

L A T E

Dr. and Mrs. William K. Wong Jr. M.D.
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8 February 2008

Senator David Y. Ige
Chair Consumer Protection & Commerce Committee
Hawaii State Capitol, Room 215
415 South Beretania Street
Honolulu, HI 96813

Senator Carol Fukunaga,
Vice-Chair Consumer Protection & Commerce Committee
Hawaii State Capitol, Room 216
415 South Beretania Street
Honolulu, HI 96813

Re: Support of Dylan's Law Senate Bill 2532, Relating to Health Insurance Coverage for
Autism Spectrum Disorders
Senate Committee on Consumer Protection & Commerce
February 8, 2008, 1:15 p.m., Room 016

Dear Chair Ige, Vice-Chair Fukunaga, and members of the Senate Consumer Protection & Commerce Committee:

We are writing as concerned parents and citizens to express support of Senate Bill 2532, otherwise known as Dylan's Law. This bill mandates health insurance coverage for autism spectrum disorders.

We are parents of a 4 year old son on the autism spectrum named Billy. Billy was diagnosed with autism by a Department of Health psychologist days before his third birthday. When he turned 3 he attended a DOE Special Education Preschool for 5 months. Unfortunately, we as parents, and our team of experts in the fields of psychology and autism, felt that the "Free Appropriate Public Education (FAPE) guaranteed to my son by federal IDEA law, was not appropriate for my son's unique learning needs. We therefore were forced to file for due process, took Billy out of the DOE Special Education preschool, and put him in a private preschool along with the Applied Behavior Analysis (ABA) therapy that we felt was appropriate for his disabling condition.

With the changes we have made to Billy's education and therapy, he has made amazing progress in one year. Here are some examples: Whereas before he could barely answer a simple question and spoke in terse, awkward 3-4 word phrases, now he is having conversations with us, speaking in sentences with over 10 words, and is able to express increasingly complex ideas. Whereas before the extent of his playing with toys was spinning the wheels of cars, now he uses them appropriately, makes the "zoom zoom" sounds, and at times even narrates what he is

doing. What we are most excited and thrilled about is that he is now talking to and interacting with his peers in preschool.

We are optimistic that with continued intensive therapy in his formative years, Billy will eventually shed his diagnosis and become a fully independent, contributing member of society. Without such therapy, children with autism become lifelong dependents of their families, and the State. For each child affected by autism, the socioeconomic drain on public resources is immense.

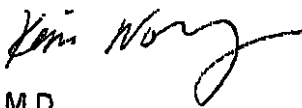
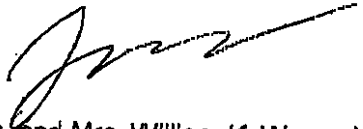
These improvements were a direct result of the intense Applied Behavior Analysis (ABA) program that we implemented for Billy. However, because this type of therapy is time consuming, highly individualized, and must be implemented by trained therapists and consultants, we truly pay through the nose. Our costs range from \$7000 to over \$10,000 per month. Despite the exorbitant cost, it is all worthwhile to see our son play with his 2 year old sister, play appropriately with his toys, converse with us, and for us to see so many other skills emerging. We feel truly blessed that due to our present circumstances we are able to afford the therapy for now. However, it is still an enormous burden on our family. Any amount of financial help from insurance companies would help us immensely and would truly be appreciated.

Autism is a complex neurobiological disorder that currently affects 1 in 150 children, according to the Center for Disease Control. It is a medical diagnosis as defined in the DSM IV - Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (ICD-9 code 299.0) which requires treatment services from trained medical professionals and a full-range of therapies. The therapies include speech therapy, occupational therapy, and intensive behavioral therapy, such as Applied Behavior Analysis (ABA), among others. With proper medical intervention and intensive therapies children with autism can improve to such an extent that they can enter mainstream classrooms unassisted. In our personal experience, such therapies are successful but expensive. Children with autism have been denied coverage for necessary therapies by private health insurance companies. It is incredulous that such a serious medical disorder has been universally denied coverage by medical insurance carriers. Medical insurance carriers must be required to provide coverage for Autism therapy. Virtually all families of children with autism are deeply in debt as a result of the lack of insurance coverage for these necessary therapies. Currently these costs are borne by families, and the Departments of Education and Health. With the epidemic increase in prevalence of this disease, the State will be facing a crisis with already strained finances and resources. In the end, the victims will be our children.

The cost of paying for the therapies out of pocket not only causes financial strain for the families, but it also causes heavy emotional distress. For many of these families, the stress is more than they can bear and many marriages end in divorce. In spite of the burdens of autism on the insurance companies, the government, the families, and society as a whole, the most important issue is the child. Dylan's Law is about all children with autism who deserve to have a better quality of life.

We urge you to pass Dylan's Law Senate Bill 2532 and make insurance coverage for autism a reality. The children with autism in Hawaii deserve to have the opportunity to thrive.

Sincerely,



Dr. and Mrs. William K. Wong, Jr. M.D.

L A T E



LINDA LINGLE
GOVERNOR
JAMES R. AIONA, JR.
LT. GOVERNOR

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LAWRENCE M. REIFURTH
DIRECTOR
RONALD BOYER
DEPUTY DIRECTOR

TO THE SENATE COMMITTEE ON HEALTH

TWENTY-FOURTH LEGISLATURE
Regular Session of 2008

Friday, February 8, 2008
1:15 p.m.

WRITTEN TESTIMONY ONLY

TESTIMONY ON SENATE BILL NO. 2532 – RELATING TO HEALTH INSURANCE.

TO THE HONORABLE DAVID Y. IGE, CHAIR, AND MEMBERS OF THE COMMITTEE:

My name is J. P. Schmidt, State Insurance Commissioner (“Commissioner”), testifying on behalf of the Department of Commerce and Consumer Affairs (“Department”). The Department takes no position on this bill, which creates a mandated benefit for the diagnosis and treatment of autism spectrum disorders for persons under age twenty-one.

The Department does not have the medical expertise necessary to express an informed opinion on the merits of this bill. In addition, mandated benefits help some patients, but also increase premiums for consumers. Weighing these complex issues is best left to the wisdom of the Legislature. It should also be noted that prior to enacting mandatory health insurance coverage, there must be a review by the Legislative Auditor pursuant to Hawaii Revised Statutes section 23-51.

We thank this Committee for the opportunity to present testimony on this matter.

testimony

From: Sarah Haws [sarahhaws@hotmail.com]
Sent: Friday, February 08, 2008 2:04 PM
To: testimony
Subject: Senate Committee On Health

Please send this written testimony to Room 016

In support of Dylan's Law SB2532.

I provide my testimony in writing supporting a law to pass that insurance companies should provided Applied Behavior Analysis treatment to children with Autism Spectrum Disorders for the following reasons:

1. Autism is a neurological disorder just like Alzhiemers disorder but does not get equal treatment from insurance companies.
2. Applied Behavior Analysis has been researched and shown to be effective for all children with Autism Spectrum Disorders in helping them learn functional skills and adapt to society.
3. If insurance companies do not help treat autism while children are young, it will cost them more when they get older. Helping children learn the necessary functional skills when they are young will help them live a happier and healthier life.
4. Divorce rate is high with families affected by autism causing emotional and physical stress on the whole family thus creating other medical and psychological problems.

In the end, research has shown that if children receive early intervention using Applied Behavior Analysis treatment, the symptoms of the disorder are decreased dramatically and sometimes near none. Early intervention for children with autism provided to them now means preventing higher treatment costs later. We also allow children to reach their full potential who can be productive contributors to society.

Sarah Haws, MSCP
Behavior Analyst/Consultant
Child Enrichment Center, LLC
(808) 284-7225

AUTISM SOCIETY OF HAWAII
P.O. BOX 2995
HONOLULU, HAWAII 96802

February 8, 2008

COMMITTEE ON HEALTH
Senator David Y. Ige, Chair
Hawaii State Capitol
415 South Beretania Street
Honolulu, Hawaii 96813

COMMITTEE ON HEALTH
Senator Carol Fukunaga, Vice Chair
Hawaii State Capitol
415 South Beretania Street
Honolulu, Hawaii 96813

Re: In strong support of Dylan's Law SB2532, Relating to Health Insurance Coverage for Autism Spectrum Disorders Senate Committee on Health, February 8, 2008, 1:15 p.m., Room 015

Dear Chair Ige, Vice-Chair Fukunaga, and members of the Senate Health Committee:

I am writing to express my strong support of Senate Bill 2532, otherwise known as Dylan's Law. This bill mandates health insurance coverage for autism spectrum disorders.

Autism is a complex neurobiological disorder that currently affects 1 in 150 children, according to the Center for Disease Control. This disorder affects boys four times more likely than girls. Autism impairs a person's ability to communicate and relate to others, and is often associated with repetitive behaviors, poor eye contact, and rigidity in routines. Children with autism often have co-occurring conditions, such as behavioral problems, speech disorders, depression, anxiety, muscle or joint problems, ear infections, vision and hearing problems, and allergies. The wide range of co-occurring problems leads to their need for services from trained medical professionals and for a full-range of therapies. The therapies include speech therapy, occupational therapy, and intensive behavioral therapy, such as Applied Behavior Analysis (ABA), among others. With proper medical intervention and intensive therapies children with autism can improve to such an extent that they can enter mainstream classrooms unassisted.

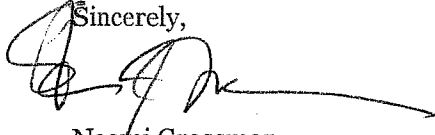
Unfortunately, children with autism are often denied coverage for necessary therapies by private health insurance companies. One important therapy denied by insurers is Applied Behavior Analysis (ABA). ABA has a decades-long record of efficacy. It is a data-based intervention for autism that has over forty years of research behind it. In a 1987 study by Ivar Lovaas, the children who underwent early intensive ABA therapy achieved higher educational placement and increased IQ levels than those who did not. ABA is recognized by The U.S. Surgeon General's 2001 Report on Mental Health as the treatment that is widely accepted as being effective for autism, and the National Institute of Child Health and Human Development acknowledges that Applied Behavior Analysis is an effective treatment for autism. Although ABA is the single intervention most often sought by parents of children with autism, insurers frequently deny it as a benefit. As a result, families are often forced to pay for these costly services out of pocket.

Too many families of children with autism are deeply in debt as a result of the lack of insurance coverage for these necessary therapies. However, the cost of paying for the therapies out of pocket not only causes financial strain for the families, but it also causes heavy emotional distress. For many of these families, the stress is more than they can bear and many of the marriages end in divorce. But in spite of the burdens of autism on the insurance companies, the government, the families, and even on society as a whole, the most important point in this issue is the CHILD.

Dylan's Law is about all children with autism who deserve to have a better quality of life.

I urge you to pass Dylan's Law Senate Bill 2532 and make insurance coverage for autism a reality.
The children with autism in Hawaii deserve to have the opportunity to thrive.

Sincerely,

A handwritten signature in black ink, appearing to read 'Naomi Grossman', with a long horizontal flourish extending to the right.

Naomi Grossman
Autism Society of Hawai'i, president

TESTIMONY IN SUPPORT OF SB2532

Legislators,

I am here to testify in support of SB2532, known as Dylan's law.

I am the parent of a child with autism. Some of you may know, autism affects 1 in 150 children, a huge increase from the 1970's when the rate was 2 or 3 per 10,000. It is the fastest growing developmental disability. It is more common than childhood cancer and diabetes combined.

The standard of care for autism is behavioral therapy. The form of behavioral therapy best studied and shown to be successful is ABA – applied behavior analysis. That is why the bill is specific in its provision for ABA therapy.

When our child was diagnosed, doctors told us to get him into behavioral therapy right away. But even though it is recommended by the best pediatric neurologists in the country, there is no insurance coverage for this. We were paying out of pocket for this critical intervention.

ABA is a proven success. Studies have shown improvement in most of the children, and some have recovered from autism using this therapy. Early intervention is critical. This can change a child's outcome from being dependant on the State as an adult, to being independent. Aside from the humanitarian justification, it is financially prudent.

Other health conditions are covered by insurance. Why should autism be any different?

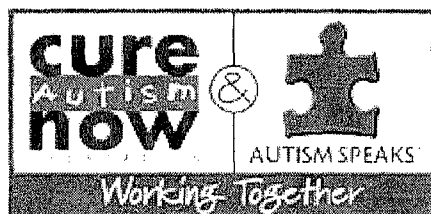
Please pass bill SB2532.

Mahalo,

Don King

Autism Speaks

Arguments In Support of Private Insurance Coverage of Autism-Related Services



October 24, 2007

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- Page 17** *Argument 7: By improving outcomes for children with autism, mandated private insurance coverage will decrease the lifetime costs of treating and providing services and will actually result in an overall cost savings in the long-run.*
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Executive Summary

Autism is a complex neurobiological disorder and is the fastest-growing serious developmental disability in the U.S. The Centers for Disease Control estimates that 1 in 150 children have autism. These children require extensive services from medical professionals. Early intervention is critical to gain maximum benefit from existing therapies. Most private health insurance plans do not provide coverage for Applied Behavioral Analysis (ABA) and other autism-related services.

This document contains eight arguments in favor of requiring private health insurance policies to cover the diagnosis and treatment of autism spectrum disorders for individuals under the age of 21. These arguments are based on epidemiological, social, and economic studies of the children and families affected by autism and prove the significant long-term financial and public health benefits of this requirement.

We first point out that children with autism have substantial medical needs and have a difficult time accessing necessary treatments through Medicaid and private health insurance. Most insurance policies contain specific exclusions for autism. This is a hardship for many families, who are often forced to cope with delayed, inadequate, and fragmented care through the Medicaid system. Often, families must pay for costly treatments out-of-pocket or forego them.

We then review some of the many studies and reports that document the effectiveness of intensive behavioral therapies in the treatment of autism. An autism insurance mandate should specifically target coverage of Applied Behavior Analysis (ABA) and other structured behavioral therapies, which are the most effective forms of treatment and have the best outcomes, both in human costs and in long-term economic benefits.

We then comment on the experiences of several states with insurance reform. Their experiences show that the policy holder costs resulting from the passage of legislation requiring comprehensive autism services have been relatively small.

Finally, we point out that the mandate offers hope that children with autism will need less intensive care in the future. They will, in short, have a better chance at a normal life.

What is Autism Speaks?

Autism Speaks is an organization dedicated to increasing awareness of autism spectrum disorders, to funding research into the causes, prevention, treatments, and cure for autism, and to advocating for the needs of affected families. The organization was founded in February 2005 by Suzanne and Bob Wright, the grandparents of a child with autism. Bob Wright is Vice Chairman, General Electric, and served as chief executive officer of NBC for more than twenty years. Autism Speaks has merged with both the National Alliance for Autism Research (NAAR) and Cure Autism Now (CAN), bringing together the nation's three leading autism advocacy organizations.

What is Autism?

Autism is a complex neurobiological disorder that typically lasts throughout a person's lifetime. It is part of a group of disorders known as autism spectrum disorders (ASD). Today, 1 in 150 individuals is diagnosed with ASD, making it more common than pediatric cancer, diabetes, and AIDS combined. It occurs in all racial, ethnic, and social groups and is four times more likely to strike boys than girls. Autism impairs a person's ability to communicate and relate to others. It is also associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe.

Argument 1: Mandated private health insurance coverage will provide services that are desperately needed by children with autism, who have greater health care needs than children without autism.

Children with autism have a tremendous need for services from trained medical professionals. These children are at risk for a range of other medical conditions, including behavioral or conduct problems, attention-deficit disorder or attention-deficit/hyperactivity disorder, stuttering, stammering, and other speech problems, depression and anxiety problems, bone, joint, or muscle problems, ear infections, hearing and vision problems, allergies (especially food allergies), and frequent and severe headaches. These problems greatly affect their overall health and their need for and use of health care services.

A recent study by James G. Guerney and others¹ highlights the broad medical needs of children with autism. Using data from the National Survey of Children's Health, Guerney showed that relative to children without autism, children with autism require more services for physical, occupational, and speech therapy. Children with autism are also much more likely to have poor health, to require medically necessary care for behavioral problems, and to be using medications. As evidenced in the chart below taken from the study, parents of children with autism were more likely to report the presence of a variety of concurrent medical conditions and the need for more visits to a range of medical service providers than parents of children without autism.

Table 2. Parental Description of Health Status and Therapy and Services Use, From the National Survey of Children's Health

Variable	Children With Autism (n = 324,000)*	Children Without Autism (n = 61,100,000)*	OR (95% CI)†
Would you say your child's health is:			
Excellent	33.7	60.2	1.0
Very good	22.8	23.6	1.0 (1.2-0.7)
Good	32.7	13.0	5.0 (3.9-6.4)
Fair	7.4	2.0	7.7 (4.2-13.8)
Poor	3.6	0.4	21.1 (9.3-47.0)
Does the child use more medical care, mental health or educational services than is usual for most children of the same age?	89.6	11.8	32.8 (24.7-40.4)
Is the child limited or prevented in the ability to do the things most children the same age can do?	68.6	5.7	36.2 (24.0-52.6)
Does the child get special therapy, such as physical, occupational, or speech therapy?	76.0	6.3	44.4 (31.9-61.8)
Does the child have any emotional, developmental, or behavioral problem for which she needs treatment or counseling?	75.4	7.0	36.0 (29.7-43.1)
Does the child currently need or use medicine prescribed by a doctor, other than vitamins?	34.7	21.1	3.5 (2.6-4.7)
If yes, is this for a condition expected to last 12 mo or longer?	31.4	14.5	11.0 (1.6-76.0)

Abbreviations: CI, confidence interval; OR, odds ratio.

*Data are given as the percentage of each group and are based on sampling fractions and weighted extrapolation from parent report of 433 children with autism and 64,789 children without autism.

†Data are adjusted for sex, primary language, age, insurance, and household educational attainment.

This reform of private health insurance coverage will address the broad medical needs of children with autism. It will ensure that these children will receive the full range of therapies necessary to ameliorate their condition.

Argument 2: Treatments for autism are difficult to access, often inadequate, and frequently delayed. Denied coverage by private group health insurance companies, parents are often forced either to pay out-of-pocket or forego the treatments their children need.

Children with autism face barriers in accessing early intensive behavioral treatments and other therapies. According to the Institute of Medicine, the term “access” is defined as “the timely use of personal health services to achieve the best possible health outcomes.”² For a child with autism, lack of access to services can be the cause of inconsistent and uncoordinated care. Children with autism often experience barriers to access with even greater frequency than children with other special health care needs. In fact, one study found that “over one-third of the children with autism were reported to have experienced an access problem with respect to specialty care from a medical doctor in the preceding 12 months.”³ A study of the Tennessee Medicaid system, TennCare, found that for children with autism, “the rate of service use was only one tenth what should be expected based on prevalence rates.” The chart below illustrates these results and the significantly lower rates of service access for children with autism.

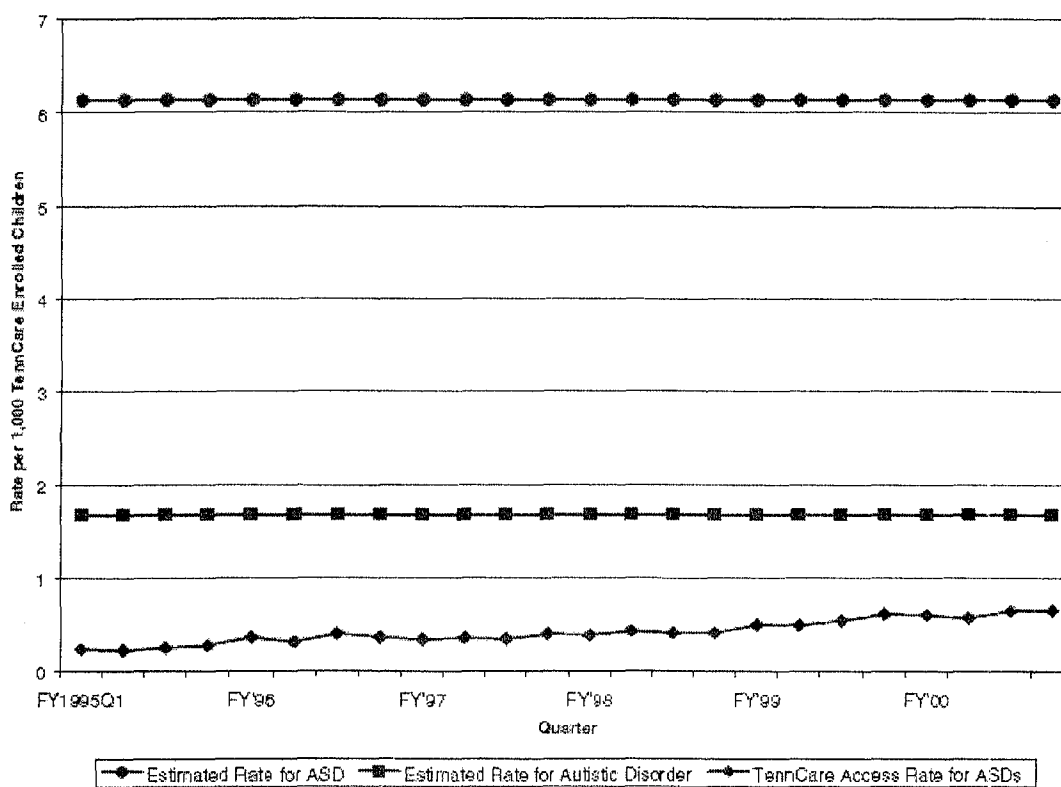


Fig. 1. Estimated incidence rates vs. service rates of autism spectrum disorders (ASDs) in TennCare for children ages 0-17 years, by quarter.

Within the Medicaid system, the amount of public money spent for services for developmental disabilities including autism is now eight times the rate of spending just a few decades ago.⁴ Medicaid accounts for 75% of all funding for services for the developmentally disabled, making it the largest single public payer of behavioral health services.⁵ Children with disabilities comprise a significant portion (15%) of all Medicaid recipients, and an even more significant portion (31%) of disabled children use the Medicaid system as their primary insurer.

Medicaid suffers from very low reimbursement rates that make it difficult for many locations to retain service providers. Moreover, services that can be accessed through the Medicaid system are often inadequate at meeting the specific needs of a child with autism. The system operates as a short-term service provider, tending to push children through treatment as quickly as possible. The success of the Applied Behavior Analysis, however, depends in part, on the amount of time the child with autism spends with the provider of the therapy.⁶

The failings of Medicaid point to the importance of the private health care system in providing services to children with autism. But nationwide there are very few private insurance companies or other employee benefit plans that cover Applied Behavior Analysis and other behavioral therapies. Most insurance companies designate autism as a diagnostic exclusion, “meaning that any services rendered explicitly for the treatment of autism are not covered by the plan, even if those services would be covered if used to treat a different condition.”⁷ A 2002 study by Pamela B. Peele and others of 128 behavioral health plans administered by one of two large managed behavioral health organizations found that all the plans had some type of limit on benefits for behavioral therapies – over half of the plans had limits on the number of annual outpatient sessions and 65 percent of the plans imposed limits on the number of inpatient days covered per year.⁸

Families that refuse to allow their children to suffer through the inadequate Medicaid system and are denied coverage by their private health insurance carriers often end up paying for therapies out of their own pockets. For these families, the financial burden is immense. Without the negotiating powers of an insurance company behind them, out-of-pocket prices are extremely high. Parents can often spend upwards of \$50,000 per year on autism-related therapies, often being forced to wager their own futures and the futures of their non-autistic children to pay for necessary autism-related therapies. Children whose parents cannot afford to pay for behavioral and other therapies and who cannot access adequate therapies through the Medicaid system simply go without these interventions.

Argument 3: Mandated private insurance coverage will bring effective autism services within the reach of the children who need them. The efficacy of Applied Behavior Analysis (ABA), the centerpiece of this legislative mandate's benefits, has been established repeatedly.

Private health insurance coverage of autism services will allow children with autism to access Applied Behavior Analysis (ABA), a proven treatment for their condition. Several studies have shown that as many as 47 percent of the children that undergo early intensive behavioral therapies achieve higher education placement and increased IQ levels. A significant portion of children who receive ABA are placed into mainstream educational settings. Children who begin their treatment with minimal IQ levels end treatment with substantially higher levels of intellectual functioning. These results have been shown to last well beyond the end of treatment. As such, the effectiveness of ABA therapy has allowed many children to forego costly intensive special education in the future.

Lovaas:

The most famous study of the effectiveness of behavioral modification treatments was conducted in 1987 by O. Ivar Lovaas.⁹ Lovaas's study showed that when compared with other treatment programs that provide minimal therapy, Applied Behavior Analysis is extremely effective in helping many children struggling with autism, providing gained capacity for intellectual functioning and allowing a child to progress educationally.

Lovaas conducted his study of the effectiveness of behavioral modification treatments on very young children affected by autism. For his study, Lovaas split his 38 subjects into two groups: 19 subjects were put into an intensive-treatment experimental group that received more than 40 hours of one-to-one treatment per week, and 19 subjects were placed in a minimal-treatment control group that received 10 hours or less of one-to-one treatment per week. Both groups were identical at intake in terms of intellectual functioning abilities, and both received their assigned treatment for 2 or more years.

Upon follow-up at age 7, the experimental group attained significantly higher results on education placement and IQ levels than the control group. According to the results of Lovaas's study, the 19-subject experimental group showed nine children (47%) who successfully passed through normal first grade in a public school and obtained an average or above average score on IQ tests.

McEachin:

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.¹⁰

For this study, Lovaas's original subjects were evaluated at a mean age of eleven-and-a-half years. The study was presented in two parts: the first examined whether the experimental group had maintained its treatment gains, the second part focused on the nine subjects who had achieved the greatest gain in the original study and examined the extent to which they "could be considered free of autistic symptomology."

McEachin's follow-up resulted in findings in three different categories: school placement, intellectual functioning, and presence of adaptive and maladaptive behaviors. In terms of class placement, the study found that "the proportion of experimental subjects in regular classes did not change from the age 7 evaluation (9 of 19, or 47%). In the control group, none of the 19 children were in a regular class, as had been true at the age 7 evaluation." (McEachin, *supra* note 10) 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." Finally, in terms of presence of adaptive and maladaptive behaviors, "the findings indicate that the experimental group showed more adaptive behaviors and fewer maladaptive behaviors than did the control group." (McEachin, *supra* note 10)

Based on these findings, the effectiveness of ABA and other structured behavioral programs, as provided by the proposed benefit, would be experienced in the short-term as well as the long-term.

Argument 4: Government and scientific organizations have endorsed Applied Behavior Analysis (ABA) and other structured behavioral therapies.

ABA is the treatment of choice for autism. Its efficacy has been recognized in a number of prominent reports, including the following:

- ❖ **The 2001 U.S. Surgeon General's Report on Mental Health**, which 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."¹¹
- ❖ **The New York State Department of Health** assessed interventions for children ages 0-3 with autism, and recommended that "behavioral interventions for reducing maladaptive behaviors be used for young children with autism when such behaviors interfere with the child's learning or socialization or present a hazard to the child or others."¹²
- ❖ **The Maine Administrators of Services for Children with Disabilities** notes in their report that "There is a wealth of validated and peer-reviewed studies supporting the efficacy of ABA methods to improve and sustain socially significant behaviors in every domain, in individuals with autism. Importantly, results reported include 'meaningful' outcomes such as increased social skills, communication skills academic performance, and overall cognitive functioning. These reflect clinically-significant quality of life improvements. While studies varied as to the magnitude of gains, all have demonstrated long term retention of gains made."¹³
- ❖ **The National Institute of Mental Health** reports, "The basic research done by Ivar Lovaas and his colleagues at the University of California, Los Angeles, calling for an intensive, one-on-one child-teacher interaction for 40 hours a week, laid a foundation for other educators and researchers in the search for further effective early interventions to help those with ASD attain their potential. The goal of behavioral management is to reinforce desirable behaviors and reduce undesirable ones."¹⁴
- ❖ **The National Institute of Child Health and Human Development** lists Applied Behavior Analysis among the recommended treatment methods for Autism Spectrum Disorders.¹⁵
- ❖ **The National Research Council's** 2001 report on Educating Children with Autism acknowledged, "There is now a large body of empirical support for more contemporary behavioral approaches using naturalistic teaching methods that demonstrate efficacy for teaching not only speech and language, but also communication."¹⁶

- ❖ **The Association for Science in Autism Treatment** recommends ABA-based therapies, stating, “ABA is an effective intervention for many individuals with autism spectrum disorders.”¹⁷

Argument 5: To combat the difficulty many families face in accessing Applied Behavior Analysis (ABA) and other structured behavioral treatments through public insurance, three states have passed autism insurance mandates that specifically require private insurance companies to provide coverage of these therapies, thus creating a public-private partnership for the provision of care.

While there are several states that have passed autism specific private insurance mandates, very few states specifically mandate coverage for ABA and other structured behavioral therapy programs. Without coverage of these crucial, medically necessary, evidence based therapies, the effectiveness of most mandates is severely diminished. For this reason, we have concluded that only the following states have passed autism insurance legislation:

South Carolina:

Senate Bill 20, better known as Ryan's Law, was passed by both the South Carolina House of Representatives and Senate on May 31, 2007.¹⁸ The bill was then vetoed by Governor Mark Sanford on June 6. On June 7, the bill was brought back to the House and Senate floors, and unanimous votes in both chambers overrode the Governor's veto. This law goes into effect in July 2008.

Coverage Includes: Treatments, including behavioral therapies, which are prescribed by the individual's treating medical doctor in accordance with a treatment plan.

Age Range: An individual must be diagnosed with autistic spectrum disorder at age eight or younger. The coverage must be provided to any eligible person less than sixteen years of age.

Dollar Cap: Coverage for behavioral therapy is subject to a \$50,000 maximum benefit per year.

Texas:

On June 15, 2007, Texas enacted House Bill 1919, effective September 1, 2007.¹⁹ While the Texas bill limits the ages for children who can benefit from coverage, it goes further than some other states in spelling out exactly what kinds of services are covered. The bill's text specifically cites which kinds of autism-related services are examples of treatments that must be covered.

Coverage Includes: Evaluation and assessment services, ABA, behavior training and behavior management, speech therapy, occupational therapy, physical therapy, medication or nutritional supplements used to address symptoms of autism spectrum disorder.

Age Range: An individual must be between ages three and five to receive this

coverage.

Dollar Cap: Same as afforded to physical illnesses

Indiana:

In 2001, the Indiana enacted House Bill 1122, requiring insurers that issue accident and sickness insurance policies on an individual basis to provide coverage for the treatment of autism spectrum disorders.²⁰

Coverage Includes: Treatment that is prescribed by the insured's treating physician in accordance with a treatment plan. The statute thus allows many different professionally accepted therapies, such as ABA, speech therapy, occupational therapy, physical therapy, and medications to address symptoms of autism.

Age Range: All ages are allowed coverage

Dollar Cap: Same as afforded to physical illnesses

Argument 6: The costs of the proposed benefit are small and will have very little impact on the cost of health insurance premiums for the individual consumer.

Earlier this year, The Council for Affordable Health Insurance, a research and advocacy association of insurance carriers, released its annual report on state health insurance mandates, *Health Insurance Mandates in the States 2007*.²¹ The report defined a mandate as “a requirement that an insurance company or health plan cover (or offer coverage for) common – but sometimes not so common – health care providers, benefits and patient populations.” (Bunce, *supra* note 21) Using this definition, the report identified legislative mandates for autism benefits in ten states: Colorado, Delaware, Georgia, Iowa, Indiana (which, as we have noted, provides comprehensive benefits), Kentucky, Maryland, New Jersey, New York, and Tennessee. The report assessed the incremental cost of state mandated benefits for autism in these ten states *as less than one percent*.

The Council’s modest estimate of incremental premium costs is consistent with state government estimates across the country. Prior to enactment of Indiana’s sweeping legislation, the Indiana Legislative Services Agency estimated additional premium costs as ranging from \$.44 per contract per month to \$1.67 per contract per month.²² In vetoing Ryan’s Law in South Carolina, Governor Mark Sanford estimated that the bill, with its \$50,000 maximum yearly benefit for behavioral therapy, would add \$48 annually to insurance policies.²³ And in Wisconsin, where pending Assembly Bill 417 would provide the same broad coverage Indiana’s statute mandates, the Department of Administration estimates policy increments of between \$3.45 and \$4.10 per month – about the same as Governor Sanford’s estimate for Ryan’s Law.²⁴

The cost estimates for Indiana, South Carolina, and Wisconsin – all states whose legislation allows a maximum benefit that can be considered high – suggest that an average autism insurance coverage mandate will cost approximately \$50 annually per policy holder. For only a modest effect on premium cost, this insurance reform holds the promise of significantly improving the lives of thousands of children.

Argument 7: By improving outcomes for children with autism, mandated private insurance coverage will decrease the lifetime costs of treating and providing services and will actually result in an overall cost savings in the long-run.

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.²⁵ The study used estimates of costs for early intensive behavioral interventions (EIBI) from childhood (age three) 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.

With a success rate of 47 percent for early intensive behavioral intervention therapy (as determined by Lovaas), 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.

	<i>Inflated total</i>	<i>1996 \$ total</i>	<i>Inflated/ student</i>	<i>1996 \$/ student</i>
At 20% normal range				
20 norm range vs. partial effect	96,085,200	36,654,400	4,804,260	1,832,720
70 partial vs. minimal effect	72,520,910	28,984,130	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	168,606,110	65,638,530	1,686,061	656,385
At 30% normal range				
30 norm range vs. partial effect	144,127,800	54,981,600	4,804,260	1,832,720
60 partial vs minimal effect	62,160,780	24,843,540	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	206,288,580	79,825,140	2,062,886	798,251
At 40% normal range				
40 norm range vs. partial effect	192,170,400	73,308,800	4,804,260	1,832,720
50 partial vs. minimal effect	51,800,650	20,702,950	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	243,971,050	94,011,750	2,439,710	940,118
At 50% normal range				
50 norm range vs. partial effect	240,213,000	91,636,000	4,804,260	1,832,720
40 partial vs. minimal effect	41,440,520	16,562,360	1,036,013	414,059
10 minimal effect	0	0	0	0
Net	281,653,520	108,198,360	2,816,535	1,081,984

Note: This table presents a comparison of financial benefits at different levels or rates of achievement of normal skills or functioning achieved by EIBI, for people ages 3-55 years, ranging from 20% of children achieving normal range skills or functioning (an assumed minimal rate) to 50% of children. At each level of effectiveness, differing rates of normal range functioning, as well as partial benefit are estimated. Costs are shown in terms of the aggregate of 100 children served, and averages per person served, with inflation and in 1996 dollars.

The study also accounts for the initial investment in early intervention by concluding that, with an initial annual cost of \$32,820, the total cost-benefit savings of EIBI services per

child with autism or PDD for ages 3-55 years averages from \$1,686,061 to \$2,816,535 with inflation.

According to a 2005 Government Accounting Office (GAO) report, "the average per pupil expenditure for educating a child with autism was more than \$18,000 in the 1999-2000 school year. This amount was almost three times the average per pupil expenditure of educating a child who does not receive any special education services."²⁶ With this insurance reform in place, more children would be able to access the early intervention services they need. That investment will, in the long run pay benefits, both economic and social, to the greater population.

Argument 8: Without passage of legislation requiring private health insurance coverage for autism, the costs associated with autism will continue not only to affect families, but will have far reaching social effects as well.

The cost of autism is borne by everyone. Michael L. Ganz's study of the societal costs of autism, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, examined how the large financial burdens of autism affect not only families with an autistic child but society in general.²⁷

Ganz broke down the costs associated with autism into two distinct categories, direct costs and indirect costs. Direct costs include direct medical costs, such as physician, outpatient, clinic services, dental care, prescription medications, complementary and alternative therapies, behavioral therapies, hospital and emergency services, allied health, equipment and supplies, home health, and medically related travel, as well as direct nonmedical costs, such as child care, adult care, respite and family care, home and care modification, special education, and supported employment. Indirect costs include productivity losses for people with autism (calculated by combining standard average work-life expectancies for all men and women with average income and benefits and estimated age and sex specific labor force participation rates).

According to Ganz's study, direct medical costs reach their maximum during the first five years of life, averaging around \$35,000. As the child ages, direct medical costs begin to decline substantially and continue to decline through the end of life to around \$1,000. Ganz goes on to report, "The large direct medical costs early in life are driven primarily by behavioral therapies that cost around \$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." (Ganz, *supra* note 27)

In terms of direct medical costs "the typical American spends about \$317,000 over his or her lifetime in direct medical costs, incurring 60% of those costs after the age of 65 years. In contrast, people with autism incur about \$306,000 in incremental direct medical costs, which suggests that people with autism spend twice as much as the typical American over their lifetimes and spend 60% of those incremental direct medical costs after age 21 years." (Ganz, *supra* note 27)²⁷

The study also found the indirect costs of autism to be significant as well. While in the first 22 years of life, indirect costs are mostly associated with lost productivity for the parents of a child with autism, the costs from age 23 on are associated with lost productivity of the actual individual with autism as depicted in the chart below taken from the study. The impact of this lost productivity can have enormous ramifications for the tax base of an entire society and the future of the older generation as their children with autism transition into adult care.

Table 4. Age-Specific and Lifetime per Capita Incremental Societal Indirect Costs of Autism*

Age Group, y	Average per Capita Cost per Age Group	
	Direct Indirect	Net Direct Indirect
3-7	0	43068
8-12	0	41138
13-17	0	38453
18-22	0	36090
23-27	32703	10038
28-32	32600	3138
33-37	30862	0
38-42	29132	0
43-47	26600	0
48-52	24831	0
53-57	17776	0
58-62	0	0
63-68	0	0
Total lifetime costs	901072	904876

*Costs presented in 2003 dollars. Costs for age 4 years and older are discounted to 2003 dollars using a discount rate of 2%. Life expectancy for men is age 68 years and for women, age 65 years.

Ganz posited that direct medical costs “combined with very limited to non-existent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general.”(Ganz, *supra* note 27)

Without the help of private insurance coverage, families affected by autism may never be able to pull their heads above water and provide their children with the medically necessary, evidence- based treatments that they need. It is to the advantage of these families, to the 1 in 150 children affected by autism, and to all of society that private health insurance coverage is provided for these services.

Conclusion

A legislative mandate for coverage of autism asks private insurance companies to make a limited, but significant, contribution to help pay for medically necessary, evidence-based treatments that have been established to be of the greatest impact in fighting this terrible disorder.

Unbelievably, it is not uncommon for insurance carriers to have line-item exclusions for treatment of individuals diagnosed with autism. Across the nation, children with autism are routinely denied insurance benefits for treatment of their disorder. We believe that private insurance companies must contribute their fair share and partner in the financial burdens with these families.

With every new child diagnosed with autism costing an estimated \$3 million over his or her lifetime, the current practices are both unfair and not cost effective in the long run for states and their citizens. Autism Speaks is confident that many more state governments will recognize the significant long-term cost benefits found in these legislative measures, will do what is right for their constituents, and will pass legislation requiring private health insurance coverage of autism services.

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