

Late

Teresa Chao Ocampo  
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February 1, 2008

Senator David Ige, Chair  
Senator Carol Fukunaga, Vice Chair  
The Senate Committee on Health  
State Capitol  
415 South Beretania Street  
Conference Room 016  
Honolulu, HI 96813

Senator Russell Kokubun, Chair  
Senator David Ige, Vice Chair  
The Senate Committee on Commerce, Consumer Protection and Affordable Housing  
State Capitol  
415 South Beretania Street  
Conference Room 016  
Honolulu, HI 96813

Meeting on Friday, February 1, 2008, 1:15pm

RE: SB 2738 RELATING TO AUTISM SPECTRUM DISORDERS

Dear Senator David Ige, Chair, Senator Carol Fukunaga, Vice Chair, Senate Committee on Health and Senator Kokubun, Chair and Senator David Ige., Senate Committee on Commerce, Consumer Protection and Affordable Housing:

I am writing to express my disappointment of SB 2738. Although this Autism bill has good intentions, as currently written, it will not benefit our children. This bill lacks specifics and details in the types of services included or excluded. It lacks definitions of those services which would qualify or disqualify a child from receiving the services. Finally, under this INSURANCE bill, the involvement of the Department of Health WILL only lead to greater restrictions in the provision of these services rather than improving the accessibility of these services.

Autism is a neurological disorder that occurs in 1 out of 150 children in the United States and 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. Parents must often make difficult choices between their autistic child and the rest of the family where they incur thousands and thousands of dollars of out of pocket expenses for therapies, drugs and blood labs that are currently not covered by health insurance providers here in Hawaii. This situation is no different than having insurers pay for cancer treatments, new drugs, and advanced medical testing. It does come down to costs however, providing services early on in an autistic child's life will decrease society's burden of providing a lifetime of support to these individuals.

SB 2738 has too many vague and undefined areas that must be clarified in order for this bill to truly benefit our children. I have the following concerns for your consideration:

- 1) **Services including Applied Behavior Analysis must be included in this bill.** It has been shown that children diagnosed between 0-3 years of age who receive intensive services using 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 as an adult. 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 Services" should also include "Habilitative Services"**. These are services such as speech that are not LOST but rather ABSENT during the developmental stages of a child's life. 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 Dysarthria 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, if untreated, can have profound effects on the developmental and functional progress of autistic children. Without Speech Therapy as a "Habilitative Service" in the diagnosis and treatment autistic children, this bill will be effectively excluding a subset of autistic children who need these services the most.
- 3) **The Department of Health should not be involved in this INSURANCE bill.** The purpose of this bill to have "insurance coverage for various services required in the DIAGNOSIS AND TREATMENT of autism spectrum disorders."

When my son was in the Early intervention program at two years two months old, we had to wait one month for a comprehensive evaluation, an additional two months for a speech therapist to provide services and over 4 months to find someone who had practical experience with autistic children. So much valuable time was ineffectively used that I had to eventually rely on the Department of Education for these services. Given the steady increase of autism cases, the DOH's challenges will only become greater. The involvement of the Department of Health will overload an agency that is already overloaded resulting in restrictions and unnecessary delays in the provision of autism services to our children who desperately need them. Surely, this is not the intent of this Insurance bill.

- 4) **The Department of Health should not be the agency to determine the "medical necessity" of these treatments.** There are many qualified and experienced physicians, psychologists and nurse practitioners in the PRIVATE SECTOR who are more than capable in determining the "medical necessity" of these treatments. This determination should not be left solely to the discretion of the DOH because this is not a government issue. This bill relates to the treatment of 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 would also decrease the potential "wait" time that children could face at the DOH before they can even be diagnosed by DOH professionals. Remember, time is crucial to these children because their therapeutic windows are so short.

- 5) **There is a lack of definition of terms in SB2738 including psychiatric care, psychological care, rehabilitative care, therapeutic care and pharmacy care.** Without clarification of these terms, how would the insurers know which services are included under this bill and which ones are not? By including definitions of these terms, it can also limit potential misuse of insurance programs. Definitions are clearly needed so that provider and patient are fully aware of services that are provided and available.

In general, SB2738 falls short of its goals. Its intentions are honorable; however, the bill as it is written will not benefit many children and in fact can possibly be detrimental to many children who will waste valuable time waiting for the "medically necessary" determination from an already overburdened DOH system.

Please consider these suggestions for positive change. If they CAN be included in this bill, it would literally mean a world of difference for these children and for the future of Hawaii. **If these changes cannot be made, I recommend that you support SB 2532** which is another Autism Insurance bill researched by a mother with two autistic children. It is comprehensive, well thought out and offers exactly what parents need in order get the types of therapies and services that our children require when treating any MEDICAL condition.

Thank you for your serious consideration in this matter.

Sincerely,



Teresa Chao Ocampo  
Parent of an Autistic son

# LATE TESTIMONY

COMMITTEE ON HEALTH  
Senator David Y. Ige, Chair  
Senator Carol Fukunaga, Vice Chair

Hearing for SB 2738

DATE: Friday, February 1, 2008

TIME: 1:15 PM

PLACE: Conference Room 016, State Capitol, 415 South Beretania Street

Chairman Ige and Members of the Committee:

I am writing to express my appreciation for the intent of SB 2738; however, it does not meet the needs of the children with autism. Instead, Dylan's Law SB 2532 is the bill of choice for the autism community. Please schedule a hearing for SB 2532.

I do not support SB 2738 for the following reasons:

- 1) SB2738 does not define any of the treatments it mandates. In particular, "rehabilitation care" and "therapeutic care" are vague terms that can be interpreted in any number of ways. ALL the terms in the statutes should be defined. SB2532 Dylan's Law does define all the identified treatments, including "habilitation".
- 2) Unlike SB2532 Dylan's Law, SB2738 does not specifically mandate Applied Behavior Analysis treatment. ABA has a decades-long record of efficacy. Although ABA is the single intervention most often sought by parents of children with autism, insurers frequently deny it as a benefit.
- 3) SB2738 authorizes the Department of Health to determine medically necessary treatments for autism; however, autism spectrum disorders are not an area of expertise for the DOH, therefore making it inappropriate for it to determine treatments.

SB2738 is no guarantee that persons with autism will get the coverage they desperately need. Without the specific language of Dylan's Law SB2532, the promise of help for families may never be realized.

Thank you for this opportunity to express my disagreement with SB2738. I urge the Committee to act against this bill and instead schedule a hearing for Dylan's Law SB2532.

Sincerely,  
Cheryl Ebisui

# LATE TESTIMONY

To: Legislature's Public Access room  
Committee: The Senate Health Committee Chair  
Date: Feb. 1st, 2008  
Time of hearing: 1:15 pm  
Room: 116

I, Mayu Hosoya Akazawa, as a mother of son Kennedy Akazawa ( DOB 3-6-02 ) who is PDD-NOS ( one of Autistic Diagnose ) with other Autistic Related diagnoses would like to request to pass Dylan's Law ( SB 2532 ).

While I appreciate the intent of the bill SB 2738, however, it does NOT meet the needs of the children with autism and that Dylan's Law SB2532 is the bill of choice for the autism community. So please schedule hearings for Dylan's Law.

SB2738 does NOT guarantee the person with autism will be covered by insurance which is not only helping children's future by their families.

My son Kennedy does need extra speech therapy as part of his "habilitation" and kids with autism can gain their ability to speak by those necessary therapies. If you have a child with autism you would do the best you can to seek out possible ways to have them recovered from autism. Dylan's law would be great support for all of us.

There was case appealing ID 07008-0059 with HMSA which we were denied of coverage of speech therapies and we are devastated. My son Kennedy does need to have EXTRA Speech Therapy to improve his condition besides the services from Department of Health and/or Department of Education. Just like a person who got cold needs to have a pill which is covered by Insurance, so does Kennedy needs his therapies covered by insurance.

We do need those therapies covered for our kids future as part of early intervention which is very very important. By consistent therapies our kids future would brighten up. Please help us by passing Dylan's law ( SB2532 ) Promise of help for families with autism never be realized unless Dylan's Law will be passed.

Thank you very much for your time to read this.  
If you have any questions, please contact me at (808) 739-1755.

Sincerely Yours,

Mayu Hosoya Akazawa

Late

**TESTIMONY TO THE TWENTY-FOURTH STATE LEGISLATURE, 2008 SESSION**

**To:** Senate Committee on Health

**From:** Dr. Maryellen Markley  
Hawaii Services for the Disabled  
**Phone: (808) 561-8096**

**Re:** Senate Bill 2738  
Relating to Autism Spectrum Disorders

**Hearing:** Friday, February 1, 2008 1:15 PM  
Conference Room 016, State Capitol

Members of the Committee on Health:

Thank you for the opportunity to provide testimony supporting Senate Bill 2738, Relating to Autism Spectrum Disorders.

I am a medical researcher studying effective treatments for autism, and have recently published a nearly year-long study treating children in Hawaii with the disease. I am here on behalf of Hawaii Services for the Disabled which finds private funding to cover medical services for persons with disabilities in Hawaii, including the nearly 2,000 children in the state known to be diagnosed with autism or autistic spectrum disorder.

We support this bill. The bill is necessary because all too often, health insurance coverage which would allow children to recover from the disease is denied under current policies due to a "loophole" exclusion in the policy coverage which states that health insurance only covers "rehabilitative" care rather than therapeutic care.

An important example of this is when an autistic child is unable to speak. Although speech therapy might be covered for an adult who has a stroke and previously was able to speak, it can be **denied under most health insurance policies** for children with autism because speech therapy would not be considered "rehabilitative" in a child who never spoke.

It is also often true that care for children with autism is only covered under the "mental health" portion of a health insurance policy's coverage. Autism is a biological disorder which is believed to be caused by exposure to an environmental trigger which is toxic to some children who were not born with the ability to properly metabolize that toxin. The exposure causes the child's body to have a biological inflammatory response which causes a constellation of symptoms commonly found in children with autism.

When health insurers lump the diagnosis of autism in with other psychological disorders such as schizophrenia or mental retardation, it often limits the amount of coverage the health insurer has to provide. For example, my HMSA policy only covers 50% of the costs of "mental health" care, and has an annual maximum of \$2,500.

So much more is known about autism than was available just a few years ago. One of the most important scientific facts is that children with autism CAN BE RECOVERED given proper treatment. Without proper treatment, however, these children can face a lifetime of unnecessary challenges. If passed, Senate Bill 2738 seeks to make sure these children can reach their fullest potential through early intervention - at a time in their lives when studies have shown they are most successfully treatable.

Passage will move Hawaii's health insurers into the 21<sup>st</sup> century on autism care and make it possible for parents of these children to get the medical care the children need without the costs of that care bankrupting them.

Parents and physicians have been petitioning health insurers for years to help them understand the reasons this care should be routinely covered under insurance policies. Unfortunately, they have received little or no positive response or recognition in return. For this reason, the families of children with autism in Hawaii are depending upon you to mandate such coverage before it is too late for so many, many of our children.

We realize that under state law, a Report from the Legislative Auditor may be required before the legislature can mandate such coverage. In that event, we hope the Committee well entertain an appropriate Concurrent Resolution to that effect at a later time during this session.

Thank you for the opportunity to provide testimony in support of this bill.

[If you need additional information, you can reach Dr. Markley at (808) 561-8096]

Late

TESTIMONY IN OPPOSITION TO S.B. 2738 RELATING TO AUTISM SPECTRUM  
DISORDERS; INSURANCE COVERAGE

Submitted to the Committee on Health  
Senator David Ige, Chair

By  
Richard Cox, Kapolei

Chair Ige:

My wife and I are the parents of a child with autism. We support the stated intent of this bill but we feel it falls short in several critical ways and therefore we must oppose its passage. Rather, we support SB 2532, known as Dylan's Law, and urge your committee to bring it up for discussion as early as possible.

Specific problems with this bill, SB2738, include:

- while there are provisions made to cover "rehabilitative" services, there is no provision for "habilitative" services. Many of our children have never possessed the skills that so many of the rest of us take for granted, such as talking. Thus, they can't be "rehabilitated", they must be 'habilitated', given the skill in the first place. Yet, SB2738 as written would not require coverage for such a fundamental life skill.
- There is no provision to cover some of the most effective, well proven techniques for producing socially significant improvement in our children's behavior, such as applied behavior analysis (ABA). ABA has a decades-long record of efficacy. Although ABA is the single intervention most often sought by parents of children with autism, insurers frequently deny it as a benefit.
- SB2738 authorizes the Department of Health (DOH) to determine medically necessary treatments for autism. Does DOH determine what is medically necessary for cancer patients, for victims of heart disease, for critical care patients? The range of medically necessary treatments for those who fall under the autism spectrum disorder is as wide as any of these other diseases/disorders and should be dictated by individual doctors. It is not appropriate to have the Department of Health dictate what the necessary treatments are.

The cost of treating a child with autism is enormous, in ways far beyond just the financial expenses. Although there are conflicting reports about the rate of divorce among parents of children with autism, a 2004 study in Britain found that children with autism are raised by a single parent 70% more often than the norm. Further, another study in 2004 found that more than 50% of mothers of children with autism suffered significant psychological distress, to the point of requiring medication or psychotherapy. Please help the parents of children with autism in Hawaii have a little less to cope with by requiring adequate insurance coverage for autism spectrum disorders.

Please vote down SB2738 in favor of SB2532, Dylan's law.



**AUTISM SOCIETY OF HAWAI'I**  
**P.O. Box 2995**  
**2752 A Pali Highway**  
**Honolulu, HI 96817**  
**808 228-0122**

February 1, 2008


The Honorable Senator David Y. Ige  
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 sendige@Capitol.hawaii.gov

The Honorable Senator Carol Fukunaga  
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

Subject: Hearing - SB2738 Autism Insurance

Dear Senators Ige and Fukunaga and members of the Senate Committee on Health:

The Autism Society of Hawai'i is an affiliate chapter of the Autism Society of America. Its members are composed of families who deal with living with the effects of autism spectrum disorders and the professionals and paraprofessionals who serve them. The Autism Society of Hawai'i will provide leadership in the field of autism spectrum disorders dedicated to supporting families who advocate on behalf of their children and are committed to reducing the consequences of autism through education, research, and advocacy.

First of all, thank you for considering this important need for the autism community. With autism growing at epidemic proportion and the health needs of these individuals require early intervention and intensive services. Currently, there is a great need to provide alternatives to accessing these important services in order to meet the unique ~~mental~~ mental health needs of children and their families dealing with autism spectrum disorders. 

We appreciate the intent of SB2738, however, it does not meet the needs of children with autism. Dylan's Law, SB2532 is the bill that the autism community is supporting. We request a

To whom it may concern, I appreciate that you are considering to pass the SB2738 Bill on having mandated Insurance Coverage for children on the Autism spectrum. However, this bill does not meet the needs of the children with Autism. Dylan's Law SB2532 is the Bill of choice for the Autism Community. SB2738 (the OTHER bill) is no guarantee that persons with autism will get the coverage they desperately need. Without the specific language of Dylan's Law SB2532, the promise of help for families may never be realized. Please let Dylan's Law be heard. Bill SB2532. See below for committee, time, and date for hearing.

THE SENATE THE TWENTY-FOURTH LEGISLATURE REGULAR SESSION OF  
2008 COMMITTEE ON HEALTH Senator David Y. Ige, Chair Senator Carol  
Fukunaga, Vice Chair COMMITTEE ON COMMERCE, CONSUMER PROTECTION,  
AND AFFORDABLE HOUSING Senator Russell S. Kokubun, Chair Senator David Y.  
Ige, Vice Chair NOTICE OF HEARING DATE: Friday, February 1, 2008 TIME:  
1:15 PM PLACE: Conference Room 016 State Capitol 415 South Beretania Street

Thank you,

Mother of a son with Autism,  
Victoria James

**LATE**

# LATE TESTIMONY

Aloha

I would like to supply testimony for SB2738 hearing that will be on 2/1/2008, Friday, at 1:15 at in Room 116 of the State Capitol.

While I am appreciate of the intent of SB2738, it **does not** meet the needs of the children with autism and that Dylan's Law SB2532 is the bill of choice for the autism community. Please schedule a hearing for Dylan's Law SB2532

Here are some main points:

1) SB2738 does **not** define any of the treatments it mandates. In particular, "rehabilitation care" and "therapeutic care" could mean just about anything (or worse, nothing). ALL the terms in the statutes should be defined. SB2532 Dylan's Law does define all the identified treatments, including "habilitation".

2) Unlike SB2532 Dylan's Law, SB2738 does not specifically mandate ABA. ABA has a decades-long record of efficacy. Although ABA is the single intervention most often sought by parents of children with autism, insurers frequently deny it as a benefit.

3) SB2738 authorizes the Dept. of Health to determine medically necessary treatments for autism. As you know, autism is NOT the DOH's forte, and it is completely inappropriate to have them dictate what the necessary treatments are.

Please schedule a hearing for Dylan's Law SB2532

Thank you for your time.

*Carolina Cristancho*  
P.O. Box 863  
Waiialua, HI 96791  
(808) 375-1580



If not now, when? *(The Talmud)*