ASA™ The Voice of Autism.
Autism Society of America

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The Honorable Pete Petersen
Alaska State Capitol
Juneau, AK 99801

Letter of Endorsement -- HB 187

ASA strongly endorses Alaska House Bill 187 since this legislation offers clear and practical solutions that will enable Alaska families to have equal access to appropriate treatments and services that would be covered by private health insurance if it were not for the diagnosis of an autism spectrum disorder (ASD).

BACKGROUND

Autism is a complex neurodevelopmental disability that typically appears during the first two years of life and affects a person's ability to communicate and interact with others. ASA estimates the lifetime cost of care for an individual with autism at $3.5 to $4 million; with access to early diagnosis and intervention, these costs can be reduced by two-thirds. However, appropriate, effective and evidenced-based interventions are costly – upwards of $50,000 a year – and frequently not covered by private health insurance plans. Many families simply cannot afford to give their children the treatments that could help affected individuals reach their fullest potential and enjoy a happy and productive life.

Although there is no known "cure", autism is treatable. According to the American Academy of Pediatrics (AAP), "early diagnosis resulting in early, appropriate, and consistent intervention" is "associated with improved long-term outcomes."

Autism Spectrum Disorder (ASD) includes three diagnoses as defined in the *Diagnostic and Statistical Manual* (DSM IV) of the American Psychiatric Association:

1. Autism: Difficulty in the developmental areas of communication, socialization and repetitive/restricted interests and behaviors.
2. Asperger's Syndrome: Similar characteristics to autism but do not have a significant delay in language.

3. Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS): This term is used when an individual displays developmental deficits but does not meet diagnostic criteria for the other two ASD diagnoses.

ASD is now the number one childhood developmental disability with 1 of every 150 children in the US being diagnosed (CDC 2007). 26,670 children born in the US this year will eventually be diagnosed with ASD (CDC, 2007), making the diagnoses more common than all types of pediatric cancer, AIDS, and diabetes combined. According to the American Academy of Pediatrics, 44% of primary care physicians reported that at least ten of their patients have ASD.

Males are four (4) times more likely to be diagnosed than females; in contrast, females are more likely to be severely impacted by autism when a diagnosis exists. Females are also more likely than males to have a co-diagnosis of mental retardation (58.2% and 41.8%, respectively [CDC, 2007]). Younger siblings of children diagnosed with an ASD are 20 times more likely to be diagnosed, resulting in families with up to five children known to be on the autism spectrum in the US. A recent study highlights the fact that relative to children without autism, children with autism are much more likely to have poor health, to require medically necessary care for behavioral problems, and to be using medications.

Societal Impact of ASD

ASD results in annual societal costs of $35 billion per year, or over $60,000 per person per year, for services, education and other publicly funded supports. (Ganz, 2006) Over the lifespan, the average societal cost of caring for one person with autism is $3.2 million. (Harvard School of Public Health, 2006) Comprehensive intervention programs for preschool aged children with autism, including behavioral and speech therapies, may cost up to $50,000 per year. (New York Times 2006) Comprehensive intervention programs for young children, including behavioral therapies, may cost up to $100,000 per year.

Autism first became a special education classification under the Individuals with Disabilities Education Act (IDEA) in 1991. Between 1991 and 1999, the number of persons receiving special education services for autism increased 500% (CDC, 2007). In 2005, approximately 224,000 children were served under the autism classification in US schools. To describe the estimates of per pupil expenditures for educating children with autism, we reviewed data collected and analyzed by the Special Education Expenditure Project (SEEP). (GAO-05-220, Special Education Report to Congress 2005)

The average per pupil expenditure for educating a child with autism was estimated by SEEP to be over $18,000 in the 1999-2000 school year, the most recent year for which data were available. This estimate was nearly three times the expenditure for a typical regular education student who did not receive special education services and was among the highest per pupil expenditures for school-age children receiving special education services in public schools. In contrast, the cost of a typical child's education was $5,000. (Senate Education Committee, 2006) Many, who are employed, tend to be underemployed in dead end or entry level positions. For the population with autism, the number of individuals unemployed has been estimated to be as high as 90% (New Jersey Autism Society). Without effective intervention, that means that of the 560,000 children currently living with autism, 504,000 may be unemployed in adulthood. This would obviously be a human tragedy.

Effective Treatment for ASD

Early Intervention

The CDC reports that "early identification and participation in intervention can improve the long term outcome for children with an ASD" (2007). The Harvard School of Public Health corroborates, writing that "improving behavioral and educational therapies for autistic children may not only lessen these costs but also improve quality of life" (Ganz, 2005).

The National Research Council report offered several key features of successful approaches to the education of children with autism, including early intervention soon after the diagnosis of autism, which can generally occur by the age of 3. The report also offered guidelines regarding educational objectives for children with autism, including the development of social skills and expressive and receptive language and communication skills. (GAO-05-220, Special Education Report to Congress 2005)

Despite the research supporting early intervention, the 2007 CDC study suggests a significant nationwide lag between the first sign of developmental delay and the receipt of an autism diagnosis and subsequent interventions, which may compromise children's potential progress, and increase their likelihood to require publicly funded supports over the lifetime. If such barriers can be eliminated, however, a child's prognosis improves dramatically. In many cases, by a certain age, children with an ASD diagnosis no longer require treatment, thereby reducing or eliminating associated costs to society.

Effective Therapeutic Interventions for ASD

While treatment plans for individuals with ASD are individually tailored to each person's unique needs according to the severity of their deficits and any co-occurring diagnoses, persons with ASD typically require a combination of medical, psychological, psychiatric, physical therapy (PT), occupational therapy (OT), speech therapy (ST), behavioral therapies (ABA) and other developmentally-based interventions. Individuals with ASDs should be engaged in functional and appropriate activities as much as possible. In 2001, the National Research Council Report recommended a minimum of 25 hours per week and the American Academy of Pediatrics recommends 20 hours or more of active engagement in evidence-based interventions. Behavioral therapy typically comprises the largest proportion of therapeutic hours, with children receiving between 10-35 hours per week in most cases. Other therapies, such as speech, PT, and OT, are generally required for 1-2 hours per week per child. Michael L. Ganz's study of the societal costs of autism supports the fact that ASD treatment costs decline over time. According to Ganz, direct medical costs reach their maximum during the first five (5) years of life.

As the child ages, direct medical costs begin to decline substantially and continue to decline through the end of life. Ganz goes on to report, "The large direct medical costs early in life are driven primarily by behavioral therapies that cost [an average of] $32,000 during the first 5-year age group and decline from about $4,000 in the 8-to 12-year age group to around $1,250 for the 18- to 22-year age group."

Behavioral Therapy

Behavioral therapies for ASD are derived from behavioral science, which is the examination of human and animal behavior using the principles of science, including observation, reproduction, testing, objectivity, etc. Behavioral therapy is also commonly known as, or otherwise includes, Lovaas therapy, early intensive behavioral intervention, applied behavior analysis (ABA), pivotal response treatment, or other similar terms.

ABA is the application of behavioral science in order to improve socially important behaviors and establish new skills. ABA-based procedures apply behavioral principles of skill development to increase or decrease a particular behavior, improve the quality of a behavior, stop an old behavior, or teach a new behavior.

Effective behavioral-based programs include intervention that is:

1. Implemented early (ideally, before school age)
2. Intensive with respect to the number of hours children are actively engaged
3. Provided in natural environments (i.e. home, school, community)
4. Actively involving of families.

Evidence Supporting Behavioral Therapy's Effectiveness with ASDs

Behavioral-based interventions are based upon decades of scientific investigation with individuals affected by a wide range of behavioral and developmental disorders, including autism. Specifically for children with autism, research demonstrates the efficacy of ABA in teaching complex communication, social, play, and self-help skills, and in reducing disruptive behaviors. The seminal article on this type of intervention was published by Ivar Lovaas at UCLA in 1987. This controlled, long-term study found that 47% of children with autism achieved normal intellectual educational functioning after treatment intensive behavioral treatment, compared to only 2% in the control group.

Since the Lovaas article was published, 20 years of research and over 500 studies continues to support the effectiveness of behavioral therapy for autism.

Lovaas's landmark 1987 study was followed in 1993 by another study of these same 38 subjects. The objective of John J. McEachin's study was to discover the long-term effects of Lovaas's early intensive behavioral treatment and to find out if the results of the experimental group were preserved over time. In terms of intellectual functioning, the study found that "the experimental group at follow-up had a significantly higher mean IQ than did the control group... indicating that the experimental group had maintained its gains in intellectual functioning between age 7 and the time of the current evaluation... [and] ... the experimental group showed more adaptive behaviors and fewer maladaptive behaviors than did the control group."

In another study, more than 50% of children with autism who participated in comprehensive treatment programs using ABA were successfully integrated into typical classrooms, with many requiring little ongoing treatment. (Harris and Handleman, 1994) Only four behavioral interventions are scientifically validated for the treatment of ASD, and all of these are derived from the principles of ABA, according to Simpson (2005).

Scientifically validated behavioral-based interventions for autism include:

1. Applied Behavior Analysis (ABA)
2. Discrete Trial Teaching (DTT)
3. Pivotal Response Treatment (PRT), and
4. Learning Experiences: An Alternative Program for Preschoolers & Parents (LEAP).

Reasons to support private health insurance coverage for ASD:

HB 187--Update of Coverage – less of a mandate

- It wasn't long ago that the medical community erroneously believed autism was untreatable. Today, research has proven otherwise. We are asking insurers to simply update their coverage to reflect the widely held belief in the scientific community that autism is treatable.

Reducing the financial burden on Alaskan Families

- Since insurance coverage is not available, families incur significant financial burdens to pay for necessary and appropriate services, sometimes as much as $50,000 a year, if not more. No family can support this burden.

- In addition to the crushing financial burden placed on families affected by autism, the time, energy, stress and emotional commitment can become absolutely overwhelming and, if left unchecked, can adversely impact employment, health and the marriage.

Cost/Benefit Analysis

- Actuarial and economic studies done in Alaska and other State's indicate adding coverage would increase policy premium costs less than 1%

- A 1998 study by John W. Jacobson and others titled, *Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case,* examined the cost/benefit relationship of early intensive behavioral intervention treatment at varying levels of treatment success. The study used estimates of costs for early intensive behavioral interventions (EIBI) from childhood (age 3) through adulthood (age 55) based on prices in the Commonwealth of Pennsylvania and compared these costs with the expected amount of income the child would earn later in life to arrive at an estimated cost savings. The Jacobson's study found that cost savings per child served are estimated to be from $2,439,710 to $2,816,535 to age 55.

- The benefit to Alaskan taxpayers, families and the school system is clear—spend a little now or, spend a lot later.

Consequences for the Status Quo

Without treatment, the taxpayers of Alaska will certainly bear the enormous financial burden of a life-time of care for children who live a normal life span and often need round the clock care. In contrast, many children who receive effective, intensive and evidenced-based treatments require less support in school and go on to lead productive lives as taxpayers.

President Obama and Federal Policy

Autism is a National health care crisis. President Obama is committed to supporting Americans with ASDs, their families, and their communities. There are a few key elements to their support, which are as follows:

1. President Obama supports increased funding for autism research, treatment, screenings, public awareness, and support services. There must be research of the treatments for, and the causes of, ASD.
2. The Obama administration supports improving life-long services for people with ASD for treatments, interventions and services for both children and adults with ASD.
3. The Obama administration supports comprehensive autism services legislation, funding of the Combating Autism Act and working in a bi-partisan fashion with Congress, parents and ASD experts to determine how to further improve federal and state programs for ASD.
4. The Obama administration supports universal screening of all infants and re-screening for all two-year-olds, the age at which some conditions, including ASD, begin to appear. These screenings will be safe and secure, and available for

every American that wants them. Screening is essential so that disabilities can be identified early enough for those children and families to get the support and services they need.

Other States

- Ten (10) states specifically require insurers to provide coverage for the treatment of autism. Eight (8) states enacted such legislation during the 2007-2008 legislative sessions: Arizona, Connecticut, Florida, Illinois, Louisiana, Pennsylvania, South Carolina and Texas. Thirty-four (34) others have reform measures pending.

Thank you for your strong leadership. If I can be of further assistance, please feel free to contact me.

Sincerely,

Jeff Sell, Esq.
Vice President of Advocacy & Public Policy

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ALTCS eligibility is determined according to a subjective determination of whether an individual is "at-risk for institutionalization." For autism, this criterion is not appropriate. The "PAS" tool, which ALTCS administers during the screening process, is weighted to provide more emphasis on items such as feeding tubes; in fact, the tool provides ZERO points for a diagnosis of autism.

Approximately 50% of personal bankruptcy cases are due at least in part to medical costs. See "Too Great a Burden: Arizona's Families at Risk." Publication No. 07-112AZ. Families USA, December 2007.

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