American Academy of Pediatrics

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June 20, 2012

Testimony of
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On behalf of the
American Academy of Pediatrics

Before the
Subcommittee on Personnel,
Senate Armed Services Committee

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Chairman Webb and Ranking Member Graham, thank you for holding today's hearing on such an important topic—the programs and policies that the Department of Defense has in place to support military families with children with special needs. My name is Vera Fan Tait, MD, FAAP, and I am representing the American Academy of Pediatrics (AAP), a non-profit professional organization of more than 60,000 primary care pediatricians, pediatric medical sub-specialists, and pediatric surgical specialists dedicated to the health, safety, and well-being of infants, children, adolescents, and young adults.

I am a pediatric neurologist and am an Associate Executive Director at AAP, as well as the Director of AAP's Department of Community and Specialty Pediatrics. In addition to my role with the American Academy of Pediatrics, I am also a member of the Child Neurology Society and the Association of Maternal and Child Health Programs. Prior to joining the AAP, I was in practice for more than 25 years and my major areas of expertise include children and youth with special health care needs, traumatic brain injury, neurodevelopmental disabilities, and neurological rehabilitation. It was my privilege to care for families with children with autism spectrum disorders and other neurodevelopmental disabilities.

I have personally experienced the struggle that many pediatricians face every day when trying to access needed medical, educational and other services for children with special health care needs. Finding needed services can be difficult even when they are adequately covered by health insurance. It is only more difficult when a primary care pediatrician or subspecialist can locate care only to find it is not covered by a family's insurance.

Caring for our nation's military families and their children has always been of paramount importance for the Academy. I am proud to say that one of the oldest sections we have at the Academy is the Section on Uniformed Services. Created in 1959, the AAP's Section on Uniformed Services has helped direct the Academy's leadership on the health and well-being of our nation's military children and adolescents. The Section is comprised of over 900 members who are active duty or retired military, as well as civilian pediatricians who serve military beneficiaries. The section works closely with the pediatric consultants to the surgeon general of each branch of the military.

An example of one of the Section's most recent accomplishments is the development of the Military Youth Deployment Support Video Program, which is designed to help children and adolescents cope with the deployment of one, or sometimes even both, of their parents or guardians to other countries around the world. The video was initially designed by the Section on Uniformed Services and was subsequently utilized by the United States Army Medical Command. So far more than 20,000 copies of the program have been distributed

worldwide to military families, various military youth serving professional agencies, and primary care offices.

The health and well-being of children in America's military families ranks as one of the top priorities of the Academy, and that is why I am honored to represent AAP here today. The impacts of long or multiple deployments on all military families can be significant and for families with children with autism spectrum disorders, neurodevelopmental disorders or other disabilities, these impacts are often significantly exacerbated.

The American Academy of Pediatrics believes that the optimal health and well-being of all infants, children, adolescents and young adults through 26 years of age—including those in military families—is best achieved with access to appropriate and comprehensive health care insurance benefits. These benefits must be available through public insurance plans like Medicaid, the Children's Health Insurance Program (CHIP) and TRICARE, as well as private health insurance plans.

AAP policy recommends that minimum health benefits for all infants, children and youth should provide all medically necessary care, and include such services as:

- preventive care
- hospitalization
- ambulatory patient services
- emergency medical services
- maternity and newborn care, and
- mental health and substance abuse disorder services.

Also included in the set of benefits should be:

- behavioral health
- rehabilitative and habilitative services and devices
- laboratory services
- chronic disease management, and
- oral, hearing and vision care.

In short, all children must have a medical home. AAP believes that medical and other services should be delivered and coordinated in a comprehensive, patient and family-centered, physician-led medical home—the quality setting for primary care delivered or directed by well-trained physicians who are known to the child and family, who have developed a partnership of mutual responsibility and trust with them, and who provide accessible, continuous, coordinated, and comprehensive care.

The health insurance plan that most military families use is TRICARE. Services covered by TRICARE are provided by pediatricians who are active duty military but also community pediatricians and pediatric subspecialists who provide care near military bases and other military facilities. AAP members providing care to children and families covered by TRICARE face unique challenges compared to other public and private programs and plans. For example, one of the challenges that military families with children face is that the TRICARE program is largely based on Medicare, a health system designed to provide coverage for senior adults. Because of this program alignment, military families often face challenges navigating the TRICARE program, many times struggling to find appropriate pediatric providers or have certain pediatric services covered. This is especially true for parents of children with special health care needs. AAP has worked closely with TRICARE programs to ensure needed services are available from routine immunizations to highly specialized and acute pediatric care.

One area of particular concern among military parents of children with special needs is the coverage of services for children with autism spectrum disorders or other neurological disorders. Recently released data from the Centers for Disease Control and Prevention confirms that the prevalence of children with ASDs is growing, as is the need for effective services to help children with ASD maximize their potential.

Autism spectrum disorders, similar to other neurodevelopmental disabilities, are generally not "curable," and complex care is required for the child along with services for the family. Unfortunately, there is often no simple solution for families and effective, family-centered care will include numerous providers. A coordinated approach to intervention and treatment among the medical home, educational institutions and the family is critical for success.

Optimizing medical care and therapy can have a positive impact on the habilitative[1] progress and quality of life for the child. Medically necessary treatments ameliorate or manage symptoms, improve functioning, and/or prevent deterioration. Thus, in addition to routine preventive care and treatment of acute illnesses, children with ASDs also require management of sleep problems, obsessive behaviors, hygiene and self-care skills, eating a healthy diet, and limiting self-injurious behaviors.

Effective medical care and treatment may also allow a child with ASD to benefit more optimally from therapeutic interventions. Therapeutic interventions, including behavioral

[1] "Habilitative or rehabilitative care" means professional, counseling, and guidance services and treatment programs that are necessary to develop, maintain, and restore, to the maximum extent practicable, the functioning of an individual.

strategies and habilitative therapies, are the cornerstones of care for ASDs. These interventions address communication, social skills, daily-living skills, play and leisure skills, academic achievement, and behavior.

An example of a demonstrated, effective treatment for ASD is Applied Behavior Analysis, or ABA. ABA uses behavioral health principles to increase and maintain positive adaptive behavior and reduce negative behaviors or narrow the conditions under which they occur. ABA can teach new skills, and generalize them to new environments or situations. ABA focuses on the measurement and objective evaluation of observed behavior in the home, school, and community.

ASD is a medical/neurodevelopmental condition with behavioral symptoms that are directly addressed by applied behavior analysis methods. ABA has proved effective in addressing the core symptoms of autism as well as developing skills and improving and enhancing functioning in numerous areas that affect the health and well-being of people with ASD.

The effectiveness of ABA-based interventions in ASDs has been well documented through a long history of research in university and community settings.[2] Children who receive early intensive behavioral treatment have been shown to make substantial gains in cognition, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.

Late last year, TRICARE proposed to extend coverage under the Extended Care Health Option for Applied Behavior Analysis interventions for Active Duty Service Members who have family members with autism spectrum disorders. AAP commented on the proposed rule and commended the Department of Defense for undertaking the important task of proposing measures to make it easier for Active Duty Service members with children with ASD to better access needed health care services for their children.

In short, though more research is needed, ABA has both long-term empirical and research data to demonstrate its effectiveness in helping children who are diagnosed with ASD, and AAP has endorsed the use of ABA treatments when determined appropriate by physicians within a medical home, in close consultation with families. ABA remains an active subject of research and we encourage the Department of Defense to maintain flexibility in the provision of ABA services as new data may emerge.

[2] "Management of Children With Autism Spectrum Disorders," Scott M. Myers and Chris Plauche Johnson, *Pediatrics* 2007; 120; 1162; originally published online October 29, 2007; DOI: 10.1542/peds.2007-2362

Beyond just ABA services, one way to make it easier for military parents with special needs children would be to examine how TRICARE currently works for its beneficiaries. The Academy supports legislation introduced in the House—the TRICARE for Kids Act[3], which could begin the process of making TRICARE work better for all parents, but especially those with children with ASD or other special health care needs.

TRICARE for Kids would require TRICARE to establish a working group of relevant stakeholders to review TRICARE policies and practices and develop a plan to ensure that TRICARE meets the pediatric-specific needs of military families, including those children with chronic and special health care needs. We believe this is an excellent collaborative model to ensure that TRICARE polices work for all children in military families.

Thank you for allowing me to testify before the subcommittee today. As I said earlier, caring for our nation's military families and their children has always been of paramount importance for the American Academy of Pediatrics. We must do all that we can to support our military families, especially those who have the added challenge of raising children with special health care needs.

I look forward to your questions.

[3] The TRICARE for Kids Act was subsequently included as an amendment to the House's FY13 National Defense Authorization Act