# HB2727

# HD2

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. (HB2727 HD2)

Companion: SB2532

Introducer(s): WATERS

Current Referral: HTH, CPH



LINDA LINGLE GOVERNOR

JAMES R. AIONA, JR.

## STATE OF HAWAII OFFICE OF THE DIRECTOR DEPARTMENT OF COMMERCE AND CONSUMER AFFAIRS

335 MERCHANT STREET, ROOM 310 P.O. Box 541 HONOLULU, HAWAII 96809 Phone Number: (808) 586-2850 Fax Number: (808) 586-2856 www.hawaii.gov/dcca

#### TO THE SENATE COMMITTEE ON HEALTH

TWENTY-FOURTH LEGISLATURE Regular Session of 2008

Monday, March 17, 2008 1:00 p.m.

#### WRITTEN TESTIMONY ONLY

TESTIMONY ON HOUSE BILL NO. 2727, HD 2 – 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 people under age 21 for the diagnosis and treatment of autism spectrum disorders.

The Department does not have the medical expertise necessary to express an informed opinion on the merits of this bill. However, while mandated benefits help some patients, they also increase premiums for consumers. 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.

LAWRENCE M. REIFURTH

RONALD BOYER DEPUTY DIRECTOR LINDA LINGLE GOVERNOR OF HAWAII



In reply, please refer to:

#### **Senate Committee on Health**

#### H.B. 2727, H.D. 2, Relating to Health Insurance

## Testimony of Chiyome Leinaala Fukino, M.D. Director of Health

March 17, 2008, 1:00 p.m.

- Department's Position: The Department of Health (DOH) cannot support this measure as written.
- 2 Section 6 of this bill establishes a temporary Autism Spectrum Disorders (ASD) Benefits and Coverage
- 3 Task Force in the DOH. The Department notes that DOH is not the appropriate agency to lead a task
- 4 force on this issue and does not have the staff or funding resources to support the extensive Task Force
- 5 work.
- 6 Fiscal Implications: No funds are appropriated to support the work of the ASD Task Force.
- 7 **Purpose and Justification:** This bill requires all health insurers, mutual benefit societies, and health
- 8 maintenance organizations to provide mandatory coverage for individuals under age 21 for the diagnosis
- and treatment of ASD beginning July 1, 2020. The Department defers to the State Insurance
- 10 Commissioner regarding the cost of implementing such mandates. This bill also establishes in the DOH
- an ASD Benefits and Coverage Task Force, with the DOH responsible for administering the work of the
- Task Force, providing a facilitator, and submitting a report to the legislature.
- The Department does not directly serve the broad population of children/youth with ASD. DOH
- services for children/youth with ASD are limited to those who are age 0-3 years receiving early

- intervention services, those with mental health concerns, and those with developmental disabilities.
- 2 Therefore, the Department is not the appropriate agency to be designated as the lead for this measure.
- Thank you for the opportunity to testify.



#### 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
March 17, 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: HB 2727 HD2 - 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 (DOH).

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.

The Council does not have expertise in the area of insurance coverage and the impact that coverage for the diagnosis and treatment of autism spectrum disorders would have as a mandated benefit. It is appropriate for 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 as required under Section 23-51, Hawaii Revised Statutes.

We support the intent of Section 7 of the bill beginning on page 12 that establishes a temporary Autism Disorders Spectrum Benefits and Coverage Task Force. We defer to DOH for financial resources needed to support the work of the task force.

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

Sincerely,

Executive Administrator

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

To: Senate Committee on Health

From: Gary L. Smith, President

Hawaii Disability Rights Center

Re: House Bill 2727, HD 2

Relating to Health Insurance

Hearing: Monday, March 17, 2008 1:00 PM

Conference Room 016, State Capitol

Members of the Committee on Health:

Thank you for the opportunity to provide testimony supporting House Bill 2727, HD2 Relating to Health Insurance.

I am Gary L. Smith, President of the Hawaii Disability Rights Center, formerly known as the Protection and Advocacy Agency of Hawaii (P&A). As you may know, we are the agency mandated by federal law and designated by Executive Order to protect and advocate for the human, civil and legal rights of Hawaii's estimated 180,000 people with disabilities.

We support this bill. It is not clear to us that there is a legal basis for a medical insurance policy to not cover the treatments described in this bill for autism spectrum disorder. Yet, there are many advocates in the community for the needs of autistic children who have relayed experiences of that nature. If that is true, then the legislature should in our view mandate such coverage. This is a serious condition which can be ameliorated with proper treatment.

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 will 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.



# Testimony of Frank P. Richardson Executive Director of Government Relations

#### Before:

House Committee on Health The Honorable David Y. Ige, Chair The Honorable Carol Fukunaga, Vice Chair

> March 17, 2008 1:00 pm Conference Room 016

#### HB 2727, HD2 RELATING TO HEALTH INSURANCE (Autism)

Chair, Vice Chair, and committee members, thank you for this opportunity to provide testimony on HB2727, HD2 which requires 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.

#### Kaiser Permanente Hawaii provides the following comments on this bill.

Kaiser Permanente's position on proposed legislative mandates of health coverage is that they are usually not a good idea, for several reasons:

- 1. First, because they generally tend to raise the cost of delivering health care, thereby resulting in higher premiums and increased cost to the purchasers and payors of health plan coverage, whether they be employer groups or individuals;
- 2. Second, because they often tend to dictate how medicine should be practiced, which sometimes results in medicine that is not evidence based and usurps the role and expertise of the practicing physician and other health care professionals who provide medical treatment and services; and
- 3. Finally, because they often lock in statutory requirements that become outdated and do not keep pace with the ever evolving and advancing fields of medicine and medical technology.

Kaiser also notes that an impact assessment report is required pursuant to Sections 23-51 and 23-52 of the Hawaii Revised Statutes, and supports HCR 62 requesting such a report, to assess among other things:

711 Kapiolani Blvd Honolulu, Hawaii 96813 Telephone: 808-432-5408 Facsimile: 808-432-5906 Mobile: 808-295-5089

E-mail: frank.p.richardson@kp.org

- a) the extent to which this mandated insurance coverage would be reasonably expected to increase the insurance premium and administrative expenses of policy holders; and
- b) the impact of this mandated coverage on the total cost of health care.

Additionally, Kaiser notes that this bill proposes a mandate that could cost, by law, up to \$75,000 per patient per year when passed, with the potential to rise over time. This could create a significant financial impact that should be reviewed prior to passing this law.

This bill also proposes definitions that differ from those already existing in Hawaii law. For example, "medical necessity" is defined at Sections 432E-1 and 432E-1.4 of the Hawaii Revised Statutes, in a definition that differs in significant respects from the definition of "medically necessary" in this bill. Such inconsistencies in law are better avoided.

Finally, Section 6 of this bill proposes an autism disorder spectrum benefits and coverage task force attached to the Department of Health to report to the legislature prior to the 2009 legislative session. Due to Kaiser Permanente's unique structure and method of providing services we request that someone from Kaiser Permanente be appointed to the task force. With approximately 20 percent of Hawaii's residents receiving care from Kaiser Permanente, it is important that any proposal for changes in benefits take into account the impact on these residents.

Thank you for the opportunity to comment.

From:

sunsetyards@mac.com

Sent:

Saturday, March 15, 2008 7:59 AM

To:

testimony

Subject:

Senate Committee on Health /HB2727, Dylan's Law

Michael Magaoay, Senator David Ige Representative James Tokioka,

The other members are: Vice-Chair, Senator Carol Fukunaga Senator Rosalyn Baker Senator Ron Menor Senator Paul Whalen

My name is Joy McDougall. I am a voting resident living on the North Shore of Oahu. I am in support of Dylan's Lay HB2727. Please give it a hearing and a positive vote to help children and families dealing with autism.

Thank you.
Joy McDougall

Tina Chorman 364C Olomana Street Kailua, HI 96734

3/16/08

Re: HB2727, Monday, March 17 2008, 2:30 p.m., Room 16

Dear Chair Senator David Ing, Vice-Chair Senator Carol Fukunaga, and members of the Senate Health Committee:

I am writing to express my strong support of House Bill 2727, 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.

From our own experience, we have seen dramatic improvements in our 5 year old autistic son, who has attended an intensive ABA program (40+ hours/week) and receives aggressive biomedical interventions for the past two years. Our child's program costs over \$100,000 a year and if we had to pay out-of-pocket, he would not be able to receive the program that fits his individual needs. Unfortunately, we were forced to file for hearing against the Department of Education to receive the appropriate education that our son desperately needed. The stress and emotional anguish of "fighting" for your child's education is one that many parents cannot handle, and often, accept a substandard placement or program for their child instead.

We cannot put a price tag on our child's future but, I do know that, if more therapies and treatments were covered by insurance companies, more autistic children in Hawaii, would be improving at much faster rates.

I urge you to pass Dylan's Law House Bill 2727 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, Tina Chorman

From: Christine Mau [chissy44@yahoo.com]

**Sent:** Sunday, March 16, 2008 1:25 PM

To: testimony

Subject: DYLAN'S LAW HB 2727

To whom it may concern,

I am writing to ask you to please pass "Dylan's Law HB 2727". I am a mother of a 7 year old autistic boy, and passing more laws in this state in order to better the learning and medical environment our children would mean the world to all parents of autistic children. I SUPPORT THIS AND ASK THAT YOU PLEASE HEAR US: PLEASE PASS DYLAN'S LAW HB 2727. Thank you so much! Sincerely,

Christine K. Mau

(mother of Sage Maxwell-7 yrs old-high functioning autism)

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March 17, 2008

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

Senate Committee on Health

Re: HB 2727 HD2 – 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 HB 2727 HD2 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 HB 2727 HD2 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.

The current language in the measure would create an Autism Disorders Spectrum Benefits and Coverage Task Force. While HMSA appreciates the inclusion on such a Task Force, we also believe that prior to this group being convened the legislature should request an Auditor's study as required under Hawaii Revised Statutes 23-51 and 23-52. This study would provide Task Force members with objective information and the groundwork with which to begin the discussion on what can be done to ensure proper services are provided through public and private resources for children with autism. Without a report of this type, the Task Force would be responsible for gathering what could be a lot of information with limited time and resources.

We would request that rather than pass HB 2727 HD2, the Committee consider holding this measure and instead request an Auditor's study be completed. The language concerning the Task Force could be reintroduced next legislative session requesting that this group specifically examine the Auditor's findings. We believe that a study of this type will provide the Task Force with an objective document with which to begin its work.

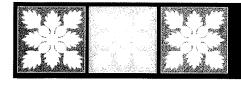
Thank you for the opportunity to provide testimony on HB 2727 HD2.

Sincerely,

Jennifer Diesman

Assistant Vice President

Government Relations



### Hawaii Association of Health Plans

March 17, 2008

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

Senate Committee on Health

Re: HB 2727 HD2 - 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 Assurance Association

**HMSA** 

Hawaii-Western Management Group, Inc.

MDX Hawai'i

University Health Alliance

UnitedHealthcare

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 on HB 2727 HD2 which would require health plans to cover screening for diagnosis and treatment of autism spectrum disorders for individuals under the age of twenty one "when ordered by a physician, psychologist or certified registered nurse practitioner." 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 intended 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. Additionally, we would point out that the bill's broad definition of medical necessity is 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 the family members of autistic children, but not to HAHP members or the employers who pay the premiums for their employees.

Thank you for the opportunity to testify.

Sincerely,

Rick Jackson

President

### Amber Alexander

202 Hoalike Street Kihei, Hawaii 96753 (808) 870-4304

March 17, 2008

To: HTH Committee, State Senate

<u>Testimony of Amber Alexander re: HB 2727,</u>

<u>Relating to Mandatory Health Coverage; Autism Spectrum Disorders</u>

Date of Hearing: Monday, March 17, 2008, 1:00 pm, conference room 016

I reside on Maui and am unable to attend this hearing. So, on behalf of myself and my family, I am submitting this testimony regarding H.B. 2727.

In August of 2006 my son, was diagnosed with Autism Spectrum Disorder. That diagnosis sent our family into a state of emotional turmoil and on the path of severe financial hardship.

Our insurance company did pay for the diagnosis of my son's condition. However, the policy specifically excludes treatment for any developmental delay, including ASD. They will not pay for speech therapy, occupational therapy, behavioral therapies. To say I and my husband were flabbergasted is an understatement.

Early intervention is critical for ASD, and without the insurance company providing the financial resources and skilled health care providers needed, we scrambled to put together our own program with the limited resources on Maui. With a lot of work, tears, and diligence, we did piece together an abbreviated program. It took us more than three months to find a speech therapist. It took us another three to find an occupational therapist. And, it was very expensive. In the first year after his diagnosis, my family spent more than \$30,000 for just speech therapy and occupational therapy. That not only wiped out whatever limited savings we had, but forced us to take a second mortgage out on our home. We are now facing severe financial hardship, but we are one of the lucky families – we were able to get our son treatment, and he is doing very well. Other families are not so lucky.

It is estimated that ASD now affects 1 out of every 166 children in this country. The only way to lessen the affects of this illness and to improve the quality of the lives of the children and their families is through early intervention, including speech therapy, occupational therapy, and behavioral therapy. Unfortunately, without the assistance of health insurers, most children will go without treatment, and most will never reach their full potential. We therefore support this bill, and ask that your Committee do the same.

Thank you for considering my input on this matter. Please feel free to call me at any time, if any of you have questions. I can be reached at (808) 870-4304.

Respectfully submitted,

Amber Alexander



Kalma K. Wong 46-220 Alaloa Place Kaneohe, Hawaii 96744 (808) 393-5218 flute866@gmail.com

March 16, 2008

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

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

Re: Testimony in STRONG SUPPORT for HB2727 HD2, Relating to Health Insurance Coverage for Autism Spectrum Disorders, Senate Committee on Health, March 17, 2008, Room 016, 1:00 p.m.

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

I am writing to express my strong support of House Bill 2727 HD2, 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, ear infections, gastro-intestinal problems, 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 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. This therapy is recognized by the U.S. Surgeon General's 2001 Report on Mental Health as being 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 treatment 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 HB2727 HD2 and help 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 <a href="mailto:flute866@gmail.com">flute866@gmail.com</a>.

Sincerely,

Kalma K. Wong Hawaii Chapter President Autism Speaks (formerly Cure Autism Now) Chapter Advocacy Chair, Autism Speaks Kerri Wong 46-312C Haiku Rd. Kaneohe, HI 96744 247-5956

17 March 2008

Senator David Y. Ige, Chair Senate Committee on Health Hawali 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:

Support of House Bill 2727 otherwise known as Dylan's Law, Relating to Health Insurance Coverage for Autism Spectrum Disorders
Senate Health Committee
March 17, 2008, 1:00 p.m., Room 016

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

I am writing as a concerned parent and citizen to express support of House Bill 2727, otherwise known as Dylan's Law. This bill mandates health insurance coverage for autism spectrum disorders.

I am a parent 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. He had been receiving services for developmental delay from the Department of Health. On his 3<sup>rd</sup> birthday, the Department of Education assumed responsibility of his services and he attended a DOE Special Education Preschool for 5 months. Unfortunately, together with our team of experts in the fields of psychology and autism, we 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 remove Billy from the DOE school, place him in a private preschool, provide the Applied Behavior Analysis (ABA) therapy that we felt was appropriate for his disabling condition out of pocket, and file for due process in an attempt to help pay for these services.

With the changes we have made to Billy's education and therapy, he has made amazing improvement 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 plays appropriately, makes the "zoom zoom" sounds, and sometimes even narrates what he is doing. What I am most excited and thrilled about is that he is now talking to and interacting with not only his 2 year old sister, but also his peers in preschool.

My husband and I 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. It is most important to begin intensive therapy in the years

between 2 and 6 yrs old so that he will have the best chances of recovery. Without such therapy, children with autlsm become lifelong dependents of their families and the State. For each child affected by autism, the potential socioeconomic drain on public resources is immense.

The improvements I see in Billy are a direct result of his intense Applied Behavior Analysis (ABA) program. 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 \$7,000 to over \$10,000 per month. We bear these costs directly without assistance from the DOE or other governmental agencies. Despite the exorbitant cost, it is all worthwhile to see our son understand and tell jokes, 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 currently able to afford the therapy. 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 routinely 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. Currently these costs are borne by the State Departments of Education and Health and the families themselves. Virtually all families of children with autism are deeply in debt as a result of the lack of insurance coverage for these necessary therapies. With the epidemic increase in prevalence of this disease, and because needed therapies are prohibitive due to cost, and as these children grow older without improvement, they will eventually become burdens of the State. It is no doubt that the State will be facing a crisis with already strained finances and resources. In the end, the victims will be our children.

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.

I respectfully urge you to pass House Bill 2727 and make insurance coverage for autism a reality. Children with autism in Hawall deserve to have the opportunity to thrive.

Thank you for reading and considering my testimony. I will be appearing in person to testify in support of this bill.

Sincerely,

Kerri Wong, Mother of Piliv

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

March 17, 2008

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

RE: Testimony for HB 2727 HD2, Monday, March 17, 2007, Room 16 at 1 p.m.

Dear Senator Ige, Fukunaka and Committee on Health,

I am writing to STRONLY SUPPORT HB 2727 HD2. This bill is an extremely important bill for children with Autism since it is related to their health and well being AND the future of our State. Consider the following facts.

In 2005, the CDC found that 8.9% of children from 0 to 17 years of age have asthma, up from 7.5% in 1995. According to estimates from Hawaii's DOH, there were over 28,600 children with childhood asthma in 2006. Although children may outgrow asthma, there are many who will not. Here in Hawaii, vog and other environmental pollutants can exacerbate this condition in children as well as adults requiring a lifetime of treatment throughout adulthood. This medical condition and the various complications related to asthma including respiratory failure, hospitalization, cardiac arrest, and emergency room visits ARE COVERED by Hawaii's health insurers.

According to the CDC's 2005 report, 1 in every 400 to 600 children less than 20 years of age has Type 1 Diabetes. Unlike childhood asthma, Type 1 diabetes cannot be out grown. Like asthma, this too can require a lifetime of treatment throughout adulthood. The treatment of diabetes and its complications such as renal failure, heart and blood vessel diseases, peripheral neuropathies, and blindness currently ARE COVERED by health insurance.

In a February 2007 CDC report, 1 out of 150 children have Autism compared to a 2004 report that found 1 in 166 children with Autism. In 2005, the CDC found that as many as 24,000 children are diagnosed with Autism in the US every year. In 2006, the CDC found that 5.5 out of every 1000 SCHOOL-AGED children are diagnosed with Autism. It has been proven that children diagnosed with Autism who receive intensive treatment early in life including those such as Applied Behavioral Analysis, Speech Therapy, Physical Therapy, Occupational Therapy in addition to Psychological services can learn to function independently in society as adults.

Unlike childhood asthma and diabetes, Autism DOES NOT REQUIRE A LIFETIME OF TREATMENT and therefore, in comparison, could not possibly "cost" as much to Hawaii's health insurers as they claim. To make this even more inequitable for our children, Hawaii's health insurers DO NOT RECOGNIZE AUTISM AS A MEDICAL CONDITION and therefore, the treatment for Autism IS NOT A BENEFIT from Hawaii's health insurers.

Statistics from Hawaii's Department of Education show that Hawaii's School-Aged Autism population EXCEEDS that of the national norm of 5.5 out of 1000. The following statistics come from the DOE's Performance Reports for the quarters October 2007-December 2007, 2006, 2005 and 2004.

Count as of 12/30/Year	# Children under Autism Category (DOE)
2002	646
2003	788
2004	897
2005	975
2006	1025
2007	1133

The official DOE enrollment for School Year 2007-2008 is 171,712 children. However, with 1133 children under the Autism category currently in the DOE, 0.66% (1133 out of 171,712) compared to the CDC's estimate of 0.55% (5.5 in 1000 School Aged children) with Autism, Hawall's children are being diagnosed at a rate HIGHER than the national average.

In the 5 year time period from 2002 to 2007, the Autism population of School-Aged students in Hawali's DOE INCREASED BY 75.4%. This statistic does not even include those children who are not of school-age. What will it be in another 5 years, 10 years? Our children need help now.

Health insurers need to recognize Autism as a condition that is medically treatable with medically necessary therapies. The DOE currently provides minimal services including speech, occupational therapy and physical therapy; however, these services are NOT medically based. They are educationally based. Since they are educationally based, these services are too narrowly focused to truly help the child to acquire practical and functional skills needed to freely participate in a community or society where the child can survive independently.

This is why HB 2727 HD2 is so important to our children. Our children deserve a chance to become independent, contributing individuals in our society. The time frame upon which to apply these medical interventions is very narrow. If left untreated, these children may have no choice but to rely on the State as adults beginning at age 21 for support including room and board at a day foster care facility, a living stipend, medical and dental insurance, transportation and other daily living expenses. This could easily add up to an additional 60 years until 80 years of age, the average life expectancy of Hawaii residents. The financial consequences of providing MILLIONS of State dollars PER individual PER lifetime will be much less if a bill such as HB 2727 HD2 is in place.

Does it make more financial sense to have health insurers cover in the short term, a treatable MEDICAL condition that SHOULD be a health insurance benefit to Autistic children in the first place? Or is it more financially practical to have the State take on the burden of providing social services to these untreated adults so that they can merely coexist in society and remain totally dependent on these services for up to perhaps 60 years or more throughout their entire adulthood?

Based on statistics from the US Department of Education and other governmental agencies, Autism is growing at a rate of 10 to 17 percent per year. At these rates, it is estimated that the prevalence of Autism could reach 4 million Americans in the next decade.

At 2, 3, 4, 5 years old, the time of diagnosis, it is highly unlikely that a child developed Autism as a mental illness from 0 to 5 years of life. They CAN develop a Neurological disorder at this age or any age involving the brain which should be a medical disorder. Autism is a neurological disorder that develops at an early age. Once a child is diagnosed with Autism, it will be a long journey from beginning to end, if there IS an end.

This is why it is so important that this Committee pass HB 2727 HD2, so that our children will have a chance to have a future.

Again, I must reiterate, Autism DOES NOT require a lifetime of treatment.

Sincerely

Teresa Chao Ocempo Parent of an Autistic Child

383-8636 (c)

From: Krista Guiteras-Duncan [kristaleilani@msn.com]

**Sent:** Sunday, March 16, 2008 6:32 PM

To: testimony
Cc: Kalma Wong

Subject: IN SUPPORT OF HB 2727

Aloha Senator David Y. Ige, Chair and Senator Carl Fukunaga, Vice Chair,

I am a Social Worker who is in support of **House Bill 2727** set to be heard on March 17, 2008 at 1:00 pm. The children of Hawaii who are challenged with Autism Spectrum Disorder, parents, consumers, and communities need your kokua. Please pass this bill.

Mahalo nui, Krista Guiteras-Duncan

Krista Leilani Guiteras-Duncan 5333 Likini St. Ste. 1806 Honolulu, HI. 96818

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From: Carolyn K Nomura [cknomura@hawaii.rr.com]

Sent: Sunday, March 16, 2008 8:24 PM

To: testimony

Subject: In Strong Support of HB2727

Please include my testimony in the written record for Senate Health Committee hearing:
Monday, March 17, 2008 @ 1:00p.m.
Thank you.

March 16, 2008

Chair Senator David Ige Vice Chair Senator Carol Fukunaga Senate Health Committee Hawaii State Capitol, Room 16 415 South Beretania Street Honolulu, HI 96813

Re: In Strong Support of HB2727 "Dylan's Law" a bill ensuring health insurance coverage for autism diagnosis and treatment

Dear Chair Ige and Vice Chair Fukunaga,

I am writing to express my strong support for House Bill 2727. The children of Hawaii are in great need of help for treatment for autism. Autism is treatable as I have witnessed firsthand within my own family, and I also know the tremendous financial and emotional burden it bears upon our families. I urge you to please give this bill your full consideration. Please pass HB2727. Thank you for your time.

Sincerely,

Carolyn K. Nomura

From:

Scot & Lofisa Seguirant [seguirans001@hawaii.rr.com] Sunday, March 16, 2008 8:37 PM

Sent:

To:

testimony

Subject:

Please pass HB2727

Aloha Chair Senator David Ige and Vice-Chair Senator Carol Fukunaga,

We are parents of an Autistic child and we would like to support HB 2727. Please pass this very important bill.

Aloha, Scot & Lofisa Seguirant.

From:

Sherri Henriques [sherrihenriques@yahoo.com]

Sent:

Sunday, March 16, 2008 7:18 PM

To:

testimony

Subject: Senate Health Committee - Dylan's Law HB2727

Dear Chair Senator David Ige and Vice-Chair Senator Carol Fukunaga,

We are parents of a child with autism and support Dylan's Law HB2727. We strongly urge you to pass it.

Thank you very much.

Sincerely,

Peter and Sherri Henriques ph. 735-9766

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From: Pauline Fleischauer [auntyp.123@gmail.com]

**Sent:** Sunday, March 16, 2008 10:19 PM

To: testimony

Subject: Re: HB2727 - "Dylan's Law"

I am a single mom of a child with autism; he's 5 and totally non-verbally. I do have him on everything that I can afford and it's very, very rigorous trying to manage it all. Having a law like "Dylan's Law" would really open up the possiblities of truly helping these children with autism. Please open up your eyes and your minds and your hearts and listen to the effectiveness a law such as this one can do for all the families that walk the walk that I do on a daily basis. Please pass "Dylan's Law" - HB2727.

Yours truly, Pauline Fleischauer

## TESTIMONY IN SUPPORT OF H.B. 2727 HD2 RELATING TO HEALTH INSURANCE

Submitted to the

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

> By Richard Cox, Kapolei

#### Chair Ige:

My wife and I are the parents of a child with autism. We support this bill and strongly urge its passage.

Only in the past 20 years has autism been recognized as a treatable medical condition and that those with autism have the ability, as well as the right, to take their place in society, to make their unique contributions just as the rest of us do. Unfortunately autism is accompanied by a host of other medical problems as well, including motor skills impairments, vision impairments, gastrointestinal problems, etc.

The challenges and costs of helping those with autism are significant and borne primarily by their families. Because autism has traditionally been seen as a mental health issue, and not as a medical condition, health insurance has not been available for its diagnosis and treatment. Thus, despite the overwhelming evidence that early intervention makes significant and permanent improvement in the health of children with autism, because insurance is not usually available to them, parents of children with autism must pay for the intensive (and expensive) treatments themselves. Many parents are then faced with the painful choice of incurring costs they can little afford or denying their children the early treatments that could mean the difference between a happy and productive life or a lifetime of institutional assistance.

Further, beyond the financial costs, there are significant familial and societal costs. 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. 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 and families of children with autism in Hawaii have a little less to cope with by requiring adequate insurance coverage for autism spectrum disorders. Please help ensure that children with autism are given the opportunity to receive the treatments that will help give them the health and happiness that the rest of us enjoy.

Please pass HB 2727 HD2.

From:

Ira I Wong [iraw@hawaii.edu] Sunday, March 16, 2008 5:04 PM

Sent: To:

testimony

Subject:

HB2727 ("Dylan's Law")

Chair Senator David Ige and Vice-Chair Senator Carol Fukunaga,

I am asking for your support of HB2727. As one who has relatives and friends with children afflicted with Autism, I have seen the financial and emotional hardship which this disorder brings to families firsthand. The passing of HB2727 would be a step in the right direction to improve the lives of local families with Autistic children.

I thank you for your time and consideration.

Aloha,

Ira Wong

<sup>&</sup>quot;And in the end, the love you take is equal to the love you make." - The Beatles

From: N.D. [bookfanatic@hotmail.com]
Sent: Sunday, March 16, 2008 8:48 PM

To: testimony

Subject: FW: HB2727 "Dylan's Law"- Monday, March 17th at 1 p.m. in Room 16

Dear Chair Senator David Ige and Vice-Chair Senator Carol Fukunaga

I urge you to vote "yes" to Dylan's Law (HB2727) which mandates health insurance coverage for autism spectrum disorders. We need to make insurance coverage for autism a reality. The children with autism in Hawaii deserve to have the opportunity to thrive. We are not asking for the moon. We are asking health insurers cover treatments for a disorder just as they cover treatments for other disorders in the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association. This is not too much to ask.

Children with autism often have co-occurring conditions, such as behavioral problems, speech disorders, anxiety, muscle or joint problems, ear infections, gastro-intestinal problems, 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. 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. The costs of this insurance reform are small and will have very little impact on the cost of health insurance premiums for the individual consumer despite what insurance companies may say.

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). Applied Behavior Analysis (ABA) is a data-based intervention for autism that has a decades-long record of efficacy. ABA therapy has shown to increase educational placements and increased IQ levels of those with autism. This therapy is recognized by the U.S. Surgeon General's 2001 Report on Mental Health as being widely accepted as the effective treatment for autism. But insurers frequently deny ABA as a benefit, and families are often forced to pay for these costly services out of pocket. Too many local 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.

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. Dylan's Law is about all children with autism who deserve to have a better quality of life than what they get from insurance companies now. Thanks for allowing me to provide my testimony. Please feel free to contact me should you have questions about this matter.

Sincerely, Dan Santos 619 Keolu Drive Kailua, HI 96734 226-0398

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From: Yamamoto, Fay A. (DHR) [fyamamoto@honolulu.gov]

Sent: Monday, March 17, 2008 9:56 AM

To: testimony

Subject: Senate Health Committee, March 17, 2008 at 1:00 p.m.; HB2727

Fay Yamamoto 2832 Kalawao Street Honolulu, HI 96822

March 17, 2008

#### **EMAIL**

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

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

RE: Dylan's Law, HB 2727, Relating to Health Insurance, Mandatory Health Coverage; Autism Spectrum Disorders, March 17<sup>th</sup>, 1:00 p.m.

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

Thank you for receiving my testimony on this important bill. I am a parent of a child with autism.

Please support HB 2727 to ensure that children diagnosed with autism spectrum disorders receive appropriate care and treatment.

Thank you for your attention to this matter.

Sincerely,

Fay Yamamoto 754-8999