# **SB2532**

## **Measure Title:**RELATING TO HEALTH INSURANCE.

#### **Report Title:**

Mandatory Health Coverage; Autism Spectrum Disorders

#### **Description:**

Requires all health insurers, mutual benefit societies, and health maintenance organizations to provide mandatory coverage for all policyholders, member, subscribers, and individuals under age 21 for the diagnosis and treatment of autism spectrum disorders beginning 1/1/2009.

Introducer(s):

**IGE** 

**Current Referral:** 

HTH, CPH



#### STATE OF HAWAII

STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
919 ALA MOANA BOULEVARD, ROOM 113
HONOLULU, HAWAII 96814
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543
February 8, 2008

The Honorable David Y. Ige, Chair Senate Committee on Health Twenty-Fourth Legislature State Capitol State of Hawaii Honolulu, Hawaii 96813

Dear Senator Ige and Members of the Committee:

SUBJECT: SB 2532 - RELATING TO HEALTH INSURANCE

The position and views expressed in this testimony do not represent nor reflect the position and views of the Department of Health.

The State Council on Developmental Disabilities recognizes the merits of this bill. The purpose of the bill is to require all health insurers, mutual benefit societies, and health maintenance organizations to provide mandatory coverage for all policyholders, members, subscribers, and individuals under age 21 for the diagnosis and treatment of autism spectrum disorders beginning January 1, 2009.

The Council brings to your attention that Section 23-51, Hawaii Revised Statutes (HRS), requires concurrent resolutions to be passed by the Legislature requesting the Legislative Auditor to prepare and submit a report to the Legislature that assesses both the social and financial effects of the proposed mandated coverage (see attached Section 23-51, HRS). Therefore, we feel it would be premature to pass this bill without having the Legislative Auditor assess the impact of this measure pursuant to Section 23-51, HRS. House Concurrent Resolution 62 - Requesting the Auditor to Assess the Social and Financial Effects of Requiring Health Insurers to Provide Coverage for Diagnosis and Treatment of Autism Spectrum Disorders addresses this section.

The Council appreciates the Legislature's interest and concern about autism spectrum disorders. Thank you for the opportunity to present testimony.

Sincerely,

Executive Administrator

## [PART IV.] SOCIAL AND FINANCIAL ASSESSMENT OF PROPOSED MANDATORY HEALTH INSURANCE COVERAGE

- \$23-51 Proposed mandatory health insurance coverage; impact assessment report. Before any legislative measure that mandates health insurance coverage for specific health services, specific diseases, or certain providers of health care services as part of individual or group health insurance policies, can be considered, there shall be concurrent resolutions passed requesting the auditor to prepare and submit to the legislature a report that assesses both the social and financial effects of the proposed mandated coverage. The concurrent resolutions shall designate a specific legislative bill that:
  - (1) Has been introduced in the legislature; and
  - (2) Includes, at a minimum, information identifying the:
    - (A) Specific health service, disease, or provider that would be covered;
    - (B) Extent of the coverage;
    - (C) Target groups that would be covered;
    - (D) Limits on utilization, if any; and
    - (E) Standards of care.

For purposes of this part, mandated health insurance coverage shall not include mandated optionals. [L 1987, c 331, pt of §1; am L 1990, c 227, §1; am L 1996, c 270, §2]

**Source**: http://www.capitol.hawaii.gov/hrscurrent/Vol01\_Ch0001-0042F/HRS0023/HRS 0023-0051.htm



SENATE COMMITTEE ON HEALTH Senator David Ige, Chair

Conference Room 016 Friday, February 8, 2008 at 1:15 p.m.

Testimony in opposition to SB 2532.

I am Rich Meiers, President and CEO of the Healthcare Association of Hawaii, which represents the entire spectrum of health care, including acute care hospitals, two-thirds of the long term care beds in Hawaii, as well as home care and hospice providers. Thank you for this opportunity to testify in opposition to SB 2532, which mandates that all health care insurance plans cover the diagnosis and treatment of autism spectrum disorders for enrollees who are under 21 years of age.

At the outset, let me say that the intent of this bill is noteworthy since it addresses serious medical conditions. At the same time, however, Hawaii's Prepaid Health Care Act (PHCA) was never meant to provide total coverage for all illnesses, injuries, and diseases because of the high costs that would be incurred. These high costs would then be reflected in health care insurance rates paid by employers and employees. Rather, the PHCA was meant to provide basic coverage to a broad population.

It is true that this bill would affect only a small portion of those who are covered by health care insurance. As such, it would add only a small cost. However, there are many different types of mandates that have been proposed in the past, that are currently being proposed, and no doubt will be proposed in the future. In the eyes of their advocates, all of these mandates are equally worthy. However, the adoption of all of these mandates would increase health care insurance costs significantly.

For the foregoing reasons, the Healthcare Association of Hawaii opposes SB 2532.



Kalma K. Wong 46-220 Alaloa Place Kaneohe, Hawaii 96744 (808) 393-5218

February 7, 2008

Senator David Y. Ige Chair, Senate Committee on Health Hawaii State Capitol, Room 215 415 South Beretania Street Honolulu, HI 96813

Senator Carol Fukunaga Vice-Chair, Senate Committee on Health Hawaii State Capitol, Room 216 415 South Beretania Street Honolulu, HI 96813

Re: Testimony in STRONG SUPPORT for SB2532, Relating to Health Insurance Coverage for Autism Spectrum Disorders Senate Committee on Health, February 8, 2008, Room 016, 1:15 p.m.

Dear Chair Ige and Vice-Chair Fukunaga:

I am writing to express my strong support of Senate Bill 2532, otherwise known as Dylan's Law. This important 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, anxiety, muscle or joint problems, car 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.

Unfortunately, children with autism are often denied coverage for necessary therapies by private health insurance companies. The therapies frequently denied include speech therapy, occupational therapy, and intensive behavioral therapy, such as Applied Behavior Analysis (ABA). Speech therapy is



5455 Wilshire Blvd. Suite 2250 Los Angeles, CA 90036-4234

**888.8AUTISM 323.549.0500 323.549.0547** fax
www.cureautismnow.ore

often denied because coverage generally only includes rehabilitative, as opposed to habilitative care. In other words, if a child never had the ability to talk, they don't need to teach him how to speak. But children with autism are delayed in development and require therapy to DEVELOP skills, such as the ability to speak and communicate.

Applied Behavior Analysis (ABA) has a decades-long record of efficacy. ABA is a data-based intervention for autism that has over forty years of research behind it. ABA therapy has shown to increase educational placements and increased IQ levels of those with autism. ABA is recognized by The U.S. Surgeon General's 2001 Report on Mental Health as the treatment that is widely accepted as the effective treatment 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 parent 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

The current policy of denying necessary treatments for autism is inexcusable. Autism is a treatable condition, and with proper medical intervention and intensive therapies children with autism can improve to such an extent that they can enter mainstream classrooms unassisted. Given the proper treatments and therapies, a child with autism can become a functioning and independent person.

The failure of insurance companies to provide coverage for effective treatments for autism is not only an injustice to families affected by autism, it is also a gross disservice to Hawaii and to the citizens of this state. It has been estimated that the cost of caring for someone with autism is \$3 million over his or her lifetime, and the cost to the country per year is \$13 billion. However, with effective treatments, it has been estimated that the cost savings per child is \$2.4 to \$2.8 million per year to age 55. Mandated insurance coverage for autism will result in a huge cost savings for everyone in the long run.

Yet, the cost of autism is more than just financial. Yes, too many families with children affected by autism are deeply in debt as a result of the lack of insurance coverage for these necessary therapies. Yes, there is a huge financial cost to the state. But autism also results in heavy emotional distress for those directly affected. For many of these families, the stress is more than they can bear and many (in fact, 80 %) of the marriages end in divorce. There is also the heavy burden placed upon the siblings of those affected by autism. These siblings not only are forced to grow up too soon because they must help out with their autistic brother or sister, they also lose the time they should have had with their parents because their parents are physically and emotionally exhausted.

And still, let us not lose sight of the fact that the focus of this issue is, and should always be, the CHILDREN with autism. In spite of the cost of autism to the insurance companies, the government, the families, and even to society as a whole, the fact remains that the highest cost of autism is felt by the innocent children who must work a thousand times harder than anyone else to do the simplest things. The children with autism deserve so much more than they have been receiving from a society that chooses to ignore them, that chooses to toss them aside simply because they are too much trouble. They deserve

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

Please pass SB2532 and help to improve the lives of children with autism.

Thank you very much for your time. If you have any questions, please feel free to contact me at 393-5218 or <u>flute866@gmail.com</u>.

Sincerely,

Kalma K. Wong

Hawaii Chapter President

Cure Autism Now and Autism Speaks Chapter Advocacy Chair, Autism Speaks



#### Kanoe Kamanao

From: christina@lokelaniohana.org

Sent: Thursday, February 07, 2008 11:54 AM

To: Sen. Paul Whalen; Sen. Ron Menor; Sen. Roz Baker; Sen. Carol Fukunaga; Sen. David Ige;

GNFPS@aol.com

Subject: Re: SB 2532

---- Original Message ----- From: <u>GNFPS@aol.com</u>

To: sendige@Capitol.hawaii.gov; senfukunaga@Capitol.hawaii.gov; senbaker@Capitol.hawaii.gov;

senmenor@Capitol.hawaii.gov; senwhalen@Capitol.hawaii.gov

Sent: Thursday, February 07, 2008 11:37 AM

Subject: SB 2532

Dear Senators,

I fully support SB 2532, which creates a mandated benefit for people under age 21 for the diagnosis and treatment of autism spectrum disorders. With 1 in 150 births resulting in an autism spectrum disorder, this is a landmark bill that allows parents to obtain the help their autistic child will need to be properly diagnosed and treated. Early treatment is crucial to reduce the debilitating effects of autism on families and to our society.

A review by the Legislative Auditor based on HRS section 23-51 is needed before an enactment of mandatory health insurance coverage can be made. Please consider writing a Concurrent Resolution during this session.

Your support in passing this bill with amendments will provide health insurance coverage for the treatment and therapies that children with autism spectrum disorder need, so they can be mainstreamed into classrooms and into jobs unassisted. With these therapies, the 1,000 children in our state with autism spectrum disorder will be able to fill jobs and be contributors to our society. Without insurance helping to pay for these medical interventions, children with autism spectrum disorder will need life-long care and require social services to cover housing and educational needs as defined by the Federal Protection and Advocacy System for People with Developmental Disabilities in the Developmental Disabilities Assistance and Bill of Rights Act of 1975. This federal act includes individually planned and coordinated services and supports housing, employment, education, civil and human rights protection, and health care for persons with autism spectrum disorders.

It is in Hawaii's economic interest to support early intervention as provided by SB 2532.

Mahalo,

Christina Chang Board Member Lokelani 'Ohana

#### Kanoe Kamanao

From: GNFPS@aol.com

Sent: Thursday, February 07, 2008 11:38 AM

To: Sen. David Ige; Sen. Carol Fukunaga; Sen. Roz Baker; Sen. Ron Menor; Sen. Paul Whalen

Subject: SB 2532

#### Dear Senators,

I fully support SB 2532, which creates a mandated benefit for people under age 21 for the diagnosis and treatment of autism spectrum disorders. With 1 in 150 births resulting in an autism spectrum disorder, this is a landmark bill that allows parents to obtain the help their autistic child will need to be properly diagnosed and treated. Early treatment is crucial to reduce the debilitating effects of autism on families and to our society.

A review by the Legislative Auditor based on HRS section 23-51 is needed before an enactment of mandatory health insurance coverage can be made. Please consider writing a Concurrent Resolution during this session.

Your support in passing this bill with amendments will provide health insurance coverage for the treatment and therapies that children with autism spectrum disorder need, so they can be mainstreamed into classrooms and into jobs unassisted. With these therapies, the 1,000 children in our state with autism spectrum disorder will be able to fill jobs and be contributors to our society. Without insurance helping to pay for these medical interventions, children with autism spectrum disorder will need life-long care and require social services to cover housing and educational needs as defined by the Federal Protection and Advocacy System for People with Developmental Disabilities in the Developmental Disabilities Assistance and Bill of Rights Act of 1975. This federal act includes individually planned and coordinated services and supports housing, employment, education, civil and human rights protection, and health care for persons with autism spectrum disorders.

It is in Hawaii's economic interest to support early intervention as provided by SB 2532.

Mahalo,

Jerry M. Schwartz Board Member Lokelani 'Ohana Honolulu, HI

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Who's never won? Biggest Grammy Award surprises of all time on AOL Music.

#### Kanoe Kamanao

From: Maui Girl [Eve\_Clute@uiuonline.org]

Sent: Thursday, February 07, 2008 11:29 AM

To: Sen. David Ige; Sen. Carol Fukunaga; Sen. Roz Baker; Sen. Ron Menor; Sen. Paul Whalen

Subject: SB 2532 Support:

Senator Ige - <a href="mailto:sendige@Capitol.hawaii.gov">senator Fukunaga - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator Baker - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator Menor - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator Whalen - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator Menor - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator Menor - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator Menor - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator Menor - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator Whalen - <a href="mailto:senfukunaga@Capitol.hawaii.gov">senator <a href="mailto:senfukunaga@Capitol.hawaii.gov">se

Here is my email testimony:

Subject: HTH: 02-08-08 at 1:15 pm in conference room 016.

Support: SB 2532

I fully support SB 2532, which creates a mandated benefit for people under age 21 for the diagnosis and treatment of autism spectrum disorders. With 1 in 150 births resulting in an autism spectrum disorder, this is a landmark bill that allows parents to obtain the help their autistic child will need to be properly diagnosed and treated. Early treatment is crucial to reduce the debilitating effects of autism on families and to our society.

A review by the Legislative Auditor based on HRS section 23-51 is needed before an enactment of mandatory health insurance coverage can be made. Please consider writing a Concurrent Resolution during this session.

Your support in passing this bill with amendments will provide health insurance coverage for the treatment and therapies that children with autism spectrum disorder need, so they can be mainstreamed into classrooms and into jobs unassisted. With these therapies, the 1,000 children in our state with autism spectrum disorder will be able to fill jobs and be contributors to our society. Without insurance helping to pay for these medical interventions, children with autism spectrum disorder will need life-long care and require social services to cover housing and educational needs as defined by the Federal Protection and Advocacy System for People with Developmental Disabilities in the Developmental Disabilities Assistance and Bill of Rights Act of 1975. This federal act includes individually planned and coordinated services and supports housing, employment, education, civil and human rights protection, and health care for persons with autism spectrum disorders.

It is in Hawaii's economic interest to support early intervention as provided by SB 2532.

Mahalo,

Eve Clute [Doctor of Public Health] P O Box 11634 Lahaina, Maui

Sharon Wong 1054 Kaupaku Place Honolulu, HI 96825 February 5, 2008

The Honorable David Ige, Chair Committee on Health 16th Senatorial District Hawaii State Capitol, Room 215 415 South Beretania Street Honolulu, HI 96813 phone 808-586-6230; fax 808-586-6231 E-mail <a href="mailto:sendige@Capitol.hawaii.gov">sendige@Capitol.hawaii.gov</a>

The Honorable Carol Fukunaga, Vice Chair Committee on Health
11th Senatorial District
Hawaii State Capitol, Room 216
415 South Beretania Street
Honolulu, HI 96813
phone 808-586-6890; fax 808-586-6899
e-mail: senfukunaga@ Capitol.hawaii. gov

RE: IN STRONG SUPPORT OF SB2532, DYLAN'S LAW, RELATING TO HEALTH INSURANCE COVERAGE FOR AUTISM, SENATE COMMITTEE ON HEALTH HEARING ON FRIDAY, FEBRUARY 8, 2008, 1:15 P.M., CONFERENCE ROOM 016

Dear Chair Ige, Vice-Chair Fukunaga, and Members of the Committee on Health:

I am in strong support of Senate Bill 2532, otherwise known as Dylan's Law, which mandates health insurance coverage for autism spectrum disorders.

My child has autism, and will have it for the rest of his life. Unbeknownst to me, my husband, and other relatives, as an infant and toddler, he displayed many of the symptoms of autism. He did not develop speech, he flapped his hands when excited, he would spin jar covers (like tops) for unusually long periods of time, he would walk on his toes, he would be terrified when hearing the vacuum cleaner, he preferred to eat 'white' food, he would get upset when the car stopped at a stop light, he could not sit still to be read to. He was diagnosed with autism at the age of three.

Many children with autism are at risk for a range of other medical conditions. As an example, my son has also been diagnosed with attention deficit disorder, functional vision problems, central auditory processing disorder, sensory issues, speech/language problems, food allergies, skin rashes, and metals toxicity.

Page 2

Senate Committee on Health

RE: SB2532, Relating to Health Insurance Coverage for Autism

February 5, 2008

My son is now eleven and he has developed into a good-natured, well-behaved, well-mannered, talking boy with a pleasant personality. Any casual observer would not think that he has a disability. He plays with his classmates, talks to everyone, tells jokes, understands that other people have feelings and can say things to comfort them when needed.

He did not miraculously improve on his own. Because of my husband and my efforts in getting him the treatments he needed, with the help of qualified health professionals, and through his own efforts, we all worked together to get him to where he is today. Many of the treatments were not covered by insurance, so we paid for them. Some of these treatments were: applied behavior analysis, speech therapy, vision therapy, neurofeedback therapy, sensory diets, modification of his diet to address his food allergies, and nutritional supplementation.

While we were fortunate to be able to pay for these treatments, our savings has been drained. There are other treatments that he needs, but we need to consider our financial status more carefully now. I know of other parents who simply cannot afford the treatments, or who have gone into debt to pay for these treatments. Clearly, this should not happen – treatments should be provided based on necessity, which will improve our children's ability to learn and become productive members of society. Otherwise, family members, the government, the taxpayers, and society will bear the burden of supporting these children when they grow to be adults, for the rest of their lives.

With the help of many qualified health professionals, my child has a great chance to become a contributing member of society; to take care of himself, and not be taken care of. Don't we want all of our children, including children with autism, to have this chance?

Thank you for the opportunity to address the needs of our children and youth adults with autism spectrum disorders.

Sincerely,

Sharon Wong (via email)

Teresa Chao Ocampo 215 N. King Street, Apt. 207 Honolulu, HI 96817

February 8, 2008

Senator David Ige, Chair Senator Carol Fukunaga, Vice Chair The Senate Committee on Health State Capitol 415 South Beretania Street Honolulu, HI 96813

Meeting on Friday, February 8, 2008, Conference Room 016 1:15 pm

RE: SB 2532 RELATING TO AUTISM SPECTRUM DISORDERS

Dear Senators Ige and Fukunaga and Senate Committee on Health:

I support SB 2532 to have various services related to Autism covered by insurance providers in Hawaii. Currently, there are 17 states that require some insurance coverage for Autism related services.

According to the Autism Society of America, Autism is a complex neurological disorder that typically appears in the first three years of life. It affects the functioning of the brain and therefore impacts the normal development of the brain in the areas of social interaction and communication skills. Autism and its many variations are recognized in the American Psychiatric Association's Diagnostic & Statistical Manual of Mental Disorders (DSM-IV-TR). Therefore, Autism is treatable.

In February 2007, the Centers for Disease Control and Prevention had issued a report that concluded that the prevalence of Autism had risen to 1 out of 150 children in the United States and almost 1 in every 94 boys. This means that there may be as many as 1.5 million Americans today living with Autism. If you review the statistics from the Department of Education, Hawaii's Autism rates have steadily increased in parallel with the national average. Financial challenges for parents are magnified due to limited insurance coverage for therapies in the treatment of Autism. Hawaii's insurance companies do not even RECOGNIZE Autism as a disease or disorder.

Parents must often make difficult choices between their Autistic child and the needs of the rest of the family where they incur thousands and thousands of dollars of out of pocket expenses for therapies, drugs and various labs that are currently not covered by health insurance providers here in Hawaii. As a parent of an Autistic child, every day is a struggle.

Routine tasks that many people take for granted such as eating, brushing teeth, changing clothes, going to school and basic safety and hygiene needs all take a toll on parents and family of Autistic children day to day. We have to teach our children how to understand pragmatic speech, how to read body language and how to understand inferences in social settings. We have to teach our children how to express their emotions and what they mean. We have to teach our children not to panic when they get wet by a few drops of rain. We have to teach our children how to survive in a world that no longer accepts individual differences. That's why we need this bill to pass. Our children need these services early in life to help them function in society independently as adults.

Granted there are some services provided by the Department of Education and the Department of Health. However, once a child reaches 3 years old and transitions into the DOE, he technically can no longer receive autism-related services from the DOH. As for the DOE, many of their

providers such as psychologists are minimally trained in Autism and many are currently without a Hawaii license to practice outside the DOE. Therefore, these psychologists would not be able to diagnose or provide any type of medical care to these children under this insurance bill.

#### Merits of this Bill are:

- 1) The Inclusion of Applied Behavior Analysis. It has been shown that children diagnosed between 0-3 years of age who receive intensive services using various forms of Applied Behavior Analysis have a much greater chance of integrating into the community socially and independently at an earlier age. Since the costs of these services can be overwhelming for those families who cannot afford such services, society will have to "pay" throughout the child's lifetime by providing basic services for this child throughout adulthood. An Autistic child has the greatest opportunity of successful integration into the community and school when he is identified early enough to receive intensive ABA services before his 8<sup>th</sup> birthday.
- 2) "Rehabilitative Care" includes "Habilitative Care". Currently insurance plans exclude Habilitative services such as speech. If the ability for speech is not LOST but rather ABSENT during the developmental stages of a child's life, then speech therapy is not covered. One of the first signs that lead parents to see their pediatrician is when their child fails to develop speech between 12 and 15 months. Many Autistic children have delayed speech due to conditions such as Apraxia which is a neurological breakdown between the brain and the muscles in the tongue, lips, cheeks, jaw and palate. Another speech condition that may be related is called Dysarthia which results from a damaged nervous system affecting the strength and control of muscles for speech and non-speech functions such as smiling. These conditions which would fall under Habilitative, if untreated, can have profound effects on the developmental and functional progress of Autistic children. With Speech Therapy included as a "Habilitative Service" in the diagnosis and treatment Autistic children, it will positively impact the lives of these children by assisting them to successfully integrate into society as independent individuals.
- 3) This bill will allow qualified and experienced physicians, psychologists and nurse practitioners in the PRIVATE SECTOR to diagnose and treat these children. It would benefit the children the most if parents have the option of seeing physicians, psychologists or certified nurse practitioners of their choice simply because of convenience or of an existing working relationship with these professionals. This matter of choice should not burden the DOE or the insurer any more than it does presently.
- 4) The definitions as listed in this bill clearly describe the types of services to be provided and by whom.

Insurance companies may argue that there will be a shift in the cost of autism related services to those private members who currently pay premiums. Despite the fact that there are organizations such as the DOE and DOH that currently provide autism related services, these groups do not provide the MEDICAL services also needed in the treatment of Autism. As we all know, these agencies have their OWN CURRENT challenges in providing these services to Autistic children such as a lack of providers experienced with Autistic children, providers with limited knowledge, limited availability of providers and too narrow a scope of services provided. Lastly, Autism is a NEUROLOGICAL DISORDER INVOLVING THE BRAIN. Therefore, it is a MEDICAL condition that should be RECOGNIZED by all insurers in Hawaii and treated as such. Please help our children, please pass SB 2532.

Thank you for your serious consideration in this matter.

Sincerely,

Teresa Chao Ocampo Parent of an Autistic child <u>Javanut418@aol.com</u> 808-585-8641 Via Fax 586-6659

February 8, 2008

LATE

David Y. Ige 16th Senatorial District Hawaii State Capitol, Room 215 415 South Beretania Street Honolulu, HI 96813

Carol Fukunaga 11th Schatorial District Hawaii State Capitol, Room 216 415 South Beretania Street Honolulu, HI 96813

Re: 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 016

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

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

Today, 1 in 150 individuals is diagnosed with autism, 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

Without intensive intervention; these children do not improve. They become more difficult to manage as they get older, and in the end will need a lifetime of managed care.

However, with proper medical intervention and intensive therapies such as Speech, Occupational therapy, and ABA children with autism can improve to such an extent that they can enter mainstream classrooms unassisted. Some even recover to the point of being indistinguishable. There is real hope that Autism is treatable.

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. ABA is the single intervention most often sought by parents of children with autism, because of its peer reviewed research. On the otherhand, insurers frequently deny coverage leaving families no choice but to pay for the services themselves.

I currently do not have retirement, or savings. I do not have resources for major medical. If something were to happen to me right now? I simply do not know how I am going to pay for it. It's a constant juggling act to find a way to sustain my daughter's ABA, and biomedical programs, and keep the creditors at bay. The financial strain has affected my performance at work. It is difficult to concentrate, because of the continued anxiety and nonstop stress. This is one of the reasons 80% of families with Autism end in divorce.

We are all in this together as taxpayers. We can invest in our children now, and help them become independent, productive adults. Or, we can do nothing now, and invest later in a lifetime of managed care. Either way, we are all going to pay. Dylan's Law is about all children with autism who deserve to have a better quality of life. Please pass Dylan's Law Senate Bill 2532 and make insurance coverage for autism a reality. Children with autism in Hawaii deserve to have the opportunity to thrive, and become independent, productive, members of our society.

Thank you for your consideration.

Sincerely, Deborah Tasato-Kodama W

#### testimony

From: Sent:

Suzi Kiss [drkiss@hawaii.rr.com] Thursday, February 07, 2008 9:46 PM testimony

To: Subject:

SB 2532

LATE

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

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.

Thank you for your consideration.

Sincerely, Suzi Kiss, Psy.D.

# LATE

To: Senate Committee on Health Re: SB2532 "Dylan's Law"

Hearing: Friday, February 08,2008, at 1:15 pm in room 016

Members on the Senate Committee on Health:

I would like to offer my SUPPORT for SB2532 also known as "Dylan's Law" which offers in-depth real needs services for children with Autism Spectrum Disorders. Autism is a complex neurological disorder that is affecting more and more children. Chilren who autism have difficulty with social interactions and communication. It is estimated 1 in 150 children are on the Autism spectrum according to the Centers for Disease Control. 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 With proper medical intervention and intensive therapies children with autism can improve to such an extent that they can enter mainstream classrooms unassisted. It behooves us to provide our keiki with the kind of proven therapies that will allow them to be fully functioning productive members of society.

This bill requires insurers to provide the comprehensive habilitative services needed by a child with autism. The gold medal standard, the proven therapy for children with autism is ABA (Applied Behavior Analysis). There are many studies that show ABA helps autistic children. It is a data-based intervention for autism that has over forty years of research behind it. The only treatment recommended by the US Surgeon General for treatment of autism is ABA. The National Institute of Child Health and Human Development acknowledges that Applied Behavior Analysis is an effective treatment for autism. Although it is very effective ABA is expensive. Most private insurers, including mine, will not cover the service even though it is the only proven therapy for autism. Therefore many parents have to pay out of pocket to get ABA services. The cost to employ of a qualified ABA therapist can can cost as much as \$10,000/month. As you can imagine, the cost of providing this care is out of reach of most of us who are not independently wealthy. Some of us have to sell our homes. We go into debt. Our marriages fall apart. Our lives are in turmoil. We are paying through the nose for something that our insurers could cover. We would truly appreciate the financial help from insurance companies SB 2532 would require.

I've known nonverbal completely aloof children become conversational, social, and indistinguishable from their typical peers once given ABA therapy. When children are given intensive ABA therapy in the early years they learn skills that will allow them to attend mainstream schools, pursue higher education, work, marry, and in short do what a neurotypical child is able to do. We aren't asking for the moon. We're asking that insurers cover a proven treatment that will allow our children to have a typical life. That's all we want. We want them to have a normal life. This bill is not important just to the local autism community. It impacts the entire community even those who do not have a child with autism. Children who do not receive early intensive ABA therapy will become a financial burden to taxpayers. If a child is able to take care of himself he will not need

to rely on government assistance as an adult. Several states, including Pennsylvania, South Carolina, and Indiana, provide such insurance coverage. It's time Hawaii provided the same coverage to help our hard-working families who are affected by Autism.

I urge you to pass SB2532 and make insurance coverage for autism a reality. Thanks for considering my testimony and should you have questions please feel free to contact me at (808) 226-0398.

**Daniel Santos** 

# LATE

Senator David Y. Ige, Chair Senator Carol Fukunaga, Vice Chair Committee on Health

Sherri Henriques 1834 St. Louis Dr. Honolulu, HI 96816 Ph. 735-9766

Friday, February 08, 2008 SB2532, 1:15 pm, Room 016

In Strong Support of Dylan's Law SB2532, Relating to Health Insurance Coverage for Autism Spectrum Disorders

I am a mother of a child with Autism. I am testifying in favor of SB2532. This bill mandates health insurance coverage for autism spectrum disorders. Thanks to the many different therapies and interventions such as, Applied Behavior Analysis (ABA) and Speech, our 4-1/2 yr. old son is recovering from autism. However, the financial burden of these effective therapies and interventions is overwhelming and we really need the assistance of insurance companies. Children with autism in Hawaii deserve a better quality of life.

I strongly urge you to vote "YES" to SB2532.

Thank you for this opportunity to testify.





An Independent Licensee of the Blue Cross and Blue Shield Association

February 8, 2008

The Honorable David Ige, Chair The Honorable Carol Fukunaga, Vice Chair

Senate Committee on Health

Re: SB 2532 - Relating to Health Insurance

Dear Chair Ige, Vice Chair Fukunaga and Members of the Committee:

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 2532 which would require health plans to provide coverage for the diagnosis and treatment of autism spectrum disorders for covered individuals less than twenty-one years of age.

The first problem with SB 2532 is the language in the measure itself. We believe that it is flawed in its definition of medical necessity and treatment. The term "medical necessity" is already statutorily defined in HRS 432E-1.4 in the Patient's Bill of Rights and Responsibilities Act. This definition was designed not only to protect a health plan's members but to allow the plan the ability to ensure that services and treatments provided meet a scientific standard for effectiveness, are necessary and appropriate. The definition of "medical necessity" and "treatment" in this measure differs significantly from what already exists including the removal of the scientific standard.

In addition, we believe that prior to passing any new legislation which would require health plans to provide benefits not currently covered in their plan offerings, the Legislature should request an Auditor's study as required under Hawaii Revised Statutes 23-51 and 23-52. This study will provide decision-makers with objective information prior to including these new benefits. With health care costs continuing to escalate it is important to consider the impact that requiring such benefits will have on the cost of health care, especially for local employers who typically bear the brunt of such cost increases.

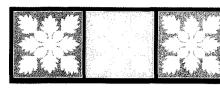
Thank you for the opportunity to provide testimony on SB 2532.

Sincerely,

Jennifer Diesman

Jenj Dri

Director, Government Relations



### Hawaii Association of Health Plans

February 8, 2008

# LATE

The Honorable David Ige, Chair The Honorable Carol Fukunaga, Vice Chair

Senate Committee on Health

Re: SB 2532 - Relating to Health Insurance

Dear Chair Ige, Vice Chair Fukunaga and Members of the Committee:

My name is Rick Jackson and I am President of the Hawaii Association of Health Plans ("HAHP"). HAHP is a non-profit organization consisting of seven (7) member organizations:

AlohaCare Hawaii Medical Assuran MDX Hawai'i University Health Alliance

Hawaii Medical Assurance Association HMSA

UnitedHealthcare

Hawaii-Western Management Group, Inc.

Our mission is to promote initiatives aimed at improving the overall health of Hawaii. We are also active participants in the legislative process. Before providing any testimony at a Legislative hearing, all HAHP member organizations must be in unanimous agreement of the statement or position.

Thank you for the opportunity to testify <u>in opposition to SB 2532</u>, which would require health. plans to cover screening for diagnosis and treatment of autism spectrum disorders for individuals under the age of twenty one. HAHP recognizes that legislative health mandates are often driven by the desire for improved health care services to the community; as health plans, our member organizations are committed to the same ideal.

This bill, however, would seem to have the effect to shift 100% of treatment responsibility and cost for autism spectral disorder to licensed health plans, including all of HAHP's member organizations. Currently, a broad range of organizations and support groups assist in dealing with this developmental disorder: Department of Education (DOE), Department of Health – Developmental Disabilities Division, the Department of Human Services through Medicaid and other community-based organizations. As we understand the bill, treatment "prescribed, provided, or ordered for an individual diagnosed with an autism spectrum

disorder by a licensed physician, licensed psychologist, or certified registered nurse practitioner if the care is determined to be medically necessary" will be mandated to be covered by health plans. As an example, this could mean that a DOE psychologist not credentialed or contracted to any HAHP member organization can order any health plan to treat autism spectral disorder until age 21 under the bill's broad definition of medical necessity that is, incidentally, not consistent with the one stated in the Patient Bill of Rights.

Health plans already are, by Division of Insurance rules, responsible for reimbursing diagnostic testing for autistic disorders. Cost-shifting the entire treatment responsibility to health plans away from the current Government-sponsored programs to private plans may appeal to someone, but not to HAHP members or the employers who pay the premiums for their employees.

We urge you to hold this bill.

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Thank you for the opportunity to testify.

Sincerely,

Rick Jackson President 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, 1:15p.m., Room 016

Dear Senator Ige, Senator 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.

My family, personally, is affected by autism. My son, age 10, is diagnosed with Pervasive Developmental Disorder, a form of autism. When we first received the heartbreaking diagnosis when he was just two and a half years old, he was considered "moderately severely affected," just borderline of severe. Prior to age two, he was a typically developing baby, very loving and interested in the world around him. After receiving his MMR vaccines at age two, he immediately became very sick and began to withdraw into himself. (Prior to this, he was not sick a day in his life.) He developed a fever, bronchitis and became severely asthmatic. Over the next few months, he had to be given two rounds of antibiotics. He started waking up in the middle of the night, screaming and crying as if he were in pain.

He lost the few words that he had before, lost interest in people or what was going on around him, and spent most of his time "stimming" or in self-stimulatory behavior. For example, he didn't play with his toys. Instead of playing, he would line them up, or organize them by color or size. He would push his trains back and forth to see the wheels turn. He had no imaginary play as other children his age did. He did not communicate with me, my husband, or his older sister anymore. I would take him to play groups and library story times, and while other children sat in their mother's laps and listened eagerly to the stories being read or participated in activities, my son would be running around or finding something he could "stim" with. When I took him to the zoo, he had no interest in the animals. We once were right up close with a beautiful elephant, and my son just squatted down to look at the dirt. I spent most of my time chasing after him because he would run everywhere and not even look back at us.

He became sensitive to touch and no longer wanted to be cuddled. He also had to be held down in order to get a haircut or get his teeth cleaned at the dentist. He would spend most of

his time at the beach, picking sand off of his legs and hands. It was as if he were in a world of his own, and I could not reach him. I feared that I would never get the privilege of getting to know my own little boy.

Thankfully, today I can say that I have my son back! He talks my ears off, has such a wonderful, bubbly personality, and is very thoughtful of others. People tell me all the time how helpful he is. He is once again very loving and gives me big teddy bear hugs! He and his sister are best friends and play (and argue) together all the time. He is doing well in school (with the help of an educational aide), and I am even told that I should enroll him in speech and drama since he has good confidence, poise, and voice projection (and he's also very dramatic!). Now he has no problems getting hair cuts or going to the dentist. He also loves the beach and makes sand castles and hunts for buried "treasure." If you met him now, you would never suspect that he was so severely affected by autism. He seems as though he is just another happy child in the fifth grade who loves to play video games and soccer.

I thank God for his wonderful progress and for an intensive ABA (applied behavior analysis) program, speech therapy, occupational therapy, a modified diet (gluten, casein, and yeast free), chelation therapy (to remove heavy metals-- mercury was one that he tested very high in), acupuncture treatments, brain gym, homeopathy, and nutritional therapy.

We were fortunate enough to have received the ABA, speech, and occupational services through the "Zero to Three" program until he was age three, and then through the Department of Health/Department of Education thereafter. We had to fight very hard to keep his much needed services once he transitioned into the D.O.E.

We could not afford to pay for all of these therapies on our own. It is a huge financial burden to have to pay for the biomedical therapies, nutritional supplements, and special diets alone, but on top of that, to pay for the Therapists, Skills Trainers, and Speech services too would be nearly impossible for us.

If my son did not receive the therapies that he did, I really do not know what his future would hold. He would probably still be that boy who could not communicate and interact with othersthat boy in a bubble, and always dependent upon others-- physically, mentally, and financially. But instead of that bleak future, I can say thankfully, because of the much needed therapies-behavior and biomedical, I am confident that he will one day be able to be an independent, productive citizen of our country and give back to the community.

I urge you to please pass Dylan's Law Senate Bill 2532. Ensuring health insurance coverage for the diagnosis and treatment of autism can help our children to reach their fullest potential and make life changing improvements. I truly believe that it will change the lives of countless children and their families, and ultimately, the world in which they live.

Thank you very much for your consideration and for taking the time to read my letter.

Sincerely yours,

Carolyn K. Nomura