



Written Testimony Provided for the  
Senate Armed Services Subcommittee on Personnel

Geraldine Dawson, Ph.D.  
Chief Science Officer, Autism Speaks  
Professor, Department of Psychiatry  
University of North Carolina at Chapel Hill  
Adjunct Professor, Department of Psychiatry  
Columbia University  
Professor Emeritus, University of Washington

June 20, 2012

Good afternoon, Chairman Webb, Ranking Member Graham, and members of the subcommittee. I am Dr. Geraldine Dawson, Chief Science Officer of Autism Speaks. I also serve as Professor of Psychiatry at the University of North Carolina at Chapel Hill.

Autism Speaks was founded in February 2005 by Bob and Suzanne Wright, grandparents of a child with autism. Since then, Autism Speaks has grown into the world's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and cures for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. We are proud of what we've been able to accomplish and look forward to continued success in the years ahead.

I am honored to appear before the Senate Armed Services Subcommittee on Personnel at this hearing on issues facing military families with dependents who have special needs. Like their counterparts in civilian life, many military families face the challenge of providing proper treatment for a child on the autism spectrum. I am here to talk about those challenges and how the military health care system can lessen their effect on families.

### *The Challenges of Autism*

I will begin by providing an overview of autism. Autism is a developmental disorder that affects a person's ability to form social relationships and communicate with others. People with autism also exhibit repetitive behaviors, some of which can interfere with their ability to learn and function. Most scientists agree that autism is caused by a combination of genetic susceptibilities that interact with environmental risk factors.

Autism is no longer considered a rare condition. It affects about 1 in 88 children, including 1 in 54 boys. Let's compare autism's prevalence to that of some other conditions:

- Pediatric AIDS – 1 in 300;
- Type 1 diabetes – 1 in 400; and
- Childhood cancer – 1 in 2,000

This year, more children will be diagnosed with an autism spectrum disorder than AIDS, diabetes, and cancer combined. The prevalence of autism has risen dramatically over the past several decades; in fact, statistics show a ten-fold increase in 40 years. Although broadening of the diagnostic criteria for autism and increased awareness account for some of this increase, experts estimate that approximately 50 percent of the increase remains unexplained. Many in the autism community use the word "epidemic" when describing autism.

Based on metrics used by the World Health Organization, autism represents a significant public health challenge. It is a highly prevalent and chronic condition with an early onset and is associated with significant functional impairments and costs. Its burden is higher than childhood leukemia, cystic fibrosis, and type 1 diabetes – an estimated \$137 billion per year.

Of course, the impact of autism cannot be measured in dollars alone. Autism takes a significant toll on families. Compared to the families of children with special health care needs other than autism, the families of children with autism are more likely to

- cut back or stop working;
- spend 11 or more hours per week providing care;
- pay more than \$1,000 annually in out-of-pocket medical expenses;
- experience financial problems; and
- avoid changing jobs in order to maintain health insurance.

According to a national survey, only one in five children with autism has adequate health insurance coverage, receives coordinated, ongoing, comprehensive care within a medical home, and had at least one preventive medical visit in the past 12 months.

Military families with a child on the autism spectrum face the added burdens of stress associated with their service. Relocating to a new duty station can cause gaps in care with lifelong consequences. When one parent is deployed, the other may bear the full responsibilities of child care. And when a parent returns from deployment, the family may have the additional challenge of combat-related mental or physical health problems.

### ***Screening, Diagnosis, and Treatment***

The care of a child with autism often begins with a sense by a family member or health care professional that the child's development is not typical. It is now possible to screen for autism at 12 months of age, and autism can be reliably diagnosed by 18 to 24 months of age. In 2007, the American Academy of Pediatrics recommended that all children be screened for autism at 18 and 24 months of age and that appropriate referrals be made if autism is suspected. Yet, the average age of diagnosis in the U.S. remains close to 5 years. Children from ethnic minority backgrounds are at a particular disadvantage. Research shows that these families have to go to the doctor many more times before receiving a diagnosis, and the age of diagnosis is much older.

Fortunately, there are effective treatments for autism that can change a person's course and outcome. Controlled clinical trials have shown that early intensive behavioral treatment significantly increases IQ, language abilities and daily living skills, while reducing the symptoms of autism. In fact, a 2010 randomized controlled trial funded by the NIH and published in *Pediatrics* reported that 50 percent of children with autism who received early treatment for 2 years had a 15 point increase in IQ (1 standard deviation). One third of the children showed an increase in IQ of greater than 30 points (2 standard deviations). This means that treatment changed these children's life trajectories, setting them on a course that increased their chances of living productive and satisfying lives. This is not only good for the individual; it results in significant cost-savings for society as children and adults need fewer services and can become productive members of society.

Among the many treatment methods available, behavioral treatments that use the methods of applied behavior analysis (ABA) have become widely accepted among health care professionals as an effective treatment for autism. *Mental Health: A Report of the Surgeon General* states,

“Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.” Study after study has provided evidence for the efficacy of early intensive behavioral treatment based for improving outcomes of children with autism.

Let me say a little more about ABA. Treatments based on behavior analysis use a scientifically validated approach to understanding behavior and how it is affected by the environment. Through decades of research, the field of behavior analysis has developed many techniques for increasing useful behaviors and reducing those that may cause harm or interfere with learning. These techniques bring about meaningful and positive changes in behavior. Success in an ABA program is measured by direct observation and data collection and analysis. Early behavioral treatment based on ABA is provided by highly trained licensed/certified professionals with expertise in ABA and involves one-on-one treatment with the child typically for 25-40 hours per week for at least two years. This early intensive investment in treatment results in significant cost savings in the long run, as many children with autism who receive such treatments can now carry on a normal conversation, enter a regular classroom, and form friendships with their peers.

### *The Growing Trend Towards Comprehensive Autism Coverage*

Autism Speaks is committed to passing insurance legislation that provides access to behavioral health treatments for people with autism. Back in 2001, only the state of Indiana required insurance coverage of effective therapies like ABA. Now 30 states (representing over 70% of the country’s population) require coverage of ABA treatment as a medical care.

Large employers like Microsoft and Home Depot provide coverage for autism therapies, as do universities such as Ohio State, Harvard, and Princeton and health care facilities like the Mayo Clinic.

After conducting an internal review earlier this year, the U.S Office of Personnel Management (OPM) concluded there is enough evidence for OPM to classify ABA as a medical therapy. This means that Federal Employees Health Benefits Program (FEHBP) carriers may propose 2013 benefit packages that offer behavioral treatments based on ABA. In communicating this decision to Autism Speaks, OPM stated, “This decision reflects our perspective that families covered under the FEHBP should have access to medical treatment that is safe, effective for their individual diagnosis, supported by sound medical evidence, and delivered by appropriate providers.”

In contrast to the benefits that will be made available to the federal civilian workforce, TRICARE-- the health care program for uniformed services members and their families-- currently provides only limited coverage for ABA treatment. TRICARE classifies ABA as an educational intervention and makes it available only through the Extended Care Health Option (ECHO), a supplement to the basic TRICARE program. ECHO benefits are cumulatively capped at \$36,000 per year which may not adequately cover the early years when intensive treatment is needed. ECHO is restricted to dependents of active-duty service members. Dependents of retirees -- including dependents of wounded warriors retired due to injuries sustained in combat -

- are unable to access ABA treatment under TRICARE. Guard/Reserve families receive intermittent care as they move between active and non-active duty status.

Families report that the ECHO \$36,000 dollar limit on care does not address the need for intensive ABA services. Using TRICARE billing rates, \$36,000 pays for an average of 11 hours of ABA therapy per week, whereas the recommended number of hours is between 25 and 40. Many children with autism, especially those who are newly diagnosed or who face severe challenges, need this level of initial treatment. The out-of-pocket costs associated with this additional medical care are unaffordable to the military family. Even the limited available benefit is difficult to access for some eligible families, who report significant enrollment delays and a lack of TRICARE authorized providers.

Without access to needed services, many military families depend on state Medicaid waiver programs. A change in duty station, however, may move a family to the bottom of a long waiting list and force a stark choice: incur significant debt or do without treatment for their child.

Given all our military families have shouldered for the last decade, they deserve better. The war fighter in Afghanistan should not have health care inferior to that of the civilian employee working within the Pentagon. We owe more than this to the families who are making tremendous sacrifices for our country.

This is not a matter for further study. Action is needed to provide the quality of care our military families deserve and have earned. On behalf of the thousands of military families affected by autism, we ask that Congress require TRICARE to provide behavioral health treatment, including ABA, to military families regardless of duty status and without a dollar cap.

Thank you, Chairman Webb, Ranking Member Graham, and members of the subcommittee, for your time, for your commitment, and for your leadership.