

What's Up with Autism? Envisioning, Developing and Implementing an Autism and the Military Child Conference

Introduction

Autism is a complex neurodevelopment disorders that appears in early childhood — usually before age three— and generally last throughout a person's life. Autism is part of a group of disorders called autism spectrum disorders (ASD) which are sometimes referred to as pervasive developmental disorders. It is reportedly one of the fastest growing developmental disabilities in the USA. According to the National Institute of Mental Health (NIMH), Autism is "...more common in the pediatric population than are some better known disorders such as diabetes, spinal bifida, or Down syndrome".

Characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive and stereotyped patterns of behavior, ASD present an evolving set of personal, familial, societal, and therapeutic challenges. Symptoms and severity vary from very mild to severe and scientists do not know yet exactly what causes ASD nor is there a known cure. For military children on the autism spectrum, their condition is made more difficult by frequent changes of residences, schools, and other variables that accompany military life.

The Centers for Disease Control and Prevention (2011) estimate that on average 1 in 110 children in the United States are diagnosed with ASD. The CDC states that "ASDs are an urgent public health concern". From Mar FY07 – May FY11, based on M2 MEPRS data, Naval Medical Center Portsmouth had six thousand eight hundred and fourteen (6814) documented encounters coded in the Autism series with PDD 299 Code Series as Primary Diagnosis. According to data from OSD/ Office of Military Community and Family Policy reports the occurrence within the military as 1 out of every 89 children.

This submission provides an overview of a two day training activity sponsored by Naval Medical Center Portsmouth, VA Department of Pediatrics/Neurodevelopmental Pediatrics. Autism and the Military Child, hosted in September 2011, was designed to educate, empower, and advance the knowledge of providers, educators, other professionals, parents, caregivers, and those on the autism spectrum. Goals were to: increase provider competency in screening and treating ASD patients; describe evidence-based intervention strategies to promote active engagement for children with ASD; provide comprehensive, evidence-based information to assist educators, other professionals, and families in developing effective educational, social and behavior programming for those with ASD and developmental delays; educate and empower providers, educators, other professionals, parents, and those on the autism spectrum with up-to-date information and resources; and, identify effective interventions and discuss future directions to advance one's knowledge and understanding of ASD.

Faculty consisted of an interdisciplinary panel of experts from local, regional, and national military and civilian agencies. Through a series of lectures and workshops, faculty provided the most up-to-date information on current knowledge and advances in therapeutic treatment options within the field, ways that this collective knowledge could be applied to the care of those with autism, methods of building effective interventions for military children diagnosed with autism spectrum disorders, and future directions toward the understanding

of these complex disorders.

Methods:

Autism and the Military Child was endorsed by NMCP's senior leadership. The need for this innovation was determined based on patient care/ quality reviews, scientific medical advances, increased number of families and population of children with autism being transferred to the Hampton Roads area through the EFMP, a needs assessment to participants of the 2007 Autism Conference sponsored by NMCP, and verbal communications and collaboration with diverse local community agencies.

Leadership/Command Support. The proposal for this training activity was presented to and received the support of the NMCP Command Executive Board. With support of senior leadership, NMCP Neurodevelopmental Pediatrics partnered with special needs families, the Hampton Roads Joint Services EFMP Committee, the Autism Society of America, TRICARE Operations, the Tidewater Multi Market Office, Staff Education and Training, and diverse other military and community agencies. Utilizing the expertise of internal marketing offices, and Management Information/Webmaster resources and to prevent waste, Autism and the Military Child went GREEN! Web-based registration was implemented and closed one (1) month before the first day of the training. Details about the conference, the agenda, registration, information on speakers, lodging accommodations, uniform of the day, presentations and handouts of sessions, etc. were all available online. Attendees were able to download and print information prior to attending the conference. No paper copies were provided. Navy Medicine East and internal NMCP Public Affairs Offices assisted with marketing. Community agencies and families assisted to get the word out through the use of social medias.

Patient Care/Quality Reviews. ASD patients experience a gamut of challenges in diverse domains when early intervention is not began. The Neurodevelopmental Division plays a large part in educating residents and healthcare providers on various developmental disabilities including autism. Quality reviews were utilized and need through this source was determined through quality reviews of consults placed to Developmental Pediatrics for ASD evaluations.

Scientific/Medical Advances. Treatment providers are responsible for possessing the skills to identify children at a young age who have autism spectrum disorders so that children can receive appropriate early intervention services. The American Academy of Pediatrics (AAP) recommends that all children from 18 to 24 months of age be screened for ASD. AAP also emphasizes the importance of early and continuous surveillance and screening to ensure that children are identified and receive access to services as soon as possible. Healthcare providers are already knowledgeable about ASD but keeping abreast of the latest updates on every aspect of ASD can be challenging. With the support of the world's largest autism science and advocacy organization (Autism Speaks), enormous strides have been made and over \$160 million has been dedicated to funding research into the causes, prevention, treatments for individuals with autism and their families. Federal legislation has been created to advance the government's response to autism. The TRICARE Management activity implemented the TRICARE Extended Care Health Option (ECHO) which provides coverage for Applied Behavioral Analysis for children with autism.

A 9 May 2011 report by an international team of investigators from the U.S., South Korea, and Canada estimated the prevalence of autism spectrum disorders (ASD) in South Korea to be 2.64%, or approximately 1 in 38 children, and concluded that autism prevalence estimates worldwide may increase when autism prevalence using a total population sample is used to identify children with ASD.

Increased number of families transferred to the Hampton Roads area through the EFMP. Within the military, each branch of the uniformed services has an Exceptional Family Member Program (EFMP). EFMP is a mandatory U.S. Department of Defense enrollment program and assignment tool that interfaces with other military and civilian agencies to provide comprehensive and coordinated medical, educational, community, and personal support to military families with a family member with disabilities and other special needs. Headquarter Office for the Navy Exceptional Family Member Program (EFMP) reports that the Hampton Roads area is the largest catchment area in the nation for the Navy's EFMP program. Currently, there are over four thousand four hundred EFMP assigned to the Hampton Roads area, of which there are over 600 active duty Navy EFMP families who has a child diagnosed with ASD.

Needs Assessment and Community Collaboration. The Neurodevelopmental Pediatric Division conducted a needs assessment of families and providers who attended the 2007 Autism Conference sponsored by NMCP. Former attendees were provided the opportunity to identify if there was a need for the training and if so what topics were most needed. Additionally, verbal contact was made with diverse local community agencies that provide services or resources to military children with autism and other disabilities to seek their input and recommendations based on their intervention with military children. Feedback from both sources proved invaluable. The feedback not only attested to the need for the conference but also served as the foundation for developing topics for this training activity.

Results

Naval Medical Center Portsmouth successfully completed a two day, state-of-the-art, multi-disciplinary Autism and the Military Child Conference. It was attended by over 500 persons. This training activity provided updated information on evolving patient management and multi-disciplinary treatment strategies for the care of those with ASD and enhanced understanding of the screening process and tools used to diagnose ASD. It empowered military families, educators, and advocates with information and resources. It highlighted the value added benefit of multidisciplinary collaboration among military families, those on the autism spectrum, military and civilian physicians, other healthcare providers, clinicians, educators, special needs advocates, social workers, and other professionals who provide services and care for military children with ASD.

Autism and the Military Child consisted of full attendee and breakout sessions. It created a forum through which medical and educational professionals established critical personal contacts to enhance optimal multidisciplinary treatment to military children with ASD. It provided time for in depth discussion by experts on ASD treatment options and optimal services to those with ASD. It offered dedicated time with the faculty for individual questions. It fostered enhanced dialogue between diverse disciplines and promoted understanding and education of autism and related disorders.

A panel of family members of children on the autism spectrum was featured who provided invaluable information about their journey through autism and the unique issues of military families. Exhibits by diverse military and community agencies offered informational materials regarding resources and support available to military families with children with autism.

In addition to providing a forum for collaboration, continuing education credits were provided to medical healthcare providers which included 10.75 AMA PRA Category 1 Credit(s)[™] and 10.75 Nursing Contact Hours.

Overall, the conference was a cost saving win-win measure for the Command, providers, and patients. No per diem costs were incurred by NMCP Staff. Additionally, this training was held at an off-site venue but within close vicinity to the MTF.

Conclusion:

Autism and the Military Child has universal applicability. Patients with complex neurodevelopmental disorders are among the most difficult to treat in the Exceptional Family Member Program (EFMP). Optimal treatment requires a multidisciplinary approach involving the child with autism and the child's family, diverse military and community healthcare providers, other professionals, clinicians, educators, and advocates. A challenge for the service member and family, the EFMP program, the Military Healthcare System (MHS) and the community is keeping abreast of best treatment strategies and available resources within and outside the MHS along with coordination of therapies and services that may be delivered in a multiplicity of settings, including the natural environment, healthcare facilities, academic settings, and diverse military or community agencies. A multi-disciplinary conference can serve as a key to enhance education and awareness of autism and to the transfer of knowledge emerging from the rapid advances in this field. It may also solidify communication networks and collaborative relationships that allow the professionals from these related fields to work together to serve military families of children with autism and other disabilities.

This innovation is adaptable and has significant potential to be replicated in other healthcare settings providing care for children with ASD. Other EFMP Category 5 sites have similar challenges and may benefit from periodic conferences of this nature. A proposal to have an annual rotational autism conference is being looked at by an OSD EFMP Committee. Hence, the impact of this innovation is still to be determined. With senior leadership/command endorsement and support, Pediatric Department involvement and coordination with diverse stakeholders within the MTF, this innovation can be institutionalized at other MTFs. In the words of the NMCP Pediatric Department Head, CDR Rees Lee, "We are caring for the children of heroes, and we want to educate and invigorate so our military is ready for the mission and not worried about what's going on back home".