



AUTISM SPEAKS™
It's time to listen.

Peter H. Bell
Executive Vice President

April 11, 2011

The Honorable Darrell Steinberg
President Pro Tempore, California State Senate
State Capitol, Room 205
Sacramento, CA 95814

RE: Senate Bill 166 – SUPPORT

Dear Senator Steinberg:

On behalf Autism Speaks, I am writing in support of your Senate Bill 166, which would require health care service plan contracts and health insurance policies to provide coverage for the screening, diagnosis, and treatment of autism spectrum disorders.

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 nation's largest autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families.

California mental health parity law (AB 88: Thompson) requires private health service plans and health insurers to provide coverage for the diagnosis and medically necessary treatments of autism. Despite having one of the strongest mental health laws in the nation, families faced with autism struggle to find adequate coverage for services which have shown to be seriously limited, inconsistent, or excluded altogether from many health plans and insurers. In addition, failure to provide treatment by private health insurance policies has resulted in significant increased costs for the state, as parents and patients with private insurance are forced to seek treatment from state operated developmental and regional centers.

Today, it is estimated that one in every 110 children is diagnosed with autism, making it more common than childhood cancer, juvenile diabetes and pediatric AIDS combined. Autism Speaks is proud to support SB 166 to ensure that children diagnosed with autism receive the medically necessary treatments to increase their quality of life and functional independence, which is consistent with the intent and spirit of California's existing mental health parity law.

Autism Speaks strongly supports health insurance coverage for autism and has devoted significant resources toward legislative efforts to ensure such coverage.¹ SB 166 requires coverage for

¹ See www.autismvotes.org for more information about our efforts to promote autism insurance reform.

intensive behavioral interventions such as Applied Behavior Analysis (ABA), which is the most commonly prescribed treatment protocol for autism.

Where the private sector has failed, the public sector has been forced to step in, to the detriment of all California residents. Families in California who have private health insurance are forced to rely on public health insurance or other government programs to meet the needs of children with autism. Private insurers are getting a free pass, while an overburdened public health system shoulders the responsibility of providing insurance or services to families who are getting little return on their purchase of health insurance.

Like the public health system, schools in California also suffer because of the lack of private insurance services. Under federal law, public schools must provide free, appropriate public education to students with disabilities. That mandate is complicated by the absence of private health insurance to treat the core symptoms of autism. For many parents, school services are a substitute for private insurance services. The goal of the educational system, of course, is not to provide medical services. Schools provide speech therapy and other related services to enable a child with a disability to receive a free appropriate public education.² Autism Speaks believes that the ability of schools to educate children is compromised when children with autism do not receive appropriate care through private insurance.

To alleviate the demand on the public health and school systems and in response to the demands of their citizenry, states around the country have enacted or are considering legislation to require insurers to provide autism services. **Indiana has long required health insurers to cover autism services.³ In the past four years, Arizona, Arkansas, Colorado, Connecticut, Florida, Illinois, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, Pennsylvania, South Carolina, Texas, Vermont, West Virginia and Wisconsin have passed similar legislation.** Autism insurance reform bills are currently pending in at least 12 other states. These bills are yet another indication of public demand for insurance coverage of the services provided in the pending California legislation.

In the absence of meaningful health insurance coverage, families often pay as much as they can out-of-pocket for services that can cost upwards of \$50,000 per year. In the process, many risk their homes and the educations of their unaffected children – essentially mortgaging their entire futures.

In California and elsewhere, families of children with autism have sought out treatment for their children. No one treatment is perfect for every child; however applied behavior analysis (“ABA”) is the treatment of choice for many children with autism. ABA is used to increase adaptive behaviors and to decrease maladaptive ones. Most ABA programs are highly structured. Each skill is broken down into small steps and taught using prompts, which are gradually eliminated as the steps are mastered. The child is given repeated opportunities to acquire and practice each step in a variety of settings.

² 20 U.S.C.S. § 1401(26)(A) (2008).

³ See Ind, Code § 27-8-14.2 (2007).

ABA is neither new nor investigational. The recent American Academy of Pediatrics clinical report on the medical management of children with autism spectrum disorders noted its decades-long record of efficacy:

The effectiveness of ABA-based intervention in ASDs [autism spectrum disorders] has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.⁴

The Academy's findings mirrored conclusions of the Surgeon General of the United States: "Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."⁵

Autism is a treatable condition, yet very few health insurance plans in California cover applied behavior analysis. SB 166 would allow insurers to continue evidence-based policy decisions. The bill thus strikes a balance between safeguarding the health-care needs of a vulnerable population and reimbursing effective medical care.

Sincerely,



Peter H. Bell
Executive Vice President
Autism Speaks

⁴ *Id.* at 1164.

⁵ U.S. Department of Health and Human Services, "Mental Health: A Report of the Surgeon General" 163-64 (1999).