SB 2738

LINDA LINGLE
GOVERNOR

JAMES R. AIONA, JR.
LT. GOVERNOR

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

LAWRENCE M. REIFURTH
DIRECTOR

RONALD BOYER
DEPUTY DIRECTOR

TO THE SENATE COMMITTEE ON HEALTH

TWENTY-FOURTH LEGISLATURE
Regular Session of 2008

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

TESTIMONY ON SENATE BILL NO. 2738 – RELATING TO AUTISM SPECTRUM DISORDERS

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

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

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

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

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 1, 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 2738 - RELATING TO AUTISM SPECTRUM DISORDERS

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

The State Council on Developmental Disabilities recognizes the merits of this bill. The purpose of the bill is to require insurers, mutual benefit societies, and health maintenance organizations to provide coverage for the diagnosis and treatment of autism spectrum disorders for covered individuals less than 21 years of age.

The Council brings to your attention that Section 23-51, Hawaii Revised Statutes (HRS), requires concurrent resolutions 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.

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

Sincerely,

Waynette K.Y. Cabral
Executive Administrator

Attachment

[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

Hawaii Association of Health Plans

February 1, 2008

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

Senate Committee on Health

Re: SB 2738 – Relating to Autism Spectrum Disorders

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 in opposition to SB 2738, 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. 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.

Thank you for the opportunity to testify.

Sincerely,

Rick Jackson
President

HMSA

Blue Cross
Blue Shield
of Hawaii

An Independent Licensee of the Blue Cross and Blue Shield Association

February 1, 2008

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

Senate Committee on Health

Re: SB 2738 – Relating to Autism Spectrum Disorders

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

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 2738 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 2738 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 2738.

Sincerely,

Jennifer Diesman
Director, Government Relations

Dylan's Law

To whom it may concern,

I do appreciate your intent for the hearing of Bill SB 2738, however this bill does NOT meet the needs of our children with autism. Dylan's Law is the bill the autism community desperately needs and PLEASE, PLEASE schedule a hearing for this law SB2532. (Dylan's Law)

Sincerely,

Jill Park
Kaneohe, HI
235-6196

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 116 State Capitol 415 South Beretania Street

Thank you,
Mother of a son with Autism,
Victoria James

Cure Autism Now
WALK NOW

Kalma K. Wong
46-220 Alaloa Place
Kaneohe, Hawaii 96744
(808) 235-4411

January 31, 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 for SB2738, Relating to Health Insurance Coverage for Autism Spectrum Disorders
Senate Committee on Health, February 1, 2008, Room 016, 1:15 p.m.

Dear Chair Ige and Vice-Chair Fukunaga:

I am writing to express my strong RESERVATIONS for Senate Bill 2738 (SB2738). Although I truly appreciate the intent of the bill, I cannot support the bill in its current form. The intent of SB2738 is to ensure health insurance coverage for individuals with autism who are less than twenty-one years of age; however, in its current form, the bill will not fulfill the needs of children with autism and provide the necessary health coverage they so desperately need.

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.

cure Autism now
FOUNDATION

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

888.8AUTISM
323.549.0500
323.549.0547 fax
www.cureautismnow.org

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).

On the face of it, SB2738 appears to provide comprehensive health coverage for individuals with autism; however; there are several problems with this bill:

1) The bill fails to define the treatments that it mandates. All the terms in the statute should be defined. In particular, "rehabilitative care" and "therapeutic care" do not have well-defined meanings. As an example, "therapeutic care" should be defined as services provided by licensed speech pathologists, registered occupational therapists, or licensed physical therapists. A lack of clear definitions for these treatments may potentially lead to no treatments being covered at all.

2) The bill fails to list "habilitative care" as a covered treatment. Children with autism are delayed in development and require therapy to develop skills, such as the ability to speak. Without specifying this treatment, a child with autism will not be able to receive the necessary treatments to become a functioning and independent person.

3) The bill fails to specifically mandate proven therapies such as Applied Behavior Analysis. ABA has a decades-long record of efficacy. Applied Behavior Analysis (ABA) is a data-based intervention for autism that has over forty years of research behind it. ABA is the application of scientific principles of behavior to improve socially significant behavior to a meaningful degree. 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 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

4) The bill also fails to mandate speech and language therapy and occupational therapy, although motor problems are common among children with autism and the inability to communicate is one of the main deficits for those with autism.

5) The bill authorizes the Department of Health to determine medically necessary treatments for autism spectrum disorders. The Department of Health should not be dictating treatment options to the professionals who work with individuals with autism. The DOH has neither the expertise nor the capacity to fulfill this requirement. What is considered to be medically necessary for children with

autism should be the responsibility of the professionals who specialize in autism spectrum disorders.

SB2738 is no guarantee that persons with autism will get the necessary health coverage they need. Please consider changing the bill to include the suggestions outlined above. Another suggestion would be to consider Senate Bill 2532, otherwise known in the autism community as Dylan's Law. SB2532 (Dylan's Law) is a more comprehensive bill that fulfills what SB2738 intended.

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

Sincerely,

Kalma K. W

Kalma K. Wong
Hawaii Chapter President
Cure Autism Now and Autism Speaks
Chapter Advocacy Chair, Autism Speaks

Via Fax 586-6659

TO: Senate Sergeant-At-Arms Office

Date: January 31, 2008

Subject: Testimony 2/1/08, 1:15 p.m. Hearing - SB2738

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 hearing for Dylan's Law.

The Autism community has concerns regarding SB2738 for the following reasons:

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.

2) SB2738 does not specifically mandate ABA which has a decades-long record of efficacy.

3) SB2738 authorizes the Department of Health (DOH) to determine medically necessary treatments for autism. This is completely inappropriate, because each child is different; each case is different. A treatment protocol or intervention should be determined by licensed medical professional.

There is no guarantee that persons with autism will get the coverage under SB2738without the specific language of Dylan's Law SB2532, the promise of help for families may never be realized.

Sincerely,

Deborah Tasatalwdamce

HAWAII DISABILITY RIGHTS CENTER

900 Fort Street Mall, Suite 1040, Honolulu, Hawaii 96813
Phone/TTY: (808) 949-2922 *Toll Free*: 1-800-882-1057 *Fax*: (808) 949-2928
E-mail: info@hawaiidisabilityrights.org *Website*: www.hawaiidisabilityrights.org

TESTIMONY TO THE TWENTY-FOURTH STATE LEGISLATURE, 2008 SESSION

To: Senate Committee on Health

From: Gary L. Smith, President
Hawaii Disability Rights Center

Re: Senate Bill 2738
Relating to Autism Spectrum Disorders

Hearing: Friday, February 1, 2008 1:215 PM
Conference Room 016, State Capitol

Members of the Committee on Health:

Thank you for the opportunity to provide testimony supporting Senate Bill2738, Relating to Autism Spectrum Disorders.

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 what the legal basis would be 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 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.

Please accept my testimony about SB 2738. Please read my testimony below to highlight that this bill SB2738 does **not** define any of the treatments it mandates. **It is imperative to DEFINE the targets specifically.** In particular, "rehabilitation care" and "therapeutic care" could mean just about anything (or worse, nothing). **ALL the terms in the statutes should be defined operationally**. SB2738 does not guarantee the child with Autism will get what he needs as recommended by the professional (psychiatrist or psychologist or BCBA etc) who knows him. **SB2532 Dylan's Law does define all the identified treatments, including "habilitation". Please schedule a hearing for SB2532 Dylan's Law.**

I am a Board Certified Behavior Analyst (BCBA) and have a Mastere's of Education in Special Education, working specifically with children with autism using Applied Behavior Analysis procedures. Many of our clients have programs requiring intensive therapy using Applied Behavior Analysis (ABA). It is a educational and behavioral set of procedures based on science, with peer reviewed research studies to support it's effectiveness. This is the only treatment recommended for Autism Spectrum Disorders by the Surgeon General. Many, many peer reviewed research articles support ABA and teaching procedures of ABA to teach skills such as toileting, other self care, eating new foods and expanding food repertoires, communication and language skills, social skills, academic skills and many more. In addition, many studies to evaluate the cost effectiveness of ABA programs have been completed and the outcomes report many millions of dollars of savings for taxpayers if the persons with Autism receive intensive ABA at a young age.

SB2738 does not specifically mandate ABA. ABA has a decades-long record of efficacy (see attached research to support ABA). Although ABA is the single intervention most often sought by parents of children with autism, sadly enough, insurers frequently deny it as a benefit.

The children I work with have so much potential. They are able to learn skills no one ever thought they could learn when they have access to an INTENSIVE ABA program. Imagine this: 3 year old child who is non-verbal, self injurious, aggressive, cannot be left alone. Imagine this same 3 year old child who receives 30-40 hours per week of intensive ABA 2 years later. He is able to ask for the items he wants, complete his assignments in a classroom.

Currently, many states (Pennsylvania, South Carolina and more) on the mainland have laws which provide coverage of ABA services for children with Autism. Several big corporations offer health insurance coverage for ABA as well such as Microsoft, Home Depot, and others offer $3500-$5000 per month benefit coverage. The military insurance (Tricare's ECHO program) offers families $2500 dollars per month to provide ABA services to their children diagnose with Autism.

Unfortunately, few parents can fund the intensive program with many hours that their child needs. These ABA programs cost money now, BUT save money in the long term, since many times with intensive ABA programs, we are able to prevent dismal outcomes for the children as they grow into adulthood. If a child is able to care for himself, he will not need the support of the system as an adult.

I have attached 4 articles for your review, 2 of which are cost benefit analyses, which analyze the money spent on ABA programs now, and estimate the savings in dollars.

SB2738 authorizes the DOH to determine medically necessary treatments for autism. It is completely **inappropriate and unethical** to give DOH the ability to determine the necessary treatments are for autism. The research already supports the effectiveness of ABA, the surgeon general recommends it, as do the National Academy of Science.

Please do not pass SB2738, and wait to hear Dylan's Law SB2532. These families we work with go through so much. Help them get the appropriate ABA treatment for their children or some of their futures will be our financial burden as taxpayers.

Please schedule a hearing to hear Dylan's Law SB2532.
Sincerely,
Amy Wiech
Amy Wiech, M.Ed., BCBA

Board Certified Behavior Analyst
Autism Behavior Consulting Group, Inc.
~Educational and Behavior Consulting Services~
website: www.AutismBehaviorConsulting.com
email: info@AutismBehaviorConsulting.com
(808) 277-7736
1 +(808) 443-0333 fax

"In God We Trust - All Others Bring Data!"
- W. Edwards Deming
If you want to be happy for an hour, take a nap.
If you want to be happy for a day, go fishing.
If you want to be happy for a month, go on a honeymoon.

If you want to be happy for a year, inherit a fortune.
If you want to be happy for a lifetime, teach children with disabilities.

LATE TESTIMONY

1054 Kaupaku Place
Honolulu, HI 96825
January 31, 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 sendige@Capitol. hawaii.gov

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: HEARING ON FRIDAY, FEBRUARY 1, 2008, 1:15 PM, CONFERENCE ROOM 016 ON SB2738, RELATING TO AUTISM SPECTRUM DISORDERS

Dear Senator Ige, Senator Fukunaga, and Members of the Committee:

My name is Sharon Wong and I have a child with autism. I agree with the intent of this bill, which gives us a good starting point to require insurance coverage for the diagnosis and treatment of autism spectrum disorders. Children and young adults with autism need treatments that will help them develop skills that typical children naturally acquire through their own observation, pretend play, and ability to apply lessons learned from others to themselves.

Currently, since these types of treatments are not covered, parents who can afford it, pay for it out-of-pocket, at considerable sacrifice with regard to their personal finances and effect of the quality of life for their family. Some parents have taken out home equity loans or have gone into debt to pay for needed treatments. Parents who are not as financially well-off have foregone the needed treatments, simply because they cannot afford it. This should not be happening - treatments should be provided based on the necessity of treatments to improve our children's ability to learn and become productive members of society.

I appreciate that this type of bill is being introduced, and am offering my comments to improve the bill. First, SB2738 should define specific treatments that are successful, such as applied behavior analysis and habilitation speech therapy services to gain and develop speech and language skills. Second, the determination of the type of treatment should not be based on the discretion of the Department of Health. Parents and professional health providers who directly work and evaluate the child should have primary responsibility in determining the required treatment. As any parent with autism knows, each child with autism is different and each child may respond differently to treatment. Each child needs to be evaluated by a health professional on a regular basis to ensure that treatments are working and that progress is being made. I do not see that the Department of Health would have the resources to provide this type of oversight.

If you are not already aware, there is another bill, SB2532, Relating to Health Insurance that deals with this very same issue. In my opinion, SB2532 is a bill that is specific and would meet the needs of children with autism. Please consider SB2532, or add the language from SB2532 into SB2738.

Thank you for the opportunity to address the needs of our children and youth adults with autism spectrum disorders. I welcome any opportunity to share my personal experiences with you.

Sincerely,

Sharon Wong
(via email)

LATE

ISTRATION

SB2738 RELATING TO AUTISM DISORDERS
COMMITTEE ON HEALTH
Hearing
February 01, 2008
Room 116
1:15 pm

TESTIMONY OF DANIEL SANTOS
619 Keolu Drive
Kailua, HI 96734
(808) 226-0398

My name is Daniel Santos and my wife and I are the parents of a young child affected by an autism spectrum disorder. While we appreciate SB2738 Relating to Autism Disorders and its attempt to provide insurance coverage for the treatment children need to recover from autism SB2738 is NOT a bill we can support in its current form for the reasons listed below.

First, there are no definitions or specifics. The bill in its current form is very vague and will allow insurers much leeway in not providing necessary coverage.

Second, there is no provision of habilitative services. Children who are affected by autism spectrum disorders need habilitative services. SB2738 in its current form allows insurers to provide only rehabilitative services meaning only services for things the child is already doing. Insurers won't need to cover things that child could do but isn't doing right now. This is not acceptable. For example, if a child is currently nonverbal an insurer will be able to say "Well your child wasn't speaking anyway so we don't need to provide him/her speech therapy."

Third, the Department of Health (DOH) determines the medically necessary treatment. This is not acceptable. The best person or people to determine a child's care and what therapies are needed are the child's doctor and treatment team. The DOH is not an expert on what my individual child's needs are. The autism professionals who interact regularly with my child can make the determination of what's needed. Hawaii has so few autism professionals because we're so geographically isolated. Please allow those who are autism professionals to do their job and make the determination of what is medically necessary treatment.

I SUPPORT "DYLAN'S LAW" which is SB2532 and HB2727. It is similar to laws passed in Indiana, South Carolina, and Texas. It mandates insurance coverage for autism disorders but it provides specifics, definitions, allows the child's autism professionals to make the determination of what's necessary treatment, and provides more comprehensive coverage. I urge the Committee to have a formal full hearing on Dylan's Law.

Thank you for allowing me to provide my testimony. Should you have any questions, please feel free to call me. My contact information is above.

Daniel Santos III

LATE TESTIMONY

Dear Sirs:

Thank you for your review and consideration of a bill that needs to be passed, but needs to be modified.

1. Currently senate bill 2738 fails to really do what needs to be done. Most people will skim the surface and believe that the bill addresses specifics that children with autism need. In reality, this bill does not really define care for our children. Autistic children need habilitative care.......that is not addressed in this bill. What that means is that if a child cannot speak, his needs are not addressed because he couldn't speak before. So he doesn't get speech therapy!
2. The bill also doesn't specify the need for ABA or applied behavioral analysis. This is STANDARD practice for many states in the US where ABA is paid for via health insurance and is the therapy given to children with autism.

The bill to approve is Dillon's Law or senate bill 2532. This bill address in depth the real needs of autistic children as bill 2738 fails to do.

I urge you NOT to pass 2738. It is meaningless.

Thank you,

Sherrie Kuroda
255-3074

To: Senator David Y. Ige, Chair
Committee on Health

Re: SB2738

Hearing Date: February 1, 2008
Hearing Time: 1:15pm

February 1, 2008

Dear Senator Ige,

I am writing as a concerned parent and citizen regarding SB2738. While I appreciate the intent of this bill and feel that it is a step in the right direction, I strongly believe that SB2738, in its current form, will not meet the needs of children on the autism spectrum.

I urge you instead to consider **Dylan's Law, SB2532,** because it is the stronger bill. It contains specific language that will ensure that children on the autism spectrum will receive the services they need to improve.

I am a 36 year old mother of a 4 year old son on the autism spectrum named Billy. Billy was diagnosed with autism by a Department of Health psychologist days before his third birthday. When he turned 3 he attended a DOE Special Education Preschool for 5 months. Unfortunately, we, as parents, and our team of experts in the field of psychology and autism, felt that the "Free Apropriate Public Education" (FAPE) guaranteed to my son by federal law, was not appropriate. We therefore were forced to file for Due Process, took Billy out of the DOE school, and put him in a private preschool along with the Applied Behavior Analysis therapy that we felt was appropriate for his disabling condition.

With the changes we have made to Billy's education and therapy, he has made an 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 uses them 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 his peers in preschool.

These improvements were a direct result of the intense Applied Behavior Analysis (ABA) program that we implemented for Billy. However, because this type of therapy is time consuming, highly individualized, and must be implemented by trained therapists and consultants, we truly pay through the nose. Our costs range from $7000 to over $10,000 per month. Despite the exorbitant cost, it is all worth it to see my son understand 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 able to afford the therapy for now. However, it is still an enormous burden on our family. Any amount of financial help from insurance companies would help us immensely and would truly be appreciated.

Here are the reasons that I believe that SB2738 are inadequate to serve the needs of children on the autism spectrum including my son.

First of all, SB2738 does NOT define any of the treatments it mandates. For example, the terms "therapeutic care" and "rehabilitation care" are vague, undefined, and therefore could mean almost anything, or worse, nothing at all.

On the other hand, Dylan's Law, SB2532 specifically defines all identified treatments, including "habilitation". The inclusion of this term is extremely important for the implementation of appropriate therapies for our children. It would, for example, cover speech therapy, and in this case would mean gaining the ability to speak and/or learning new words, whereas "rehabilitation", as stated in SB2738, typically means recovering skills that were lost. Our children are developmentally delayed. They require skills that they never had. Rehabilitation does them no good. The term "habilitation" needs to be included and furthermore defined in an effective law.

Secondly, SB2738 does not specifically mandate the use of Applied Behavior Analysis (ABA) in the treatment of autism. ABA has a strong research-based foundation of effectiveness with children on the autism spectrum. Most parents of autistic children learn this through desperate internet searches, research, and talking to other parents. Although ABA is the most sought-after intervention, insurers frequently deny it as a benefit and parents are forced to either pay for it out of pocket (many parents who choose this option must take drastic measures to afford such treatment, such as sell their homes, and many go bankrupt in the process. Thankfully, we have not had to do this yet), use an alternative but less effective intervention with no research base, or settle for no therapy at all. In addition, SB2738 authorizes the Department of Health to determine medically necessary treatments for autism. It is not appropriate for the DOH to dictate what are necessary treatments.

The term ABA is included in Dylan's Law, SB2532. As I have written above, we chose ABA intervention for my son. It has been extremely effective in helping his behavior, gaining speech and language skills, play skills, and social skills.

Finally, SB2738 offers no guarantee that persons with autism will receive the coverage they so desperately need. If you do not have an autistic child of your own you cannot know what it is like to be in our shoes. This is such an emotionally charged issue, and just as every child affected with autism is unique, so is every family, and that family's experience. What us families have in common are the struggles. We struggled early on when our child was young and still not talking. We struggled with not knowing what was wrong with our toddler, and even wondered if we were bad parents and it was our fault that our baby wasn't developing normally. Now, we struggle every day with our child's behavior at home and in public. We struggle with the public school system, and because many of us seek due process, we struggle with legal issues. Many of us struggle in our marriages because having an autistic child is such an enormous stressor on our family life. We struggle with guilt because we feel we are not paying enough attention to our other children. We struggle with the uncertainty about our child's future and the very real possibility that we will have to take care of him/her for the rest of our lives. Furthermore, many of us struggle under the enormous financial burden of expensive but effective therapies and interventions for our kids. It is these therapies that give our families and our children much needed hope. We sorely need the help of insurance companies to handle this immense financial burden.

SB2738 is a step in the right direction, but it is not enough. We need a bill that will be specific enough to provide real and effective help and relief to families. Dylan's Law, SB 2532 contains that specific language that will, in the end, offer us real help and hope. I urge you to hear **Dylan's Law, SB2532** and give our families who are struggling with an autistic child the promise of a brighter tomorrow.

I urge you to contact me if you have any questions.

Sincerely,

Kerri Wong

Kerri Wong

46-312C Haiku Rd.
Kaneohe, HI 96744

kltwong@yahoo.com

247-5956

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

Senator Russell S. Kokubun, Chair
Committee on Commerce, Consumer Protection, and Affordable Housing

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

Friday, February 1, 2008
SB2738, 1:15 pm, Room 116

Opposition of SB2738, Relating to Autism Spectrum Disorders

I am a mother of a child with Autism. I am testifying against SB2738, Relating to Autism Spectrum Disorders. I appreciate the intent of the bill, however, it does not meet the needs of the children with autism. Dylan's Law **SB2532** is the bill of choice for the autism community and I strongly request that you schedule a hearing for Dylan's Law.

SB2738 does not define any of the treatments it mandates. In particular, "rehabilitation care" and "therapeutic care" could have many meanings. All the terms in the statutes should be defined. SB2532 Dylan's Law does define all the identified treatments, including "habilitation". Insurance companies currently do not cover most speech therapy sessions because the policies do not cover "habilitation" (i.e. gaining the ability to speak or develop new words), but only "rehabilitation" (i.e. recovering skills).

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

SB2738 authorizes the Dept. of Health to determine medically necessary treatments for autism. I believe this is completely inappropriate as they are not educated enough about autism and necessary treatments. In our case, the DOH psychologist misdiagnosed my son. It was only after I had my son evaluated by a psychiatrist/pediatrician well educated in autism that he was correctly diagnosed and necessary treatments were recommended.

SB2738 is does not 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. I urge the committee to veto SB2738 and to schedule a hearing for SB2532. Thank you for this opportunity to testify.

LATE TESTIMONY

PLEASE DELIVER TO:
CPH/HTH Committee
Friday
2-1-08
1:15pm
Room 016

February 1, 2008

To: Sen. David Ige, Chair
Sen. Carol Fukunaga, Vice Chair
Senate Health Committee

Sen. Russell Kokubun, Chair
Sen. David Ige, Vice Chair
Senate Commerce, Consumer Protection and Affordable Housing Committee

From: Cynthia J. Goto, M.D., President
Linda Rasmussen, M.D., Legislative Co-Chair
Philip Hellreich, M.D., Legislative Co-Chair
Paula Arcena, Executive Director
Dick Botti, Government Affairs Liaison

RE: SB2110 Relating to Health Insurance (Mandates health insurance coverage to screen for colorectal cancer by colonoscopy every ten years, beginning at age fifty)

SB2738 Relating to Autism Spectrum Disorders (Requires insurers, mutual benefit societies, and health maintenance organizations to provide coverage for the diagnosis and treatment of autism spectrum disorders for covered individuals less than twenty-one years of age.)

The HMA supports the intent of the above-stated bills to provide for needed medical care, but has concerns about adding to Hawaii's already long list of mandated health insurance benefits. The addition of more benefits increases health care costs, thereby increasing premiums and putting health care coverage out of reach for more of our residents. For that reason and those explained below, the HMA is opposed to mandated benefits.

Mandated benefits should consist of core benefits that are limited to medical needs. Many existing benefits, such as mammograms, immunizations, mental health and alcohol and drug dependence treatment, are necessary to maintain the health of Hawaii's citizens. These benefits warrant mandating because they are cost effective by preventing future illness, which would be far more costly to treat and cure. The HMA strongly believes that every member of our society needs and deserves a core group of medical and surgical benefits, including psychiatry and addition medicine.

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Hawaii Medical Association
1360 S. Beretania St.
Suite 200
Honolulu, HI 96814
(808) 536-7702
(808) 528-2376 fax
www.hmaonline.net

Over and above these benefits, the HMA generally favors free market solutions and opposes mandated benefits, because they significantly increase the cost of health care and ultimately increase the number of uninsured or underinsured people. However, it is important to retain some flexibility in order to reflect advances in medical science and to address those instances in which the free market does not induce third party payers to cover new diagnostic and therapeutic services.

While it is vitally important to consider the cumulative cost of mandated benefits, the delivery of quality health care should not be prohibited with an arbitrary cap.

Following the 2001 legislative session, the HMA participated in the Mandated Benefits Task Force, convened by the Insurance Commissioner, and served on committees led by former Representatives Ken Hiraki and Dennis Arakaki and Senator Brian Taniguchi. The task force and its committees spent a significant amount of time discussing this issue.

Unfortunately, the legislature did not act upon the recommendations of the task force. While the report is 6 years old, we think it would be helpful for this committee to review the Task Forces' report and re-visit this issue before adding mandated benefits.

Thank you for the opportunity to testify on this matter.