

# **Military-Connected Children with Special Health Care Needs and Their Families**

## **Conference Summary and Recommendations**

**Sponsored by the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the HSC Foundation**

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*Eunice Kennedy Shriver* National Institute  
of Child Health and Human Development



THE HSC HEALTH CARE SYSTEM

**The HSC Foundation**

*Editor's Note: This transcript has been edited; however, as in most transcripts some errors may have been missed. The editors are responsible for any errors of content or editing that remain.*



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## Preface

The *Eunice Kennedy Shriver* National Institute of Child Health and Human Development (NICHD) and the HSC Foundation collaborated to sponsor a meeting to bring together military families, researchers, and stakeholders to learn more about military children with special health care needs and the issues the families confront as they care for their children. With notable and similar missions, these two organizations deemed this collaborative conference a mutually beneficial opportunity to achieve their respective goals and to work with leaders in the field who serve dutifully serve this population. The HSC Foundation is the parent corporation of HSC Health Care which provides a comprehensive approach to caring. The Foundation is dedicated to helping with access to services for those who face barriers because of illness, disability, and other causes. The signature initiative of the Foundation is related to youth transition. Youth and veterans with disabilities often face obstacles as they transition from military to civilian life and from youth to adulthood. The Foundation's National Youth Transitions Initiative is both a physical center and an initiative for youth and young veterans with disabilities. It provides transition-related services and activities related to public policy, best practices, and innovation.

One of the 27 Institutes and Centers that comprise the National Institutes of Health, the NICHD envisions a world in which all children have the potential to live productive lives free of disability and illness. Research on children in military families aligns with the needs of the NICHD. Funding opportunities from 2012 focused on research about children in military families. This conference builds on that work with a focus on a specific area—military children with special health needs. Special needs are not precisely defined. An estimated 14 percent of children in the United States have special needs, but little is known about the prevalence of special needs in military-connected children, and not enough is known about long-term effects. It is known that military families face stressors that others do not. The realities of military life can put children at increased risk for behavioral or social problems. The coordination of services can be difficult, and one duty station might not offer the same services as another. The field needs more data about the challenges these children face.

The meeting was strategically held in April to commemorate the Month of the Military Child. For this conference, special health care needs are defined as having or being at increased risk for a chronic physical, developmental, behavioral, or emotional condition and that requires health and related services of a type or amount beyond that required generally. The conference speakers and panelists were asked to discuss what is known about military connected children with special health care needs in terms of their educational, psychosocial, and physical health statuses. Together with audience participants, the conference organizers and researchers explored gaps in the knowledge base especially as they relate to disparities in health care access and utilization within these families.

## Executive Summary

The HSC Foundation and the NICHD underscored the goal to increase participants' knowledge and awareness of military connected children with special health care needs and their families and to identify areas where more research and expanded services are needed. Meeting objectives included:

- Examining current knowledge about the demographics and health status of military children with special health care needs
- Identifying the gaps in knowledge about these children and how these gaps may be addressed
- Recommending next steps for research and services to improve the health and quality of life for these children and their families.

The conference organizers included parents, advocates and services providers on the panels and working groups to ensure all voices were heard and to help inform the basis of a comprehensive plan of action. Similarly, the meeting was attended by researchers both academic and clinical, parents civilian and military, federal representatives whose work directly relates to the topic of the meeting. Educators and members of parent support and advocacy groups also attended the Conference.

The meeting concluded with the general consensus that much more needs to be known about this population of children and more services need to be provided to help the families overcome the barriers and challenges to care. The HSC Foundation and the NICHD plan to review the meeting proceedings and determine the next steps for collaboration. Key discussion points and recommendations from the plenary sessions and breakout groups include the following:

- Nearly 2 million children and youth are military-connected, with the largest group under 5 years of age. Approximately 20 percent or more have special needs, but there is no way to specifically identify military children with special needs.
- In the past 10 years, about half of active-duty service members have deployed at least once, and National Guard and reserve forces have accounted for one-third of all deployments. The average length of deployment is 12 months for the Army, 7 months for the Marine Corps, 6 months for the Navy, and 3 to 4 months for the Air Force. The cumulative length of deployment is associated with family stress and the health and mental health of family members.
- Participants suggested developing communities of care, creating more education and training for service providers, and addressing the dearth of mental health service providers for children. Data can help illustrate what families are dealing with and how they handle their challenges.
- Data about the approximately 2 million military-connected children are not disaggregated where the children are served. In most areas, military and civilian cohorts cannot be compared. A longitudinal study that looks at positive youth development and school performance is needed.

- We need to better understand challenges and barriers facing families and systems. This can be informed by both quantitative and qualitative research. A participatory conversation must be started between researchers and study participants.
- Military families with special health care needs face complex issues and rely heavily on both military-specific and community-based programs. Policies must be aligned to the problems to eliminate barriers to care.
- Studying health care utilization in children with special health care needs (CSHCN) is challenging in all systems, as well as among military children. To understand health care utilization in the military, it is important to understand the diversity of the children in this group and the many subgroups.
- Children and families are involved in multiple care systems. Family environment and unmet needs are associated with a child's developmental outcomes, and military families can have special unmet needs that are associated with complex family environments.
- CSHCN have diverse needs. Between 13 percent and 18 percent of these children have health care expenditures that are three times greater than those of a typical child. Even with these increased expenditures, CSHCN have more unmet health care needs than other children.
- Communication is the big take-away. Parents have to ask the questions, not only of educators but also of health care providers. Educators are the catalysts who bring parents and health care providers together to talk about the children.
- It is important to know about the stressors that families face and what works to alleviate them. Resilience is a factor that should be considered.
- If parents are strong, they will find a way for their child. The focus should be on making families strong. Adults should tell children what they need. They are insightful, they will express themselves, and they will tell you.
- An issue that warrants further exploration is how to support parents of special needs children in the military. Some parents experience depression, anxiety, and conflict. Couples need respite care, they need workshops, and they need skills to strengthen their marriage when they are not in the military.
- Many deployed forces are reserve and National Guard and are spread out across the continent in small communities. They can have problems in attaining access to care. These areas can be deemed medically underserved (MU), which would identify the areas as locations where special educators and others could receive loan forgiveness for working in that area.

# **Day One/Topic One: Military Children with Special Health Care Needs: What is Known? What are the Gaps in Research and Practice?**

The goal of the sessions addressing this topic was to provide an overview of the current state of the science and clinical practice regarding children with special health care needs and their families. There is a dearth of empirical research on these children and their families and a great deal needs to be known in terms of the demographic characteristics, family functioning particular health care needs, availability of services and evidence-based interventions. This session began with an overview of the big picture of special health care needs in both civilian and military families. Parents offered their unique perspectives on their experiences and the ways in which policies, practices and research can have an impact on their family lives and also on the lives of military families having similar experiences. An operational definition was offered and discussed by the session presenters and audience participants.

## **Opening Plenary: Defining Children with Special Health Care Needs**

*Dr. Judith Palfrey*

*T. Berry Brazelton Professor of Pediatrics, Harvard Medical School*

Dr. Palfrey said the fact that this conference is a joint endeavor of HCS and the NICHD speaks to Dr. Guttmacher's leadership. She thanked both groups for putting the health care needs of military children on their agenda. She conceptualized this conference in three words: family, community, and society. All three are critically important—military families, military communities, and how the broader society values military families. What is done at the societal level to embrace military families and communities?

Dr. Palfrey presentation put in context what is known about children with special health care needs (CSHCN) and how military children fit in this particular framework. The goals of her talk were to define CSHCN, discuss the prevalence of this group in the United States, describe a medical home, highlight early intervention, and discuss community-based services and transition services for CSHCN.

The Maternal and Child Health Bureau (MCHB) of the Health Resources and Services Administration (HRSA) has defined children's special health care needs as chronic physical, developmental, behavioral, or emotional conditions that require health and health-related services beyond those generally required by children. This is a broad brush of need, Dr. Palfrey said, and it includes children with physical disabilities (for example, cerebral palsy, spina bifida), sensory disorders (blindness, deafness), cognitive disorders (developmental delay, cognitive impairment), and social disorders such as autism, depression, or attention deficit hyperactivity disorder (ADHD).

Nationwide, 13 percent of children meet the MCHB definition for CSHCN, and about 6 percent have moderate to severe functional limitations. This information is from surveys of parents, and the numbers have been stable through the years. When asked whether a child has ever had any of the conditions, that number rises to about 30 percent.

A number of conditions in children have increased in prevalence from 1980 to the 2010s. These include asthma, obesity, depression, ADHD, inflammatory bowel disease, leukemia, diabetes, congenital heart disease, and autism spectrum disorder (ASD). The reasons for the increases are not clear. Obesity has only recently been labeled a disorder, although it is a risk factor for many other conditions. The increase in ASD has been profound, with a 20- to 30-fold increase over the past 30 to 40 years. The current estimate for ASD is 1 in 68 children and 1 in 40 boys.

Increases in survival have been observed in children with congenital heart disease, leukemia, cystic fibrosis, sickle cell disease, spina bifida, cerebral palsy, HIV infection, and Down syndrome. Survival of low birth weight infants increased from 50 percent in 1980 to 80 percent in 2010, but that comes with a price that can include chronic lung disease, short bowel syndrome, cerebral palsy, and vision and hearing abnormalities. Health systems are not entirely ready for the implications of longer survivals, although increasingly sophisticated assistance with medical technology includes oxygen, tracheostomy, gastrostomy, total parenteral nutrition, and shunts.

Data on special needs children are available from the Data Resource Center for Child and Adolescent Health (<http://www.childhealthdata.org>). The website defines how the information is gathered and allows the dataset to be customized to users' needs. For example, it is possible to ascertain differences by race and ethnicity and differences between English-speaking and non-English speaking groups. Children in poverty and underserved groups generally have more complex conditions and unequal access to services. This information helps define CSHCN and illustrate the groups where the impact is greatest.

Any discussion of the medical home begins with Dr. Cal Sia, a physician in Hawaii who is credited as the father of the concept of the medical home. A medical home provides excellent care that is accessible, family-centered, comprehensive, continuous, coordinated, compassionate, and culturally competent. The pediatrician shares responsibility. The medical home includes concerted outreach to families, with an emphasis on the cultural context, and integration with schools, recreation, vocation, and other community services.

Early intervention is another critical concept and includes both community-based services and transition services. The earlier a condition can be identified, the better. Lorenz has identified critical periods of intervention, and a number of researchers have documented the benefits of early intervention.

Children live, play, and go to school in a community, and another important approach is to think about how to enrich the community to serve the children. Families and communities are becoming increasingly sophisticated in understanding health. Many health and health-related services are now routinely delivered in the community. Family and children must be the focus, and family support is critical. The community-based team can include family counsel, social services, sibling projects, the pediatrician and other medical providers, the school, insurance, and

religious and spiritual supports. Other facets of family support are respite services, educational workshops, group sessions, parent-to-parent outreach, and a parent library of resources. Prevention efforts are most effective when they involve local community partners.

Education also is a critical part of children's health care needs. Dr. Palfrey will soon publish the third edition of Project School Care, a plan for integrating children assisted by medical technology into educational settings, which includes incorporating individualized health care plans into Individualized Education Programs (IEPs). She cautioned that putting plans together can be difficult and requires a great deal of effort.

The individualized health plan is a document for family and caregivers that summarizes medical information. It is comprehensive and includes contact information, insurance information, primary diagnosis, medications, allergies, consultants, hospitalizations, emergency visits, routine therapies, equipment and supplies, school information, recreation and vocation, a narrative history, a review of systems, and family-centered goals.

Transition is another important consideration for CSHCN, and it includes several aspects: transition among primary, specialty, and hospital care; educational transition; and college and vocational planning.

Dr. Palfrey concluded that "it's all about the kids."

## **Keynote Address: Current Knowledge about Military-Connected Children with Special Health Care Needs and Their Families**

*Dr. Elizabeth Ellen Davis*

*Developmental Behavioral Pediatrician; Director of University of Washington Leadership in Education in Neurodevelopmental and Related Disabilities; Past Chair, Section on Uniformed Services, American Academy of Pediatrics (AAP)*

Dr. Davis grew up in an Air Force family and was commissioned as an Army second lieutenant in 1980. She has retired from active duty, but continues working and seeing military-connected children with special needs. For this presentation, she was asked to paint the landscape of military-connected families with special needs children. She discussed children and the military structure, demographics, and culture and also explained who service members are and the difference between active-duty military, National Guard, and Reserves.

When the draft ended in 1973 and the military became an all-volunteer force, the nature of military service changed. Previously, the military family had not played a big role in the military mission, and service members were discouraged from having families. Most service members were drafted and were young; few planned on military careers, and almost all were single. In the current, all-volunteer force, half of service members plan on military careers, and 60 percent have family responsibilities.

Supporting the family became a priority for personnel policy. Programs emerged to support family members and contribute to military-connected CSHCN. Examples are the Exceptional

Family Member Program (EFMP), TRICARE/Extended Care Health Option (ECHO), housing, childcare, and attention to problems caused by geographic mobility. Another concern is the effect of parental wartime deployment on children.

The Department of Defense (DoD) exists to support the military mission. This is done in parallel through the separate branches of the DoD and through the Office of the Secretary of Defense to the defense programs and field activities. The DoD has recognized the significance of the family and its impact on military readiness, performance, and retention and recruitment. It has identified family readiness as a critical component in personnel readiness.

In 1988, what is now known as the Office of Military Community and Family Policy was launched to set the stage for modernized responsive engagement by the DoD in order to address the evolving needs of military families. In 2010, the Office of Community Support for Military Families with Special Needs, or Office of Special Needs (OSN), was created to consolidate policies across the services, develop strategies for care coordination, and provide oversight to military families with special needs.

The U.S. military is diverse and dynamic, and the military mission is directly linked to service member readiness, which, in turn, is directly linked to family readiness. The DoD's 2012 annual report to Congress defines family readiness as a family's preparedness "to effectively navigate the challenges of daily living experienced in the unique context of military service."

Dr. Davis reviewed some demographic information about the U.S. military force, as reflected in the 2012 DoD demographic report. The total number of military personnel is 3.6 million. The Army is the largest active-duty force, with 545,057 personnel, followed by the Air Force, with 328,000; the Navy, with 314,339; the Marine Corps, with about 200,000; and the Coast Guard, which is part of the Department of Homeland Security, with 41,000.

For each officer, there are five enlisted personnel. The average age of officers is 30 years old, and 85 percent of officers have college degrees. One-third of officers continue a full career in the military. Of enlisted personnel, 95 percent have high school diplomas, and most enter the military after high school, with the average age under 25 years old. Two-thirds of active-duty service members are between 18 and 30 years of age, and only 9 percent are older than 40. Only 14 percent of enlisted personnel reach retirement.

Women make up 14.5 percent of the military's active-duty force, and 30.3 percent of active-duty members identify themselves as minorities.

Active-duty personnel, National Guard, reserves, and family members (spouses and dependent children) total 5.3 million (42 percent service members, 58 percent dependents). Active-duty families often live on or near a military installation with neighbors and friends who are military. Community resources are organized around military activities, including childcare, financial and legal supports, and deployments. New families are often "sponsored" by more experienced military families when they move to a new area. Active-duty families are typically young, with young children. About 15 percent of the active-duty force lives overseas.

National Guard and reserve members train and are called up for active-duty service when needed. They rarely live near a military installation and seek health care in the communities where they live. They primarily have civilian jobs. Their demographic data more closely resembles their civilian peers between 18 and 40 years of age than active-duty personnel.

Dr. Davis described the family model of military families as “conservative,” with 82 percent of families consisting of a married husband and wife. Service members marry young and are three times more likely to be married than those who have never served. They have their first child on average by age 25, and half of spouses are employed. Spouses work less, and for less, than their civilian peers. Only 30 percent live on their base, but three-quarters live within 20 miles of the installation. At least 60 percent have relocated in the past 3 years. They move, and they move overseas.

Nearly 2 million children and youth are military-connected, with the largest group under 5 years of age. Dr. Davis estimated that 20 percent or more have special needs, but there is no way to specifically identify military children with special needs.

In the past 10 years, about half of active-duty service members have deployed at least once, and National Guard and reserve forces have accounted for one-third of all deployments. The average length of deployment is 12 months for the Army, 7 months for the Marine Corps, 6 months for the Navy, and 3 to 4 months for the Air Force. Increasingly, research demonstrates that the cumulative length of deployment is associated with family stress and the health and mental health of family members.

Military service members and their families have a strong cultural identity. A 2011 survey showed that almost two-thirds of active-duty military members grew up in military families themselves. They expect separation and relocation. Another expectation is that spouses are willing and able to handle everything other than the military member’s readiness. This has implications for children with special needs, whose families must deal with multiple additional layers of responsibilities.

Where a service member is assigned and where the family lives determine what schools the children attend, what medical services and therapies are available, what childcare options are available, which state-specific services can be accessed, and whether the family is eligible for Medicaid or Supplemental Security Income (SSI). Military families move frequently and move far away, and this affects military-connected CSHCN more than other military children and more than civilian CSHCN.

EFMP was created in 1979 to ensure that overseas assignments that included family members could meet the family’s medical and educational needs. It is only for active-duty service members, who enroll in an EFMP for their branch. When EFMP enrollees are considered for reassignment, medical and educational needs are a factor. Assignments in the continental United States typically have support for special educational needs through the Individuals with Disabilities Education Act (IDEA). Alaska and Hawaii are considered overseas assignments.

Each installation has a program to help families find services in both military and local civilian communities. Dr. Davis described a case she consulted on that resulted in compassionate reassignment. A family with a 10-year-old boy with nonverbal autism and a history of elopement (running away) was assigned to Fairbanks, AK. The temperatures in Fairbanks can reach 40 degrees below zero, placing the boy in physical danger if he ran away. Dr. Davis spoke with the family and wrote a letter on their behalf, and the service member was reassigned.

The EFMP definition of CSHCN is provider-centric. Indications for enrollment are any serious, life-threatening, or chronic condition requiring specialty care or more than annual follow-up with a primary care provider; any condition requiring health care services beyond primary care; and any special educational services. This definition does not capture all military-connected CSHCN. The current EFMP enrollment is 120,000. The process has barriers when tied to assignment.

Dr. Davis reviewed military medical benefits that are relevant to CSHCN. TRICARE is a comprehensive health program with eligibility and benefits determined by Congress. It provides for a network of military medical health care resources and civilian network providers. TRICARE Prime is used by a majority of active-duty families and is essentially free. It includes physical therapy, occupational therapy, speech and language therapy, and psychological services. Dental coverage has a separate program, and eyeglasses are not covered. There are three regional contractors in the United States.

ECHO, a supplemental program for eligible active-duty family members, was established in 2005. In 2012, the majority (88 percent) of ECHO participants had a diagnosis of ASD. Use of the applied behavior analysis (ABA) benefit has quadrupled since 2009. Co-pay is based on military rank.

Transitions in health care are by age. Military children and youth are covered by their parents' basic TRICARE policy if they are younger than 21 years of age. Young adults under the age of 23 years are covered by their parents' TRICARE if they are full-time students. Under the TRICARE Young Adult program, young adults can purchase care until they turn 26 if a parent is on a TRICARE plan. Indefinite coverage regardless of age is available for adult children with special needs for individuals who require that the majority of their activities of daily living be handled by parents.

The DoD Child Development Program has been touted as one of the best child care programs in the country. It serves more than 200,000 military children from birth to 12 years old daily, with more than 750 child development centers and school-age care facilities at more than 300 locations worldwide, in addition to approximately 4,400 family child care homes. Almost all are accredited programs, and the DoD subsidizes the cost. Approximately 27,000 of the children who use child care services are CSHCN, although the definition of special needs is branch-specific.

Dr. Davis reiterated that geographic mobility is a reality of military life. Military personnel move every 2 to 3 years. Active-duty military personnel are three times more likely to have moved within the past year than other Americans. Parents of children with special needs must relearn systems and re-assemble the continuum of care.

The DoD Education Activity (DoDEA) program is a unique school system that serves more than 84,000 students worldwide in the Pacific, Europe, and the United States. This is only 10 percent of all military children, and the large majority of military children attend public or private schools in their area. Even on-post, schools are usually run by local departments of education. In DoDEA sites, 4,349 children receive special education services in the Americas, 3,838 in Europe, and 2,025 in the Pacific.

While there are no solid data on the number of military CSHCN, some key indicators from states with a large active-duty military presence can shed some light. For example, the prevalence of CSHCN ranges from 10 percent to 17.2 percent in California, Texas, Georgia, Virginia, and North Carolina, the states with the largest number of active-duty military. The percentage of children with unmet needs in those states ranges from 17.3 percent to 27.4 percent, and the percentage of children in those states diagnosed with ASD who have IEPs ranges from 5.2 percent to 8.8 percent.

With no DoD registry of beneficiaries for special health care needs, definitive prevalence and outcome data about specific conditions are not available. In general, most military childhood chronic conditions have the same prevalence as in civilian populations. In the military health system, researchers have found that autism prevalence is at least 1 in 88 children (Freedom of Information Act [FOIA] release 2007); asthma prevalence is 6 percent to 9.6 percent, although race and ethnicity disparities persist (Stewart, K.A., et al., *Archives of Pediatric and Adolescent Medicine*, 2010); and ADHD prevalence in 4- to 8-year-olds is 8.3 percent, with about half on medications (in press, Gorman, G. et al., *Military Medicine*). About 0.15 percent of military children have life-threatening conditions (Randall, V., et al., *American Journal of Hospice and Palliative Care*, 2011), and 71 of 100,000 experience inflammatory bowel disease (Betteridge, J.D., et al., *Inflammatory Bowel Disease*, 2013).

Dr. Davis turned to special education eligibility. The primary indications for children in DoD special education programs are developmental delays and speech and language disorders. Researchers are looking at different outcomes, including externalized behaviors (aggression, behavioral problems, defiant behaviors), internalized behaviors (depressive symptoms, anxiety, withdrawal, sadness), academic performance, and peer relationships.

Children and youth experience sadness and worry when a parent deploys, and the well-being of the at-home parent is strongly associated with children's well-being at all ages. The cumulative length of deployment is associated with increased spouse and child stress. Gorman and colleagues (*Pediatrics*, 2010) found that pediatric behavioral disorders increased 19 percent and stress disorders increased 18 percent in children of deployed service members compared with children of non-deployed parents. Mansfield and colleagues (*Archives of Pediatric and Adolescent Medicine*, 2011) observed a dose response pattern between parental deployment and increased mental health diagnoses at all ages.

Several groups offer support programs and interventions to support military families who experience wartime deployments of a family member. These include the Center for the Study of Traumatic Stress (<http://www.centerforthestudyoftraumaticstress.org>), MilitaryOneSource

(<http://www.militaryonesource.mil>), and the Tragedy Assistance Program (<http://www.taps.org>). Pediatricians are the frontline providers and need to recognize, respond, and refer when necessary.

The only comprehensive study of CSHCN in the military that used the definition presented by Dr. Palfrey is a study performed by Dr. Thomas Williams and colleagues that was published in *Pediatrics* in 2004. It used the military health system's claims data from 1999 to 2001 and the CSHCN screener in the annual health care survey of TRICARE beneficiaries. The study found that 23 percent of TRICARE Prime children under 18 whose parents responded to the survey were CSHCN. These 23 percent accounted for 44.4 percent of outpatient visits, 46.8 percent of non-primary care visits, 38.3 percent of primary care visits, 52.7 percent of specialist visits, 32.1 percent of emergency room visits, 64.8 percent of patient admissions, and 76.2 percent of inpatient days.

Dr. Davis shared a number of resources for parents and people who work with CSHCN:

- MilitaryOneSource has a Special Needs Toolkit with a drop-down menu that is very useful ([http://www.militaryonesource.mil/efmp/parent-tool-kit?content\\_id=268726](http://www.militaryonesource.mil/efmp/parent-tool-kit?content_id=268726)).
- Organization for Autism Research (OAR) offers the OAR Guide for Military Families (<http://www.operationautismonline.org/guide-for-military-families>). Military family resources include system navigators, a new parents support program, and family support programs.
- The AAP has a Section on Uniformed Services with a 50-year history, 900 members, and a military medical home website (<http://www.aap.org>). TRICARE for Kids also offers advocacy.
- The Specialized Training of Military Parents (STOMP) program serves military parents of CSHCN worldwide. It provides information and training about laws, regulations, and resources for military families of children with disabilities; connects families; assists parents and professionals in developing their own community parent education/support groups; and provides a voice to raise awareness of issues faced by military families of children with disabilities. The website is <http://www.stompproject.org>.

Dr. Davis concluded with a list of evidence gaps adapted from Chandra and London (*Future of Children*, 23:2, 2013; <http://www.futureofchildren.org>). First, where are the military CSHCN in the military, in the United States, and in existing surveys? Military status should be a routine part of data collection in national surveys. Longitudinal studies are needed to determine how military children fare over time and over generations. Is a central institutional review board (IRB) possible? What can be generalized from the military to civilian population? What is known about dose effects of risks and resilience, interventions for trauma, and health care utilization in a single-payer system? Do civilians, particularly researchers, understand the diversity of the military?

## *Discussion, Questions, and Recommendations for Consideration*

Dr. Davis addressed a question about EFMP and noted that her role in EFMP was identification and enrollment. The process can be unwieldy, but the paperwork is now the same for all branches, with additional questions for different conditions. Most primary care providers do not have the time to fill out the forms. As the network expands, more and more children are participating in civilian and military care, and there are gaps in who will fill out the paperwork.

For some conditions, such as ADHD, if there are no comorbidities and the provider can manage on his or her own, there is no need to enroll in EFMP. Many families do not want to be enrolled because they do not want a diagnosis to exclude them from a desired assignment. EFMP wants to support families where they are assigned and has that ability, but not everywhere. There are places where service members cannot go with a certain condition.

The Office of Special Needs (OSN) is working on a process to standardize EFMP enrollment. Each service has its own policy, but they are working toward a single DoD policy. Related to family support, OSN is examining how to determine family metrics. A number of activities are ongoing in different areas.

A key question for researchers in the area of special needs is how to determine where specialized and inclusive services can be provided. Another question is how to disseminate information more broadly without diluting the services. Studying EFMP might be one approach. Dr. Davis noted that the information is tied to a difficult data system. Children with a condition are identified by where the service member is assigned, which might involve more than one assignment.

The OSN is working on an information technology roadmap to examine and analyze all of the systems and determine whether they might be able to talk to each other. The office is looking at many possibilities, will be able to come up with some good options. Dr. Davis noted that the OSN is often looked at to come up with answers.

An audience member noted that in working with families seeking help for children with behavioral problems, including autism, the topic of EFMP often comes up. Classifications can interfere with career development and family aspirations. Clinicians have tried to develop remote therapy techniques so that families are not required to stay in particular places. The audience member asked whether some problems could be addressed with home therapy using technologies such as Skype. Military families are ready for that.

The military has a large tele-health program for service members and is interested in expanding it. In-home therapy has been investigated and is in the status of a research proposal. Pediatricians can conduct cardiac assessments remotely, and they should be able to determine through remote assessment where children with various needs should go and how fast. Some children might need more help, but they can be followed. A timeline (for example, 5 years since the last hospitalization for asthma) can help establish the intensity of follow-up. This is an example of how health care for military families can be more inclusive.

An audience member asked where the data in the Williams 2004 study of military CSHCN came from, and how the investigators were able to gather the information with so many receiving care

in the community. Dr. Davis said the data were gathered from 1999 to 2001 in a health care satisfaction survey and attached screener that the military has been sending to parents since 1985. Dr. Palfrey said the study also incorporated claims data that included purchases and covered care.

It was noted that from the perspective of physical therapists, particularly those with TRICARE contracts, the renegotiation of contracts with regional providers is resulting in cuts in reimbursement. Some providers are forced to drop out because they cannot afford to provide services. This is compounded by a shortage of providers, particularly in rural areas. Dr. Davis noted that only 5 percent of physical therapists treat children, and it is a problem if they are dropping out.

Ms. Crandall commented that regarding school-based services, a majority of school systems deliver care using a case-based approach based only on numbers. She would urge a workload approach. Military children could benefit from this approach. Their issues can be even more complex than those of civilian children. It might be useful to brainstorm different solutions to address these problems.

Dr. Palfrey asked about ideas for providers who serve youngsters in special settings. Dr. Davis observed that most children are healthy. Some parents of children with significant special needs—perhaps 5 percent—legally stay in the military to continue to receive services for their special needs children. Some branches serve children with the most needs by “homesteading” around military medical centers to maximize inpatient and outpatient care in places such as San Diego; Tidewater, Virginia; or Walter Reed Medical Center in Washington, DC. The DoD’s OSN will work for this. Children can be divided into three groups: those who receive military treatment and care coordination, those who receive military and civilian treatment, and those who receive care in a civilian network. The third category probably accounts for 50 percent of all care. TRICARE providers should know the EFMP process in order to determine how to figure out how to get services for the children they see in their offices. She said that the largest service gaps are for children who are racial/ethnic minorities or are non-English speakers.

An audience member asked for an overall assessment of the effectiveness of providing services for military-connected CSHCN. It varies by place. Children’s special needs are supported when bases have good relations with medical centers and are knowledgeable about their local resources. The military treatment facilities are doing a good job with special health care needs, but many inconsistencies are apparent. It involves many people in many places. Raising the standards will result in continued improvement.

A special needs parent, commented that in the world of autism, presently 10 percent of children, at best, receive some care, but 90 percent receive none. Dr. Davis emphasized the need for accurate population statistics to know whether progress is being made in addressing needs.

## **Panel Presentation: Military-Connected Children with Special Health Care Needs: The Parent's Perspective**

*Mary M. Keller, Ed.D (Panel Moderator), President and CEO, Military Child Education Coalition*

Dr. Keller began by underscoring the fact that not enough is known about military-connected children. She spent 21 years in the school system in several Texas school districts, the last 8 years as assistant superintendent and superintendent. One of her school districts served Fort Hood, and half of the children in the district were military-connected. Dr. Keller noted that most military-connected children attend public schools.

Dr. Keller asked participants to draw a Venn diagram with three overlapping circles: one large, one medium-sized, and one small. Based on the top 25 school districts that serve military-connected families, the largest circle is children eligible for section 504 services. Section 504 is a part of the Rehabilitation Act of 1973 prohibiting discrimination based upon disability. Disabilities are defined as any disorders that substantially reduce the student's ability to access learning in the educational setting. The definition covers a wide range of conditions, including asthma, diabetes, eating disorders, and depression. But some children, even with disorders, may not qualify for special services. The second circle is EFMP, which is for children in active military families, and the smallest circle is children in special education. Special education services are extremely difficult to obtain and available only when families demonstrate that their children have not responded to other interventions to affect their educational outcome. The circles overlap, and some children can qualify for more than one program.

Most school districts do not ask on enrollment forms whether a child is military-connected, which makes it very difficult to disaggregate data. Parents might think that EFMP children automatically qualify for special services in the public schools, but that is not true.

It is important that parents be their child's best advocate by informing the schools and knowing about the educational services their child has received, what educational services they could be eligible for, and the medical services they receive. Dr. Keller emphasized the difficulty of receiving services. The Military Child Education Coalition helps people ask the right questions, from the pediatrician asking whether a family is military-connected to the educator asking about previous services. The medical home is on wheels and needs to travel with the child.

Dr. Keller added that she is the grandmother of a special needs child, and her son is in the Naval Reserves.

*Panel Member: Anissa Davis, Military Spouse, Navy*

Ms. Davis is a Navy spouse for 16 years, and her daughter Mila is attending this conference. Her children are now 22, 15, and 12. She did not think she had children with special needs, but listening to the presentations, she realized that she did. Two of her children have asthma, and her stepson, the oldest, had behavioral needs and was diagnosed with ADHD. He had been diagnosed simply as a "bad child" and had poor grades, was acting up, and didn't do his

homework. When the family moved to from Washington, DC, to Virginia, he was diagnosed with ADHD and put on proper medications. He ended up a model student. She decided to become involved with the topic and became president of a family readiness group as part of the Navy Fleet and Family Support Programs. She works with families whose children were misdiagnosed, and part of her mission with families is to help them find resources when their spouses are deployed.

*Panel Member: Lynda Honberg, Director of Strategic Partnerships, Family Voices*

Ms. Honberg has been a captain in the Public Health Service, where she worked for the Child and Health Bureau. Recently, after her retirement, she joined Family Voices (<http://www.familyvoices.org>), a nationwide nonprofit advocacy group that helps families with children with special needs or disabilities negotiate the health care system. Many of the families are military. Ms. Honberg is also the mother of Sarah, who will graduate from the University of Maryland this year. Sarah is a success story. When she was born, she was covered by the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS), which became TRICARE. Sarah was born with a rare genetic syndrome and has had 28 surgeries. The military system has considerable turnover in medical staff, and the ongoing surgeries resulted in a problem with continuity of care. This is a frequent complaint of military families. Another problem is that military members and people in the uniformed services are not eligible for provisions of the Family and Medical Leave Act. Sarah was in the neonatal intensive care unit (NICU) for 2 months after her birth, and Ms. Honberg did not have the leave to spend time with her. Parents of CSHCN need help to coordinate their children's care, which can be incredibly complicated. That is another problem she hears about from parents all over the country. Many parents are not aware of their options. Ms. Honberg had resources, a good family network, and a background in health care and still struggled. Sarah has done well and is transitioning from college to adulthood.

*Panel Member: Jeremy Hilton, 2012 Military Spouse of the Year*

Mr. Hilton, a graduate of the Air Force Academy, Navy veteran, and part of the Military Special Needs Network, has a child with autism. His wife is still on active duty. He reiterated the complexity of finding appropriate medical, educational, and support services for children with special needs. His daughter Kate was born with severe hydrocephalus, and the family dealt with intense medical issues from her birth to age 5. Multiple services had to be put into place every time the family moved, a process Mr. Hilton described as "brutal." They moved five times in 5 years. Only a small percentage of the effort involves dealing with the military system. Most of it involves dealing with the community, and there is a disconnect between the military and the community. Kate is a medically complex case, but there are thousands of other children like her.

*Panel Member: James Richards, Navy Spouse, NIH Veterans Recruitment Force, Budget Analyst, NICHD*

Mr. Richards is a Marine veteran who currently works at the NICHD and is a member of the Veterans Recruitment Force. He noted that half of male military spouses are veterans

themselves. His wife is in the Navy. He married in 2000; his son was born in 2010, and his daughter was born in 2012. His daughter did not gain weight as she should have. When their daughter was 13 months old, his wife was deployed to Afghanistan for 14 months. The little girl trended downward and stopped gaining any weight at all. He tried to make meals fun, and the nutritionist said candy could be part of everyday food. When his wife returned from Afghanistan, their daughter was 4 years old and weighed 25 pounds. She began to gain weight. His wife was fortunate enough to be stationed at Walter Reed with a long-term posting.

### ***Lessons Learned and Recommendations***

- Mr. Richards said **parents should not be afraid to ask for help**. Coming from the Marines, he thought he could do it all and didn't need support. He had to "eat some humble pie." His sister helped him through his wife's deployment, and he asked for help from his colleagues. Working for the NICHD made that easier.
- Mr. Hilton indicated that there are both **formal and informal parent-to-parent training** programs. Parents need to reach out to other parents. STOMP, a federally funded parent training and information program, was established to assist military families with children with special education or health needs and provides valuable assistance. It can provide a point of contact that allows families to move forward.
- Ms. Honberg said **connecting with other families** saved her. She was able to find others who shared her daughter's diagnosis. An important piece of advice is to try to stay optimistic. There was a time when she never would have believed she would see Sarah graduate college. A parent who has a child with an incredibly rare condition fears the worst; she advised to try, instead, to network with families and see the best.
- Ms. Davis said her advice is to **seek out parents in a similar situation**. There is nothing like knowing you are not alone. Ask questions. Find a family support center. Support centers have resources that are ready to help. But parents must seek help; no one will care about their child as much as they do.
- Dr. Keller said parents of children with special needs often focus on what their children cannot do and how they can fix things. She asked panelists about the blessings, gifts, and strengths they have learned from their child.
- Mr. Hilton said that when he was in the Navy and he and his wife both had careers, they did not expect Kate to have the problems she did. It was a shock to them. Besides making him a better father, he learned that **children with special needs teach their parents a great deal with their resilience**. At one point, their pediatrician had an honest discussion with them about institutionalizing her. Now she is reading almost at grade level and walking, which she did not begin until 5 years of age.
- Ms. Davis spoke of the gratification of watching her oldest son overcome ADHD hurdles and knowing there was not something wrong with him that she couldn't master. He is now 22, off medication, and a father. Her younger **children can now manage** their asthma on their own. Her older son also has asthma and is in the Junior Reserve Officers' Training Corps. He is able to participate in drills and knows to use his inhaler first.

- Ms. Honberg said **families are advocates for their children**. Sarah is in early childhood education; she is now an advocate and understands what families face in obtaining services.
- Mr. Richards said **resilience and family strength** are the themes.
- Ms. Honberg said her biggest fear was that Sarah would not have friends. She lost considerable school time for her surgeries and does not look the same as other children. Ms. Honberg was never sure whether Sarah's special needs affected her friendships or lack thereof. Adolescent girls are not always nice. **The community is important**, and the family has been in the same house for most of Sarah's life. She cannot imagine what this is like for military families who move around so much. Some of Sarah's friends date back to their preschool days. It must be very difficult for children to be forced to change their medical providers, their schools, and their friends.
- Ms. Honberg said one topic that the panel has not addressed is the fact that children with special needs are much more likely than others to be bullied. Sarah was bullied for one summer. They also can face informal bullying by adults. People say stupid things and ask insensitive questions. **As a society, it is necessary to sensitize everyone to the fact that people with disabilities are people like everyone else.**

## **Panel Presentation: Health Care Access and Utilization by Military-Connected Children with Special Health Care Needs and Their Families**

*Cicely Burrows-McElwain, L.C.S.W.-C. (Panel Moderator), Public Health Advisor, Child Trauma Program, Substance Abuse and Mental Health Services Administration*

This session focused on behavioral health and highlighted research on the provision of mental health services, utilization of health care services and policy.

### ***Providing Mental Health Services to Military Connected Children***

*Paramjit T. Joshi, M.D.*

*Chair, Division of Psychiatry and Behavioral Sciences, Children's National Medical Center; Professor of Psychiatry, Behavioral Sciences and Pediatrics, George Washington University School of Medicine*

Dr. Joshi trained first as a pediatrician and then as a psychiatrist. She has studied mood disorders for many years and has published extensively on child and adolescent mood disorders, bipolar disorder, trauma, and violence. She introduced herself as a physician, an educator, and a product of the military. Her father served in the Indian army, and she is familiar with military life and the effects of deployment.

Dr. Joshi began thinking of mental health as a children's issue and devoted her career to it because mental health impacts a large number of the nation's youth, families, and communities. Mental illness is treatable, and the best outcomes occur with early identification and intervention.

Unidentified and untreated mental illness in children can lead to tragic and costly consequences, but these consequences can be avoided with timely action.

Everyone in the pediatric community and many in the general public know how difficult it is for patients to access mental health care in this country. Approximately 5 percent of all children need mental health services. Half of all lifetime cases of mental illness begin by age 14 years, and 75 percent begin by age 24. Only about 20 percent of children with mental illness receive treatment, and there is typically an 8- to 10-year delay between the onset of symptoms and the time a person is diagnosed and receives treatment. This can result in severe consequences for behavioral, emotional, and mental development.

There are many consequences of unidentified and untreated mental illness in children. Half of children with unidentified mental illness drop out of high school, the highest dropout rate of any disability group. Mental illness is an underlying factor in 90 percent of teenage suicides, and suicide is the third-leading cause of death in youth and young adults. Also, 70 percent of youth in state and local juvenile justice systems have underlying mental illness. Children with mental illnesses are being warehoused by the juvenile justice system, Dr. Joshi said.

Dr. Joshi showed a map depicting the geographic locations of practicing child and adolescent psychiatrists and the rates of psychiatrists per 100,000 children, which are generally very low. Large areas of the country have no child psychiatrists at all. In the Washington, DC, area, there are just over 100. The total number of child psychiatrists in the United States is just over 8,000. The picture is even worse in the rest of the world. In India, there are 10 child psychiatrists, and there are none in Iraq. These few practitioners are not going to be able to address the problem of children's mental health on their own, and collaborations are necessary. The situation is heartbreaking.

Children of military families have unique mental health challenges. Dr. Joshi reminisced about her own childhood, her father's frequent deployments, and the family turmoil that was involved. That is what initially sparked her interest in the career of child psychiatry. Not just military families, but all families, are best understood within the context of social, emotional, and cognitive development. Children respond differently depending on their developmental level. Any exposure to any kind of stress can result in a multi-tiered cascade of negative life events.

There is an expectation that military families are supposed to endure this stress, and Dr. Joshi said she remembers thinking, "Is it fair?" She still does not know the answer to that question, but she remembers her father telling her to do the right thing and just march forward. The challenges of military children include the loss of loved ones, displacements and moves, and a lack of educational and community structure. Children need stability in education, but military children deal with drastic changes in daily routine and community values.

Parental post-traumatic stress disorder (PTSD) has a huge effect on children. Dr. Joshi cited a study (Chemtob, et al., 2010) of 116 children who were exposed to the September 11, 2001, terrorist attacks in New York. Nearly one-fourth of the children were exposed to one or more high-intensity events at the World Trade Center, including seeing people jump out of buildings,

seeing dead bodies and injured people, seeing a tower collapse, being caught in debris or smoke, or seeing a plane hit the tower.

Chemtob and colleagues compared behavioral problems in children whose mothers had PTSD and depression, depression alone, PTSD alone, and neither disorder. Children with mothers who had both depression and PTSD were at increased risk for emotionally reactive behavior, anxiety and depression, somatic complaints, withdrawn behavior, sleep problems, and aggressive behavior problems. In military families, the problems intensify when both parents are deployed, face combat, and subsequently experience depression and PTSD.

Most studies have looked at mothers, not fathers, but an Israeli study of both parents with PTSD found results similar to the World Trade Center study. The same researchers (Chemtob et al.) were looking at the same features as in the post-9/11 New York study—emotional reactivity, anxiety and depression, somatic complaints, sleep problems, aggressive behaviors, and attention disorders. Again, children with mothers with both depression and PTSD were at greater risk for problems in the children. Assessment of a subsample of the fathers found that wives of men with PTSD had a nine-fold greater risk of depression, although there was no notable evidence for an increased likelihood of the mothers having PTSD. Most of the men (70 percent) with PTSD also had depression. The authors of this study concluded that a father's PTSD has a devastating influence on children's behavioral problems.

Dr. Joshi reviewed the history and an overview of the Department of Psychiatry and Behavioral Sciences at the Children's National Medical Center, which is where military children with serious mental health problems are hospitalized. Founded in 1948 by the late Dr. Reginald Lourie, the department is one of the oldest of its kind in the country. It has three major programs: psychiatry, psychology, and neuropsychology. There are 34 full-time faculty members, with 12 child and adolescent psychiatry fellows and 4 psychology interns. Some of the residents are from the Walter Reed National Military Medical Center, as are some postdoctoral fellows and interns. The hospital has a long and important relationship with the military, and Dr. Joshi welcomes military participation. Members of the military bring much to the education and training experience.

### ***Health Care Utilization among Children with Special Health Care Needs***

*Mary Jo Larson, Ph.D., M.P.A.*

*Senior Scientist, Institute for Behavioral Health, School for Social Policy and Management, Brandeis University*

Dr. Larson conducts health services research and specializes in vulnerable populations. She studies services used by military families. She commented that she has had the opportunity to work with the lead author of the 2004 assessment of military CSHCN, Dr. Williams, who has sponsored much of her work.

Studying health care utilization in CSHCN is challenging in all systems, as well as among military children. To understand health care utilization in the military, it is important to understand the diversity of the children in this group and the many subgroups. Also, children and families are involved in multiple care systems. Family environment and unmet needs are

associated with a child's developmental outcomes, and military families can have special unmet needs that are associated with complex family environments.

CSHCN have diverse needs. Between 13 percent and 18 percent of these children have health care expenditures that are three times greater than those of a typical child. Even with these increased expenditures, CSHCN have more unmet health care needs than other children.

Children in special education are characterized by functional impairments in education settings. They make up between 6 percent and 9 percent of all children. Looking at three sectors for CSHCN (special education, special health care, and mental health services), 66 percent of the children are in special education only, while 26 percent are in two sectors, and 8 percent are in three sectors.

Health care use varies by group, Dr. Larson noted. Nearly half (49 percent) of children classified as both CSHCN and special education (dual diagnosis) use psychiatric drugs, compared with 21 percent of CSHCN only and a very small percentage of children in special education only. Emergency department visits occur in 21 percent of children with both CSHCN and special education categorization, 15 percent occur in children with CSHCN only, 17 percent occur in children with special education categories only, and 9 percent occur in children who are categorized in neither group. Mental health visits are documented in 38 percent of dual diagnosis children, 15 percent of those in the CSHCN-only group, 10 percent of special education children, and 1 percent of children who are in neither group.

A new study of the economic costs of ASD by Lavelle et al. (*Pediatrics*, 2014) used three types of data—parent surveys, school services, and health care claims—and determined that the economic burden associated with ASD is substantial. Focusing only on health care underestimates this economic burden. Health care accounts for only 18 percent of additional costs, special education accounts for a much higher percentage of the costs.

Dr. Larson presented an overview of the military health system, a large entity and a system of both health care delivery and insurance. More than one plan is offered, but most active-duty family members are covered by TRICARE Prime. Beneficiaries include 2 million family members of active-duty service members of a total of 9.5 million TRICARE beneficiaries (in fiscal year 2009). Family members in TRICARE Prime may use services at military treatment facilities and a network of civilian providers.

The Williams 2004 study documented that, in 2001, 7,483 of TRICARE Prime enrollees were children. Of these, 15 percent received additional services for special health care needs and 9 percent received only medications for special needs. The proportion of CSHCN, as identified by a special health care needs screener for children older than 1 year of age, was somewhat lower than in the national study, with 5.4 percent of children limited in any way. The largest category was the 18.3 percent of TRICARE children with medication needs. In other categories, 6.0 percent of TRICARE children received emotional, developmental, or behavioral counseling; 4.2 percent received special therapy such as speech; and 11.0 percent received additional medication, mental health therapy, or education.

The Early Intervention Collaborative Study (EICS) is the largest longitudinal study of children with special needs. It was described in a 2001 monograph from the Society for Research in Child Development. It identified children at age 3 and followed them until age 10, examining how they developed and changed over that period.

The study looked at 190 children and families in early intervention programs; the children had been diagnosed with Down syndrome, motor impairment, or developmental delay and were already receiving services. Investigators collected longitudinal interview data with parents and child observations at five time points between entering early intervention and age 10 years. Outcomes included communication skills, social skills, and mental age. The study also looked at parent outcomes—specifically, how parents changed or adapted over the span of the study. It is unusual in its focus on the dynamic and reciprocity between child development and parent adaptation.

Contextual variables were important to outcomes. Family climate and process mattered. For example, mothers who were more responsive and growth-promoting in their interactions with their children had children who showed greater growth in three of four measures. On average, mothers of young children with these special needs faced interactive challenges, and CSHCN exhibited lower skills than children in a normative sample. This implies a need for programming that centers on interventions focused on mother-child relations and family relatedness.

In another family relations finding, parents reporting higher family relatedness (for example, a sense of connectedness and expressiveness) when children were age 3 had children with greater gains in social skills at age 10. Looking at parental outcomes, by the time the children were 10 years old, 38 percent of mothers and 44 percent of fathers had child-related stress scores in the clinical referral range. Fathers' scores sharply increased while the child was younger than 3 years old, and mothers' scores increased in a linear fashion. Support helpfulness was related to mothers' levels of parent-related stress, and problem-solving coping skills were related to fathers' levels of parent-related stress.

The EICS has implications for military families, Dr. Larson said. The central role of family processes in children's development implies a role for intervention to support families and a need to learn the adaptive strategies that military families use to address these challenges. For school-aged children, IEPs target the child but do not address the needs of the parents and family. Services are needed to support healthy family processes of school-aged children with special needs when stress is highest, including services that target military fathers. Services also are needed that support positive interactions between mother and child beyond toddler age.

Dr. Larson also presented data from a study of children's health services use the year before a parent was deployed. Health care changes associated with a parent being deployed included increases in psychotropic medication use and increases in specialist services. There was no indication of additional emergency visits or institutional care, but the study was not restricted to CSHCN. The use of military treatment facilities decreased, and the use of civilian providers increased. Dr. Larson concluded that children were affected by the deployment of a parent and emphasized the importance of studying families.

## ***Military Health Systems: Policy, Access, and Utilization***

*L. Christopher Plein, Ph.D.*

*Eberly Professor of Outstanding Public Service, West Virginia University*

Dr. Plein noted that Medicaid, which can be very difficult to negotiate for families seeking coverage and related services. He commended the sponsors of this conference for presenting an opportunity to come together to identify problems and consider solutions associated with Medicaid and other issues relating to military children with special health care needs.

In addressing active-duty military families with children who have special needs, Dr. Plein said he wanted to focus on six words: perception, definitions, expectations, capacity, resiliency, and discretion. Briefly, perception is important because much of what is heard about problems and challenges in this context is perceived. Definitions are critical because how the problems are defined is central to any discussion. For example, what is meant by special needs? Expectations also must be considered; different groups and individuals might have different expectations. Capacity is vital. It's one thing to talk about access and coverage, but another to talk about availability and delivery. Resiliency is another word to keep in mind. It varies, as the stories of the earlier session illustrated. Discretion is important because programs are administered by people who use judgment. The interface between the individual who has discretion to make a decision and the family is at the heart of these discussions.

Usually, military families turn to Medicaid for supplemental services and coverage, although they must deal with waivers and waiting lists. Structurally, Medicaid is ill equipped to respond to active-duty military family needs, but it might be a crucial resource for those leaving the military. Medicaid is highly variable across states, presenting one of several barriers. It is a state-federal partnership and differs in modes of delivery, optional services, and management from state to state. Medicaid also is likely to be under budgetary stress, and it is politically contentious.

A waiver is temporary permission for a state to operate a program in a different way than was established by law. Waivers add to the variability of Medicaid. Medicaid is so variable that it is not set up to accommodate people moving from state to state. It is contingent, and its continuity is not dependable. Medicaid is one of largest portions of a state's budget, and state budgetary pressures on Medicaid are evident everywhere. Last year at this time, Virginia committed to not expanding Medicaid, but now there is a great deal of conversation about it.

Some Medicaid barriers are truly political—a product of the evolution of the program over time. The political pressures Medicaid is subject to make it difficult for the program to be effective. This conference has emphasized the prevalence of special needs children in civilian as well as military families. This presents systemic challenges and program delivery challenges. The challenges can be viewed in three dimensions: (1) underlying systemic challenges such as increased demand; (2) large political forces; and (3) aspects of program performance for which programs and managers can be held accountable.

Education and awareness about Medicaid are important for military families. Military families need to know about health care options both in and out of the military health system. DoD

support personnel can play a major role as resources. But it is crucial for families to exhaust options they have in the military before they move to Medicaid.

In thinking about policy needs and development, Dr. Plein said he would try to ease the transition for a family leaving the military that needs Medicaid. Eligibility is often a barrier. The states of California, Kansas, and Washington are exploring Medicaid program innovations to help families nearing separation from the service. Changes in eligibility are coming. The Affordable Care Act (ACA) changes the landscape of Medicaid through eligibility expansion. The expansion of Medicaid to 138 percent of the federal poverty level is a big game changer. The ACA also encourages further promotion of home- and community-based services, although waiting lists already exist. One effort is to try to mainstream programs.

Dr. Plein concluded that Medicaid has been a large part of the architecture of the American health care system. It began as a program to help those most at risk: namely, the poor. Now, it serves a broader base and encourages new modalities of delivery: managed care, for better or worse. It is exploring new modes of community care and is important to military families, but ill-suited, by the fact of its design, to pay for services for those still in active duty.

## **Working Group Sessions: Recommendations and Points for Further Consideration**

### ***Family Issues of Military-Connected Children with Special Health Care Needs***

*Ms. Kaeser (Working Group Moderator),*

*Chief, Office of Legislation and Public Policy, NICHD*

*Jennifer Dailey-Perkins (Working Group Moderator)*

*Transition and Outreach Specialist, DoDEA*

### **Summary of Working Group Discussions**

- The NICHD examines topics such as the impact of violence and the effect of exposure to violence and neglect on children and families. It is important to know about the stressors that families face and what works to alleviate them. Resilience is one factor that has been mentioned.
- Some existing data are good, although better studies across systems are needed. School data are collected in schools, and demographic information and cohort data are forwarded to the National Center for Education Statistics. Eight states are participating. It is possible to tell how districts are being served, but data about the approximately 2 million military-connected children are not disaggregated where the children are served. In most areas, military and civilian cohorts cannot be compared. About 70 percent of military children are younger than 10 years of age. A longitudinal study that looks at positive youth development and school performance is needed.
- The 2011 Defense Reauthorization Act asks the DoD to look at special needs of military children, noting that only anecdotal information is available.

- Of 800 major school systems that serve military children, only 120 receive impact aid data, and teachers do not see those data. Impact aid is a replacement for tax dollars.
- The National Survey of Children with Special Health Care Needs (NS-CSHCN) is a very elegant study, a randomized controlled trial with a digital dial study with cell phones. However, it has no marker for military children. The group recommended adding such a marker to the survey.
- Regarding whether such a survey would reach military families serving overseas, it was noted that the DoDEA program is a system that skews toward mild to moderate disabilities. She said that military personnel are not covered by the Americans with Disabilities Act (ADA) in foreign countries.
- Group members noted that directories of human resources are directly tied to orders, and every branch has such a directory. They provide real-time data on how many military personnel are in a certain country. Also, the data from DoDEA are 2 years old. Impact data did not delineate military personnel until the military asked for it. One of the best rubrics for IEPs is at the U.S. Department of Education's Office of Innovation and Improvement for charter schools. It documents a child's experience from the time he or she walks through the door. In different school districts in northern Virginia, the IEP process is completely different. Special education is a huge undertaking that is defined differently in different districts. A parent advocacy tool is needed for working with special education IEPs.
- The examination of special education students in the Hurricane Sandy area could be instructive. And Houston received 40,000 students overnight from Hurricane Katrina.
- Another relevant group might be children of migrant workers and children who experience natural disasters.
- On the topic of medical homes, the possibility of an individualized health plan that families could access would be extremely helpful provided confidentiality was maintained.
- An issue that warrants further exploration is how to support parents of special needs children in the military. Some parents experience depression, anxiety, and conflict. The problems have a multiplier effect. Couples need respite care, they need workshops, and they need skills. Most do not have the skills to survive a marriage when they are not in the military. The Prevention and Relationship Enhancement Program, PREP, Inc. (<https://www.prepinc.com>), is an organization that does a good job of addressing these issues, providing resource materials for those who teach relationship education. The group is conducting research in the Army. It might not be able to identify families with special needs children, but it has obtained good results in reducing divorce and distress, particularly with minority families. The program has been studied internationally for three decades. In Oklahoma, it sponsors retreats for Fort Sill couples and has a good military connection. Unfortunately, most military personnel are not aware of the existence of PREP, Inc., or of similar research-based preventive interventions.
- The Marine Corps requested the National Council on Disability to conduct a study of the services and supports needed by military families with members with disabilities. The

report on the EFMP program, published in 2011, covers all the issues this group has discussed.

- It was noted that while medical professionals see children only when parents bring them in, teachers see their students every day. This means teachers are in a good place to observe behavioral changes and become aware of family problems. It is important to get these topics into teacher training programs and in-service teacher professional development so that teachers know what to look for and what referral options are.
- Another research possibility is to explore community resources for low income, non-native English speakers. The National Clearinghouse for Military Family Readiness, at Pennsylvania State University, reviews programs and is a good resource.

### **Issues for Further Consideration**

- Inconsistency of care across locations
- Effects of deployment on families, including being a single parent/sole caretaker while a spouse is deployed
- Connection between DoD policy and civilian policy, which might not align
- Substantial differences in health care services between military branches, including within the respective EFMPs
- Use of trained paid family outreach specialists: It can be burdensome on parents to volunteer to provide information to other military families. Outreach specialists could help families manage transitions and serve as a bridge between formal and informal networks. A Coast Guard program has a network of 20 dedicated family specialists who are paid to assist families who have CSHCN, but the Coast Guard is geographically dispersed, which creates challenges in knowing about resources.
- Parent networks are difficult to find; often, strong programs on paper do not provide effective services for parents.
- EFMP is a very transitive program, with its effectiveness dependent on the personnel's training and local resources.
- Lack of information about where military dependents attend schools, with different military student identification programs likely to be implemented differently in each state.
- It is difficult to find out how research is being applied. This process needs to be more transparent.

### **Research Gaps and Suggestions for Next Steps**

- Military culture is often a barrier to academic research; including a disconnect between policymakers, those providing support on the ground level.
- Research on a qualitative network analysis is needed to help ascertain what people involved in the system in different ways perceive as problems and solutions.
- A national educational policy standard for CSHCN is needed.

- More information for families on how to navigate TRICARE to receive available benefits.
- A need to define the problem, including who special needs families are, how many there are, and where they are located.
- Utilization of social media and mobile apps to reach young families with information and education about resources.
- Discharge planners who can help families develop a team of coordinated care personnel.
- Long-term staffing is needed, including nurses, who can help EFMP coordinators provide information they do not have available.

### ***Health Care Utilization by Military-Connected Children and Their Families***

*Rebecca Lombardi (Working Group Moderator)*

*Office of Community Support for Military Families with Special Needs, DoD*

This working group discussed needs and issues that warrant further exploration or research:

- Data indicate that children of Hispanic families have fewer health care behavioral needs, but it was not clear whether that had been validated.
- Access to care can be a problem in small, rural communities. The military can make compassionate reassignments to locate families near services. This approach is often used when elderly parents need care, but it also can be used for other reasons. The matching of needs and resources is important. Each service has a different way of addressing the situation. It involves a small number of people, but it limits active-duty readiness, which must be addressed as an obstacle to ensuring that the service member does not end up not being needed and out of a job.
- Many deployed forces are reserve and National Guard and are spread out across the continent in small communities. They can have problems in attaining access to care. These areas can be deemed medically underserved (MU), which would identify them as locations where special educators and others could receive loan forgiveness for working in that area.
- Privacy issues arise when trying to obtain Zip code data. Local communities often know about resources that the DoD and the state do not. The DoD has claims and encounter data that are useful to a point. Periodically, the DoD adds additional survey questions. Making it known that the group wants certain information matters.
- Data might be available through the National Guard at the state level. Reservists and National Guard members are entitled to different things when they are not activated. It can be difficult to gather some of this information.
- A participant noted that a number of states have had success in expanding their school questionnaires. The addition of an identifier within school records pinpoints a population with special needs. From there, they could find out whether the child is military-connected. The states are just now becoming aware of this need.

- Children who meet the definition of a condition that has them on long-term medication can be identified in a military database, but only if the military families sign up for TRICARE. Some children might not have access to the health care they need. The schools would want to know this.
- Getting military identifiers into national and state settings and obtaining data would be helpful. When family members, separated military, and veterans are all counted, those with military connections can account for 20 percent of the population.
- No single program will work for every family, and not every family wants to be included or excluded at the same level.
- Coding for medical professionals differs for military and non-military purposes, with the latter requiring a diagnostic code. The system drives the diagnoses, which then remain in the electronic medical records and are not reviewed. A better way than just looking at claims data is needed.

### ***Health Care Utilization by Military-Connected Children and Their Families***

*Maria Barkmeier, Ed.D. (Working Group Moderator)*

*Florida Military Family Special Needs Network; Former Program Analyst, Office of Community Support for Military Families with Special Needs, DoD; Former Chief, Special Education Branch, DoDDS-Europe, DoDEA*

Participants made the following points about the challenges military families face in getting help for children with special health care needs:

#### **TRICARE/ Extended Care Health Option (ECHO) Issues**

- TRICARE should be more in line with Medicaid. Medicaid is not for active-duty family members.
- ECHO was an impressive benefit when it began, and a great deal of work was invested in getting it in place. Over time, as the world has moved forward, it is not as impressive.
- A problem with ECHO is that if patients want respite care, they must use an additional service. A policy change might be needed so that more could benefit.
- Respite care under ECHO has a set of eligible providers, but the patient cannot keep using the same provider. The patient must make extra phone calls every month.

#### **Office of Special Needs (OSN) Initiatives**

- A TRICARE survey will allow for the identification of areas where the need is most severe. Part of the goal of the survey is to identify issues and gaps for families.
- The OSN is trying to broker conversations among the military branches to embrace each other and standardize services.
- The OSN is trying to improve communication; a new committee will be set up to pay more attention to problems and build accountability.

- The OSN has reached out to a consortium of groups representing patients with disabilities and is partnering with them.
- The OSN publishes a newsletter every 2 months to communicate changes.

### **Parents' Issues and Concerns**

- Every time a family moves, it must re-establish care. For those with children with special needs, it can be overwhelming to start from scratch with new doctors each time.
- Pediatric specialists are concentrated regionally and sometimes nationally; a patient might have to travel across the country for service. While this might work for adult needs, it does not work for a medically complex, fragile child.
- It is usually possible to fix “one-off” problems, but the odds must change so that the system is responsive to all children who need care. This would take a policy change, but would open up an area of TRICARE so that it addresses the needs of the child trying to fit into an inflexible situation. The policy should not be a detriment to the needs of the child. It should pair up with access and best practices.
- Continuity of individuals and relationships is important.
- There is a need for stronger collaboration and increased communication. The problems families face go beyond the health care system to the schools and community. The DoD needs to look outside itself to find pilot programs and communities working with Medicaid and the school districts, and it must coordinate solutions beyond the bounds of TRICARE.
- More feedback is needed. Perhaps in the form of an exit interview when changing stations, especially for families with special needs children to determine what works. Feedback from providers is also useful.

### **Research Gaps**

- A great deal of research has been conducted on military children, but it does not necessarily address the specific target population of children with special needs.
- Better methods of identification and research are needed to identify children with special needs and how co-conditions might exacerbate this.
- Children at risk may not be at “diagnosable” levels, but still have a great deal of vulnerability.
- To change policy to make it more child-centered, there is a TRICARE study for children. The DoD needs to study policies and practices to see whether they meet the needs of children and to make recommendations to either make improvements or see whether legislation is needed. A report is expected in the summer.
- The results of the TRICARE for Kids legislation should provide a starting point for additional research or pilot programs or for highlighting best practices.
- Many people are interested in working with claims data, but it is a major undertaking to look at just this population.

- Identify health care disparities among ethnic groups.
- Find ways to insert military identifiers into surveys.
- Use claims data to identify need for and availability of services.
- Identify MU areas and potential use of telemedicine to reach rural communities.
- Collect data on military-connected children by state or installation, including ages 0 to 3, and survey instruments.

### **Barriers to Overcome**

Many issues are specific to military families, but child health issues exist in the entire population. Barriers inherent in the DoD structure may exacerbate existing vulnerabilities within the family.

- *Military branch differences.* Differences exist in available services among the different branches of the military. Services should be standardized so that they are DoD-wide and not branch-specific.
- *View of families.* A family strength perspective is needed. More emphasis on family-centered programs and collaboration would help address service member needs. Many comorbidities are seen in service members with PTSD and there may also be challenges at the family level including children with behavioral problems.
- *Poor communication.* The more feedback is encouraged and accepted, the more will be learned about what works. Feedback can be formal or informal.
- *No central repository.* A data dictionary that can be used by everyone and a database with questions from family members are needed.
- *Fragmentation.* The DoD encourages many services, but efforts are scattered and lack coordination.
- *Bureaucracy.* Questions must go through a chain of command. This may increase the time it takes for families to receive services they need.
- *Lack of training.* Not all divisions have services for special needs. More training is needed about how to reach out to the community and use community resources beyond those available on the base.
- *Slow approval of research.* Studies to reach out and get information from families can take 2 to 3 years to set up and obtain approval from IRBs.
- *Technical barriers.* Some people who have access to data cannot get access to families. Technical barriers could inhibit longitudinal studies. For example, it might not be possible to move beyond baseline data to the next phase of data collection.
- *Duplicate services.* How many are there? Could they be coordinated on the most significant topics?

## Recommendations

- *TRICARE improvements.* Align TRICARE more with Medicaid. As military families exit service, they will need to access state agencies.
- *Centers of excellence.* Create these centers as a pilot project within a few communities. Follow up research could evaluate the pilot and decide which aspects to replicate.
- *Collaborations.* The DoD should look outside itself and at partners who can collaborate and who have the same interest in coming up with solutions.
- *Networks.* Create a national network and pattern for dealing with complex care.
- *Centralized resources.* Create a centralized office or resource where a parent can get help. Many services exist that families know nothing about.
- *Information sharing.* Explore ways to disseminate information when changes occur.

## Other Topics the Group Addressed

- Impact on siblings who may not have special health care needs
- Scarcity of pediatric psychologists
- How stress affects the child and family with special needs
- Need to assess communities where families are currently living and what community best serves different children with special needs
- Navigating a very complex system for services for children with special needs
- Data about where students are being served and data that can be disaggregated to identify military families
- Gap between basic research and applied research
- Further research to include younger parents, minority and diverse parents, parents from low socioeconomic backgrounds, and parents who speak a language other than English

## Day One Summary

The panel presentations and group discussion focused on the special health care needs of children in general and then the specific needs of military families. Recommendations from the group discussions underscored the notion that the need is not just the child's; it is a family issue. Families shared stories of their children's challenges, their support, how to be resilient, how to cope, the protective factors in their lives, and the needs of military spouses. Considerable discussion also addressed health care utilization and barriers to services. One clear message was the need for data, including longitudinal data to follow children and see barriers across developmental milestones. Quality data are needed to understand the experiences of military families and the decisions they must make on a daily basis. Their military career decisions are often based on services that are available where they might be deployed.

Participants suggested developing communities of care, creating more education and training for service providers, and addressing the dearth of mental health service providers for children. Data can help illustrate what families are dealing with and how they handle their challenges.

Military families with special health care needs face complex issues and rely heavily on both military-specific and community-based programs. Policies must follow the need of problems to eliminate barriers to care. The group noted a need to look at the system holistically and to identify policies that meet children's needs in a timely manner that is consistent with best practices. Another need is to identify gaps in the multiple systems. Action can be taken in specific areas to ensure and improve access.

## **Day Two/Topic Two: Health Disparities in Children with Special Health Care Needs**

The purpose of this topic was to explore whether and to what extent disparities may exist for children with special health care needs and their families in terms of access and utilization of services. Central to this topic is the availability of existing data to help identify where disparities exist so that resources and support can be provided where they are most needed. Audience participants provided their assessment of the utility of available data addressing disparities and the working group session explored in more depth issues of access and utilization.

### **Opening Plenary: Health Disparities in Civilian Children with Special Health Care Needs**

*Dr. Myra Rosen-Reynoso*

*Senior Research Associate, Institute for Community Inclusion (ICI), University of Massachusetts, Boston*

*Mr. Ngai Kwan*

*Research Associate, ICI, University of Massachusetts, Boston*

Current data suggests that military families are young with young children; they live far from their families, and they move frequently. Consequently, it is difficult to disaggregate military children in existing U.S. datasets. There is a good deal to be learned however from studies of civilian families with special health care needs.

Dr. Rosen-Reynoso described the National Center for Ease of Use of Community-Based Services, which is located at ICI. She described the data that the Center uses, what it says about civilian children with special health care needs and how that relates to military children. The Center is funded by the MCHB, which lists six core outcomes to be achieved. These include: (1) partnering with families; (2) coordinated, ongoing, comprehensive care within a medical home; (3) adequate private and/or public insurance to pay for needed services; (4) early and continuous screening for special health care needs; (5) community-based services for CSHCN that can be used easily; and (6) services necessary to make transitions to adult life.

All CSHCN will receive coordinated ongoing comprehensive care within a medical home. All families of CSHCN will have adequate private and/or public insurance to pay for services. All children will be screened early and continuously. Services for CSHCN will be organized such that families can use them easily. Families of CSHCN will partner in decision-making at all levels and will be satisfied with services. Finally, all youth with special health care needs will receive services to make appropriate transitions to adult health care, work, and independence.

The website for the Center is <http://www.communitybasedservices.org>. It also has a Facebook page and resources in Spanish and English. It is adding information based on the ACA, conducts informational webinars, and links to other groups such as Family Voices. The Center's mission is

to advance policy and practice solutions that improve the ease of use of community-based services for families with CSHCN, organizing family-based service systems so that families can use them easily.

Dr. Rosen-Reynoso reiterated that the MCHB defines CSHCN as children who have or are at risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and health-related services of a type or amount beyond that required by children generally. She commented that a parent she spoke with said that it did not seem the Center focused on diagnosis, and that is correct. Diagnosis can be misleading. Children with the same diagnosis can have very different needs and different functional limitations. Most children in the Center's dataset do not have a single diagnosis.

The Data Resource Center for Child and Adolescent Health (<http://www.childhealthdata.org>) has been an excellent resource. The staff is very helpful, and the website is easy to use. The data can be sorted in various ways; for example, investigators can compare children, access family level data, or assess trends since 2001. Data are from several states, and states have been able to use data to obtain grants to address their specific interests.

Prior studies on disparities in ease of use show that before 2001, little information was available on families' experiences navigating community-based systems of care. From 2005 to the present, disparities in ease of use are well documented. In general, African American and Hispanic families are less likely to find services easy to use, but they are four times more likely to find data easy to use if they participated in decisions about their child's care.

The 2009-2010 National Survey of Children with Special Health Care Needs (NS-CSHCN) screened more than 196,000 households for CSHCN. More than 370,000 children were screened, and more than 50,000 CSHCN were identified, with 40,000 participating as subjects for the full interview. About 5 percent of the interviews were conducted by cell phone, which was helpful with mobile families.

Changes in sampling make comparisons with the 2005/06 survey problematic, but the changes were made in survey items for ease of service use measure. The new measures were developed by an MCHB technical expert panel.

Mr. Kwan continued the presentation with an explanation of the context of measurement. The 2005-2006 NS-CSHCN contained only one question about ease of use, a yes/no question: "Thinking about [CHILD'S NAME]'s health needs and all the services that he/she needs, have you had any difficulties trying to use these services during the past 12 months?"

In the 2009-2010 survey, seven questions asked about ease of use. The first six were sub-questions to a general question about difficulties or delays getting services (eligibility, availability, waiting lists or backlogs, cost, getting information, other reasons), and the seventh asked how often parents had been frustrated in their efforts to get services. It was more sensitive than the 2005-2006 survey.

In the 2005-2006 survey, 89 percent of the families of CSHCN said services were easy to access, with a range of 82 percent to 94 percent across the states. In 2009/10, that percentage decreased significantly to 65 percent, with a range of 54 percent to 74 percent across the states.

Overall, the ethnic-race distribution was similar for the general population of children under 18 years of age and the population of CSHCN. There were more boys than girls in the sample, and the male-female distribution was consistent across ethnic minority groups. About 51 percent of the sample had private health insurance, with the highest rate (61 percent) in non-Hispanic whites. African Americans were the most likely to have public insurance, and Hispanics had the highest non-insured rate. Most of the military children were in an insurance group labeled “other comprehensive,” a mixed category that was about 3 percent nationally.

Measures used in the survey were child characteristics (age, gender, complexity of health care needs), family socioeconomic characteristics (parental education and poverty status), access and provider factors (insurance coverage and medical home), and household descriptors (household language and family structure).

The differences in ease of use criteria by age were not statistically significant, with the national average at 65 percent and the range from 64 percent at 15 years and older to 71 percent at younger than 1 year old. Ease of use by race and ethnicity was highest for whites, followed by African Americans and then Hispanics. Families of children with the most complex conditions reported the lowest ease of use, compared with the highest ease of use category for those with special needs that were managed primarily by medication. Those with private insurance and a medical home reported the highest ease of use. In the insurance categories, the lowest percentage meeting the ease of use criteria was the uninsured (32 percent).

Based on multivariate correlates and children characteristics, ethnic minorities and Hispanics were less likely to report ease of use. In a second model that included family structure and family characteristics, single mothers were less likely to report that services were easy to use. Family income also had an impact—the lower the income, the more difficulty with services. Modeling according to severity and complexity of condition found that families with children who have emotional, behavioral, and developmental limitations and those with functional limitations had 83 percent lower ease of using services. Those with no insurance had 76 percent lower ease of use than those with private insurance, and families without a medical home had 69 percent lower ease of use compared with those with a medical home. A final model included the range of medical variables and demonstrated that emotional and behavioral disabilities (EBD) and functional limitations played a major role, with families of children in those categories more likely to say services were not easy to use.

Dr. Rosen-Reynoso continued the presentation with a discussion of limitations of the work. Children with EBD and functional limitations were in the top tier of CSHCN in the pyramid that Dr. Palfrey showed. Meaningful information about children receiving private care could not be extracted from the data, and that approach needs further work. It is also unclear how medical home is measured for military children, and that is clearly a key factor.

Analysts were unable to compare the more recent data with the 2005/06 data for a number of reasons. The response rate has declined for telephone surveys; this is currently being addressed by examining additional cell phone sampling or other methods. Also, there was a positivity bias in parent self-report. Investigators were unable to analyze race/ethnic groups other than whites, African Americans, and Hispanics. Vietnamese and Somali groups were mentioned, but specific data were not available.

Dr. Rosen-Reynoso summarized that gender, race, a single mother head of household, income, lack of insurance, and complexity of health care needs were all significantly related to ease of use of services. Having a medical home is a key factor, and 75 percent of Hispanic children from a home that did not speak English did not have a medical home, compared to 63 percent of English speakers.

These data have theoretical, practical, and policy implications for military children. The next step is to address the specific reasons families experience difficulties and delays by subgroups, with a specific focus on diverse populations. There is also a need to increase receipt of care within a medical home.

Those serving both military and civilian children—providers, parents, advocates, and others—have shared goals. They should build on existing understanding of and commitment to CSHCN, advocacy, and new insights into improving policy and practice. Another goal is to facilitate and inform the formulation of new ideas about how to make a difference in improving system performance and health outcomes for all CSHCN.

More data are needed for a shared research agenda that increases understandings of the similarities and differences in the civilian and military populations. A shared research agenda also can assess system performance, set priorities, and monitor progress. Now is the time to move forward, with an excellent opportunity to see what works and measure the impact of changes.

### ***Discussion, Questions, and Points for Consideration***

In response to a question about understanding access with different types of insurance, Dr. Rosen-Reynoso replied that families with both private and public insurance tend to fare better. Differences in services between children who do and do not have insurance are dramatic. Models by insurance and race suggest that underserved populations with public insurance do better without multiple insurers.

The insurance question must be probed further. Some military children might be on multiple plans, but this information is tricky to capture with this dataset. Military families do have access to some sort of insurance. This can be factored out of the equation in terms of access and more focus can be placed on other potential barriers, such as racism. Admittedly, these variables can be complicated.

Dr. Davis noted an asthma study which looked at children with TRICARE coverage and found racial/ethnicity disparities in the prevalence of diagnosis and utilization. This could be done with

other variables. Dr. Rosen-Reynoso emphasized the importance of including military children in a discussion of disparities.

A big challenge for independent researchers has been gaining access to military families. To apply for funding the applicant must demonstrate the feasibility of the study. Many investigators have had difficulty getting definitive letters of support. Another challenge is that a researcher might have access to a particular base, but once they begin data collection, the door might close.

The IRBs present other challenges. An independent IRB for researchers, however, might be a barrier to researchers within the military.

Another challenge is that academic researchers might not be familiar with the military culture, what the unique needs are, and how to collaborate. The military has a culture that is often not familiar to civilians, even in matters as simple as how the time of day is stated. This is not insurmountable, but it is necessary to admit the differences.

Military researchers need independent researchers to partner with, and it is important that independent researchers reach out for military partners to help them understand the terminology, framework, and other aspects of military life. It was suggested that at least one person on the research team should have prior military experience, and it helps to have military identification.

Understanding of military culture is very disconnected for civilians. Civilian researchers often do not have understandings of the differences between active-duty and other statuses. Personal connections are needed. Opportunities to promote research collaborations beyond military grants are possible. Home-visiting childcare grants have military families as a category. With some creativity, these worlds can come together. In some cases, agencies are serving military-connected families and might not know it. These potential opportunities need to be looked at very carefully.

Racial/ethnic differences and the importance of a medical home were apparent from Dr. Rosen-Reynoso's data. People have been working on this for 10 to 15 years now, and the MCHB supports taking this direction. Some unique situations occur in the military. Everyone has some sort of insurance, but racial and ethnic differences still exist. Researchers must not be afraid to ask questions about access and racism. The goal is that in 10 years, every child will have a medical home. The NIH must work on emphasizing this.

## **Working Group Sessions: Recommendations and Points for Further Consideration**

### ***Health Disparities in Military-Connected Children***

*Dr. Myra Rosen-Reynoso (Working Group Moderator)*

*Senior Research Associate, ICI, University of Massachusetts, Boston*

*Dr. Judith Palfrey (Working Group Moderator)*

*T. Berry Brazelton Professor of Pediatrics, Harvard Medical School*

### **Summary of the Working Groups' Discussions**

The working group's major themes were mitigating disparities and important next steps for stakeholders to take. Participants addressed the need to identify populations and nuances within them, health and access disparities, and the diverse nature of those with special needs. Other topics of discussion included understanding positive and negative factors, existing MOUs, and IRBs as an obstacle.

- There is a need to strengthen and build a network of researchers, taking advantage of the considerable talent that exists across the country. Another need is to better understand challenges and barriers facing families and systems. This can be informed by both quantitative and qualitative research. A participatory conversation must be started between researchers and subjects.
- The working group emphasized the need for better understanding of the experiences and requirements of reserve, National Guard, and Coast Guard families. This is an area for research and understanding. It is also necessary to understand the distinct context of military-related research in terms of culture, regulation, and time demands. Military culture is distinct, and researchers must respect that. Research in the military also involves specialized regulatory aspects.
- TRICARE is a health benefit; it is important that researchers are aware of this. It is also an aspect of helping military members negotiate transitions. This is a definitional issue in research. This conference is not only about research; it is also about action.
- Participants should remember the importance of Title V, the MCHB block grant, which is the source of programs and resources.
- At the micro level, socioeconomic factors and race are issues. Military families face challenges from mobility, the impact of deployment, possible stigma of rank and its socioeconomic implications, and isolation.
- To understand the unique circumstances of military families, researchers should employ home visits and Skype. They must understand the differences between strategic and tactical methods and long- and short-term approaches and understand the communication points and key deliverables.
- Resources to help researchers get to military families include Project DOCC; the Florida Family Café; and partnerships with family, state, and nonprofit agencies with a military track.

- The conversation between the USDA and the DoD is important. The relations with land grant universities have been useful. A number of DoD studies partner with land grant universities and extension services, which can play an important role in connecting with families and supplementing resources for translational research, applied research, and service outreach.
- Military health care is foreign to civilian health care and research. The quality is comparable, but they speak different languages. In thinking about the whole child, it is important to move beyond a focus on only the problems of military life. Military children grow up as citizens of the world. Some view moving as something as easy as spring cleaning. Participants recommended using a military person to interface with the military to do research and help get access and enhance communications.

### **Research Needs and Gaps**

- An important variable is the education level of a child's mother, which has been found to have a highly predictive value for a child's success in school.
- There is a need for identifiers to pull out data about military children.
- Demographic studies must include mixed racial groups. Filipino groups make up a large part of the military. Hispanic families might use members of their extended family as primary caregivers when service-member parents are not nearby.
- Research can be complicated when dealing with reserve and National Guard families, as they are often in rural areas and not on bases.
- Finding ways to reach military families within the general population studies is important. Even a DoD connection can encounter access problems when personnel deploy, and base commanders are not helpful. General population studies should have at least one question asking whether children are military-connected.
- Utilization data, along with information on how they can help military families with special needs, are needed. Title V is in every state, and it would be useful to help military families access it. The Web address—<http://mchb.hrsa.gov>—provides Title V information by state with contact information. Title V is a block grant for states. It is not discretionary. It allows the states to provide various services for the overall maternal and child populations. The law authorizes that 30 percent must go to special needs families.
- Participants urged researchers to visit a military location and walk through a program before developing survey questions. It is helpful to conduct comprehensive site visits to see what people at the local level are doing. Subject matter experts play an important role in evaluating proposals and providing input for the research agenda. Some highly competent family leaders in the field also can speak on behalf of the population and participate in grant reviews and discretionary programs. Some have relevant professional backgrounds. Family involvement should be encouraged.
- Researchers who have trouble accessing military family data should go to the source—families with profoundly disabled children who interact with many medical subspecialties.

- Every military task has an expected outcome. Every visit must be formalized, and survey questions take at least 160 days for approval. This timeline is essential in working with the federal government and bases. If a project goes outside the DoD and adds civilians, definition as an internal or external group becomes a question. Another requirement is posting in the Federal Register, which will factor into the timeline.
- The academia and the military arenas must collaborate, strengthen their research abilities, and disseminate information about research resources that are available.
- Prior military service, while not required, helps gain access to commanders. They can relate better to those who have been senior personnel and speak their language, and are more likely to provide access and listen. An email is not likely to open doors. A list of sources with such backgrounds would be helpful, especially when cutting across services.
- A DoD guide on the Congressionally Directed Medical Research Program website links to a guide for funded investigators.

### **Topics for Further Exploration**

- Participants would like to see more on the reserve and National Guard members, which is where military and civilian populations intersect.
- Most discussion is about those attached to standard military bases. National Guard and reserve families might not have access to needed services because of geographic isolation. In the civilian population, some rural families must drive 6 hours for specialty care. In some states, their documentation status is an issue.
- Another question was whether access is affected when one or both parents come back from service with a disability. The Veterans Administration (VA) is having problems helping veterans with disabilities—does that affect service to the children in any way? If the service member or caretaker does not know where to look and lacks a network, it can be difficult. In addition, a caretaker can suffer from depression, so there is a need to look at the impact on the caregiver of caring for a special needs spouse as well as a special needs child. The VA, the DoD, and others could identify these individuals and bring together state resources.
- There continues to be a concern about the need to identify the population. Part of this can be done through a survey, and existing administrative data can also be helpful. It seems there are multiple barriers and variables to obtaining quality care. Even the large military installations have distance issues. Rank can be a variable; this has many implications and can be a proxy for demographic issues.
- There are access disparities and the two most difficult types of specialty care to access for children with special needs are mental health and oral health.
- For some families much of their life is in the community outside the military. Families with children who have rare disease may find the base pediatrician and the military programs of little help, and may need to go outside to get specialized help for the child. Some families, unfortunately, do not have that option.
- Programs are not clearly defined. Parents need to know about the programs—what they are and what resources and access are available. Military families move frequently, as do

their support and liaison people. This highlights the need for knowledge of local and state resources. Continuity can be a problem.

- There are questions about how TRICARE affects what the military health care benefit includes. Some providers do not understand that, and they need to know. It is important to know what the clinicians want, what the family members want, and what is possible.
- The ongoing problem of the transient nature of the military population and the need for school systems to develop policies based on best practices. This includes attendance and graduation policies. Educators know that children with disabilities have trouble graduating; they need to meet school standards while mitigating their limitations from disability.
- It is important to be strategic in collaborations and not just tactical. Everyone has intelligence to contribute, and it is more effective with a strategic approach. People are reporting on the relevance of minority and socioeconomic factors. In the military, race is not as much a factor as gender, which defines which jobs people can have. As women are cleared for combat, it is a new world, but people are not sure how to handle it.
- TRICARE provides a wonderful laboratory, particularly related to disparities.
- More information is needed from the perspective of single mothers. Another topic to explore is techniques to achieve behavior change through health communication.
- The parents of a child with a rare disease must learn how to become advocates.
- No one lives in a vacuum, and involvement of the whole community is necessary. Children have specific and unique needs, which are exacerbated by special needs.
- Project DOCC (Delivery of Chronic Care) is an excellent and effective program that perhaps could have techniques that would be useful for other programs.
- The only treatment for hydrocephalus involves brain surgery. Hydrocephalus can develop secondary to TBI and might not be properly diagnosed.
- Another topic that has not received much attention is the potential for stigma, especially stigma about mental illness, and the resultant fear of reporting a child's condition. Families must know that it is acceptable to ask for help.
- There must be a greater focus on the development and use of evidence-based programs to advance understandings.
- There is a need to focus on policy improvement to not impede progress. Access to care is important and problematic and could greatly improve children's lives. It is an actionable item.

## **Recommendations for Breaking Down Silos and Departmentalization**

Memoranda of Understanding (MOUs) should be a continuing interest with various partners. Highlighted below are a number of important points from the working group:

- An overarching theme is how to collaborate.
- Since IRBs are a big issue, setting the ownership and operational policy must be considered within an MOU.
- Including family members on the group that writes informed consent has worked well.
- The importance of families should be considered from the beginning of the process.
- Write research so that results are translatable to practice and actionable. Quality improvement studies and rapid turnaround are of great interest.
- Continue to think about groups with greater disadvantages. Immigrants are an important group, as are single parents.
- Use the MOU with the USDA and 4-H to gather data for research. All installation child development centers are required to track their data for reimbursement and already identify CSHCN. This is submitted to the USDA and would be easy to use for research. Operation Military Kids and the 4-H camps for the National Guard and reserves track the same USDA data, so it is available on and off post.

## **Day Two/Topic Three: Educational Practices, Health Resources and Services for Serving Military-Connected Children with Special Health Care Needs**

For this final agenda topic we discussed the importance of coordination of services. In particular, the central role of the school was discussed and how special and general education services can be coordinated to ensure that students no students slip through the cracks. A final panel discussed the intersection of policy and practice with a focus on TriCare for Kids as well as array of health services and supports provided by the HSC Foundation.

### **Panel Presentation: Educational Practices Supporting Military Connected Children with Special Health Care Needs**

*Ms. Lorie Pickel (Moderator)*

*Chief, Early Education Branch, DoDEA*

Ms. Pickel is the spouse of an active-duty Navy service member and mother of an 11-year-old son. DoDEA schools begin educating children at age 3. She emphasized the importance of early intervention and noted that the best results for children occur when health care providers and

educators work together. The closer health and education come together, the further it pushes children up.

Ms. Pickel quoted President Obama from his second State of the Union message:

*In states that make it a priority to educate our youngest children ... studies show students grow up more likely to read and do math at grade level, graduate high school, hold a job, form more stable families of their own. We know this works. So let's do what works and make sure none of our children start the race of life already behind.*

Education begins when parents bring their babies home from the hospital, Ms. Pickel said. Military bases offer excellent early access programs for children. She reviewed some demographic statistics about military-dependent children. The largest group is ages 0 to 4 years, with 464,036 children and a large majority outside of DoDEA programs. Of 295,356 military-dependent children ages 5 to 8 years, 39,168 are in DoDEA programs. In the 9- to 13-year-old group, 28,345 of 283,201 are in DoDEA programs. In the 14- to 20-year-old group, 18,256 of 189,473 are in DoDEA programs. Ms. Pickel emphasized that most military-dependent children are in community schools, and resources should reflect that.

To discuss best practices, Ms. Pickel said, it is necessary to consider reality. What is realistic in schools? What can educators accomplish with real children? She proposed taking that view, assessing what is happening in DoDEA schools, and determining how to transition it to community schools.

Three presenters addressed various aspects of educating military children with special needs.

*Dr. David Cantrell*

*Branch Chief, Student Support Services, DoDEA*

Dr. Cantrell directs strategies and policies for DoDEA special education services. Of a total of 80,121 DoDEA students, 11 percent (8,813) have IEPs. The most common reasons children receive special education services are learning impairment, communication impairment, ASD, developmental delay, physical impairment, or emotional impairment. DoDEA wants to provide a continuum of services based on the child's needs, and it should be consistent with services in the civilian population.

DoDEA supports students with inclusive education, individual instruction, and small group instruction. Again, this is consistent with civilian education.

With the high mobility rate of military children, a school will have a military child for an average of 2 years. This underscores the need for transition support. Often, children come and go from a school multiple times. Over 12 years of education, a child might have attended eight different schools in the United States, Asia, and Europe. The DoDEA Partnership Branch focuses on the importance of transfer and works to mitigate the impact of transfer. Transition support comes from the Interstate Compact on Educational Opportunity for Military Children; the DoDEA Partnership Branch; Military K-12 Partners; Military OneSource; and the Military Child Education Coalition. Parents with questions can contact these resources.

Dr. Cantrell emphasized that his experience with DoDEA has been that in addition to working with a child's individual program team, it is important to consider the community. Often the school is the single constant in a child's life. Sometimes both parents are deployed. DoDEA provides a robust support program with continual support services for students with disabilities, but not in isolation from other students. Continuous improvement enhances student achievement and program compliance, aligns with curriculum content standards, identifies needed resources for all special education services, provides transition support, and supports child-find services to identify children with special education needs.

Ms. Pickel added that DoDEA has adopted Common Core state standards, which could lead to consistency and common standards.

*Rebecca Walawender*

*Deputy Division Director, Office of Special Education Programs, US Department of Education*

Ms. Walawender monitors state education programs and assessed ADA compliance. She is the mother of 6-month-old twins. She discussed how IDEA can impact military-dependent children.

IDEA is a single law with two parts that impact children with disabilities. Part C covers infants and toddlers from birth through age 2 with disabilities, and part B covers children from 3 through 21 years of age (age 25 in Michigan) with disabilities in public schools. (Part A provides definitions, and part D covers funding explanations.)

Part C is administered through state health agencies, with early intervention services delivered in a natural environment. Services are provided in accordance with an individualized family services plan. Part B is administered through state educational agencies and local education agencies (school districts). It provides for free appropriate public education in the least restrictive environment, which can differ from child to child. Services are provided in accordance with an IEP. Ms. Walawender added that Title I provides services to economically deprived children, and that IDEA is a civil rights entitlement. The standards between parts C and B are different; part C is voluntary and not necessarily free. Usually services are billed to public or private insurance. Part B is free.

A child qualifies for part C if he or she experiences developmental delay in one of five areas—cognitive, physical, adaptive, communication, and social or emotional—or has a diagnosed physical or mental condition that has a high probability of resulting in a developmental delay and requires early intervention services. Physical conditions include speech or hearing impairment. Developmental delays are defined by the states or territories.

It is very expensive to deliver these services, Ms. Walawender said. Part B costs a total of \$11.7 billion per year, and part C costs \$475 million per year. When states accept part C money, they are obligated to follow the federal regulations. The federal government was never intended to fully fund special education and related services; it pays up to 40 percent of the excess cost of educating a child with a disability. Children with disabilities are students first, not disabled first.

To qualify for IDEA under part B, children must have at least one disability from 13 IDEA-defined disability categories: autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairments, specific learning disability, speech or language impairment, TBI, or visual impairment. These disabilities are related to education, Ms. Walawender explained, and must impact the child in school. For example, a child with a club foot that does not impede educational progress would not qualify for special education and related services.

To determine eligibility, a parent may request or a public agency may refer a child for an initial evaluation to determine whether a child has a disability. A parent must provide written consent for the initial evaluation. Even if a school district suspects that a child has a disability, parental consent is required for referral for evaluation. Some parents might object to their child being classified as disabled because of the potential harms of labeling.

The initial evaluation is to determine whether a child has a disability, and the second is to determine the content of the IEP. Eligibility is never based on a single measure; rather, assessors use a variety of technically sound assessment tools. They must assess all areas of suspected disability, cannot be discriminatory, must administer tests in the child's native language, and must be trained.

In a provision relevant to military children, assessments of children with disabilities who transfer from one public agency to another in the same school year are coordinated with those children's prior and subsequent schools as necessary and as expeditiously as possible to ensure prompt completion of full evaluations.

Determination of eligibility must be made by a group of qualified individuals who consider all evaluation data, including parent input. Eligibility cannot be based on lack of appropriate instruction in reading or math, or because of limited English proficiency. A child must have a disability and require special education and related services to be eligible for IDEA.

The IEP is a written statement for a child with a disability that includes an explanation of how the child's disability affects involvement and progress in the general curriculum, annual goals, a list of the special education and related services the child will receive, and an explanation if the child will not be educated with his or her typically developing peers. The IEP should be broad and not so specific that it is dependent on a specific teacher.

After the initial eligibility assessment and development of the IEP, the parent must consent again for the initial provision of special education and related services to the child. This will be the last consent necessary.

Service delivery must begin as soon as possible after the IEP is developed and parental consent is provided. Services must be consistent with the IEP.

A principle of IDEA—that highly mobile children should have timely and expedited evaluations and eligibility determinations—is particularly relevant to military children. It is also relevant to homeless and migrant children. Initial evaluations must be completed within 60 days of consent

or according to a state-established timeline, and the Office of Special Education Programs strongly encourages that the evaluations be completed much sooner—in 30 days, if possible. The previous school district and the new school district must coordinate as expeditiously as possible if an evaluation was begun but not completed in the previous school district. Educational records must be promptly exchanged in accordance with the Family Educational Rights and Privacy Act. No general education intervention process can delay the completion of an evaluation if a parent requests that the evaluation be completed.

A second IDEA principle is the requirement of comparable services when a child moves from one school district to another. Comparable means services that are similar or equivalent to those described in the child's IEP from the previous school district, whether in the same state or in another state, as determined by the child's newly designated IEP team in the new school district. Comparable services include services during the summer, such as extended school year services.

Ms. Pickel commented that DoDEA is funded by the DoD, and IDEA is funded by ED. DoDEA is trying to align with ED's provisions and spirit.

*Mr. John Mathewson*

*Vice-President of Operations, HSC Foundation*

The HSC Foundation sponsors an integrated health care system for youth with complex needs. In a graphic representation, Mr. Mathewson displayed the HSC Foundation, the parent organization, at the top of a large circle representing the HSC Health Care System. Around that circle are the HCS programs: Health Services for Children with Special Needs (HSCSN), HSC Pediatric Center, HSC Home Care, HSC Health and Residential Services, and the National Youth Transitions Center. All of the programs focus on transitions, and each has a physical space as well as a program.

Mr. Mathewson highlighted transition-age best practices from both literature reviews and real-life experience. Five Core Guideposts from the National Collaborative on Workforce and Disability/Youth were initially published in 2004. They review literature and demonstrations over more than 20 years and were vetted by more than 50 major advocacy groups and stakeholders over a full year. The Guideposts view services through the lens of a holistic framework of what youth need and are centered in the disability and work transition community.

The review specified five core guideposts. Youth need: (1) school-based preparatory experiences, (2) career preparation and work-based learning experiences, (3) youth development and leadership, (4) connecting activities, and (5) family involvement and supports. Mr. Mathewson reviewed each guidepost separately.

For Guidepost 1—school-based preparatory experiences—in order to perform at optimal levels in all education settings, all youth need to participate in educational programs grounded in standards; clear performance expectations; and graduation exit options based on meaningful, accurate, and relevant indicators of student learning and skills. In addition, youth with disabilities need to use individual transition plans to drive their personal instruction and use strategies to continue the transition process post-schooling. They must have access to specific and individual learning accommodations while they are in school; develop knowledge of reasonable

accommodations that they can request and control in educational settings, including assessment accommodations; and be supported by highly qualified transitional support staff who may or may not be school staff.

For Guidepost 2, career preparation and work-based learning experiences are essential for youth to form and develop aspirations and to make informed choices about careers. Experiences can be provided during the school day or through after-school programs, and will require collaborations with other organizations. Youth with disabilities might need to understand the relationships between benefits planning and career choices; learn to communicate their disability-related work support and accommodation needs; and learn to find, formally request, and secure appropriate supports and reasonable accommodations in education, training, and employment settings.

Guidepost 3, youth development and leadership, is a process that prepares young people to meet the challenges of adolescence and adulthood through a coordinated, progressive series of activities and experiences that help them gain skills and competencies. Youth leadership is part of that process. These activities also can help address the military challenge of frequent relocation. Youth with disabilities also need mentors and role models, including persons with and without disabilities, and an understanding of disability history, culture, and disability public policy issues as well as their rights and responsibilities.

For Guidepost 4, connecting activities, young people need to be connected to programs, services, activities, and supports that help them gain access to chosen post-school options. These can include transportation, housing, tutoring, and financial planning and management. Youth with disabilities also might need appropriate assistive technologies; community orientation and mobility training (for example, accessible transportation, bus routes, housing, health clinics); and exposure to post-program supports such as independent living centers and other consumer-driven, community-based support service agencies. Other potential needs can include personal assistance services such as attendants, readers, interpreters, or similar services; or benefits-planning counseling, including information regarding the myriad of benefits available and their interrelationships so that youth may maximize those benefits in transitioning from public assistance to self-sufficiency.

Guidepost 5 is family involvement and supports. Young people with disabilities need a champion who can be resourceful and creative, ask the questions that need to be asked, and use a network to find resources. Participation and involvement of parents, family members, and/or other caring adults promote the social, emotional, physical, academic, and occupational growth of youth, leading to better post-school outcomes. Youth with disabilities need parents, families, and other caring adults who understand the disability and how it may affect his or her education, employment, and daily living options. They need someone with knowledge of rights and responsibilities under various disability-related legislation; knowledge of and access to programs, services, supports, and accommodations available for young people with disabilities; and an understanding of how individualized planning tools can assist youth in achieving transition goals and objectives.

More information about the Guideposts is available at <http://www.ncwd-youth.info/topic/guideposts>.

Mr. Mathewson continued with a description of HSCSN, which offers the oldest continuous dataset of its type. It is a care coordination plan for SSI participants or those with related illnesses in the District of Columbia up to age 26. It began in 1996; currently, 6,000 members are covered under Medicaid for medical, behavioral, dental, prescription, long-term care, vision, and social supports. The program helps stabilize families and encourages the greatest level of independence possible across all entities, with an emphasis on social determinants of health. Families sign an agreement to demonstrate their commitment to the program.

HSCSN has one of the longest continuous enrollments of children with disabilities in managed care in the United States. HSC is planning a collaboration with the NICHD to analyze the data. Some 65 percent of members have a behavioral health diagnosis. The program partners with more than 100 community-based organizations and has an intensive outreach process with vans for transportation, a caregiver's advocacy group, and a life skills area for behavioral help for youth who might not want to see a psychiatrist. The program moved closer to direct care delivery with the recent opening of the Congress Heights Life Skills Center.

The Congress Heights Life Skills Center is an innovative collaboration between HSCSN and Urban Behavioral Associates. It offers psychiatry, psychology, rehabilitation, therapy assessment, application, and integration services. The initial population the Congress Heights program supports is individuals with ADHD, although most with ADHD also have coexisting disorders. About half of care is provided in the community rather than in the office.

The Congress Heights Life Skills Center works to educate and empower parents in navigating schools. It helps teachers deal with children with various mental health disorders and participate in IEPs for students who are learning disabled, emotionally disabled, or both. It assists some clients with emotional regulation that disrupts or interferes with teaching or interactions with other same-aged peers. It collaborates with the parent and special education coordinator in developing appropriate behavioral intervention plans. There is a great need in schools to deal with difficult behaviors. A program like this one did not exist in Washington, DC, until HSC initiated it.

Mr. Mathewson concluded with a mention of *Partnering with Your Child's School: A Guide for Parents*, a booklet to help parents of children with health or mental health care needs learn about available resources and develop partnerships with their child's school. Initially published in 2007, it developed from a collaboration between the HSC Foundation and the George Washington University Graduate School of Education and Human Development. It was validated by focus groups of parents, youth, and community stakeholders. The guide is available at [http://www.hscfoundation.org/aboutus/publications/partnering\\_with\\_schools\\_english\\_guide\\_508.pdf](http://www.hscfoundation.org/aboutus/publications/partnering_with_schools_english_guide_508.pdf).

## **Panel Presentation: TRICARE for Kids: Best Practices in Medical, Behavioral, and Mental Health Services to Military-Connected Children with Special Health Care Needs**

*Dr. Steven Cozza (Moderator)*

*Professor of Psychiatry, Uniformed Services University of the Health Sciences*

Dr. Cozza is a child and adolescent psychiatrist. He was in active duty in the Army and served at Walter Reed. Now retired from the military, he conducts research on PTSD. This panel was conducted as a discussion rather than presentations.

Dr. Cozza introduced the session with a passage he co-wrote for the fall 2013 issue of the journal, *The Future of Children*, which was devoted to military children and families:

*The history of military children...tells a complex story of the interrelationship among these children, their military parents and families, and the military and civilian communities in which they live. Though these children face many hardships, they also demonstrate health and wellness in many ways, and they live in communities with rich traditions and resources that strive to support them...*

*The children of military families deserve to have policies and programs designed to fit their developmental needs. Given the extraordinary sacrifices that military personnel make, and the invaluable services that they provide...a balanced approach to the study and understanding of military children—one that measures the effect of risks but also incorporates a focus on strengths—will give us the clearest and most comprehensive picture of this population.*

Many challenges in caring for mental health problems within the TRICARE and military health care systems are national. Military children live in communities all over the country. A second focus is on access. Another aspect is the importance of engagement. Dr. Cozza said Mr. Mathewson's comments were on target. To engage military families, it is necessary to recognize the problems of PTSD, TBI, and other health problems that are common in the military.

Dr. Cozza introduced the other members of the panel:

- Mr. Jeremy Hilton, a graduate of the Air Force Academy, Navy veteran, military spouse, and father of a special needs child, advocates for both military and non-military families on issues including special education and medical care.
- Ms. Kara Oakley, an attorney and founder of Oakley Capitol Consulting, focuses on policy, strategy, and advocacy and is actively involved in crafting legislature to improve health care for military-connected children.
- Capt. Kathryn Beasley retired from the Navy after 30 years of active duty in a wide range of positions and now serves as Deputy Director, Government Relations (Health Affairs) for the Military Officers Association of America and co-chair of the health subcommittee of The Military Coalition.

- Ms. Mary Andrus is assistant vice president for government relations for Easter Seals.

Dr. Cozza asked panelists about major disconnects that need to be remedied in the health care system for military children.

- Ms. Oakley said one of the major disconnects for military families is that TRICARE is based on Medicare, an adult system, and does not take the specific needs of children into consideration. Children's needs are addressed as an afterthought. This highlights the need for legislation.
- Capt. Beasley said she began her military service in 1979 at 22 years of age. Women in the Navy were mostly nurses, and none were married. She came in as a nurse. Through the years, the role of women evolved, with some marrying and having families. In the 1980s and 1990s, health care was through CHAMPUS, a very fragmented system with many disconnects. The TRICARE program came into being in the mid-1990s; it has evolved and been modified. It can take a while to effect change when working with the government, Capt. Beasley observed, and 30 years ago she would never have been sitting in a forum like this, discussing military children.
- Ms. Andrus said from the outside, one of the big disconnects is the lack of communication between programs. For example, Medicare and Medicaid do not talk to each other; that is why dual eligibles have been created. Outside the military, there is not much knowledge of TRICARE. It is important to close gaps so care that does exist can be accessed.
- Mr. Hilton commented that TRICARE is generally a good program and probably works for 90 percent of its recipients. The other 10 percent are often the families of special needs children who need to take advantage of new therapies, but who fall through the cracks.
- Ms. Andrus said one of problems within TRICARE is getting coverage for applied behavior analysis (ABA), one of the preferred approaches to dealing with autism. ABA also is effective for other developmental problems, but TRICARE will not cover it for children who are not diagnosed with autism. The Autism Speaks group is trying to educate Congress about this. She added that Easter Seals would like to work with as many children as possible if the therapy appears to be appropriate. Also, in an attempt to control costs, a ceiling of payments per year has been set for ABA, although that is not the standard of care and might not relate to the actual needs of a child. Limitations should be based on need, not an arbitrary number. If policy change is not forthcoming, advocates should pursue legislation.

Dr. Cozza asked panelists to define TRICARE for Kids.

- Ms. Oakley said advocates for children's health have been trying to fix different sections of TRICARE for years, trying to make it more applicable to the needs of children. An opportunity arose 2 years ago in the person of Rep. Steve Stivers, a freshman congressman from Ohio whose daughter had a significant illness. Rep. Stivers was in the

National Guard and deployed, putting him in touch with issues related to children's health care for military families.

- TRICARE for Kids was legislation that recognized that children are not simply little adults, but individuals with unique health care needs. For example, timely services for children are even more important than they are for adults, and benefits of coverage should meet those needs. The legislation calls for a comprehensive review of TRICARE policies and practices that relate to children. The review includes access to care, pediatric health care, the ECHO program, adequacy of care management, assessment of support of other DoD programs, links to other community programs, and strategies to mitigate frequent transitions. The DoD report is due in July 2014.

Dr. Cozza shifted the discussion to particular challenges for military families such as transitions, movement overseas, and switching from active duty to veteran status.

- Mr. Hilton indicated that every time his family moved, he would begin, 5 to 6 months ahead of the move, to compile a package of services his daughter needed. He has been in Washington, DC, for 5 years and is still learning about available services. It takes 6 months after a relocation for him to feel comfortable with his daughter's care package. Most of the moves have been across state borders, making it very hard to transfer the IEP. Medicaid also changes from state to state. Relocation is a stressful period of people's lives, and the stress builds up.
- Capt. Beasley said the military lifestyle is unique, and transition with a special needs child presents unique challenges that can be very frustrating. This should not be underestimated. Families encounter varying levels of services. Data and research about this are needed. Military families with special needs children will find themselves straddling two, three, or four systems—direct care, purchased care, TRICARE. Each has its own bureaucracy.

Dr. Cozza asked about mental health interventions for military families, particularly for complex cases.

- Ms. Oakley said she has concerns that some community standards of care are not supported by the way TRICARE pays. Examples are reaching the family where it is and wraparound models of care. These are difficult for TRICARE beneficiaries to access, and TRICARE adds unnecessary barriers. Another example is substance abuse treatment, for which TRICARE does not differentiate between adult and adolescent access and limits of treatments. Adolescents generally will need much more frequent treatment than adults. Intense outpatient treatment can work around a child's school day, but it is not covered by TRICARE. She hopes the TRICARE for Kids report will consider this and change the framework.
- Dr. Cozza said that given the scarcity of resources for child psychiatry, TRICARE reimbursement rates are often unacceptable. TRICARE tends to be patient-focused, but the disorders impact the family in its entirety. It is important to change from patient-focused to family-focused models to strengthen prevention.

Dr. Cozza noted that models exist for best practices.

- Mr. Hilton said the July 2013 AAP policy statement emphasized the need to consider the definition of medically necessary. TRICARE has stopped allowing certain genetic testing. ABA coverage is another example. The AAP statement says medical necessity is “to promote optimal growth and development in a child and to prevent, detect, diagnose, treat, ameliorate, or palliate the effects of physical, genetic, congenital, developmental, behavioral, or mental conditions, injuries, or disabilities.” This broad approach is not reflected by TRICARE, which is too narrow.
- Ms. Oakley reiterated that TRICARE uses Medicare precepts, which are based on older adults. The heaviest users of care are being managed by pediatric specialists in academic medical centers, but pediatric specialists are in great shortage and not located in every Zip code. TRICARE has very inflexible geographic limits. CSHCN need a national network of specialists who can talk to each other and help manage care of complex cases as they transition from one community to another.
- Ms. Andrus said many systems must come together for successful treatment of a child with complex needs. Successful treatment means economic savings. Systems must overlap, be osmotic, and flow back and forth. She encouraged communication among systems.

### ***Summary of Panel Discussion***

Capt. Beasley remarked that the symposium has been excellent, identifying research gaps and the need for more data. The work over these 2 days might provide a framework for moving forward. In a budget-constrained environment, the framework could be used to develop policy to address the unique needs of CSHCN. But the work should not be done in a vacuum. All stakeholders must be included. As TRICARE benefits change in the constrained environment, more evidence-based research is needed to inform policy on children. The increasing number of American veteran women also must be addressed. Many have children, and it is necessary to capture this population and focus on their needs. Many are homeless, and it is important to understand their situations.

Ms. Oakley spoke of the need for more data collection and research, particularly applied research. She proposed pilot demonstration projects of some best practices. Also, policies must align with the needs of children. If advocates and stakeholders do not speak out and create projects to collect data, no one will. A specific suggestion is to create several communities of excellence that can provide complex care in the communities. Complex care management in a community of excellence would provide an excellent source for data collection.

Ms. Andrus agreed with the need for good data, along with the ability to determine what it says and how to use it. Modeling an existing program such as early intervention is a strong approach to fix TRICARE. If it is possible to make the system work for the most complex cases, it can work for everyone.

Mr. Hilton said there is an opportunity to change children's health care, based on this audience.. An entire generation of veterans will be coming off active duty. This group is on the right track, but there is more work to do.

## **Closing Plenary Session: Take Home Messages: Education and Health Care of Military Connected Children with Special Health Care Needs: Where Do We Go From Here?**

- It is important for parents to be educated about the system their children are in. Educators do a good job of meeting parents where they are and encouraged parents to seek information.
- Parents attending this conference have demonstrated that a single person can make an impact on the national stage. Their actions have had an impact not only on military, but homeless, migrant, and other children.
- Communication is the big take-away. Parents have to ask the questions, not only of educators but also of health care providers. Educators are the catalysts who bring parents and health care providers together to talk about the children. Educators might not want to intrude on a parent's privacy, but they can bring together different entities and open lines of communication among them.
- Communication must be bi-directional, with schools reaching out to parents and parents to schools. DoDEA is actively updating policies to help transitions. Its graduation policy is in the final stages of revision, with a section for high school seniors. Another section is about transitioning from local schools to DoDEA. It recognizes the importance of school systems working actively with parents.
- Participants were excited about the range of individuals who participated in this conference. It is inspiring and hopeful when considering what can be done for military families moving forward. The presence of families has been striking and has kept the discussion real. If parents are strong, they will find a way for their child. The focus should be on making families strong. Finally, ask the children what they need. They are insightful, they will express themselves, and they will tell you.
- Access to services and specialty care for children with special health care needs has been and continues to be very difficult for some parents. There needs to be specific incentives from the DoD to attract special educators to rural communities where access is problematic.
- Hiring highly trained professionals is a challenge for DoDEA and school systems across the country. DoDEA has an active human resources department that recruits specialists, but a pool of specialists is simply not available for some communities. DoDEA does its best and uses contract help when it cannot fill positions with permanent staff, but it can be difficult to find qualified personnel.
- In addition to the need for personnel, specialized equipment also is needed. This includes mobility equipment. For the visually impaired, low-vision devices can be almost as important as having an instructor. It is difficult to educate without the proper equipment.

School systems often do not count sensory loss when it is secondary to other impairment, and visually impaired individuals are undercounted in some systems.

- Related to ancillary services and assistive technology, in some states, a student can be classified as special needs if he or she needs only a related service, whereas in others, the student must require special education. The federal system has a robust program of assistive technology, but ED only makes grants to other systems and has limited ability to influence what happens at the local level beyond that. It is important to advocate at a local level to make sure children are getting what they need. Children with low-incidence disabilities have the same rights as children with high-incidence disabilities.
- According to Title IV, it is possible to qualify for 504 accommodations but not for an IEP.
- Parents looking for actionable items should share their pursuits. Facebook is an excellent tool that can reach many people quickly. The National Council on Disabilities report from November 2011 includes many specific recommendations. If meeting participants can walk away from this conference and spread the word, they have made a great deal of progress.

## Conference Planning Committee

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