that Soldiers requiring evacuation may prefer to receive their care close to supportive Family and has developed a system to allow Soldiers to designate a preferred treatment location as part of the pre-deployment process.

**Facilitate the Continuum of Care and Benefits.** The communication between the DOD and VA continues to improve. As a pilot program, the Army Medical Command is co-locating Veterans Health Administration (VA) and Veterans Benefits Administration liaisons with the Walter Reed WTU nurse case managers to support the continuum of care and benefits, easing the transition for Warriors transitioning from the military to the VA. The Army has developed formal mechanisms to seek the Soldier’s approval and electronically transmit the required medical and administrative documents between the Army and the VA to expedite the continuum of care process.

**Improve the Medical Evaluation Board (MEB) Process.** Previously Soldiers undergoing a MEB had to make an appointment with their nurse case manager to find out the status of their MEB. MEDCOM has created the MyMEB Web site on the Army Knowledge Online Web page, allowing Warriors to go online and access the status and progress of their MEB. In addition, a physician dedicated to assisting Soldiers with the MEB process is being assigned for every 200 Soldiers in the process. To further assist Soldiers in expediting the MEB process, the Medical Command is implementing new access to care standards for Warriors in Transition. Only Soldiers preparing to deploy will have priority over Warriors in Transition for non-emergency appointments.

**Enhance Physical Evaluation Board (PEB) Representation.** The Army called Reserve Component lawyers and paralegals to active duty to provide additional legal advocacy for Warriors undergoing the PEB process to act as legal advocates for these Warriors in Transition.

families. The facility, which has an ID Rapid machine, will be open from 7:30 to 11 a.m. and 12:30 to 3:30 p.m., Monday through Friday. Additionally, the Okubu Barracks has been designated specifically to house Wounded Warriors assigned to the BAMC WTU. During the past few months, thirty-six rooms on the first floor of the barracks complex have been renovated and are in full ADA compliance. Recently, $1.5 million was provided by IMCOM to the Garrison to convert an additional twenty-eight rooms to ADA-compliant quarters. IMCOM also provided $4.83 million to add water softeners and anti-scalding devices for burn patients and for the installation of TV cables. Another project being planned is the installation of elevators in the Okubu Barracks to provide expansion of Soldiers quarters to the second floor, if required.

The Garrison staff is also investigating ways to support travel to administrative and medical appointments for the WTU by obtaining two additional ADA-compliant buses with wheelchair lifts that will be operated by the WTU in coordination with the Garrison.

Additional progress was made for Warriors in Transition during the Biennial AMEDD (Army Medical Department) Physical Evaluation Board Liaison Officer (PEBLO) Training Conference, held in May, in San Antonio, Texas. More than 200 PEBLOs, physicians, administrators, and other stakeholders from military installations around the world attended. The theme for the conference was “Maintain an Army Strong! Through Efficient and Compassionate PDES Processing.”

Brig. Gen. Reuben D. Jones, the Adjutant General of the Army, in his role as Commander, United States Army Physical Disability Agency (USAPDA), provided the keynote address. During opening remarks, he stressed that overhauling the Physical Disability Evaluation System (PDES) is key to fixing the cumber-
some, inconsistent, and confusing bureaucracy for wounded and ill Soldiers and family members. “If there is only one action taken, this is it,” he said.

Maj. Gen. Gale S. Pollock, Commander, U.S. Army MEDCOM, and acting Army Surgeon General, spoke during the closing workgroup session. She praised the quality of care that Army medical professionals provide, while recognizing that access to care is an issue of concern.

During the conference, PEBLOs and MEB physicians received certification on the new PDES Transformation Initiatives (TI), a system designed to improve and facilitate medical processing of over 15,000 injured Soldiers in the PDES.

The conference also included dedicated training tracks and updates on medical hold and medical holdover, MEB, the Army Wounded Warrior Program (WWP), retirement services, Social Security, and VA policies and procedures.

According to Maj. Gen. Pollock, the AMAP vision for Army Medicine, the Department of Veterans Affairs (VA), and other support agencies is the creation of a sustainable healthcare system open to all injured and ill Soldiers for medical treatment, vocational rehabilitation, and successful return to active duty, or transition back into civilian life with follow-up healthcare provided by the VA.

In the June 6, 2007 issue of MEDCOM Now, Pollock notes that AMEDD is providing the highest quality and most advanced medical care for Soldiers on the battlefield, and saving more lives of Soldiers wounded in combat than ever before.

Yet Army leaders and medical professionals know that some wounds lie beneath the surface and are not always visible upon first assessment. According to Pollock, brain injury and psychological stress from combat deployments are a primary healthcare concern for the Army leadership.

In the weeks ahead, the Army will launch a chain teaching program (where a subject is taught to leaders, who then teach it to soldiers, continuing the sessions down through the Army’s chain of command) to ensure that all Soldiers know how to identify symptoms of post-traumatic stress disorder (PTSD) and traumatic brain injury (TBI). It will reach more than one million Soldiers and ensure early intervention. The goal is to educate all Soldiers and leaders to increase their awareness and understanding of these potentially debilitative health conditions. “As Soldiers deploy on multiple and extended tours to the combat zone, recognition, diagnosis, treatment, and prevention of PTSD and TBI are of utmost importance to our leadership, Soldiers and their Families,” Pollock noted.

At BAMC, “We are standing up a special team of professionals to assist in the management of Traumatic Brain Injury,” Col. (Dr.) Sheridan said.

BAMC’s commitment to Soldiers and their families continues with implementation of the broad initiatives of the AMAP and its installation initiatives.

Phil Reidinger is Director of Public Affairs of the Army Medical Department Center and School and U.S. Army Garrison at Fort Sam Houston, Texas.
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Brooke Army Medical Center (BAMC) Steps Up Care for Warriors in Transition, Families
Community of One

From Our Families...To Your Families
Visual Impairment and Blindness
Addressing One of the Growing Concerns of Today’s Veterans

By Michael D. Williams, Ph.D.

Visual impairment and blindness are issues facing the veteran and non-veteran populations in a variety of ways. It is estimated that in the United States more than 26 million people over the age of 40 are affected with some type of visual disorder. More than four million people age 55 or older are affected by vision loss that is severe. And over 1.1 million people are legally blind, according to estimates from the National Eye Institute (NEI).

Normal vision in the U.S. is considered to be 20/20. Low vision is generally recognized to be significant, uncorrectable visual impairment from 20/70 to 20/190 but not yet legal blindness. The generally accepted definition of legal blindness is a central visual acuity of 20/200 or less in the better eye (with corrective glasses) or a visual field (peripheral vision) with the widest diameter no greater than 20 degrees in the better eye.

Currently, the number of veterans in the U.S. diagnosed with low vision is estimated to be more than one million. The number of veterans diagnosed with legal blindness is estimated to be more than 160,000. Over 45,000 veterans diagnosed as legally blind have enrolled for care through the Department of Veterans Affairs (VA).

The VA has historically provided rehabilitation programs for veterans who are legally blind and is currently in the process of aggressively implementing innovative new service delivery models that focus on the needs of veterans who are struggling with the onset of low vision. The challenge of helping these veterans with low-vision and blindness has greatly increased, in large part due to the increasing numbers of older veterans. The increasing number of younger service members who have sustained vision impairment and blindness as a result of injuries received while serving on active duty in the current Global War on Terror has further increased the demand for vision rehabilitation within the VA.

The impact of visual impairment and blindness is very individualized and includes a wide range of eye conditions, from the older veteran whose vision gradually worsens due to macular degeneration or some other age-related eye problems, to the serviceperson who is totally blind as a result of a traumatic injury. Veterans who must cope with a significant loss of vision require individualized, specialized care and treatment, suited to their specific cause of blindness. Physical and medical condition, age, ability to cope with frustrating situations, learning ability, and the overall needs and lifestyle of the veteran are important considerations.

A person confronted with visual impairment or blindness may feel limited and frustrated in performing everyday activities previously taken for granted. Tasks such as dressing, eating, writing, reading, and traveling may become difficult to perform independently. Communication with other people by ordinary means is often hampered, as is the ability to keep up with daily news and current events. Social interaction, recreation, and hobbies may also be limited or curtailed as a result of visual impairment. Frequently, a person may be forced into premature retirement, often resulting in loss of income and financial security.

As a result of the strong potential for negative ancillary effects due to visual impairment or blindness, it is not uncommon for the individual who is newly vision impaired or blinded to undergo a period of personal stress. Individuals may experience a loss of self-esteem or believe the future holds little promise. Spouses, families, and loved ones may likewise experience pressure, strain, or uncertainty as a result of their loved one’s diminished vision.

To help the veteran cope with the multifaceted issues related to vision loss, the VA established the Blind Rehabilitation Service to provide a wide variety of reha-
bilitation programs and services to veterans who are visually impaired or blind. These programs are designed to improve quality of life for veterans who are visually impaired or blind through the development and enhancement of skills and capabilities needed for personal independence, adjustment, and successful reintegration into the community and family environment. Components of the VA Blind Rehabilitation Service include: ten inpatient Blind Rehabilitation Centers; Visual Impairment Services Teams (VIST) and VIST Coordinators, located at many VA Medical Centers and VA Outpatient Clinics; Blind Rehabilitation Outpatient Specialists (BROS); National Consultants; and Computer Access Training (CAT) Programs. In addition, there are a variety of low-vision services and blind rehabilitation programs within the national VA system, including: Visual Impairment Services Outpatient Rehabilitation (VISOR) programs and Visual Impairment Centers to Optimize Remaining Sight (VICTORS).

Assistive Technology and Sensory Aids for Veterans with Vision Loss

The VA Blind Rehabilitation Service has a long history of providing cutting-edge assistive technology to veterans with vision loss and blindness. It issued over $19 million in blind aids and assistive devices to veterans in 2006, through the VA Prosthetics and Sensory Aids Service, totaling some 114,000 individual items. Each veteran who is legally blind and who undergoes visual impairment rehabilitation is evaluated with, prescribed, and taught the use of appropriate assistive technology and sensory aid devices. Issuance of assistive devices to veterans is based upon need, the demonstrated ability to use the devices, and adherence to clearly defined criteria. Devices issued to veterans are intended to assist in overcoming the disability of blindness and vision loss and to augment their ability to function effectively and efficiently after rehabilitation is completed. Generally, VA Blind Rehabilitation Specialists (whose scope of practice and level of expertise include the ability to determine appropriateness of prosthetic items) request assistive devices and technology deemed necessary for the veteran with visual impairments following the completion of assessment and rehabilitation training.

Devices and assistive technology most often provided to those with visual impairment and blindness range from the most basic low-tech devices to highly sophisticated, cutting edge computerized technology. Examples of non-optical devices commonly prescribed by the VA include items such as memo organizers; Braille, large-print or “talking” time pieces, including clocks and watches; letter, signature, and check-writing guides and templates; kitchen and appointment timers; beverage level indicators; and bar code readers to assist with identification of a variety of items, including clothing, medicines, and food items.

Perhaps the most commonly prescribed category of assistive devices targeting veterans with visual impairment involves optical low-vision devices (OLVDs) and aids. Specific criteria have been established by the VA to ensure appropriate and legitimate issuance of OLVDs. They include the determination of significant vision impairment by a qualified eye care practitioner (an optometrist or ophthalmologist). Typically, when OLVDs are provided, it is also necessary to provide training and instruction on the correct and appropriate use of the device. Training in the use of OLVDs is provided in the VA by specialists who have appropriate professional competencies, including optometrists, ophthalmologists, blind rehabilitation specialists, or others who possess training in low vision therapy.

Generally speaking, OLVDs can be characterized as addressing three primary areas of visual functioning, including 1) near visual tasks, involving reading or performance of “near spotting” tasks; 2) intermediate visual tasks, such as writing and performing other activities of daily living; and 3) distance visual tasks, such as quick object spotting (locating addresses, reading signage, etc.). Devices typically prescribed to veterans to address deficits in near vision include spectacle-mounted lenses that magnify the image; small, portable pocket magnifiers; stand magnifiers; and Closed Circuit Televisions (CCTVs). Visual impairment that interferes with intermediate vision function can be addressed by OLVDs such as OptiVISORS™, magnifying lamps, and spectacle-mounted telescopic lenses. Distance-related OLVDs typically include hand-held monocular telescopes and telescopic lenses. Often, tinted filters and other sunwear are also used to assist the visually impaired individual with adapting to varying lighting conditions by improving contrast sensitivity and reducing glare. Other adaptive devices that target enhancement of vision and visual functioning include lighting devices and high-power lamps, reading stands and copy holders, and optical character readers (OCRs) that scan written text and play it back in an audible format.

Closed Circuit Television (CCTV) devices have been available to users with visual impairments since the 1970s. At one time, these devices were considered to be experimental and were thought best used by someone with an educational or vocational need. Over the years, the CCTV has become a commonly used device for all manner of daily living tasks, including reading (mail, books, magazines,
Visual Impairment and Blindness

newspaper articles), writing, viewing photographs, medication management, hobbies, etc. This has led the CCTV to become one of the most commonly issued devices by the VA to veterans with visual impairment and blindness. As such, the CCTV has become the centerpiece of a class of low-vision devices that assist many veterans to maintain their independence and dignity.

Other types of assistive technology and aids that are commonly prescribed include mobility canes and mobility enhancing devices. The general purpose of these devices is to assist people with obstacle detection, provide some measure of protection from obstacles, and to extend the tactile sense of the user in order to provide information about the environment. Some may also require a support cane. There are several types of support canes available, with red and white markings conforming to specifications for a cane for those with blindness. Included in this general category are rigid canes (the long cane), folding or collapsible canes, and support canes. In most cases, instruction and training on the device must be provided by a university trained Orientation and Mobility (O&M) Specialist. Other types of mobility devices include sound-enhancing or localizing devices, laser canes, and other electronic or mechanical aids.

The VA Computer Access Training (CAT) Program provides specialized services to eligible veterans with visual impairment and blindness, including: a comprehensive adaptive computer needs assessment; recommendation of appropriate computer equipment; training on recommended equipment; issuance of equipment upon successful completion of training; and follow-up technical support, as required. Eligible veterans may be able to receive local training and issuance if there are local qualified providers in the veteran’s community. The equipment issued by the CAT program is state-of-the-art computer technology with all necessary peripherals and accessible hardware/software to meet the veteran’s identified needs.

Training typically encompasses comprehensive instruction on accessible hardware/software, computer literacy, familiarization with the computer keyboard, fundamentals of disk operating systems, and fundamentals of word processing, Internet access, and email.

Although partial or total loss of vision can be overwhelming, the problem is not insurmountable. Rehabilitation can be the start of a new life. It is the beginning, the training ground, the base that prepares the veteran to assume or continue a meaningful place in the family and in society. Rehabilitation assists the veteran with visual impairment in building the strength, skills, and self-confidence to live a normal, happy, well-rounded life. Additionally, the increased sophistication and availability of assistive technologies and devices that target vision loss and blindness offer the veteran with visual impairment an array of tools and strategies to compensate for loss of vision.

For more information regarding the VA Blind Rehabilitation Service, please visit the VA Blind Rehabilitation Service Web site, at http://www.va.gov/blind-rehab or contact one of the ten inpatient programs listed in the sidebar above.

Reference materials for this article can be requested from kdauphinee@eparent.com.

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United States Military Section

The Military Child Education Coalition™ and Pre-K Now: Working Together to Expand Pre-Kindergarten Options for Children

By Stephanie Surles and Holly Barnes Higgins

At its annual conference in July, the Military Child Education Coalition (MCEC™) released a report in conjunction with Pre-K Now, a public education and advocacy organization that advances high-quality, voluntary, pre-kindergarten options for three- and four-year-old children. This report, titled Pre-K for Military Families: Honoring Service, Educating Children, examines the unique challenges faced by today’s young military families and calls on state leaders to actively support America’s military personnel by providing high-quality pre-kindergarten to their children. The report is available in Portable Document Format (PDF), at http://www.militarychild.org/preknow.asp.

States across the country are making impressive progress toward providing Pre-K for all three- and four-year-old children, but many families still lack access to high-quality programs. Because eligibility for Pre-K varies widely, a military-connected child may be able to attend in one state but could lose that opportunity when moving to a new state.

“Access to high-quality Pre-K programs is imperative for military children and their families,” according to Mary Keller, Ph.D., executive director of MCEC. “In this time of extended deployments, Pre-K programs can provide military children with the stability, education, and caring attention they need to cope with life’s uncertainties.”

“Research shows that all three- and four-year-old children benefit from high-quality Pre-K, and for children of the Armed Forces, Pre-K provides an essential element of stability,” says Libby Doggett, Ph.D., executive director of Pre-K Now. “A good Pre-K program can help these children cope with frequent moves and the stress of parental deployment by giving them continuity in a difficult time, so they can develop the social, emotional, and educational skills needed for success in school.”

Studies conducted over the last several decades have consistently found positive outcomes for children involved in quality Pre-K. For example, they are less likely to repeat grades, more likely to graduate, more likely to make good decisions regarding their health, less likely to experience depression, and more likely to maintain secure employment as adults.

Access to high-quality pre-kindergarten options is also an issue for children with special needs. In some areas, children with suspected developmental delays or disabilities may be eligible for pre-kindergarten programs. Interested parents should check with their local school district office to see if this is an option in their current location. For advice on determining whether Pre-K is right for your child and how to identify a quality program, please see MCEC’s Preparing for the Journey, available in the MCEC Store, at http://www.militarychild.org.

Research from the National Institute for Early Education Research shows that the benefits of quality early education are not limited to special needs or to key risk factors, such as difficult economic circumstances. Instead, Pre-K programs were shown to be important for all children.

In this case, however, MCEC and Pre-K Now saw a special group of children that should be assured a place in a nurturing Pre-K classroom, wherever the military life took them and their families. Now, policy makers and families in states without access to Pre-K have a model toward which to work.

Expanding access to high-quality Pre-K programs for military children provides a tangible method for supporting members of our military and those they care the most about—their children.

The Military Child Education Coalition (MCEC) is a nonprofit organization focused on the academic and school-related needs of all United States military-connected children. MCEC believes strongly that parents are the first and best advocates for their child. For more information, please contact Stephanie Surles, MCEC’s Director of Research and Product Development at stephanie.surles@militarychild.org, or visit MCEC’s Web site at http://www.militarychild.org.

Pre-K Now collaborates with state advocates and policymakers to lead a movement for high-quality pre-kindergarten for all three- and four-year-olds. For more information, please contact Holly Barnes Higgins, Media Relations Director •

www.eparent.com/EP MAGAZINE • October 2007 81
Since June, Brooke Army Medical Center (BAMC) has implemented a series of sweeping changes designed to improve the quality of care for Warriors in Transition and their Families.

The changes are driven by the Army Medical Action Plan (AMAP), an Army initiative designed to eliminate bureaucratic roadblocks for Warriors in Transition so they can focus on recovery and have a smooth transition back to military duty or civilian life.

The first and perhaps most dramatic change is the formation of a Warrior in Transition Battalion. The battalion, which stood up June 15, replaces the former active-duty Medical Hold and reserve Medical Holdover companies. Reserve and active duty Warriors in Transition are now combined in three companies under the battalion.

All battalion Soldiers are in a transitional status, meaning they are wounded or ill and undergoing treatment at BAMC.

“We’re all one team so it makes sense to keep everyone under the same umbrella,” said Master Sgt. Scott Waters, senior operations NCO, Warrior in Transition Battalion.
The reserve and active duty Soldiers were separated in the past to ensure familiarity with administrative processes, which differ for each component; however, “AMAP gives us the resources we need to accommodate all Soldiers without differentiation,” Waters said. “We now have the extra help we need to successfully manage and track our Warriors in Transition without separation.”

Since AMAP, the ratio of Soldier to platoon sergeant has reduced dramatically. Whereas before there were 50 Soldiers to each platoon sergeant and no squad leaders at BAMC, there are now 12 Soldiers per squad leader and about 30 Soldiers per platoon sergeant.

‘Triad of Care’

But with myriad issues, ranging from severe injuries to Family problems, there’s “a lot to be done even with that ratio,” Waters said. To ensure Warriors in Transition have top-notch care, the Army created the “Triad of Care” concept, which is an integral part of the battalion.

Each triad comprises a case manager, primary care manager, and squad leader or platoon sergeant. Each Warrior in Transition is assigned to a triad, which ensures consistency and continuity of care for the Soldiers and their Families.

“It eases the process for both the Soldiers and the healthcare providers,” said Lt. Col. Donna Rojas, chief of case management. “There’s no confusion about who to call when there’s a question or concern. The providers know exactly which squad leader to call and vice versa. And, the Soldier knows exactly who to contact as well.”

Case managers

Rojas provides oversight for the case managers, who serve as a pivot point for the triad. Responsible for just about every aspect of a patient’s healthcare plan, case managers ensure Warriors in Transition attend appointments, understand their treatment plan, and are on hand to aid with everything from housing issues to Family dilemmas.
tion,” said Lt. Col. Mary Burns, chief of medical management. “Case managers, PCMs, and squad leaders are all looking out for the best interests of the Soldiers; the key is to meet regularly and catch issues early.”

Prior to AMAP, each case manager had about 35 Warriors in Transition assigned. But thanks to an influx of resources, there are now 10 case managers assigned to each company, and the ratio has reduced to about 18 Soldiers per case manager.

Primary care managers
PCMs also have reorganized to provide better continuity of care. Prior to AMAP, several PCMs were unofficially designated for Warriors in Transition but didn’t have a space dedicated for care and their time was divided with regular patients. BAMC now has officially assigned three healthcare providers and a designated area of the Family Medicine Clinic to better serve wounded and ill service members. Additionally, the ratio of patients to PCM has dropped from 1,200 to 1 to 200 to 1. The reduction in patient load allows PCMs to spend more time with each service member, increasing from 20 minutes to upwards of over an hour.

“A PCM meets with every Warrior in Transition within 24 hours of arrival and conducts a head-to-toe evaluation,” said Dr. Sara Pastoor, chief of Primary Care. “We assess every aspect of the patient’s healthcare needs, including any specialty care that may be needed as well as preventive healthcare, such as tobacco cessation.

“I’m overwhelmingly impressed with and proud of everyone providing Warrior in Transition services at BAMC,” Pastoor added. “It can be emotionally draining to provide the amount and type of health care needs involved, but it is a privilege to be exposed to the sacrifices and heroism. It’s a challenging job for the PCMs because it takes, not just a thorough knowledge of medicine, but also a thorough administrative knowledge of the system.”

Squad leaders/platoon sergeants
The last branch of the triad, the squad leaders and platoon sergeants, serve as the “enlisted Non-Commissioned Officer (NCO) boots on the ground,” Waters said. “We are there 100 percent for the Soldiers and their Families from the time we’re notified a Soldier is coming.”

Squad leaders take care of everything from picking up the Soldier or Family Members at the airport or emergency room to transporting them to medical appointments, “everything that doesn’t involve medical care,” Waters said.

The process starts as soon as the battalion is informed a service member is incoming or checking out of the hospital. “We help the Soldiers get situated and then the next morning, we pick them up, introduce them to the case manager and start in processing,” said Waters, adding that the United States Army Garrison Fort Sam Houston also provides ongoing support with transportation as well as barracks maintenance and upgrades to accommodate varying physical needs.

The NCOs work closely with the case managers to ensure an open flow of communication. “We overlap in a lot of areas,” Waters said. “Sometimes the Soldier feels more comfortable talking with a case manager or vice versa. We keep each other in the loop to ensure all needs are being met.”

The help is ongoing as the squad leaders stay abreast of developments that may hinder care, such as Family problems back home or a pattern of missed medical appointments.

“Most Warriors in Transition are on some type of medication and may forget an appointment,” Waters said. “They may just need a simple reminder, and we’re here to do that.”

As the war continues, each branch of the triad will continually seek ways to improve processes and programs to ensure Warriors in Transition receive the best care possible, said Col. Barry Sheridan, chief of Warrior in Transition Services. “BAMC has always cared about its Warriors in Transition,” he said. “But now, AMAP is giving us the resources we need to do what we do even better.” •

Elaine Wilson is the editor of the Fort Sam Houston News Leader. She arrived at Fort Sam Houston from the active-duty Air Force, where she served for nearly 8 years. Her last assignment was at Incirik Air Base, Turkey. She currently serves in the Air Force Reserves.
United States Military Section

Renovations Ease Daily Living for Wounded Warriors

By Cheryl Harrison, Fort Sam Houston Public Information Office

On a daily basis, the majority of Americans wash their face and hands, take a shower or bath, and more than likely reach up to choose an outfit from the closet. All normal routines, usually accomplished without a second thought.

Another group of Americans, which includes Wounded Warriors, has the same routine, yet it is not accomplished without forethought, planning, and execution.

At Okubo Barracks, near Brooke Army Medical Center (BAMC), renovations have been underway for some time to make navigation and daily routines easier to accomplish for wounded service members.

Pvt. 1st Class Terrance McBride, enjoys lounging in a recliner while in his room at Okubo Barracks. Family photos, personal items, and a recliner add a coziness to his home away from home.

"With far more wounded Soldiers than anticipated, renovations needed to be accomplished," said Jack Hagans, Directorate of Public Works. "Two of the seven wings are finished, where we have taken two-person rooms and converted them into rooms for one."

The original rooms had two small bedrooms, a common area, and a full bath. The rooms were small and had sharp corners and angles to maneuver, not to mention they were dark, cold in appearance, and not functional for wheelchairs.

Some of the rooms on the first floor of Okubo Barracks have been renovated to one-person rooms with a living area, bedroom, and wheelchair-accessible bath. Tubs were removed and tiled, roll-in showers were installed with handicapped rails. Sinks are lower and left open beneath for easy reach and with room for knees and wheels. Closets were installed with lower rods for hanging clothing as well as lower shelving for storage and linens. Included in the upgrades are thresholds with ramps for rolling wheels and easy entry into the rooms, a simple solution for a difficult maneuver, when confined to a wheelchair.

The seven wing barracks was built for Warriors in Transition and even though it is in essence a part of the hospital, the atmosphere around Okubo is that of apartment living. A few differences are evident; all floors are tiled, the laundry has washers and dryers that are lower than the norm, but it is a home away from home environment.

Behind the doors of the first-floor units is the temporary home of a Wounded Warrior. The entrance is wider, and in some instances, a key is not required. Burn victims, for instance, need only to swipe a pass key, and the door will automatically open. Enter the common area or living room and notice an openness, lots of light and, in the case of Pfc. Terrance McBride, a cozy place to call his own during healing and rehabilitation.

McBride was injured during a training incident while downrange. Both of his hips and legs were crushed and the right leg broken so severely, amputation below the knee was McBride’s only hope of walking again.

McBride’s first floor apartment displays family photos, personal items and even a recliner that he enjoys while watching television.

When asked if he was comfortable in his renovated room, McBride responded, “I can’t complain at all, a lot of people fix it to their liking. I bought myself a recliner from the PX. One guy I know has a futon sofa in his room."

“I get along pretty well. I’ve been up and walking for about four months now. Everything is different now, and I just have to alter the way I do things,” added McBride.

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In 2005, the Department of Defense implemented traumatic injury protection insurance under the Servicemembers’ Group Life Insurance. The program, known as Traumatic Servicemembers’ Group Life Insurance (TSGLI) is a traumatic injury protection rider under the SGLI and is designed to provide financial assistance to any member of the uniformed services covered by SGLI who sustains a traumatic injury that result in certain severe losses.

To date the insurance program has provided about $136 million in assistance to traumatically injured Soldiers, but despite those figures, the program still faces challenges with educating service members about the program.

Beginning late this summer and through fall, the Army will be implementing the “Boots on the ground” program that will place TSGLI counselors in major Military Treatment Facilities (MTF) throughout the Army to provide a full stance of claims assistance, medical staff and caseworker education. These counselors will be working through Warrior Transition Units and Soldier Family Assistance Centers.

Every member who has SGLI also has TSGLI. This coverage applies to active duty members, reservists, National Guard members, funeral honors duty and one-day muster duty regardless of where the injury occurs, on or off the job.

The only exception to this coverage is under the retroactive program. This benefit provides retroactive coverage under provision PL 109-15 for members who sustain severe losses due to a traumatic injury between October 7, 2001 and December 1, 2005 if the loss was the direct result of injuries incurred in Operations Enduring Freedom or Iraqi Freedom.

The coverage is automatic for those insured under basic SGLI and the premium for TSGLI is a flat rate of $1 per month for most service members. Members who carry the maximum SGLI coverage of $400,000 will pay $29 per month for both SGLI and TSGLI. The only way to decline TSGLI is to decline basic SGLI coverage. TSGLI is not available to spouses and children under Family SGLI.

Not all injuries or conditions are covered under TSGLI. The definition of a qualifying traumatic injury is an injury or loss caused by application of external force or violence (a traumatic event) or a condition whose cause can be directly linked to a traumatic event. TSGLI provides an insurance benefit for one or more of 44 scheduled physical losses due to external force or violence. For more information on these exclusions and for a complete list of all traumatic losses and the TSGLI schedule of payments, visit www.insurance.va.gov/sgliSite/TSGLI/TSGLIFAQ.htm.

To be eligible for payment of TSGLI, you must meet all of the following requirements:

• Servicemember must be insured by SGLI.
• Servicemember must incur a scheduled loss and that loss must be a direct result of a traumatic injury.
• Servicemember must have suffered the traumatic injury prior to midnight of the day that you separate from the uniformed services.
• Servicemember must suffer a scheduled loss within 2 years (730 days) of the traumatic injury.
• Servicemember must survive for a period of not less than seven full days from the date of the traumatic injury. (The 7-day period begins on the date and time of the traumatic injury, as measured by Zulu [Greenwich Meridian] time and ends 168 full hours later.)

TSGLI provides one-time, tax-free payments between $25,000 and $100,000 depending on the loss directly resulting from the traumatic injury. Coverage continues for 120 days from date of separation, or up to one year if totally disabled at the time of separation from service.

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Rob “Robbie” Robinson, facility manager, Okubo Barracks, acted as tour guide, showing the before and after rooms. He also pointed out the changes and highlighted what was done and still needs to be done.

“For future renovations, recliners are on the list. I also recommended lighter wall colors rather than the issued gray. It gives a better feel, and all new furniture is being planned,” said Robinson.

“In the very near future, the Fort Worth District Corps of Engineers will award a construction contract to replicate the current handicap friendly design to the first floor of Wing G of Building 3631 and the first floors of Wings A and B of Building 3635 by September 30. This will add an additional capacity of 28 rooms to the current 36 rooms that have already been renovated. The project is scheduled for completion in the third quarter of fiscal year 2008,” added Hagans.

Okubo Barracks was named for Technician 5th Grade James K. Okubo, who distinguished himself while serving as a medic with the 442nd Regimental Combat Team. Over the course of two days in October of 1944, with enemy fire, minefields and roadblocks, Okubo heroically came to the aid of about 25 battle buddies. Then a few days later, on November 4, he saved the life of a wounded crewman from a burning tank. For his gallantry, Okubo was awarded the Medal of Honor.

Okubo’s name honors the halls of Building 3631, temporary home of today’s Wounded Warriors and America’s heroes.

Cheryl Harrison has been a writer and photographer for the Fort Sam Houston News Leader for the past two years. Before that, Cheryl was a graphic designer for the 12th Services Division at Randolph AFB, TX. In her spare time Cheryl writes articles and submits photos for the Oak Hills Church (in San Antonio) monthly publication “The Crossings.” Cheryl has many years of military experience having worked for the government for over 20 years and was an Air Force “brat.”

**Traumatic Servicemembers’ Group Life Insurance**

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**TSGLI vs. Disability Compensation**

Do not confuse TSGLI with disability compensation. TSGLI is not meant to serve as an ongoing income replacement, like some other types of insurance. Its purpose is to help the Soldier through the tough times that occur as the result of a traumatic injury, while disability compensation is intended to provide ongoing financial support to make up for the loss of income-earning potential due to service-connected injuries.

In addition, TSGLI has no effect on entitlement for compensation and pension benefits provided by the Department of Veterans Affairs or disability benefits provided by the Department of Defense (DoD). It is an insurance product similar to commercial dismemberment policies.

For more information, call the Army Wounded Warrior program at 1-800-237-1336 and ask for a TSGLI assistant or e-mail tsgli@hoffman.army.mil; the Office of Servicemembers’ Group Life Insurance at 1-800-419-147; or email at osgli.claims@prudential.com.

Minnie Jones is a public affairs specialist specializing in community relations for the Fort Sam Houston Public Information Office, and a frequent contributor to the Fort Sam Houston News Leader. Minnie is also a senior master sergeant who has served 29 years in the Air Force Reserve.

(Sources: U.S. Department of Defense, Office of the Assistant Secretary of Defense, Department of Veterans Affairs and U.S. Army Human Resource Command)
Negotiating the Intricacies of Future Planning
When There is a Divorce

Autism
and the Digestive Tract

Seizures and Teens
Using Technology to Develop Seizure Preparedness

Legal Options for Resolving Disputes in Special Education

United States Military Section

Community of One
From Our Families... To Your Families

Warrior Care Support Program

Living In The New Normal: Supporting Children Through Trauma and Loss
1) Under the state and national flags, Medal of Honor Recipients (from left) Don Ballard, Bob O’Malley, Drew Dix, David McNerney, Jack Lucas, and Col. James Stone dedicate a memorial tree for first time visitor, Lucas, to Gainesville, Texas. Gainesville established a program eight years ago, which invites Recipients to visit Gainesville; so far, 19 have accepted the invitation. (Photo by Gary Alexander)

2) Vietnam Medal of Honor Recipient David McNerney talks with Texas A&M cadets during this year’s “Medal of Honor Weekend,” hosted by Gainesville, Texas. Each year the small north Texas town plants an oak tree in honor of each Recipient who visits the “Medal of Honor Host City Program” community—the only one in the nation. Thus far, 19 Recipients have been honored in this way. (Photo by Gary Alexander)

3) Marine Iwo Jima Medal of Honor Recipient, Jack Lucas, is assisted by a young Marine during last September’s Congressional Medal of Honor Society convention in Green Bay, Wisconsin. Lucas, one of only three surviving Recipients from the famous World War II battle, was also a recent guest of the Gainesville, Texas Medal of Honor Host City Program where he signed copies of his book, Indestructible. Several Host City Program officers were invited to the annual gathering. (Photo by Gary Alexander)

4) Medal of Honor Recipient Drew Dix waves from a vintage WWII Jeep during Gainesville, Texas’ annual parade, part of a weekend celebration hosted by the community’s “Medal of Honor Host City Program.” Dix was awarded the Medal of Honor for his actions during the 1968 Tet Offensive, which are recounted in his combat memoir, Rescue of River City. (Photo by Gary Alexander)

5) Colonel Bob Howard, the most decorated living member of the United States military and new President of the Congressional Medal of Honor Society. (Photo by Gary Alexander)
We at EP wish to recognize and owe a great debt of gratitude to all the men and women who have served and are serving now.

Community of One
From Our Families...To Your Families
Two Flags Raised on Mount Suribachi

On Friday, February 23, D plus 4, a 40-man combat team consisting of a handful of men from battalion headquarters and the remnants of 3rd Platoon in Company E, 2nd Battalion, 28th Marines, 5th Marine Division under the command of Company E's executive officer, Lieutenant Harold G. Schrier, successfully scaled HOTROCKS, the code name for Mount Suribachi. At the top a Marine picked up a length of iron pipe and secured a small American flag that measured 28” X 54” brought up by the platoon. The first flag was raised between 1020 and 103. Technician Sergeant Louis R. Lowery, still photographer for Leatherneck magazine, took pictures of the first raising. However, the flag was too small to be seen through the haze of battle, which was one account given for a second flag raising, and a larger battle ensign that measured 4’ 8” X 8’ was borrowed from LST 779 that was beached near the base of Suribachi. A runner, Private First Class Rene Arthur Gagnon, took it to the top of HOTROCKS. The first flag came down at the exact time the second flag was raised. Joe Rosenthal, Associated Press photographer who was ascending Suribachi as Sergeant Lowery descended, arrived in time to take the picture of the second flag raising, which became the most famous photograph, as well as the most controversial, of the Pacific War. Even the time of the raising was controversial. It was given an estimated range of between 1200 and 1400 hours. The battle ensign was caught in the strong north wind and visible to all parts of the island and ships off shore.

The men who raised the first flag were: Sergeant Henry Oliver “Hank” Hansen, Corporal Charles W. “Chuck” Lindberg, First Lieutenant Harold George “Hal” Schrier and Sergeant Ernest Ivy “Boots” Thomas, Jr. They were aided by Corporal Robert A. Leader, and Private First Class Leo J. Rozeck, who located a 12-14 foot length of water pipe for the flag pole and passed it to the summit.

The men who raised the second flag were: Corporal Harlon H. Block, Pharmacist’s Mate Second Class John Henry “Doc” Bradley, Private First Class Rene Arthur Gagnon, Private First Class Ira Hamilton “Chief” Hays, Private First Class Franklin Runyon Souses, and Sergeant Michael Strank. (Courtesy of: Jacklummus.com)

Brief History of Veterans Day

Veterans Day, formerly known as Armistice Day, was originally set as a U.S. legal holiday to honor the end of World War I, which officially took place on November 11, 1918. In legislation that was passed in 1938, November 11 was “dedicated to the cause of world peace and to be hereafter celebrated and known as ‘Armistice Day.’” As such, this new legal holiday honored World War I veterans.

In 1954, after having been through both World War II and the Korean War, the 83rd U.S. Congress—at the urging of the veterans service organizations—amended the Act of 1938 by striking out the word “Armistice” and inserting the word “Veterans.” With the approval of this legislation on June 1, 1954, November 11 became a day to honor American veterans of all wars.

In 1968, the Uniforms Holiday Bill ensured three-day weekends for federal employees by celebrating four national holidays on Mondays: Washington’s Birthday, Memorial Day, Veterans Day, and Columbus Day. Under this bill, Veterans Day was moved to the last Monday of October. Many states did not agree with this decision and continued to celebrate the holiday on its original date. The first Veterans Day under the new law was observed with much confusion on October 25, 1971.

Finally on September 20, 1975, President Gerald R. Ford signed a law, which returned the annual observance of Veterans Day to its original date of November 11, beginning in 1978. Since then, the Veterans Day holiday has been observed on November 11. (Courtesy of www.military.com)
IN HONOR OF VETERANS on Veterans Day, 11 November 2007

The President of the United States
in the name of The Congress
takes pleasure in presenting the
Medal of Honor
to

BALLARD, DONALD E.


Citation:

For conspicuous gallantry and intrepidity at the risk of his life and beyond the call of duty while serving as a HC2c. with Company M, in connection with operations against enemy aggressor forces. During the afternoon hours, Company M was moving to join the remainder of the 3d Battalion in Quang Tri Province. After treating and evacuating 2 heat casualties, HC2c. Ballard was returning to his platoon from the evacuation landing zone when the company was ambushed by a North Vietnamese Army unit employing automatic weapons and mortars, and sustained numerous casualties. Observing a wounded marine, HC2c. Ballard unhesitatingly moved across the fire swept terrain to the injured man and swiftly rendered medical assistance to his comrade. HC2c. Ballard then directed 4 marines to carry the casualty to a position of relative safety. As the 4 men prepared to move the wounded marine, an enemy soldier suddenly left his concealed position and, after hurling a hand grenade which landed near the casualty, commenced firing upon the small group of men. Instantly shouting a warning to the marines, HC2c. Ballard fearlessly threw himself upon the lethal explosive device to protect his comrades from the deadly blast. When the grenade failed to detonate, he calmly arose from his dangerous position and resolutely continued his determined efforts in treating other marine casualties. HC2c. Ballard’s heroic actions and selfless concern for the welfare of his companions served to inspire all who observed him and prevented possible injury or death to his fellow marines. His courage, daring initiative, and unwavering devotion to duty in the face of extreme personal danger, sustain and enhance the finest traditions of the U.S. Naval Service.
MEDAL OF HONOR RECIPIENT
Don “Doc” Ballard

By Gary Alexander

“It shall be the privilege and responsibility of the City of Gainesville, Texas to welcome our Nation’s Medal of Honor Recipients at every opportunity.
In so doing, we pay homage to the principles which the Medal of Honor represents... Duty, Honor, Country”
— Medal of Honor Host City Program of Gainesville, Texas

Medal of Honor Recipient
Don “Doc” Ballard has a demanding schedule of meetings, public appearances, conventions, and reunions. Like many of his fellow recipients, he attends all presidential inaugurations and monument dedications, and is a sought-after speaker at patriotic events. It is not unusual for Doc to crisscross the country, sometimes making two or three trips a month. Yet he can’t recall the exact number of times he’s visited Gainesville Texas—a town of 16,000 along the Red River just a few miles from the Oklahoma border. “Those of us who have had the chance to visit Gainesville never miss the opportunity to encourage other recipients to do so as well,” says Ballard. A Vietnam War veteran from Kansas City, Ballard was the first to answer the invitation from Gainesville’s Medal of Honor Host City Program. Each year the program invites a number of recipients to participate in its Medal of Honor Weekend, and this year the organizers hope to welcome the 25th recipient since the celebration began in 2001. “Gainesville exemplifies the patriotism which is vibrant and thriving in rural America but is too often overshadowed by the continual focus on the excess and cynicism of this country’s metropolitan population centers,” he said, noting that is one of the reasons he enjoys returning, sometimes just for an unannounced long weekend.
Ballard, a Navy Corpsman, was serving in Third Battalion, Fourth Marine Regiment in 1968, when his unit was ambushed by the North Vietnamese. Reacting immediately to the first cries of “Corpsman up!” Ballard rushed to the fallen Marines still under hostile fire and pulled them to a safer position for treatment. Soon this position became untenable as Ballard and his fellow Marines found themselves in the center of a crossfire between Marine and enemy forces. Suddenly an enemy hand grenade landed near the wounded. Ballard quickly grabbed it and threw it back as the machine gun and small arms fire increased. Moments later, a second grenade bounced into the middle of the small group of Americans. With no time to throw it away, Ballard instead covered the grenade with his body to protect his seriously injured comrades.

Later, Ballard would tell a reporter that after what had seemed like an eternity, and no explosion, he reached underneath him to grasp the grenade, rolled over, and in the same motion threw the grenade away. A split second later, witnesses say, the grenade exploded in midair, but out of harm’s way. Ballard was already back to treating his casualties. “I didn’t have time to think,” he said. “It was instinctive, and it was the right time to be in the wrong place.”

Since then, Ballard said that he has come to believe that it is often harder to wear the Medal than it was to earn it because for the rest of their lives Medal of Honor Recipients shoulder a heavy burden—they represent the American military and all its veterans and the very core values of the nation. “I would be remiss if I didn’t say that we also wear the Medal for all those who made the ultimate sacrifice and were heroes, but no one was there to witness their actions. We speak for those who could never speak for themselves.”

At the end of his enlistment, Ballard left the Navy and joined the Army just a day or two before he was to receive the Medal from President Richard Nixon. Learning of his decision to join the Army, General William Westmoreland offered him a direct commission and an active duty assignment. For family reasons, Ballard turned the offer down but was later persuaded to accept the commission in the Kansas Army National Guard, where he remained until he retired at the rank of Colonel. He was inducted into the Kansas National Guard Hall of Fame in November 2001.

“I believe the Gainesville Host City Program’s approach follows closely (the Congressional Medal of Honor Society’s) mission statement, which is to foster Americanism and patriotism in our country,” Ballard said. “We love to talk to students at all opportunities because each generation must produce civic and military leaders when their time comes,” he said, noting that for this current generation it is harder to “answer the call” than in the past.

“We grew up in a patriotic environment, which was reinforced by the school, the church, and the community, so the message was clear and understandable,” Ballard recalled. “And… there was a draft; it was a real fact of life for young men as soon as they turned 18.”

Ballard believes that nowadays, however, young men and women desiring to join the all-volunteer military must overcome the negative peer pressure of friends and classmates who would not consider military service or who even oppose it. The Kansas City businessman said that older veterans and especially Medal of Honor Recipients have a responsibility to support the military and the young veterans of the war in Iraq and Afghanistan and to encourage them to use that experience to help guide the nation in the future.

These young Americans made the right choice by serving their nation, he said, even though they had to sacrifice—some of them at a great personal price—when their peers have not. “They made an informed decision to serve,” said Ballard. “And, often, despite grievous wounds and shattering experiences, they know that they made the right decision to serve and will call on that experience for the rest of their lives. Hopefully, they will use it to influence others.”

“The last thing we want to do is send ignorant people to the polls; an uninformed vote flies in the face of the ideals of this nation,” Ballard said. “And that’s why I support the Gainesville program. By bringing us down here we help reinforce the message of ‘duty, honor, country.’” he said. “We do our best to emphasize patriotism that is found less frequently in schools, civic organizations, and churches.” •

Gary Alexander is a Marine veteran of the Vietnam War, a former journalist and photographer, and editor and media relations director. He has been a psychotherapist since 1990. He is currently the historian for and a member of the executive board of the Medal of Honor Host City Program in Gainesville, Texas, and continues work on a non-fiction book about his experiences in Vietnam. He is a recommended member of the Home of Heroes Speaker’s Bureau on the subject of Medal of Honor recipients and the history of the Medal of Honor. He can be reached at Trauma Treatment Consultants, 1109 Hillcrest Blvd., Gainesville, Texas 76240, (940) 372-0078.
History

Back in the mid-1990s, Don Pettigrew and I were privileged to attend reunions of the Iwo Jima Survivors Association, which were held annually in Wichita Falls or Dallas. For two Marine Vietnam veterans, meeting these men was a pilgrimage…an honor. The second reunion of Iwo Jima Survivors we attended reminded us how the half century since five Marines and a Navy Corpsman raised the flag on Mount Suribachi had decimated their numbers. At the time the only survivors of the two flag raisings were Charles W. Lindberg from the first group and James Bradley from the well-know second raising of the American Flag. Many were hobbled by old wounds and advanced age as they met in Wichita Falls one February to remember and honor those who died young in the black sand of the five-mile by two-mile Island, and those who had passed on later.

The Battle of Iwo Jima is near synonymous with the Medal of Honor—the nation’s highest award for valor in combat. And Iwo Jima—the bloody crucible that cost over 7,000 American lives and 20,703 Japanese—remains the most highly decorated single engagement in U.S. history. Twenty-seven Medals of Honor were awarded in a little more than three weeks; 13—virtually half—were awarded posthumously. Twenty-two were earned by Marines and the remaining five went to Sailors. Fully one—quarter of all the Pacific War Medal of Honor Recipients earned their medals taking Iwo Jima.

In 1996 three Iwo Jima Medal of Honor Recipients were scheduled to attend the annual Iwo Jima Survivors Association. The first night Don and I met Marine Hershel “Woody” Williams and Rufus Herring, a Navy boat commander who received the first Medal of Honor at Iwo Jima. Later, Don was talking with Cy Young, one of the reunion’s organizers and discovered that the third Recipient was unable to attend because the group didn’t have sufficient funds for his airfare and expenses. We were floored. How could the cost of a plane ticket stand in the way of flying a Medal of Honor Recipient anywhere?

Surely any airline would gladly and proudly donate the microscopic cost. Don did not let it go. He began calling the major domestic airlines. “They said the answer never changed…none of the airlines he contacted would provide one of the nation’s greatest heroes with a trip to Wichita Falls. Not long after we met him, Rufus Herring became ill and a few months later he passed away. Since then roughly 50 have passed away; only 109 now survive.

Don returned home still stunned at the lack of respect shown these great men; he and his wife, Lynette, decided to do something about it. They contacted me and a number of other volunteers and it was decided that what was needed was a unique way a small North Texas community could show its respect and appreciation for America’s veterans. The committee’s vision was to go beyond a static reflection of patriotism such as a memorial or statue; we
needed to establish a multi-faceted program that could teach and inspire... especially students. The answer lay with the nation’s greatest heroes. Gainesville’s Medal of Honor Host City Program was born.

Beginnings
It was decided that we would invite recipients of the nation’s highest award for valor to visit Gainesville as a destination, or even when simply passing through North Texas. Here they would be welcomed and, time permitting, tour the city and give Gainesville the chance to show its gratitude. As a small token, each Recipient would be provided a stipend to defray his expenses while visiting. It evolved that we would formalized the visits into an annual “Medal of Honor Weekend” celebration each spring and invite as many Recipients as possible. Thus far 19 Recipients have visited, meeting with residents, speaking to the children and allowing us to show them that a patriotic pulse beats strongly in small-town America.

It’s been over seven years since we started and ours is the only program of its kind in the country. Seed money was provided through the City of Gainesville and not long after the first Medal of Honor Recipient to visit was 1st Sergeant David McNerney who was the Grand Marshal of the city’s 2002 Christmas Parade. Impressed by his reception, McNerney has returned each year since. Additionally, the late Medal of Honor Recipient and World War II Aviator, Marine Brigadier General Robert E. Galer and his wife, Sharon, maintained a summer home at nearby Lake Kiowa and were very supportive in the program’s early days. The committee then created the next level of the Host City Program’s mission by inviting Recipients to participate in an annual, three-day celebration around March 25th—Medal of Honor Day.

National Medal of Honor Day
The United States Congress has designated March 25th of each year as National Medal of Honor Day, a day dedicated to Medal of Honor recipients. (Public Law 101-564.)

Conceived in the State of Washington, this holiday should be one of our most revered. Unfortunately all too many Americans are not even aware of its existence.

Why March 25th?
The date of March 25th was chosen to highlight this special day because it was on March 25 (1863) that the first Medals of Honor were presented... to six members of Andrews’ Raiders. If you haven’t read the story you can follow the hyperlink below titled The First Presentation to read about that historic day. http://www.homeofheroes.com/moh/history/history_first.htm.

What Can You Do About It?
National Medal of Honor day is celebrated in some communities, however for the most part the occasion comes and goes with little notice. As a patriotic American there are a few things YOU can do to commemorate this day:

• Fly Your Flag with pride and patriotism on this day.
• Remember Our Heroes. As a gesture of your appreciation, why not take just a few moments in the week prior to National Medal of Honor Day to mail a “Thank You” card to one of our living Medal of Honor recipients. You can find a list of the living as well as information on writing to them among the pages of this site.
• Inform Your Local Media. Most newspapers aren’t even aware that this special day exists. Why not tip your local media to the occasion. Before you do, check out our database of Medal of Honor recipients from your city and state as well as any who might be buried in your city. This information can give your media a “local angle” that can increase the probability that they will consider doing a story to remind Americans of our heroes.
• Consider doing something in your local schools, or even on a civic level, if there is a Medal of Honor recipient living near your location. Visit our site on School Ideas for more information on school assemblies. http://www.homeofheroes.com/ideas/assembly.html
• If there is a Medal of Honor recipient buried in your home town, get a school class, scout troop, or other youth organization to “adopt a grave site”. You can read in our School Ideas pages how one school in Pueblo has used just such a program as a part of their Social Studies program.

Gary Alexander is a Marine veteran of the Vietnam War, a former journalist and photographer, and editor and media relations director. He has been a psychotherapist since 1990. He is currently the historian for and a member of the executive board of the Medal of Honor Host City Program in Gainesville, Texas, and continues work on a non-fiction book about his experiences in Vietnam. He is a recommended member of the Home of Heroes Speaker’s Bureau on the subject of Medal of Honor recipients and the history of the Medal of Honor. He can be reached at Trauma Treatment Consultants, 1109 Hillcrest Blvd., Gainesville, Texas 76240, (940) 372-0078.
Talk, Listen, Connect™:
Helping Families During Military Deployment

A KIT REVIEW

By Maria Caroff

Talk, Listen, Connect™: Helping Families During Military Deployment is a wonderful kit for families experiencing the deployment of a parent or another member of the family. The kit includes a Sesame Street DVD, a parent/caregiver magazine, a children’s activity poster, and a survey, all in both English and Spanish. The DVD includes a special section for grown-ups, another section for the two songs sung in the program, and the option to select subtitles. In true Sesame Street style, the project mixes muppets, moppets, and adults in humorous, heartwarming, and enlightening fashion.

The DVD will hold the attention of both children and adults, providing both age groups with ideas, comfort, and insight. It also stands up to multiple viewings. The DVD and the parent/caregiver magazine address pre-deployment, deployment, and homecoming concerns realistically and creatively. The magazine has a helpful list of books and Web sites. There is also a printable copy of the parent/caregiver magazine and additional downloadable material, including the Talk, Listen, Connect video, at http://www.sesameworkshop.org/tlc.

The DVD, magazine, and poster all give a lovely boost to military families with the message: “In recognition of the contributions made by The Armed Forces of America—the Army, Navy, Air Force, Marines, Coast Guard, National Guard and Reserves…”

The kit is a creation of sesame-workshop™, the nonprofit educational organization behind Sesame Street (www.sesameworkshop.org). The collaborative effort is a good example of a project that can be done well and at the same time reach a broad audience. It was produced in partnership with and funded by Wal-Mart, with additional support provided by the New York State Office of Mental Health (OMH) and the Military Child Education Coalition™ (MCEC™). The list of advisors to the project reflects a strong level of care and expertise, with both distinguished military and civilian individuals and organizations represented.

Familiar, colorful Sesame Street characters appear on the poster, which breaks down the separate elements in the kit’s title. Some of the tips offered for coping with deployment include:

Talk
• Keep all lines of communication open with your child, spouse, and those around you.
• Make sure your child knows how special and how loved he or she is.

Listen
• There are going to be lots of changes. Some may be difficult.
• The deployed parent isn’t the only courageous person in the family.

Connect
• Your child is not alone. Your family is not alone.

The parent/caregiver magazine notes the following key information to be aware of during the time of pre-deployment when preparations for departure are being made:

The deployed parent hasn’t left yet but isn’t really available. The work hours are often long. Mom or Dad may be home or perhaps away training; there are already comings and goings. This may be the phase when young children need the most reassurance. They may not quite understand why a parent is leaving. They may even feel that somehow they’ve done something to cause that parent to leave. Offer concrete information to your young child in ways that he can understand. Prepare and plan as a family. Knowing what to expect may help your child feel less afraid. Even when you’re not all together in one spot, you’ll still be connected.

And this simple but oh-so-sound advice: Let your child know that others care. Tell him when a friend or extended family member asks about him.
Good preparation prior to deployment can help to ease some of the difficulty of the parent’s time away:

- Spend as much time together as possible, and give plenty of hugs! Make audio or video recordings of the deployed parent reading favorite bedtime stories or sharing familiar lullabies. These can be played during those times when the parent is missed the most.
- Share appropriate information with your child in a way she will understand.
- Emphasize the special training the parent has had.
- Build a support system around your family.
- Swap special personal objects.
- Find ways to keep the deployed parent ‘close.’

When the deployment has occurred:

Things change once a parent has been deployed... You may have to rethink the way some things are done at your home. You’ll find yourself creating a new ‘normal...’” Maintaining familiar routines comforts children and helps them feel secure. If you’ve always read one book and sung one lullaby at bedtime, don’t change now! Keeping your child busy—with family and friends, outdoor activities, and preschool programs—will help fill the days with positive thoughts and will give your child things to look forward to... New routines can make your time together even more special. Camp out in the living room on Saturday nights, or have a weekly backward day—sandwiches for breakfast and eggs for dinner. Be creative!

To maintain a feeling of connectedness within your family and to promote healthy communication that increases the child’s well-being:

Reach out to, and connect with, important people in your child’s life. Talk to extended family, clergy, coaches, neighbors—anyone you’re counting on for help, so they’ll be better able to offer support. Set up lines of communication with your child’s caregivers and teachers. Talk about what you are doing with your child and why.

Prepare your child for important holidays:… Talk to your child’s teacher about the best way to handle school holiday events. Can the child bring a grandparent or someone else? Know in advance how you’re going to celebrate birthdays, religious holidays, Mother’s or Father’s Day, and so on. If possible, the deployed parent can choose some cards or gifts before leaving.

Fun and regular activities, as well as shared chores, provide some equilibrium. Some families are able to connect via a webcam and the Internet. Also important, “Carefully monitor what your child watches or hears on TV or radio, turning off any coverage of wars or other violent events that may be disturbing. Make sure your child’s caregivers do the same.” Simple but profound statements, like the one offered by Elmo’s Dad to him, can have a significant impact: “No matter where I am I’ll still be able to see the moon, just like you.”

If the child can see the optimistic side of the situation, so much the better. “Keep things positive. Discuss with your child ways in which the family has grown stronger.” Additionally, it is important for the child to know that, “like the deployed parent, the entire family is courageous. Teach your child that being brave doesn’t mean he can’t be sad or scared. It simply means he’s doing his best despite those feelings.”

The “For Grown-ups” section of the DVD as well as the family interviews included in the main program are both heartwarming and heart-wrenching. The vulnerability is apparent in the eyes of parents and children. So, too, is the admiration.

A father of four, sitting together with his wife and children, says, “Just to know I had all my kids that thought
Talk, Listen, Connect

“You just kind of sit back and just observe and watch, and start feeling your way back into your family. You don’t jump in and start playing Daddy and putting down rules and everything else.”

of me as a hero was really neat. It was really good.” His daughter gazes up at him intently as he speaks.

“When my Daddy has to go somewhere, he will ask me to watch him (his younger brother), so I can be like a watcher and a leader for my little brother,” one youngster says, his eyes gleaming as he speaks, while he and his brother are at a playground with their father.

The grandmother of a single mother in the Air Force, who has been deployed three times, indicates that her daughter asked her if she would help with the children before joining the Army. “When Mom comes back,” says the children’s grandmother, who is clearly unable to eat the food that is on the table, due to her emotional state in discussing her daughter’s absences, “I’m out of the picture. It’s no more me for two weeks. She tries to pack all her hours into the few hours that she has with them in order for them to have something to remember when she goes back…I just try to carry on how she started out. That’s all I do—just what she started.”

One mother describes the burden on her son who was six years old the first time his father deployed. “He understands more this time,” she says, and so it is harder on him this second time around. Seeking confirmation from her son, he affirms this, yet it wasn’t necessary as his eyes and face tell the tale.

Family members describe spending a lot of time playing together before the parent deploys. Parents and other caretakers left at home talk of remaining active and busy to help pass the time and serve as a distraction.

Mementos are a significant source of comfort. One mother displays patchwork pillows and a quilt that the family cherishes, with many photos of her husband and the family. (Operation Kid Comfort, a program of Armed Services YMCA (ASYMCA) provides free quilts for children six and under and pillows for children age seven and up (http://www.asymca.org/c4-2.html)).

The time of the parent’s homecoming, while a joyful occasion and one long looked forward to, carries its own, often unexpected, challenges. Elmo finds himself not knowing what to say to his father when he arrives home. Being aware of these possibilities ahead of time can ease the transition:

It’s a happy time for your family—but it’s also one more change, which means your child will need your special support.

Together Time—Before
• Talk with your child about what to expect.
• Involve your child in planning something special…

Together Time—the Day of
• If your child feels shy…
• Talk! Tell your young child that things may seem strange at first…

Together Time—After
• Take it slow; be patient.
• Continue healthful routines.
• Thank your extended team!

Describing the reintegration of the returning parent back into the family, one mother says with a laugh, “You’re in such a routine without him that it’s hard to put him back in it.” Her husband notes, “You just kind of sit back and just observe and watch, and start feeling your way back into your family. You don’t jump in and start playing Daddy and putting down rules and everything else.”

Another father, holding one of his three children, relates, “Connor wasn’t really used to coming to me to ask questions or for comfort. He was more used to his Mom, since she was there, and she was around. That kind of bothered me. I understood it, and I was prepared for it whenever I came back. But when I got back, it was very hard to swallow that I wasn’t number one in the skin department. That was one of the hardest things, that I wasn’t comfort enough for him. But he eventually got used to it.”
Families that have a family member with disabilities transition to their new location with the least amount of disruption possible. The family needs to make contact with these agencies early. They will have information on the location where the family will be moving and the services their exceptional family member may need.

Physical Disability

The family needs to fill out the proper EFMP paperwork (DD Form 2792, Exceptional Family Member Medical Summary for medical issues and, if the child has an Individualized Education Program (IEP), DD Form 2792-1, Exceptional Family Member Special Education/Early Intervention Summary for educational issues). This is the information that the receiving installation will use to verify that the services the family needs are available to them within a seventy-mile radius. However, it is up to the family to ensure that the needs of the family member can be, and are, met. Families may need help and resources beyond those afforded them through the EFMP office.

How can a family find out what other resources are available at the new location? One of the new resources available to all military families is MilitaryHOMEFRONT (http://www.militaryhomefront.org). The new Plan My Move Web-based program provides access to information about your entitlements and benefits, points of contact, checklists, planning tools, and information on education and employment. Plan My Move will put you and your family in charge of a smooth relocation to your new duty assignment. The Web site requires information regarding current duty assignment, next installation assignment, and your anticipated departure date. The first screen is an indication you are not dealing with just any other PCS site – after you enter this information, you are asked if you have a family member with special needs.

The Web site gives you a three-month calendar of activities you need to do to prepare for departure as well as useful strategies and tips. For example, one Tip of the Day notes, “Help the relocation manager help you obtain all the benefits to which you are entitled.” Tell the relocation manager whether you are married and if your spouse is a military member. Provide the number of children or other family members living with you."

The Web site also links you to an informational page regarding your current installation as well as the installation where you are being assigned. One of the more interesting features of this new tool is the ability to find information about the community itself. By using a drop-down menu, visitors to this site can get information about a variety of topics, including: community and school information, housing office contacts, transportation office information, and others.

Another interesting feature of the site is the ability to develop checklists, planning tools, and informational resources beyond those afforded them through the EFMP office.

www.eparent.com/EP MAGAZINE • November 2007 87
Military deployments change lives. Today in the news, it is easy to find stories about United States Military Service Members returning from deployment with injury or illness. And in some unfortunate cases, one will find stories of Service Members not returning at all. But what about the children of these brave men and women who give their all to the United States?

There are nearly 1.8 million military-connected children in this country. Of these children, 700,000 currently have at least one parent deployed. The Global War on Terror demands great sacrifices of its Service Members, and consequently, military-connected children often face complicated circumstances and losses that force them to adjust to a different life—a “New Normal.” Intermittent communication, the emotional stresses of separation, and the potential for injury or death of a loved one are just a few of these potential challenges. While all of these challenges are important and worthy of discussion, the Military Child Education Coalition™’s Living In the New Normal: Supporting Children Through Trauma and Loss™ (LINN™) initiative focuses primarily on grief and loss experienced by the children of a loved one who has been injured, is suffering from combat-related illness, or has died in the line of duty.

What relevance does this subject matter have for children with special needs? Approximately 13 to 15 percent of all military children have disabilities. This means that of 700,000 children with deployed parents, between 91,000 and 105,000 of them are potentially children with special needs. Children with special needs already face unique concerns—compound this with a military lifestyle full of transition and the potential for the traumatic loss or injury of a loved one.

One of the keys to the MCEC’s initiative and an underlying philosophy is the importance of positive psychology. The natural human tendency is to focus on the negative, but from the perspective of positive psychology, the underlying question should be, “How can we use this challenge to help the child cultivate resilience and hope?” Encouraging the courage of children and recognizing their strengths will bolster their confidence and, in essence, their ability to meet life’s challenges. Children are courageous, flexible, and resilient, and through deliberate encouragement from the adults in their lives, they can enhance these coping skills.

In order to promote this philosophy and meet the mission of the Living in the New Normal initiative, the MCEC did extensive research over several years, creating three key modules. Two components focus on enabling the teacher, the counselor, the business owner, the coach, the friend, and others to better help military families as they transition to their New Normal. The third facet of LINN is focused on providing adults and children with worthwhile vetted resources and reliable references related to adjusting to a New Normal.

The first of these components is public engagement. While the military strives to provide support to families struck by trauma, all mem-
Military HOMEFRONT and Expansion

lists. Information about travel, documents to hand-carry, and arrival checklists are available to customize to fit your family’s needs.

When you take a close look at the community and school information portion of the site, you will find a number of different options to research. The site offers information on Department of Defense Education Activity (DoDEA) schools. It contains information about the Department of Defense Dependents Schools (DoDDS) overseas and the Department of Defense Elementary and Secondary Schools (DDESS) stateside. Another remarkable feature of the Military HOMEFRONT Web site is that it allows military families access to demographic data about the public schools near military installations.

Thanks to a partnership between Military HOMEFRONT and Expansion Management, military families also have an additional resource to help them make informed decisions about nearby communities. Expansion Management is an organization that assists companies with fewer than 500 employees. The organization strives to educate its readers on how they can evaluate and compare various communities and sites throughout the country and around the world. The intent is to determine which communities will best enhance their long-term business requirements while supporting the needs of the families.

Specific information about the schools can be found through the School Report link. The School Report provides demographic information in numerous categories, including: location/school type, gender makeup, test information, pupil-teacher ratio, special education, and enrollment statistics, to name a few. Military families can use this information to assist them in choosing a school. (This information does not rank schools.).

As you can see, moving will still be one of the most challenging experiences we face as military families, but with the right tools and a great attitude, we can all make the move, the “Great Military Adventure” that every family can be happy with.

Living in the New Normal—continued from facing page

members of a military family’s community can help to enhance this network. Through public engagement, the MCEC provides the forum for deliberative discussion resulting in a community-created, effective, sustainable home front to support military children. A system that is aware of the uniqueness of the military lifestyle and is equipped with the appropriate tools and resources will be able to provide the support and understanding necessary to encourage healing.

The second dimension of LINN is a two-day professional development institute providing extensive resources, information, and strategies to educators and community professionals in supporting children who experience grief, trauma, and loss. Adults who attend the two-day course will not only know how to consciously maintain this normalcy, but also will be given suggestions and practical activities to help children express their emotions.

Children may cope with and express trauma and grief differently than adults, but they do feel it just as deeply. Additionally, military-connected children feel both the primary loss and also secondary loss, such as relocation, the loss of the familiar military community and culture, and changes to their support network and friends.

Children with disabilities such as autism find comfort and calm in routine, order, and normalcy. This means that the potential secondary losses must be quickly recognized and a plan developed to maintain as much structure as possible. Settings such as school can provide predictable, safe, and stable environments in which children may find solace. A solid, informed support system is crucial to the health and well-being of any child as they work through grief and loss to a new state of contentment—to their New Normal.

During times of deployment, many military children face trauma and loss and must learn to adapt to an altered existence. Most military children meet this challenge valiantly. The MCEC’s Living in the New Normal: Supporting Children through Trauma and Loss initiative recognizes these amazing children and strives to build a bridge to their smooth transition to a New Normal. The MCEC, though, can only do so much. The friend, the coach, the teacher, the community must buy in for every child to thrive. For more information about the MCEC or Living in the New Normal, please visit www.MilitaryChild.org or call 877-953-1923.

Jaclyn Collins has managed the Marketing, Publication, and Legislation efforts at the Military Child Education Coalition for the past year. A military child for the first eighteen years of her life, and a military spouse for the past three, Jaclyn is deeply affected by and attached to the unique challenges that face all military children.
Temperatures exceeded 115 degrees on July 11 during the five-hour mission in the city of Amerli. More than 50 Soldiers were on site and tensions were high; Amerli was the scene of a massive suicide truck bombing just four days earlier.

Soldiers kept alert but visibly struggled under the weight of dozens of pounds of battle gear. Throughout the sun-scorched day, all but two Soldiers limited their movement as much as possible. All but two could afford that luxury.

Spcs. Vanessa Bolognese and Aimee Collver, combat medics, Personal Security Detachment, 3rd Infantry Brigade Combat Team, 25th Infantry Division, continuously walked up and down the lines of men. “Drink water,” they repeated. “Are you feeling OK?” they asked. They were the two Soldiers charged with ensuring that each man stayed hydrated and returned safely to base. As usual, they were the mission’s only dedicated medical personnel.

Bolognese and Collver kept all their male counterparts healthy “outside the wire” that day in Amerli just as they do every day in the Kirkuk Province, Iraq. Neither is doing exactly what she thought she’d be doing in the Army, but neither would trade her job for another.

“Before I enlisted, I was going to school to become a registered nurse,” said Bolognese. “I wanted a medical job, and my military occupational specialty is called Health Care Specialist,” said the 21-year-old from Chino Hills, Calif. “In fact, the first time I heard the term ‘Combat Medic’ was during advanced individual training at Fort Sam Houston. They pretty much told us there, ‘You will be deploying. You will be working in Iraq.’”

Bolognese’s colleague and roommate had similar motivations. “I’d been working in a nursing home after high school,” said Collver. “When I walked into the recruiter’s office, I knew that I wanted a medical job,” explained the 23-year-old from Puyallup, Wash. “The healthcare specialist job was available, and I was told that I would be working in a hospital setting,” she said. “Of course, I don’t work in a hospital, and nothing out here in Iraq is anything like what I thought.”

What each combat medic is doing in Iraq is working as the designated medical asset to the 3rd Infantry Brigade Combat Team’s, Personal Security Detachment. The PSD’s primary mission is to transport certain members of the brigade’s command group around 3IBCT’s area of operation. The PSD also provides personal security during a mission in Amerli, Iraq, July 11.
security for the command group to and from their various destinations and while on site, according to Staff Sgt. Jeremy Brandon, non-commissioned officer-in-charge, PSD, 3IBCT.

Brandon is a native of Jacksonville, Fla. and is serving his third combat deployment. He’s charged with supervising both Bolognese and Collver and explained why each Soldier is vital to mission success.

“We often conduct operations as an independent element,” explained Brandon. “For that reason, we need to have our own dedicated medical support. Bolognese and Collver are that support. We always have one of them with us wherever we go,” he said. And Brandon couldn’t be happier with their performance.

“Both Soldiers are everything that one could ask for in a medic,” he continued. “They have done an outstanding job staying on top of their skills. They’ve constantly taken it upon themselves to retrain and stay certified and have done an excellent job both outside the wire and back here on the forward operating base, by taking the initiative to give us various medical classes.”

Brandon’s PSD Soldiers agreed.

“We all respect them for their abilities as medics and as Soldiers,” said Sgt. Brian Tabor, squad leader, PSD, 3IBCT. Tabor is a five-year veteran serving his second combat deployment. “We haven’t had any issues because they’re female,” emphasized the Sacramento, Calif., native.

“Bottom line: They’ve been a valuable asset to the PSD and it’s been a good thing having them with us.”

Even though Bolognese and Collver are not working in the comfortable confines of a hospital, each love their job and wouldn’t choose to do anything else.

“Of course, the job is mentally challenging because of the unknown anytime you leave the wire,” said Collver. “But I love being with this group because there’s so much camaraderie. I take a lot of pride in knowing that they’re well taken care of because I’m there for them,” she said.

“Their well-being depends on me when I’m with them,” echoed Bolognese. “In that sense, it’s wonderful to know that when I look back at my deployment I can say that I did go out there every day and risk my life to take care of other Soldiers,” she said. “That’s a lot more than most people can say.” •

(Right) Spc. Vanessa Bolognese, combat medic, Personal Security Detachment (PSD), 3rd Infantry Brigade Combat Team, 25th Infantry Division, helps pull security during a mission in Amerli, Iraq, July 11. PSD combat medics are expected to perform fundamental security functions in addition to medical functions when in the field.
Health Net Federal Services, LLC, the government operations division of Health Net, Inc., launched its Warrior Care Support (WCS) Program on August 8, 2007. The program directly connects severely injured or ill Warriors and their family or care support members to a single point of contact for total healthcare support once a Military Treatment Facility (MTF) determines care will be best delivered within the civilian healthcare sector.

Health Net provides specialized and individually focused support to assist Warriors in obtaining the necessary physical and behavioral healthcare services, including social services, in a timely, coordinated fashion. Each Warrior is assigned a specific “Health Care Coordinator” who personally guides him or her through the care continuum to facilitate the best in quality healthcare as well as a seamless transition throughout the various stages of healthcare services and military status changes. The Health Net program is designed to encourage Warriors to focus on their recovery and leave the navigation of healthcare services to the Health Net Care Coordination Team.

What is a Warrior?
TRICARE Management Activity (TMA) defines Warriors as “Soldiers who have served in a combat zone or received hazardous duty pay and believe they have a disease or disability connected to their service.”

Health Net extends this definition for the WCS program to include Active Duty Service Members (ADSMs) who have a severe injury (combat or non-combat related; e.g.: injured in combat, injured while on training drills, injured in an automobile accident) or a combat-related behavioral health diagnosis.

An ADSM in any of the Uniformed Services, including a Reservist or National Guard member with active duty status, who is severely injured or ill and meets the WCS program diagnosis criteria will be evaluated for enrollment into the Health Net WCS program.

How the Program Works
Following a Warrior’s transfer of care to the civilian sector, the Health Net Care Coordinator tracks a Warrior’s previous and current healthcare services, completes a comprehensive assessment of his or her condition, and personally connects with the Warrior to establish a relationship. The coordinator will work with the MTF and Veterans Affairs physicians, physical therapists, and other providers to coordinate care, empower Warriors with knowledge about their healthcare choices, and assist with claims and authorizations for civilian care.
Members of the Health Net Care Coordination Team include handpicked professionals with experience in utilization management, transitional care, case management, social services, and behavioral health services. In addition, a team of Health Net physicians works closely with the Health Net Care Coordinators to provide support and counsel.

Warriors receive a welcome packet that includes Warriors’ benefits, details of services provided through the Health Net WCS program, and a wallet-sized Platinum Card with the name and phone number of their designated Health Net Care Coordinator.

How does a Warrior get into the program?

There are several points of entry:
- Heath Net Call Centers (1-877-TRICARE/1-877-874-2273), responding to inquiries from ADSMs or a family member
- Referrals from Medical Management (e.g.: Utilization Management, Transitional Care, Case Management, or other Health Net associates)
- MTF or civilian provider referrals or authorizations
- MTF or VA care planning conferences
- Direct referrals from MTF and Warrior Transition (WT) Case Managers

Benefits for the Warrior
- A designated Health Net Care Coordinator who oversees and guides healthcare service access and administrative processes in the civilian network.
- Consistency and familiarity with one person who provides individual attention and knows the Warrior’s case.

- Simplified process and seamless transition in and out of civilian care settings.
- Assistance with benefits coverage and associated changes due to change in military status.
- Access to a comprehensive Health Net provider network, including specialty care, such as services from Traumatic Brain Injury (TBI), Post-Traumatic Stress Disorder (PTSD), and other severe-condition specialists.
- Easy access to behavioral health services for life assistance programs, stress management, emotional well-being and reintegration.

Health Net Federal Services’ Warrior Care Support team includes medical management’s leadership including Kimberly Morgan, Vice President, Candace Maynard, Director, Eileen Yaeger, Director, Naomi Nasshan Director, Elita Johnston, Director, Kathleen Prisco, Manager, Paula Ackerman, Manager, and Marti Wolf, Manager.

These individuals comprise over 50 years of TRICARE experience with several of these individuals participating in the original CHAMPUS Program in 1988. Their years of experience with the Transitional Care Program, provided the insights and avenues of opportunities to enhance the service to our Activity Duty Service men and women with the development of the Warrior Care Program.

For more information about Health Net Federal Services’ Warrior Care Support Program, please call 1-877-TRICARE (1-877-874-2273).
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From Our Families...To Your Families
May Institute
Responding to the Critical Need for Autism Services

By Dennis C. Russo, PhD, ABPP and Eileen G. Pollack, MA

As May Institute has evolved over the past five decades into a national organization with more than 200 program locations, we have been guided by our mission of helping families navigate the complex world of autism and related disabilities. Earlier this year, that mission led us to Columbus, Georgia, where we opened our newest program, taking resources to families stationed at Fort Benning, home to a military community of more than 100,000.

In 1955, when Dr. Jacques and Marie-Anne May opened the doors to what would become May Institute's first school for children with autism, their twin boys were among its first students. The Mays were parents, but they were also visionaries whose dream was to create a place that would take "a total and complete involvement with the child...a special sensitivity to the needs of others...and an extraordinary kind of imagination."

Jacques and Marie-Anne understood that their boys' journey with autism would include unexpected turns and unfamiliar territory. Although that journey began in the early 1950s, when very little was known about autism, the challenges the May family faced resonate today with families across the country and beyond.

Military families are often confronted with a very particular set of challenges as they navigate that journey with their children. (See accompanying article, "One Family’s Story" on page 51.)

Autism, a neurological disability that causes difficulty with behavior, communication, learning, and social interaction, can create enormous stress on a family - stress that is magnified when one spouse is away for extended periods of time, when trans-
Major Bill Nelson and his wife, Karen, are very familiar with the challenges that confront military families who have a child with autism. They were stationed in Korea when they began thinking something might be wrong with their son. “We had our suspicions when Peyton was two and a half,” says Karen. “We went to see a developmental pediatrician who recommended early intervention services, which Peyton got during a medical visit to Tripler Hospital in Hawaii. He wasn’t officially diagnosed with ASD until we moved to Fort Campbell, Kentucky, when he was three years old.”

By this time, two physicians had recommended speech and occupational therapy, but the Nelsons discovered that finding professionals who could provide these services at a military installation was nearly impossible. “I had to search to find a speech therapist at Fort Campbell,” Karen says. “Peyton saw an occupational therapist there, too. But those were the only services we could get for a while.”

Doctors had also recommended applied behavior analysis (ABA) therapy, but there were no ABA therapists to be found at Fort Campbell. When the Nelsons moved to Fort Benning in Columbus, Georgia, Karen continued her search.

Karen found an ABA therapist through a chance encounter with a fellow officer’s wife whose son has a developmental disability. The boy was receiving in-home ABA services from Jade Lewis, BS, BCABA (Board Certified Associate Behavior Analyst), a May Institute behavior therapist who commutes between Atlanta and Columbus, a round-trip distance of about 200 miles. Karen and Bill were thrilled when Jade, who is now an employee of the new Southeast Regional Autism Center, moved to Columbus and started to work with Peyton.

ABA – The Missing Link

“ABA was the missing link for us,” says Karen. “Jade rocked our world. She is what we needed. Occupational and speech therapy are great, but we needed Peyton to behave and cooperate,” she explains.

Seven-year-old Peyton is now a second-grader at Lloyd Elementary School, which is part of the Department of Defense school system at Fort Benning. He is in a “life skills” classroom, but joins his typically developing peers for music, art, physical education, and lunch.

The school has been very receptive to Jade coming in and consulting with teachers on how to work with Peyton’s behaviors. “She converses with his teacher and is on his IEP (Individualized Education Program) team,” Karen says. “Her job is to make his behaviors better so the teachers can teach him.”

ABA – The Missing Link

Karen, Peyton, and Bill celebrating Christmas together.

A System for Success

Using the principles of ABA, Jade is also helping Peyton and his parents develop a system to get his homework done. “We needed a system,” says Karen. “We weren’t being consistent and sometimes it got ugly. He would have meltdowns.”

Peyton’s homework system works like this: He gets to watch his favorite cartoon DVD for a few minutes. When a pre-set timer goes off, he sits down and starts his homework. He chooses which page of homework to start with and which pen or pencil he wants to use. Then he gets a small treat (a tiny piece of candy). When he completes a page, he may watch a few more minutes of his cartoon. When the timer goes off, the process is repeated. “It’s worked beautifully,” says Karen. “He’s really done well.”

Jade explains how ABA therapy is truly a partnership between family and therapist. “I couldn’t have made this much progress with Peyton on my own,” she says. “His parents have been supporting everything we have been doing with him. I just gave them the tools they needed and they ran with it.”

Like loving, supportive parents everywhere, Karen and Bill Nelson have hopes and dreams for their child’s future success and happiness. “I’m hoping Peyton can be mainstreamed as much as possible,” says Karen. “He’s very smart. He has lots of potential.”

One Family’s Story

Karen, Peyton, and Bill celebrating Christmas together.

ABA – The Missing Link

Karen, Peyton, and Bill celebrating Christmas together.

ABA – The Missing Link

Karen, Peyton, and Bill celebrating Christmas together.
fers create abrupt changes in daily routines, and, most of all, when effective services are not easily accessible.

A Personal Perspective
For May Institute President and CEO, Walter P. Christian, PhD, ABPP, who is largely responsible for the exponential growth of the organization over the past 30 years, opening the Southeast Regional Autism Center in close proximity to Fort Benning, was both a personal and a professional decision.

Christian is well acquainted with life on military bases and with the challenges that families often face when trying to access services for their children with special needs.

His daughter, Katherine, and her family have lived on various bases over the past 10 years and are currently stationed at Fort Benning. When Christian’s grandson was diagnosed with a disability several years ago, the young boy began receiving services from May Institute’s Atlanta office, about 100 miles away. His services, like all those provided by the Institute, are based on the principles of applied behavior analysis (ABA) – the most effective method to teach children and adolescents with autism and other developmental disabilities. (See accompanying sidebar to the right for more about ABA.)

“Families were willing to travel long distances to get care, and the need for ABA services was overwhelming.”

That’s when May Institute stepped in. For the past five years, behavior consultants from the Atlanta office have been providing home-based services to military families stationed on Fort Benning or in the surrounding Columbus area, traveling back and forth as needed.

Earlier this year, the Institute made the decision to expand its reach to better support Fort Benning families affected by ASD. The recent opening of the Southeast Regional Autism Center in Columbus finally brought resources directly into the community, with consultants providing services at the point of need, in local homes and schools.

“We offer screenings for children who may be exhibiting signs of ASD,” said Christian. “A local presence allows us to provide training and education to physicians, teachers, and parents, as well as home-based therapy to children with autism and other developmental disabilities.”

As this new center expands its operations, the goal is to provide services at other bases throughout the Southeast.

Helping Families at Fort Benning
Well aware of the growing number of children being diagnosed with Autism Spectrum Disorder (ASD) throughout the country, Christian recognized that there would probably be a significant number of children on the installation with autism or other related disabilities who could benefit from ABA.

“It quickly became clear to us that the types of services military families needed weren’t available to them in their community,” Christian said.

Applied Behavior Analysis: Effective and Individualized
Applied behavior analysis (ABA) is the treatment of choice for children with autism. It is a methodology, or framework, that applies scientific interventions to address behavioral needs.

What most attracts parents to a program of ABA are its positive and reinforcing tone, its strong focus on teaching new skills, the documentation of progress in reports and charts, its foundation in research, and the manner in which it is individualized for every child.

ABA helps with the development of language, social interactions, and independent living by applying basic behavioral practices – a positive reinforcement, teaching in small steps, prompting, and repeated practice. ABA can also help reduce both everyday social problems and serious behavior disorders.

Hundreds of scientific studies have shown that ABA is the most effective method to teach children and adolescents with autism and other developmental disabilities. ABA has been endorsed by the National Institutes of Health (NIH) and the Association for Science in Autism Treatment (ASAT) and has been identified by the Surgeon General of the United States as the most effective way to treat autism.
About May Institute

May Institute is a nonprofit organization that provides educational, rehabilitative, and behavioral healthcare services to individuals with autism and other developmental disabilities, brain injury, mental illness, and other behavioral healthcare needs. The Institute also provides training and consultation services to professionals, organizations, and public school systems.

Since its founding over 50 years ago, May Institute has evolved into an award-winning national network that serves over 25,000 individuals and their families annually. With corporate headquarters in Randolph, Massachusetts, the Institute operates more than 200 service locations in the Northeast, Mid-Atlantic, Southeast, Midwest, and on the West Coast. Six May Institute schools serve children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities. A seventh school serves children and adolescents with brain injury.

An active center of research and training, the Institute maintains affiliations with more than 40 universities, hospitals, and human service agencies worldwide.

May Institute is the first nonprofit human services organization in the country to receive top national honors from the Society for the Advancement of Behavior Analysis (SABA) and the Association for Behavioral and Cognitive Therapies (ABCT). The Institute received the 2005 Outstanding Training Program Award from ABCT and the 2007 Award for Enduring Programmatic Contributions in Behavior Analysis from SABA.

In 2005, May Institute sponsored the initial development of the National Autism Center (NAC), a groundbreaking nonprofit organization dedicated to supporting effective, evidence-based treatment approaches for autism, and to providing direction to families, practitioners, organizations, policy-makers, and funders. Together, May Institute and the National Autism Center are committed to identifying and applying universal standards for the treatment of autism and to providing care and hope to families throughout the country.

For information about May Institute programs and services, please visit the May Institute Web site, at www.mayinstitute.org. For additional information, call (800) 778-7601, or send an email to info@mayinstitute.org. To contact the May Institute’s Southeast Regional Autism Center, call (706) 571-7771.

Looking to the Future

We know much more today than in 1955, when many people believed that emotionally cold or uncaring parents were responsible for their child’s disability and when children were typically institutionalized for life. We know the critical importance of an early diagnosis and the benefits of early and intensive treatment.

We are hopeful that ongoing research efforts will one day unravel the mysteries of autism. And, in the meantime, we know that effective treatments for children and adults with ASD are available now, offering tremendous hope for meaningful and lasting improvements in their lives.

Christian and May Institute are committed to bringing that hope to families throughout the country. With his dream of supporting military families now a reality in Columbus, he looks to the future. “I believe we have far surpassed Jacques and Marie-Anne’s vision by creating a national network of programs that is, indeed, extraordinary,” he said. “We will continue to meet the needs of families, and advance the care available for children with ASD. There is still much to be done.” For information about May Institute programs and services, please visit the May Institute Web site, at http://www.mayinstitute.org.

For additional information, call (800) 778-7601, or send an email to info@mayinstitute.org. To contact the

May Institute operates more than 200 programs across the country

Its corporate and regional offices are as follows:

May Institute Corporate Headquarters
• Randolph, Mass.

May Institute, Southeast Region
• Atlanta, GA
• Columbus, GA
• Orange Park, Fl

May Institute, Northeast Region
• Yarmouthport, Mass.
• Fall River, Mass.
• West Springfield, Mass.
• Manchester, Conn
• Freeport, Maine

May Institute, Midwest Region
• West Peoria, Ill.

May Institute, Mid-Atlantic Region
• Mount Holly, New Jersey

May Institute, West Coast Region
• Santa Cruz, Calif

May Institute’s Southeast Regional Autism Center, call (706) 571-7771.

Dennis C. Russo, PhD, ABPP (Diplomate of the American Board of Professional Psychology), is Chief Clinical Officer of May Institute. A recipient of the Lee Salk Distinguished Service Award from the Division of Pediatric Psychology of the American Psychological Association, Dr. Russo holds a faculty appointment at the Tufts University School of Medicine. He is a past president of the Association for Advancement of Behavior Therapy and the Society of Pediatric Psychology, and has been elected as a Fellow of the American Psychological Association.

Eileen G. Pollack, MA, is Vice President of Communications at May Institute. She has been involved in human services program development and management, and corporate communications, for nearly twenty years.
Injured vets get help reforging their lives

By Tim Woodward, Staff of the Idaho Statesman

With Boise State University setting annual enrollment records and building its name as an athletic power, it’s easy for those of us in this part of Idaho to ignore the achievements of Idaho’s other universities. We shouldn’t. Credit the University of Idaho (UI) with an idea that other universities would do well to emulate.

Instead of talking about supporting our troops, UI is doing it in a meaningful way. Tom Prewitt is proof. He graduated from the university in May with a degree in wildlife resources and now works for the Coeur d’Alene Tribe as a wildlife habitat biologist. What does that have to do with supporting our troops? Prewitt was one of our troops. He has a permanent disability from injuries suffered while serving in the Army in Afghanistan.

Graduating from college might still be a dream for him if not for a UI program that helps wounded veterans and their spouses. It’s called Operation Education™, and Prewitt is its first graduate. The program is the first of its kind in the nation. The idea for it came when Heidi Linehan of the university’s office of development spent time with veterans at Walter Reed Army Medical Center in Washington, D.C. “She was moved by the spirit of the veterans going through rehab there,” Operation Education™ chairwoman, Karen White, said. “She came to me because I have a background in physical education and a connection with the president. (UI President, Tim White, is her husband.) “She wanted to know how we could help injured veterans, and we decided the obvious thing was to provide scholarships and help them with their education. These are people who need to rethink how they’re going to make a living, contribute to society, and feed their families, and higher education is the key. It’s what we can do to thank them for what they’ve done in behalf of our country.”

Operation Education™ provides veterans severely wounded since Sept. 11, 2001 with tuition, fees, books, transportation, on-campus housing, medical assistance, child care, and other benefits. Two students have enrolled through it this year. Spouses also are eligible. “We made it available to spouses because wounded veterans might not be able to work outside of the home due to their injuries,” UI spokeswoman, Joni Kirk, said. “The spouse in those cases will be the breadwinner.” It’s hard to overestimate the value of that kind of help for those who have been sustained disabilities serving their country.

College has become so expensive that G.I. Bill benefits typically fall $19,000 short of paying for a four-year education, and veterans with disabilities have additional expenses other students don’t. Operation Education™ can mean the difference between going to college and just dreaming about it. It can make the difference between dead ends and a productive life. The assistance is different for each student.

For Prewitt, who is married and has a young son, child care was a crucial component. For Chase Clark, it’s physical therapy, which a local hospital provided without charge. “The difference
was night and day,” White said. “His grades improved, and suddenly, he had a twinkle in his eye.” Clark, 22, is a sophomore studying landscape architecture. His injuries were so traumatic that he still doesn’t talk about his military service, but Operation Education™ has given him a new start. “It’s made all the difference in the world,” he said. “It’s helped me with anything I’ve needed, backed me up, and provided excellent support. It’s something that needs to get out to more veterans.”

Their injuries qualify the veterans for help through Vocational Rehabilitation, which is administered by the Department of Veteran’s Affairs, but the rest of their financial assistance is privately funded. “We have about 237 donors who have contributed over $190,000,” said Linehan, now the program’s director of development.

“Part of that is a $50,000 pledge from Boise. These aren’t necessarily UI alums either. They’re doing it because of what the program is doing for veterans. The connection is in their hearts.” Karen White sends hand-written thank-you letters to each donor, regardless of the size of the donation. And her husband plans to send letters to all college presidents in the country, urging them to consider similar programs at their schools. “We’re hoping this kind of help will be available at colleges and universities throughout the nation,” Linehan said. “What a great thing that would be for our veterans. I wake up every morning knowing we’re doing the right thing.”

Tim Woodward was born and raised in Boise, Idaho. He attended Boise High School, Boise Junior College. Tim is a Vietnam Veteran, and graduated with a degree in journalism in 1971 from the University of Idaho, and has been a reporter and columnist ever since.

Operation Education Redefines Civilian Life for Wounded Veterans

By Joni Kirk

On any given day, Tom Prewitt spends time analyzing wildlife in Northern Idaho to ensure the animals are adjusting to rehabilitated habitats. Sitting in tall grass or slugging through riverbank mud as a wildlife habitat biologist, Prewitt is at home in the wild and is one with nature.

A 2007 graduate of the University of Idaho and scarcely a month into his career, Prewitt says he’s already achieving his dreams. While wrapping up the final semester of his wildlife resources degree, Prewitt was hired by the Coeur d’Alene Tribe. He began work immediately after his May 12 graduation.

He manages mitigation land acquisitions for the tribe, helping to rebuild terrestrial and aquatic habitat that was lost to hydroelectric dam construction by the Bonneville Power Administration (BPA).

“We’re rehabbing land acquisitions as replacement habitats to offset those that were lost when BPA built and filled the dams,” Prewitt said.

An example of the prompt and easy career transition that all university graduates hope for following commencement, Prewitt’s success is meaningful at a different level.

“If not for this scholarship, along with others, I would have been forced to spend more time at work instead of studying,” said Prewitt. “Money started to become scarce the first semester after my son was born, so I cannot thank the University of Idaho enough for creating Operation Education™, which recognizes veterans’ unique needs such as mine.”

Prewitt’s graceful stride as he walks across campus with his wife, Andrea, and son, Logan, on graduation day belies the daily pain he still struggles to overcome. Only if he’s watched carefully can someone detect a slight limp.

A veteran of the United States Army, Prewitt sustained injuries from activities related to his duties, including permanent disability in his knees, three surgically repaired ligaments in his left ankle and a weak right ankle. His injuries hamper day-to-day activities.

In his laid-back manner, despite his injuries, Prewitt shows no disdain for the military. He relays his experience in a matter-of-fact way.

Following his 1998 high school graduation in Boyd, Wisconsin, Prewitt enlisted as a heavy construction equipment operator for the Army’s 101st Airborne Division. Early in his military career, his unit supported Joint Task Force Six along with the Marine Corps, in Texas, for drug and immigration enforcement operations along the U.S.–Mexico border. Several months after the Sept. 11, 2001, tragedies,

Reprinted with permission

Cpl. Prewitt and his unit were assigned to Kandahar, Afghanistan.

As he relays the events of his first day in the war zone, he’s still visibly shaken. Prewitt said he didn’t know fear until he boarded a plane in Germany in January 2002, and war became a reality. His was the first Army unit to enter the Afghanistan war zone.

“We had to load our M16s prior to takeoff, and when we landed, we were told by the Air Force to hurry up and get off their plane,” said Prewitt. “That’s when the danger of the situation sunk in.”

During the six-month tour in Afghanistan, his unit was responsible for reconstructing and maintaining the runway at Kandahar Air Field in support of Operation Enduring Freedom (OEF). Prewitt and his unit ensured some 1,700 air-lifted troops had an operable airfield from which to take off and land.

After finishing his service stateside at Fort Campbell, Kentucky, Prewitt began taking courses at Lexington Community College, in Lexington, Kentucky, in preparation for a wildlife resources degree—a field of interest since he was a teenager.

Prewitt shakes his head as he recalls the temporary job he held while going to school. “I was doing landscape work and busting my back for $10 an hour. It made me realize I was in college because I didn’t have the body of a young man anymore, and I couldn’t do this work forever.”

With enough credits under his belt, he applied for transfer to the University of Idaho and was accepted. In August 2004, the Prewitts eagerly prepared for their move to Moscow, Idaho. Tom Prewitt was about to realize his dream. Or so he thought.

The day they moved, Prewitt received recall orders from the Army, much to his frustration.

Upon reporting for duty in South Carolina, Prewitt finally was able to meet with a surgeon and was exempted from active duty. He completed his commitment to the Army in April 2006 and returned to Idaho to complete his degree in wildlife resources.

Last fall, through the Hawley-Jameson Foundation, the University of Idaho awarded him a scholarship to assist with his second year of college. The scholarship was established by the University of Idaho to assist wounded members of the U.S. military, and is designed to assist veterans and their families as they seek to enhance their future through higher education. The program is the first of its kind in the nation.

“The instant I heard about Operation Education™, I knew it was a scholarship for me. I deal with pain every day of my life,” said Prewitt. “I heard that the scholarship was established for disabled vets from Iraq and Afghanistan to pursue their education and not feel that their disability hinders them.”

He applied for the scholarship in December 2006 and received funds to help cover his educational costs for the spring semester of 2007, his final semester at the university. “Money was tight for a while, so it was a relief to get it,” he said.

This May, with his wife and son looking on, Prewitt received a University of Idaho degree in wildlife resources, commencing a new chapter in his life.

Cy Kammeier, editor of Purple Heart Magazine, said Operation Education™ is a real feather in the hat of the citizens of Idaho. “I am confident it represents a wise investment, one that will enable veteran Tom Prewitt to continue making a contribution to all Americans,” Kammeier said.

A second University of Idaho stu-
dent, not yet publicly named, also is receiving financial assistance from Operation Education™.

“We are encouraged that our vision for Operation Education™ has been realized so readily,” said Karen White, University of Idaho first lady and chair of the scholarship program. “The Operation Education™ Scholarship program is making a meaningful difference in the lives of the wounded veterans that it supports, as well as in the lives of their families.”

The Helping Our Heroes Foundation, which provides funding, services, and volunteers to veterans wounded in operations in Iraq or Afghanistan, provided initial funding for the scholarship program and has pledged continued support of the program. Additional support for Operation Education™ has come from University of Idaho alumni and supporters.

Two alumni donated $25,000 to establish the Lt. Donald Frank Ware Endowment as the first alumni

response to Operation Education™. An F-100 fighter pilot, Ware was killed in a mid-air collision during a combat training exercise over England in 1963. He attended the University of Idaho for one year and then received an appointment to the U. S. Air Force Academy, graduating as a member of the Academy’s second graduating class in 1960. He also was “Top Gun” in his fighter combat training class.

The two alumni, a couple, who wish to remain anonymous, have known many returning veterans who received severe physical wounds as well as emotional scars that may never be fully understood. “These veterans deserve any and all assistance we can provide to help them resume a normal life,” said one of the donors, a class of ‘65 alumnus.

She emphasized that just being treated by the veterans hospitals, receiving some dollar compensation, and being “dumped back into society” will not prepare returning veterans to be the valuable, experienced citizens we so sorely need. The Operation Education™ Scholarship will

Other Universities and Colleges Reaching Out to Veterans

Numerous scholarships exist for children and/or spouses of deceased and disabled veterans. Following are three other scholarship programs for wounded veterans, which are different from the customized aid packages provided by the University of Idaho.

Texas A&M University (launched in March 2005)
Provides 25 scholarships, known as Honored Service Scholarships, each valued at $3,000. They are intended to supplement the living expenses of the veterans who qualify for the stipends and have a demonstrated need for such assistance. To qualify, a recipient must meet specific Veterans Administration (VA) requirements for disability assistance and be a resident of Texas.

University of Wyoming (launched in August 2001)
The Marna M. Kuehne Foundation of Sheridan created an endowed scholarship fund for veterans with disabilities who wish to pursue undergraduate or graduate degrees. There are more than 5,200 Wyoming veterans whose disabilities are directly connected to their military service. The average annual award can range from $1,000 to $10,000, depending upon the recipient’s financial need.

Dartmouth College (launched in September 2007)
Created a program to provide individualized college counseling to seriously injured veterans.
help them overcome difficult obstacles and ensure they receive a college education. “These terrific young women and men can teach us so much about courage and perseverance. We, as a nation, cannot turn our backs on them,” said her husband, an alumnus from the class of ’63. “Through this scholarship, the university will work with them to regain self-esteem and the ability to support their families. In return, society will be rewarded many times over.”

The couple hopes that other alumni join them in donating to the scholarship program. They also urge current students to begin the habit of “giving back,” by donating. Individuals, as well as all groups, can participate.

“We encourage other colleges and universities to establish similar programs for wounded veterans seeking to complete an education and transition to civilian life,” White said. “We’ve done the hard work necessary to create a pilot program; now it’s their turn to step up and provide opportunities for these men and women who have served our country so graciously and honorably.”

Information about Operation Education™
To learn how to help the Operation Education™ Scholarship program, call the University of Idaho, at (208) 885-7069, toll-free at (866) 671-7041, or visit http://www.uidaho.edu/givetoidaho.

To obtain an application for the scholarship, veterans should contact John Sawyer at the University of Idaho at (208) 885-7979 or johns@uidaho.edu, or visit www.uidaho.edu/OperationEducation. •

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#### Crunching the Numbers for Veterans

- As of 2007, there were more than 24 million veterans living in the U.S. and Puerto Rico.
- 1.7 million veterans are female.
- More than 2.8 million veterans report having a service-related disability; over 246,000 are 100% disabled.
- 6.9 percent of veterans (1.7 million) are not able to work due to a disability.
- The Montgomery GI Bill provides educational assistance for veterans completing: three years on active duty; two years on active duty if the person signed up for two years; or two years on active duty and four years in the Reserve.
- The number of veterans using benefits for college or university study, or for business, technical, and vocational training, has steadily increased. This trend likely reflects changes in labor market education requirements.
- The percentage of veterans emphasizing the importance of educational benefits to achieving their goals has steadily increased. This reflects enlistment incentives promulgated in recent years, which have encouraged people to volunteer by emphasizing the education benefits they can obtain through military service.
- The majority of veterans currently are married (74.9 percent) and more than half (54.6 percent) has an annual family income of $50,000 or less.
- The Montgomery GI Bill currently provides active duty veterans with up to $1,075 monthly, for a maximum of thirty-six months, to cover education expenses, depending on years of service, rank, and other considerations.
- The average cost of one year’s tuition, room and board, and fees for in-state students at public institutions for 2007-08 is $16,640, which totals $66,560 for a four-year degree.
- Average tuition and fees are up 40 percent from five years ago, increasing 6.3 percent in the last year alone.
- In 2005, median earnings of four-year college male graduates were 63 percent higher than median earnings of high school graduates. Among women, earnings were 70 percent higher.


#### A message from Dr. Karen White, University of Idaho first lady and chair of the Operation Education Scholarship Program

Operation Education™ is the nation’s leading scholarship and assistance program for disabled military veterans. It is available to military personnel who sustained permanent disability while serving our nation since September 11, 2001. Spouses of qualifying veterans also are eligible for the scholarship.

We at the University of Idaho recognize that for many disabled veterans, returning to a normal and productive life is about more than just money. Therefore, the Operation Education™ Scholarship Program offers a comprehensive package with three vital components that are customized to meet each scholar’s personal needs. Each individual plan will address the academic, home and social, and financial challenges a veteran may encounter during his or her transition back to civilian life.

Operation Education™ offers tutoring and provides adaptive equipment such as computer hardware and voice recognition software, as well as note takers and learning specialists to assist a student in the classroom. Additionally, the Program offers assistance through mentoring, internships and job placement services. Operation Education™ can assist with on-campus housing and transportation, medical assistance, childcare, and personal and family counseling services. The Program also provided scholarship assistance for tuition, fees, books and living expenses.

We want to do everything we can to assist this special group of veterans and their families. It’s one way we can say ‘thank you’ for the extraordinary sacrifices they have made for our country.

Doing everything we can includes providing educational opportunities for spouses of qualifying veterans as well. We realize that in some cases the spouse will be the person who will be called on to provide financial support for the family. Our goal is to make Idaho, the West and the world better places in which to think, create, work and live. This is what Operation Education™ is all about.
The Military Child Education Coalition (MCEC™) has recently released a new support for military families facing deployment, with the addition of another kit to its Growing, Learning, and Understanding: Making Meaning through Early Literacy™ (GLU™) initiative. The GLU initiative focuses on developing early literacy skills in children from birth through second grade. It consists of theme-based sets of resources, including activities and information sheets centered around a book or other resource, that are packaged together in engaging kits.

While the themes of the GLU kits cover various aspects of literacy—including language acquisition, reading, art, and mathematical skills—all of the kits are also designed to meet the needs of young military children. The most recent GLU kit, While You Are Away, focuses on the specific needs of children whose parent is or will be deployed.

As all military families know, the deployment of any family member poses unique challenges. The deployment of a parent can be especially confusing to a baby or young child, who may not yet understand the passage of time, the requirements of their parent’s job, or changes to the daily routine. Deployment can also be challenging for the parent, who may worry that special moments will be missed or that their child may not recognize them upon their return home.

The While You Are Away GLU kit helps families address these deployment-related issues and more. The kit’s contents cover pre-deployment, deployment, and reunion, so families are assisted throughout the entire deployment cycle. Suggestions for adapting to changing schedules and responsibilities; ideas for ways to stay connected, even when geographically separated; and nurturing the love between parent and child throughout the deployment cycle are among some of the additional issues covered.

As with the other GLU kits, parents and care providers are encouraged to use careful observation and understanding of their own children, as well as research and information regarding the development of young children, as they explore the kits and use the activities. Adaptations for different ages and abilities are included within the activities to ensure that the information and ideas can be tailored to the specific needs of each child.

The While You Are Away GLU kit and all other GLU kits are available to parents, educators, and anyone else working with young children. For an overview of the series and its contents, or to purchase a GLU kit, visit http://www.easycart.net/MilitaryChildEducationCoalition/Educational_Resources.html.

MCEC is a nonprofit organization focused on the academic and school-related needs of all United States military-connected children. MCEC strongly believes that parents are the first and best advocates for their child. For more information, contact Jaclyn Collins, MCEC’s Administrative Assistant for Marketing and Special Projects, at jaclyn.collins@militarychild.org or visit MCEC’s Web site at http://www.militarychild.org.

Stephanie Surles, JD, MPA, is Director of Research and Product Development at MCEC.
Military families who have a member with autism would like to have expanded options for providing care, easing financial burden, and increasing the prospect for greater results for their family member. The Department of Defense (DoD) issued a report in July, covering its belief in the efficacy of applied behavior analysis (ABA) as a form of treatment for autism and the necessity of expanding TRICARE’s Extended Healthcare Option (ECHO) coverage to increase families’ ability to receive ABA for their family member.

Because the field of ABA is considered to be in its infancy, and since coverage as well as education, certification, and supervision requirements for ABA are not nationally standardized or consistent state to state, the DoD is attempting to provide beneficiaries with coverage, safeguards, and expanded care while at the same time respecting the profession and its role in establishing its own standards.

Family members and government experts participated in the discussions that led to the Department of Defense Report and Plan on Services to Military Dependent Children with Autism (July 2007) and the demonstration project that is now under way. Some excerpts from the report follow. For a full copy of the DoD report, visit: http://www.tricare.mil/mybenefit/Download/Forms/DoD_Report_Autism_doc/DoD_Report_Autism_doc.

The Department proposes a change in policy and a demonstration program under the Department’s demonstration authority under 10 USC 1092 to expand the availability of ABA services to ECHO beneficiaries with autism. The change in policy would expand the definition of who can be a TRICARE-authorizd supervisory ABA provider. The demonstration program will permit TRICARE cost sharing of services by ABA tutors under a modified corporate services model. This policy change and demonstration will allow military families to make more effective use of the special education benefit in the ECHO program.

It is the intent of the Department that the provider qualifications set forth for the ABA Tutor demonstration be in place as a temporary bridge until national standards are established by an appropriate nationally recognized certifying body for ABA providers. To this end, the Department intends to support nascent efforts within the industry to accurately and credibly define a new ABA provider class that performs “hands-on” ABA services.

The Department intends to retain the ECHO benefit as currently outlined in 32 CFR 199.5, except for the changes in provider qualifications that will be implemented in the policy change and demonstration program noted above.

The Department sought family input into the autism services plan by solicit-
available under ECHO and that TRICARE requirements for ABA providers are too stringent. Additionally, participating family members were afforded the opportunity to review and comment upon a draft of this report. Representative examples of family member input are included as Attachment 3.

Government experts in policy and operations that affect the nature and delivery of services to children with autism were engaged on a frequent basis over several months to review a number of recommendations both related to the required plan and those outside its scope. Government experts acting in their official capacities who participated in the development of the Report to Congress included representatives from a number of offices including the TRICARE Management Activity (TMA), Army Office of the Surgeon General, Army Exceptional Family Member Program, Deputy Under Secretary of Defense for Military Community and Family Policy, Navy Bureau of Medicine and Surgery, United States Coast Guard, DoDEA (Education Directorate), U.S. Department of Education Office of Special Education Programs, and the Office of the Air Force Surgeon General. Additionally, the former Coordinator of Autism Programs at the National Institute of Mental Health was consulted.

TRICARE will modify the TRICARE Policy Manual description of an authorized ABA provider in order to expand the pool of TRICARE-authorized ABA supervisors. …

Plan: TRICARE will define licensed and/or certified providers within the mental health, education and related fields whose training, education, and experience are compatible with accepted standards for ABA supervisors in the profession. These professionals will have the opportunity to become TRICARE-authorized ABA providers under the ECHO program. This change will test the advisability and feasibility of permitting TRICARE reimbursement of professional providers not currently authorized to render ABA services for consulting, training, behavioral plan development and supervision of ABA tutors. 2) Recognize ABA tutors as TRICARE providers: The Department will implement a demonstration project to expand the pool of TRICARE-authorized providers who can deliver hands-on services. This will allow TRICARE to reimburse ABA “tutors.”

Goal: To provide a temporary bridge to increase availability of and access to ABA services for TRICARE beneficiaries by permitting TRICARE cost-sharing for ABA services when provided by individuals recognized as ABA “tutors” who work within a modified corporate services model, implementing a treatment plan prepared and directed by a TRICARE-certified ABA supervisor, pending development of nationally recognized standards for ABA tutor training, knowledge and experience, and state regulation and oversight of individual and corporate ABA providers.

The proposed “ABA tutor” demonstration project is seen as an interim solution to a problem which the industry is both acutely aware of and is seeking to solve. The identification and description of a new ABA provider class is an effort most coherently and comprehensively tackled by the profession itself. In this way such a provider class will be integrated into the evolution of the profession and will mature as the profession matures. The potential impact on children with autism demands nothing less than a thoughtful, well-established and comprehensive process for determining the education, 23 training, experience, supervision and competency standards for this class of providers. Since the Department has an acute need for ABA providers today, and industry implementation of ABA tutor certification will likely not occur until at least 2009, the Department will develop TRICARE-determined provider standards now – consistent with our best educated guess about the provider requirements that are likely to be adopted by industry in the future.

A number of recommendations have surfaced as an important by-product of the effort to respond to Congress’s request in Section 717. While these recommendations were not specific to the charge in the congressional language, the Department has every intention of exploring them for items that can be implemented within existing statute and regulation. Specifically, the ability of families to access the respite care benefit available through the ECHO program has emerged as a consistent item of concern among family members and their representatives. While it is expected that the TRICARE policy modification and demonstration project in and of themselves will lead to increased use of the ECHO respite benefit, the Department intends to carefully review the construction of this benefit and consider changes that are necessary to make it available to more families.

Other concerns identified by family members that merit additional consideration by the Department 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. Still other significant concerns noted by family members on the final page of Attachment 3 are outside the purview of the Department of Defense. The Department intends to retain the ECHO benefit as currently outlined in 32 CFR 199.5, except for the changes noted in the demonstration project described previously. TRICARE will continue to work with Department officials as well as family members as it explores opportunities to improve services to special needs children, including those with autism.
United States Military Section

VA, DoD Announce “Recovery Coordinators”
New Resource for Those Seriously Injured on Care and Federal Benefits

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The Department of Veterans Affairs (VA) and the Department of Defense (DoD) recently signed an agreement to provide “federal recovery coordinators” to help ensure medical services and other benefits are provided to seriously wounded, injured, and ill active duty service members and veterans.

The agreement puts into place one of the top recommendations of the President’s Commission on Care for America’s Returning Wounded Warriors, co-chaired by former Sen. Robert Dole and former Health and Human Services Secretary Donna Shalala.

The agreement initially establishes that the first federal recovery coordinators will be provided by VA in coordination with DoD and will be located at top military treatment facilities throughout the nation. They will coordinate services between VA and DoD and, if necessary, private-sector facilities, while serving as the ultimate resource for families with questions or concerns about VA, DoD, or other federal benefits.

“This agreement ensures our nation’s active duty service members and veterans who have been wounded receive the very best care during their recoveries,” said Acting Secretary of Veterans Affairs Gordon H. Mansfield. “Service members, veterans and their families can be assured they will have an ultimate resource they can rely on whenever help is needed from VA or DoD.”

Job postings for the new positions have been made at http://www.va.gov, with the first 10 federal recovery coordinators scheduled to be hired by Dec. 1. Plans call for the new employees to be trained and in place at four of the military’s major healthcare facilities during January 2008.

The coordinators will ensure the appropriate oversight and coordination is provided for care of active duty service members and veterans with major amputations, severe traumatic brain injury, spinal cord injury, severe sight or hearing impairments and severe multiple injuries. The coordinators will also work closely with family members to take care of services and needs.

The first 10 coordinators will work at military healthcare facilities and at any other locations where patients are later assigned. They will be located at Walter Reed Army Medical Center in Washington, D.C.; the Naval Medical Center in Bethesda, Md.; the Brooke Army Medical Center at Fort Sam Houston, Texas; and Balboa Park Naval Medical Center in San Diego. Additional recovery coordinators will be added in the future as needs are determined.

The coordinators will have a background in healthcare management and work closely with the clinicians and case management teams to develop and execute another major recommendation from the Dole-Shalala panel, individual federal recovery plans for the wounded. Those plans specify what services are needed across the continuum of care, from recovery through rehabilitation to reintegration to civilian life.

The coordinators will have access to and support from the VA’s Under Secretary for Health, VA’s Under Secretary for Benefits, DoD’s Under Secretary of Defense for Personnel and Readiness, as well as the commanders of facilities where service members and veterans receive treatment.

“The coordinators will have the training, resources, and support from the highest levels of VA and DoD to help remove any barriers to care and benefits for the service members, veterans, and their family members,” said Dr. Michael J. Kussman, VA’s Under Secretary for Health. “VA provides the best healthcare available anywhere. This will ensure returning Global War on Terror heroes receive the care they deserve.”

These federal recovery coordinators are in addition to 105 patient advocates VA has hired, trained and put in place since June 2007. Those advocates, most veterans of combat in Iraq and Afghanistan, ensure a smooth transition of wounded service members through VA’s healthcare system, while also cutting red tape for other benefits.