**DAVID Y. IGE**GOVERNOR

21



**VIRGINIA PRESSLER, M.D.**DIRECTOR OF HEALTH

State of Hawaii
DEPARTMENT OF HEALTH
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### **Testimony COMMENTING on SB 791**RELATING TO AUTISM SPECTRUM DISORDERS

## SENATOR JILL N. TOKUDA, CHAIR SENATE COMMITTEE ON WAYS AND MEANS

Hearing Date: 3-3-15 Room Number: 211

1	Fiscal Implications: Deferred to legislative audit, DHS and others
2	<b>Department Testimony:</b> The Department of Health appreciates the intent of S.B. 791 to
3	improve the access of individuals with autism spectrum disorders (ASD) to appropriate services
4	S.B. 791 amends Chapter 431, Hawaii Revised Statutes to provide coverage for the
5	treatment of ASD in children, and with maximum benefits stipulated in the bill. One of the most
6	important sections on the bill is (h) "This section shall not be construed as reducing any
7	obligation to provide services to an individual under any publicly funded program, an
8	individualized family service plan, an individualized education program, or an individualized
9	service plan." This is essential as many families receive access treatment through the
10	Department of Health Early Intervention Section and school programs. These programs should
11	not stop and actually should be bolstered in many cases. This insurance benefit could help
12	families obtain enhanced services in school settings or in homes, which are important placed to
13	provide these services for many children.
14	This bill will also allow best practice, evidence-based treatments such as Applied
15	Behavioral Analysis (ABA) that have been shown to improve socialization and language of
16	individuals especially children with ASD. Treatment of ASD at an early age using ABA and/or
17	other treatments will increase the opportunity for children to develop the skills and functioning
18	needed for adult life. Improved outcomes may lessen the need for long-term supports when
19	children with autism become adults.
20	The Developmental Disabilities Division serves many adults with autism spectrum

disorders who have significant socialization, and language problems as well as significant

- 1 service needs. Most of these individuals did not have the opportunity to receive intensive
- 2 treatments as children. Addressing insurance coverage for children at the earliest possible age
- 3 will make a large impact on programs, and more importantly on the well-being of families.



DAVID Y. IGE GOVERNOR

SHAN S. TSUTSUI

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

CATHERINE P. AWAKUNI COLÓN DIRECTOR

JO ANN M. UCHIDA TAKEUCHI DEPUTY DIRECTOR

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

#### TO THE SENATE COMMITTEE ON WAYS AND MEANS

## TWENTY-EIGHTH LEGISLATURE Regular Session of 2015

Tuesday, March 3, 2015 9:05 a.m.

#### Written Testimony Only

### TESTIMONY ON SENATE NO. 791 – RELATING TO AUTISM SPECTRUM DISORDERS.

TO THE HONORABLE JILL N. TOKUDA, CHAIR, AND MEMBERS OF THE COMMITTEE:

My name is Gordon Ito, State Insurance Commissioner, testifying on behalf of the Department of Commerce and Consumer Affairs ("Department"). The Department takes no position on this bill, and submits the following comments.

This bill adds a new mandated health insurance benefit requiring insurers, mutual benefit societies, and health maintenance organizations to cover the treatment of autism spectrum disorders.

Adding a new mandated coverage may trigger section 1311(d)(3) of the federal Patient Protection and Affordable Care Act which requires states to defray the additional cost of benefits that exceed the essential health benefits in the state's qualified health plan.

We thank the 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
March 3, 2015

The Honorable Jill N. Tokuda, Chair Senate Committee on Ways and Means Twenty-Eighth Legislature State Capitol State of Hawaii Honolulu, Hawaii 96813

Dear Senator Tokuda and Members of the Committee:

SUBJECT: SB 791 - Relating to Autism Spectrum Disorders

The State Council on Developmental Disabilities (DD) **SUPPORTS THE INTENT OF SB 791.** The bill requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism diagnosis and treatment.

According to the U.S. Centers for Disease Control and Prevention's Autism and Developmental Disabilities Monitoring Network (2010), about 1 in 68 children have been identified with Autism Spectrum Disorder (ASD). That rate is anticipated to significantly increase within the next decade.

SB 791 proposes to provide coverage for individuals under the age of 11 years with coverage for treatment to a maximum benefit of: 1) \$30,000 per year for services for a maximum of four years between the ages of three to nine; or 2) \$30,000 per year for services for children ages zero to six and \$25,000 per year for services for children ages seven to ten, provided that limits shall be evidence-based.

The Council believes that individuals over the age of 11 years definitely continue to progress and benefit from evidenced-based treatment and therapy. Whereas, children with ASD provided with early treatment and therapy, such as "applied behavior analysis," learn meaningful skills of interacting and coping essentially increasing their independence and preparing them for adulthood. Moreover, services provided early on may decrease or minimize long-term services and supports needed as the child becomes an adult and through the individual's lifetime. Individuals with ASD may require treatment early on and taper off as they get older into adulthood. The amount of treatment can vary according to the severity of the person's ASD.

We appreciate the bill's initiative to provide coverage to individuals 11 years of age and under. Recognizing that ASD is a lifelong condition that may require lifelong services, the Council respectfully asks for your consideration to amend

The Honorable Jill N. Tokuda Page 2 March 3, 2015

the bill to delete the age limit. However, should your Committee decide to set an age limit, we recommend two options for your consideration:

- 1. Age 26 years, which would be consistent with what children are now covered under the Affordable Care Act.
- 2. Age 21 years, which would be consistent with Medicaid coverage.

Thank you for the opportunity to provide testimony **supporting the intent of SB 791 and offer an amendment** for your consideration.

Sincerely,

Waynette K.Y. Cabral, M.S.W.

**Executive Administrator** 

Rosie Rowe

Rasie Rome\_

Chair

#### **Board of Directors**

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### COMMENTS ON S.B. 791, RELATING TO AUTISM SPECTRUM DISORDERS

# THE SENATE THE TWENTY-EIGHTH LEGISLATURE REGULAR SESSION OF 2015 COMMITTEE ON WAYS AND MEANS

Tuesday, March 3, 2015, 9:05 a.m., Conference Room 211

The Honorable Jill N. Tokuda, Chair The Honorable Ronald D. Kouchi, Vice Chair

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

This bill would enact cost-sharing legislation similar to laws enacted in more than thirty States to require health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism diagnosis and treatment. No appropriation of State funds is required.

#### I. Actuarial Report - Cost of Autism Insurance Coverage

The actuarial report required by Act 185, Hawaii Session Laws 2014, estimates that the cost to policyholders of providing for treatment of autism spectrum disorder through applied behavior analysis would be \$24.00 per year in 2015, or \$2 per month. The total cost for 362,000 policyholders (Wakely Appendix D, page 2) would be, therefore, \$8,688,000 per year.

#### II. Need for Additional Funding of Autism Treatment

- 1. Twenty-five years ago, only 1 in 200 children (0.5%) had autism, about 85 of the 17,000 born that year; all but 3 or 4 (1 or 2 in 10,000) were misdiagnosed with other disorders, including mental retardation or developmental disability. Today, the Centers for Disease Control (Autism and Developmental Disabilities Monitoring Network (2010)) estimates that autism affects 1 in 68 births (almost 1-1/2% of 19,000 births). Autism cases in Hawaii, therefore, have more than tripled over the past 25 years from approximately 80 to 280 new cases each year. Large numbers of children with autism are just now beginning to reach adulthood, a "tsunami" that will present a public health crisis in the near future.
- 2. This worrisome increase is mostly a new social condition what we know about the symptoms and causes show that society has not faced this condition before, which is why we are so unprepared. Because of this there has been a dramatic increase in research by the

federal government and many private groups such as Autism Speaks. However promising this sounds, we are still stuck with an unknown number of years of an extremely expensive condition.

- 3. The best estimate of the lifetime costs of care (done by the Harvard School of Public Health) is \$3.2 million per person, averaging \$42,000 per year over a lifetime of 75 years. The majority of the costs must be borne by the State, as few families can afford bearing the expense themselves.
- 4. The cost of lifetime care can be reduced in many cases through appropriate treatment at an early stage of life. Autism is a neurologic condition in which the inner connections in the brain are mis-wired. This is a physical fact, so it does not respond to the usual medical treatments like medications and surgery. The reason for this is that the brain is a different organ than the heart, lungs, kidneys, etc. Brain function is based on our experience with the environment. Thus, correction of mis-wiring requires corrective changes in the child's life experience. These changes require intensive exposure to positive, corrective social behavior and language experience. This is why medical insurance has previously not covered these social and language treatments, seeing them as 'habilitative'. However, current neuroscience, genetics and brain imaging all point to the benefits of the kind of behavioral and social-language treatments that this Bill is proposing. There is also abundant evidence-based data showing that these treatments are effective and do reduce long-term impairment. What's important is that the earlier autism is diagnosed and given effective treatment, the better is the outcome and the less the financial impact on families and the state.
- 5. The reason that universal insurance coverage for autism treatments is so important is the fact that it involves all social and ethnic groups. Thus, insurance needs to be broad-based. Fortunately, the experience of 30+ other states shows that autism insurance causes a very small increase in insurance costs given the broad base of the condition.

#### III. No Appropriation of State Funds Required

In a message transmitting the actuarial analysis by Wakely Consulting Group, the Insurance Commissioner interpreted Section 1311(d)(3) of the ACA, 42 U.S.C. § 18031(d)(3), to require the State to fund the cost of autism mandates. While some health insurance carriers have taken that position, *see* Kaiser Health Newsletter attached, their interpretation is inconsistent with the clear language of the ACA.

Under ACA Section 1311(d)(3), 42 U.S.C. §18031(d)(3), the State must pay for insurance mandates that are in addition to the ten "essential health benefits" specified in ACA Section 1302(b), 42 U.S.C. § 18022(b). The coverages mandated by this Bill are *included* in those categories, and the Bill does not mandate additional benefits.

This Bill would mandate coverage for (1) behavioral health treatment; (2) pharmacy care; (3) psychiatric care; (4) psychological care; and (5) therapeutic care. Section 2(n) ("treatment for autism"):

• Items (1), (3), and (4) are included in the ACA's "essential health benefits" for "Mental

health ... services, including behavioral health treatment." ACA Section 1302(b), 42 U.S.C. § 18022(b)(1)(E);

- Item (2) is included in "Prescription drugs." 42 U.S.C. § 18022(b)(1)(F);
- Item (5) includes speech pathology, occupational therapy, physical therapy, and social worker care. Those are included in "Rehabilitative and habilitative services." 42 U.S.C. § 18022(b)(1)(G).

The Bill's mandates exceed the "benchmark plan" (HMSA's Preferred Provider Plan), but the ACA does not require the State to pay for benefits that exceed the benchmark plan if they are "essential health benefits." There is, therefore, no reason why the State would be liable for the additional premiums, but even if were, the cost would be a small fraction of the annual cost of lifetime care.

#### IV. Additional Concerns

- 1. Section 2 of the Bill (adding HRS §431:10A-\_\_(a)) and Section 3 (adding HRS §432:1-\_\_(a)) would limit benefits to children under eleven years of age. S.B. 2054 (2014), however, included individuals to age 21. A higher age limit (to age 26, the age limit for dependent coverage under the ACA) should be enacted because the lack of treatment services in the past has increased the need for treatment of older individuals. In the future, a reduction of age eligibility might be reasonable.
- 2. Benefit limits in HRS §431:10A-\_\_(d) and HRS §432:1-\_\_(c) are substantially lower than last year's bill -- \$25,000 per year instead of \$50,000 for a much shorter period. ABA therapy, to be successful, would require higher benefits in many cases. Wakely's actuarial report is based on the previous benefit levels, and there is no basis for believing that the lower benefits would result in appreciable cost savings. In fact, they may result in waste if treatment ends prematurely so that potential benefits are not attained.
- 3. Subsection (f) provides that an insurer may request a review of treatment plans, but it does not specify any procedures or standards for such review or who would bear the cost.

Thank you for the opportunity to testify.

Respectfully submitted,

Ryan Lee, M.D. President, Autism Society of Hawaii

John P. Dellera, J.D. Legislative Committee



### **Health Law Tempers New State Coverage Mandates**

By Michelle Andrews | September 16, 2014



This KHN story can be republished for free. (details)

For decades, states have set rules for health coverage through mandates, laws that require insurers to cover specific types of medical care or services. The health law contains provisions aimed at curbing this piecemeal approach to coverage. States, however, continue to pass new mandates, but with a twist: Now they're adding language to sidestep the health law, making it tougher than ever for consumers to know whether they're covered or not.



State coverage mandates vary widely.

They may require coverage of broad categories of benefits, such as emergency services or maternity care, or of very specific benefits such as autism services, infertility treatment or cleft palate care. Some mandates require that certain types of providers' services be covered, such as chiropractors. They may apply to

all individual and group plans regulated by the state, or they may be more limited.

While patient advocates view state mandates as a crucial tool in their efforts to address coverage shortcomings, the insurance industry generally opposes mandates, saying they drive up the cost of insurance.

Since the health law established a comprehensive set of "essential health benefits" that

individual and small group plans must cover (unless they existed prior to passage of the law in 2010), it was hoped that mandates would no longer be much in demand, says Sabrina Corlette, project director at Georgetown University's Center On Health Insurance Reforms.

Mandates are "not the most rational way to build a benefit package," says Corlette.

To discourage states from passing mandates that go beyond essential health benefits requirements, the law requires states, not insurers, to cover the cost of mandates passed after 2011 that apply to individual and small group plans sold on or off the state health insurance marketplaces. If a mandate increases a plan's premium, states will be on the hook for the additional premium cost that's attributable to the mandate.

The payment requirement is waived until 2016, says Kelly Brantley, a senior manager at Avalere Health who's looked at mandates related to infertility coverage, and regulations describing how the process will work haven't yet been issued.

Rather than forgoing mandates altogether, some states are simply excluding from the mandates plans that the states would have to pay for. The result: Consumers who buy individual or small group plans may not get the mandated benefits that are required in large group plans. (Self-funded plans, used by many large employers to pay employee claims directly rather than buying insurance for that purpose, aren't bound by state mandates.)



That's what's happening with state mandates related to autism coverage, says Lorri Unumb, vice president of state government affairs at Autism Speaks, an advocacy group.

By the group's count, 37 states and the District of Columbia have <u>mandates requiring</u> <u>autism coverage</u>. In 26 states, autism coverage is part of the essential health benefits, typically because coverage was mandated before 2012 and so was included in that state's "benchmark" plan that sets the standard for coverage there.

New mandates are different. "For the most part, the states that have passed autism mandates post Dec. 31, 2011, have excluded ACA-compliant plans from the mandate,"

Unumb says.

States have taken different approaches to structuring new mandates so they don't have to pay for them, says Justin Giovannelli, a research fellow at Georgetown's Center on Health Insurance Reforms, who has examined state laws in this area. The law may say that the mandate only applies to large group plans, for example, or that it doesn't apply to any plans that are required to provide the essential health benefits. A state may say that if the mandate increases premiums by a certain percentage the provision doesn't apply.

Confused? Policy experts fear consumers will be too.

"Your state has passed a law but everything is so market specific it's hard to know what coverage you're getting," says Katie Keith, research director at the Trimpa Group, a consultant for autism and other advocacy groups.

Although some states are trying to sidestep having to pay for new mandates by limiting which plans are included, advocates say uncertainty about who is going to have to foot the bill is having a chilling effect overall.

Last year, the California legislature sent a bill to Gov. Jerry Brown that would have mandated that large group plans cover fertility preservation services such as freezing eggs or sperm for cancer patients and others who are facing medical treatments that might cause infertility.

The governor vetoed the mandate, even though the state would not have been required to pay for it because it didn't apply to small group or individual plans. In his veto message, the governor said that "we should not consider mandating additional benefits until we implement the comprehensive package of reforms that are required by the federal Affordable Care Act."

"It's bad for consumers in many respects," says Barbara Collura, president and CEO of Resolve, an infertility advocacy group. "Because of the uncertainty [about state payment obligations for mandated benefits], no one really knows how this will work, and uncertainty causes people not to want to do anything."

This story has been updated to correct Justin Giovannelli's title.



#### **Easter Seals Hawaii**

Administrative Offices 710 Green Street Honolulu, Hawaii 96813 Phone: 808.536.1015 Toll Free: 888.241.7450

Fax: 808.536.3765

March 2, 2015

To: COMMITTEE ON WAYS AND MEANS

Senator Jill N. Tokuda, Chair

Senator Ronald D. Kouchi, Vice Chair

From: Ron Brandvold, President & CEO

Re: Support the Intent of SB 791, RELATING TO AUTISM SPECTRUM DISORDERS Hearing Scheduled for March 3, 2015 (9:05 am)

For over 60 years, Easter Seals Hawaii has provided exceptional, individualized, family-centered services to empower infants, children, youth and adults with disabilities or special needs to achieve their goals and live independent fulfilling lives. Easter Seals Hawaii is a statewide CARF accredited organization with 15 facilities from Waimea, Kauai to Hilo, Hawaii providing a variety of programs including Autism Services. These services include Applied Behavior Analysis /Verbal Behavior-Based Therapy, Speech/Language Pathology, Assessment, Training, Education and Consultation. Easter Seals Hawaii strongly supports mandated coverage for services to individuals within the Autism Spectrum and therefore supports the intent of SB 791 and offers the following recommendations:

#### 1. Amend the Age and the Annual Maximum Benefit

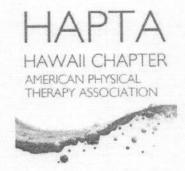
To adequately address the needs of individuals within the Autism Spectrum, amend the mandated benefit age cap to provide medically necessary services through age 21 yrs. to encompass the EPSDT as well as the IDEA eligibility range.

Amend the mandated annual benefit cap to \$50,000 per year to ensure the effective support of those individuals needing intensive Applied Behavior Analysis at 30-40 hours a week. Applied behavior analysis is included in SB 791 definition of "behavioral health treatment" as an evidence-based intervention necessary to develop, maintain, or restore to the maximum extent practicable, the functioning of an individual. A lower benefit cap may be a barrier to reaching that objective.

#### 2. Creation of the Process for Licensure

Without the provisions for licensure, access to BCBAs and therefore services will continue to be severely constricted. Easter Seals Hawaii is aware of and supports other proposed legislation related to licensure (SB40/SD2) welcomes the opportunity to work with this Committee and other community stakeholders to address this issue.

Thank you for your willingness to collaborate as demonstrated by the inclusion of the many amendments discussed in last year's session.



Chair Jill Tokuda and Senate Members Ways and Means Committee

SB791 RELATED TO AUTISM SPECTRUM DISORDERS Tuesday, 3/3/15 9:05 am, Room 211

Position: SUPPORT

Chair Tokuda and members of the Ways and Means Committee,

The Hawaii Chapter of the American Physical Therapy Association (HAPTA) is a non-profit professional organization serving more than 300 member Physical Therapists and Physical Therapist Assistants. Physical Therapists within the school system, Early Intervention and many private pediatric practices work with children on the Autism Spectrum on a daily basis. The chapter supports SB 791 which would provide requisite coverage for autism diagnosis and treatment by health insurers, mutual benefit societies, and health maintenance organizations. Thirty other states have enacted similar legislation.

We would like to testify in support of this legislation. According to the U.S. Centers for Disease Control and Prevention (2010) the prevalence of Autism Spectrum Disorder (ASD) was approximately 1 in 68 children which represents a significant rise over the past twenty years. Similarly, the costs of caring for these individuals across their lifetime has also sharply increased. The research has shown that ASD is a neurodevelopmental disorder which cannot be cured. However, research has indicated that there are measurable benefits to the type of behavioral and social-language treatments that this Bill is proposing. Furthermore, data demonstrates the efficacy of the treatment in long-term reduction in impairments. Early diagnosis and the introduction of effective treatment will improve overall functional outcomes for these children. Furthermore, a decrease in the cost of care over the individual's lifetime, which are often the responsibility of state programs, will also decrease.

A neurodevelopmental disorder is defined by the American Academy of Developmental Medicine as a precise genetic or acquired biological brain disorder or condition that is responsible for childhood-onset brain dysfunction. Therapeutic Care as defined in Item (5) includes speech pathology, occupational therapy, physical therapy and social worker care. Insurances in Hawaii has covered these services when treatment is aimed at the "reduction of disability and restoration to the best possible level of functional" for other developmental disorders such as cerebral palsy. The coverage mandated in this Bill will provide the same level of coverage to the

One concern is the limitation of the benefits to children under eleven years old. ASD is a lifelong disorder. The Patient Care and Afford Care Act includes an age limit for

dependent children to age 26. We believe a higher age limit should be considered to ensure these much needed services for this population.

HAPTA, therefore, submits this testimony in support of SB791 because no child with an Autism Spectrum Disorder in the State of Hawaii should go without proper treatment due to the cost of services. They should have the opportunity, like other children with neurodevelopmental disorders, to reach their highest potential with the possibility for independent living and to be a contributing member of our community.

Thank you for this opportunity to submit testimony on this very worthwhile Bill.

Cindy Tamayo, PT, MA

Legislative Committee

Hawaii Chapter of the American Physical Therapy Association

Gregg Pacillio, P.T.

President

Hawaii Chapter of the American Physical Therapy Association



#### Testimony of Phyllis Dendle Director, Government Relations

#### Before:

Senate Committee on Ways and Means The Honorable Jill N. Tokuda, Chair The Honorable Ronald D. Kouchi, Vice Chair

> March 3, 2015 9:05 am Conference Room 211

#### SB 791 RELATING TO AUTISM SPECTRUM DISORDERS

Chair Tokuda and committee members thank you for the opportunity to provide testimony on this bill to mandate coverage of treatment for autism spectrum disorders.

#### Kaiser Permanente Hawaii supports this bill.

Kaiser Permanente Hawaii supports passage of legislation to mandate insurance coverage for individuals with an autism spectrum disorder that is evidence based and focused on the care and treatment of the patient. We believe that patients should be tested and diagnosed in accordance with the guidelines provided by the American Academy of Pediatrics. We believe that the mandate should provide coverage when it is most likely to provide the maximum benefit for the individual. In addition, we want to assure that the providers of the treatment for these individuals are appropriately credentialed and regulated because of the vulnerability of the individuals they are serving.

Kaiser Permanente has testified in favor of a mandate as described above and has sought to amend legislation which did not meet these standards without much success for the last two legislative sessions. We are happy to see and to support SB 791 introduced by Senators Josh Green, Rosalyn Baker and Russell Ruderman. We believe this is the right way to cover this kind of care and we believe it is time to do so.

We recommend that the date left blank on page 1 line 10, page 8 line 11 and page 16 line 2 be January 1, 2017.

Thank you for your consideration.

711 Kapiolani Blvd Honolulu, Hawaii 96813 Telephone: 808-432-5210 Facsimile: 808-432-5906 Mobile: 808-754-7007 E-mail: phyllis.dendle@kp.org

## TESTIMONY OF THE AMERICAN COUNCIL OF LIFE INSURERS COMMENTING ON SENATE BILL 791, RELATING TO AUTISM SPECTRUM DISORDERS

March 3, 2015

Via e mail: WAMtestimony@capitol.hawaii.gov

Honorable Senator Jill N. Tokuda, Chair Committee on Ways and Means State Senate Hawaii State Capitol, Conference Room 211 415 South Beretania Street Honolulu, Hawaii 96813

Dear Chair Tokuda and Committee Members:

Thank you for the opportunity to comment on SB 791, relating to Autism Spectrum Disorders.

Our firm represents the American Council of Life Insurers ("ACLI"), a Washington, D.C., based trade association with more than 284 member companies operating in the United States and abroad. ACLI advocates in federal, state, and international forums for public policy that supports the industry marketplace and the 75 million American families that rely on life insurers' products for financial and retirement security. ACLI members offer life insurance, annuities, retirement plans, long-term care and disability income insurance, and reinsurance, representing more than 90 percent of industry assets and premiums. Two hundred nineteen (219) ACLI member companies currently do business in the State of Hawaii; and they represent 92% of the life insurance premiums and 89% of the annuity considerations in this State.

As drafted, SB 791 would amend Article 10A of Hawaii's Insurance Code to require all individual and group <u>accident and health or sickness insurance policies</u> issued or renewed after a stated date to provide coverage for the diagnosis and treatment of autism spectrum disorders for individuals under 11 years of age.

By its terms, <u>Article 10A of the Code (by reference to HRS §431:1-205)</u> <u>defines "accident and health or sickness insurance" to include disability income insurance</u>.

Disability income insurance provides cash payments designed to help individuals meet ongoing living expenses in the event they are unable to work due to illness or injury. Unlike health insurance disability income insurance does not provide coverage for the insured's health care or medical treatment; further, the cash payments are made directly to the insured – not to the insured's health care providers. Finally, the disability insurance policy typically does not dictate how the cash payments received by the insured are to be used by the insured.

ACLI submits that the intent and purpose of this bill is to require only health insurers to provide coverage for autism spectrum disorders – not disability income insurers.

In order to dispel any confusion as to what this bill is intended to cover, ACLI suggests that paragraph (b) of the new section proposed to be added to §431: 10A (beginning at line 13, page 1 of the bill, be amended as follows:

(b) This section shall not apply to <u>disability</u>, accident-only, <u>mMedicare</u>, <u>mMedicare</u> supplement, student accident and health or sickness insurance, dental-only, and vision only policies or policies or renewals of six months or less.

Again, thank you for the opportunity to comment on SB 791.

LAW OFFICES OF OREN T. CHIKAMOTO

A Limited Liability Law Company

Oren T. Chikamoto

1001 Bishop Street, Suite 1750

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E mail: otc@chikamotolaw.com



March 2, 2015

Senate Committee on Ways and Means Senator Jill Tokuda, Chair Senator Ronald Kouci, Vice Chair

State Capitol 415 South Beretania St Honolulu, HI 96813

Re: In Support of SB791

Relating to Health. Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism diagnosis and treatment.

Dear Chair Tokuda, Vice Chair Kouci, and Members of the Committee:

I am Lorri Unumb, Vice President for State Government Affairs at Autism Speaks and the parent of a child with autism. Autism Speaks is the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Our state government affairs team has played a role in most of the now 38 states that have enacted autism insurance reform laws. Autism Speaks is pleased to submit testimony in strong support of SB791.

In previous sessions, Autism Speaks has testified to this committee in support of mandatory health insurance coverage for autism spectrum disorder including Applied Behavior Analysis (ABA). We have shared an overview of autism spectrum disorders and our national experience with autism insurance legislation. Our testimony has included a discussion of the epidemic increase in prevalence of autism; research documenting the efficacy of ABA therapy; actual claims data from states which were among the first to enact autism insurance reform laws; and the long-term cost savings and fiscal imperative of autism insurance reform.

Autism Speaks strongly supports SB 791 and makes note of the following items for consideration during the committees' deliberations:

#### Page 1, line 9: "issued or renewed in this State after January 1"

According to the National Association of Insurance Commissioners, Hawaii applies mandated coverage for the benefit of its residents if the residents work for (and receive insurance from) an employer who has a branch office or principal place of business in Hawaii, regardless of whether the policy was written in Hawaii, so long as the language of the mandate supports such application. To prevent Hawaii residents whose policies happen to be written elsewhere from losing the benefit of this mandate, Autism Speaks recommends striking "in this State" from line 9.

#### Page 1, line 11: "under eleven years of age"

Autism Speaks opposes artificially-drawn age caps and believes such caps violate federal mental health parity law. (See Final Rules Under Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, 78 Fed. Reg. 68240.)

Should the legislature decide to nevertheless include an age cap, it is imperative that the cap be applied only to "behavioral health treatment" and not to all autism –related treatment, such as medications, psychiatric care, etc. Given that "behavioral health treatment is already limited by age in paragraph (d), Autism Speaks recommends striking "under eleven years of age" from paragraph (a).

Page 2, line 9: "coverage for treatment provided under this section"
Autism Speaks recommends changing this language to "coverage for behavioral health treatment under this section" in order clarify that only behavioral health treatment is subject to paragraph d's age and dollar restrictions and to be consistent with the final sentence of paragraph (d), which states that payments made for treatment other than behavioral health treatment shall not be applied to any maximum benefit established under this subsection.

#### Page 2, paragraph (d):

Autism Speaks opposes artificially-drawn dollar limits on treatment and believes such limits violate federal mental health parity law.

Such limits also ensure that children whose parents pay for private health insurance receive inferior coverage to children on Medicaid, since Medicaid coverage under the Early and Periodic Screening Diagnostic and Treatment program is limited only by medical necessity and not by random dollar limits.

With regard to the age restrictions, note that autism is a lifelong condition. While more intense "comprehensive" ABA therapy to address multiple treatment goals is most commonly prescribed at a younger age, "focused" ABA therapy to address isolated maladaptive behaviors may be required at times throughout the lifespan. Recognizing this fact, the median age cap on ABA in the 38 other states that require autism coverage is 21 years. Seven states impose no age cap on coverage for ABA. Due to the fact that treatment intensity decreases with age, a higher age cap would have a negligible impact on cost of the benefits. In the legislature decides to include an age cap, Autism Speaks recommends that the cap be set either at age 21, to be

consistent with Medicaid coverage for ABA, or age 26, the age at which children are no longer dependents under the Affordable Care Act.

Page 3, line 7: "provisions for other medical services covered by the policy" In this paragraph ensuring financial parity for autism treatments, Autism Speaks recommends that the language be amended to read "provisions for substantially all medical services covered by the policy." Pursuant to federal mental health parity law, the "substantially all" standard is the appropriate measure by which to gauge whether a mental health benefit is being treated on par with non-mental health benefits. See attached explanation from United Healthcare.

Page 3, paragraphs (f) and (g): "Except for inpatient services"

Autism Speaks questions whether the sentences permitting insurers to review medical necessity and continued authorization are meant to exclude inpatient services. Autism Speaks also questions whether the sentences in paragraphs (f) and (g) are duplicative, as it is our understanding that reviewing a treatment plan for continued authorization of coverage is the same as reviewing for medical necessity.

Page 4, lines 7-8: "Services and supplies that are not clinically appropriate"
Autism Speaks recommends changing this language to "Services and supplies that are not medically necessary," since medical necessity is the governing standard.

#### Page 4, line 11: "Services provided outside of the State"

Autism Speaks recommends striking this line. Should an individual with autism require, for example, intensive, inpatient treatment at a specialized autism center such as the Kennedy Krieger Institute in Baltimore, which has a program especially for severely aggressive or self-injurious children, there is no reason why the child's health insurance should not cover an otherwise coverable service simply because the treatment occurs outside the State. Such a limitation likely violates federal mental health parity law, unless substantially all medical services are likewise restricted to in-state treatment. So, if, for example, a resident of Hawaii with private health insurance would be able to seek treatment at the Mayo Clinic for a rare heart condition and receive coverage for such treatment, then a resident of Hawaii with autism must be able to likewise receive coverage for medically necessary, out-of-state treatment.

#### Page 4, paragraph (i):

While Autism Speaks is in favor of creating coverage for as many Hawaii insureds as possible, including those who purchase Affordable Care Act plans, we simply wish to alert the committee that including Applied Behavior Analysis (ABA) benefits in Affordable Care Act plans may trigger a cost to the state. Under the ACA, states must defray the cost of a mandate that exceeds the essential health benefits. At present, Applied Behavior Analysis is not an Essential Health Benefit based on the benchmark plan selected for Hawaii. (ABA is an Essential Health Benefit in a majority of states.) However, it is unclear at this point whether the state will incur a cost for adding this benefit, because the U.S. Department of Health and Human Services has not yet announced whether the Essential Health Benefits package will continue to be based on a state's benchmark for 2017 and beyond. Further, it is possible that the new benefits set forth in SB791

will not be considered "new" or in excess of the Essential Health Benefits (and thus will not trigger a cost), because they are "habilitative" in nature and the U.S. Department of Health and Human Services has stated that mandates enacted to fulfill the obligation to include "habilitative services" as an Essential Health Benefit will not be deemed "new" mandates. *See* Final Rules under Patient Protection and Affordable Care Act, HHS Notice of Benefit and Payment Parameters for 2016, 80 FR 10749 (February 27, 2015) ("States are required to supplement the benchmark plan if the base benchmark plan does not include coverage of habilitative services as defined in this final rule. We are codifying the definition of habilitative services as a minimum for States to use when determining whether plans cover habilitative services. State laws regarding habilitative services are not pre-empted so long as they do not prevent the application of the Federal definition. State laws enacted in order to comply with § 156.110(f) are not considered benefits in addition to the EHB; such laws ensure compliance with § 156.110(a) which requires coverage of all EHB categories. Therefore, there is no obligation to defray the cost of such State-required benefits.")

#### Page 5, paragraph (I):

Autism Speaks recommends that this paragraph be stricken. There is no scientific justification for requiring all individuals with well-established ASD diagnoses using valid instruments under the DSM in effect at the time of diagnosis to undergo re-evaluation upon publication of a new edition of the manual. Such re-evaluation might be called for on a case-by-case basis where the presentation of symptoms suggests it, but a bright-line rule that simply requires all individuals to be re-diagnosed is not sound, would serve to prevent timely access to care, and would further exacerbate waiting lists for diagnoses that currently exist.

#### Page 5, paragraph (m):

Although there is currently no license in Hawaii for behavior analysts (the professionals who provide and supervise ABA programs), Autism Speaks can support this approach so long as the legislature understands that a license will need to be created for behavior analysts within one year of the implementation of this benefit, per subparagraph (1). The Senate is moving such a licensure bill, SB40, which Autism Speaks supports; both the Commerce and Consumer Protection committee and this committee have considered and passed SB40. Autism Speaks does not support any requirement that requires or permits any other type of licensed professional to oversee Board Certified Behavior Analysts.

Page 6, line 9: "Autism has the same meaning as defined by the most recent" DSM. The term "Autism" is not defined in the DSM; only "Autism Spectrum Disorder" is defined. As such, the term being defined in the bill should be "Autism Spectrum Disorder."

Thank you for considering my comments. We encourage the committee to pass SB791 and look forward to working with you and the health plans to reach consensus on acceptable terms of coverage.

Respectfully submitted,

Komi Swely Ulmb

Lorri Shealy Unumb Vice President, State Government Affairs Autism Speaks

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- Regulations published as the Interim Final Rule are effective on the first day of the plan year beginning or renewing on or after July 1 and must be complied with even though it is not the Final Rule.
- The U.S. Department of Labor (DOL), Department of The Treasury and Centers for Medicare and Medicaid Services (CMS) are seeking feedback on the interim final regulations via an open comment period which ends May 3.
- Regulations are not applicable to Medicaid Managed Care Plans. Separate regulations will be provided from CMS for those plans, but they are still subject to the law.

#### **Benefit Requirements**

Establish six classifications of benefits: Parity for treatment limits and financial requirements defined by the regulations, is to be applied classification by classification:

- 1. Inpatient In-Network
- 2. Inpatient Out-of-Network
- 3. Outpatient In-Network
- 4. Outpatient Out-of-Network
- 5. Emergency
- 6. Prescription Drugs
- The definitions of what constitutes Inpatient, Outpatient and Emergency are not defined by the regulations but instead defined by the plan or applicable state law. However, the terms cannot be defined differently for mental health/substance use disorder than for medical/surgical.
- Benefits for mental health and substance use disorder are not mandated, but to
  the extent benefits are provided in one of the six classifications, they must be in
  parity with that classification's medical benefits. Plans are not required to cover
  all mental health conditions or all substance use disorders but may define which
  they will or will not cover. Fully-insured plans are still subject to state mandates
  which may require certain mental health or substance use disorder benefits.
- Financial requirements and quantitative treatment limitations must be in parity
  with the requirements and limitations applied to substantially all benefits for the
  applicable classification on medical benefits. "Substantially all" means the
  requirement/limitations apply to at least two-thirds of the benefits in that
  classification.
- Regulations do not allow recognition of distinction between primary and specialty financial requirements/treatment limitations for parity purposes.
- Regulations prohibit separate cost sharing, e.g., no separate but equal deductibles or out-of-pocket maximums.
- Parity applies to non-quantitative limits and specifically lists the following

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classifications and specifies these **must** be in parity:

- Medical management standards, such as medical necessity
- Formulary design for prescription drugs
- Standards for provider admission to network, including reimbursement rates
- Plan methods for determining usual and customary rates Fail-first or step therapy requirements (e.g., must try certain treatment before obtaining approval for another treatment
- Exclusions for failure to complete a course of treatment These limits must be comparable to and applied no more stringently for mental health/substance use disorder benefits than they are for medical benefits.

#### **Product Requirements**

- Employee Assistance Program (EAP) gatekeeper models are prohibited.
- A plan sponsor cannot avoid parity requirements by establishing a separate group health plan for mental health/substance use disorder benefits.
- Plan sponsors with multiple medical benefit plans but a single mental health/substance use disorder plan must ensure compliance for parity purposes between the mental health/substance use disorder benefit plan and each medical plan.
- No guidance is available yet on cost exemption. (This remains under development)

#### **Parity Relevance**

Federal Mental Health Parity is relevant to all group health plans (fully insured and self-funded) with few exceptions, such as self-funded non-ERISA government (non-federal) plans that have expressly opted out under existing law and groups with 50 or fewer total employees.

#### **Reference Materials**

The Federal Mental Health Parity – A Summary of the Interim Final Rules: What You Need to Know <a href="broken: brochure">brochure</a> provides an overview of the new Federal Mental Health Parity regulations. The document highlights the key provisions, including implementing parity regulations for financial requirements and treatment limitations.

For more information please contact your UnitedHealthcare representative.

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3/3/15 COMMITTEE ON WAYS AND MEANS Senator Jill N. Tokuda, Chair Senator Ronald D. Kouchi, Vice Chair

> Conference Room 211 Hawaii State Capitol 415 South Beretania Street

My name is Anne Lau and I am the Clinical Director of the Autism Behavior Consulting Group clinic. I am writing to show my **SUPPORT** for **SB 791 with amendments**.

I have been working in the field of Applied Behavior Analysis (ABA) here in Hawai'i for over 10 years. I have seen the difficulties that parents have had in trying to secure the services that their doctors were recommending. I have seen families cash in their life savings, sell their house, and go into nasty battles with school districts.

The scientific research is very clear (Eldevik, et.al. 2010, Rogers & Vismara, 2008, Cohen, Amerine-Dickens, & Smith, 2006, Sallows & Graupner, 2005, Howard, et. al. 2005, Eikeseth, et. al. 2002, Smith, Green, & Wynn, 2000, McEachin, Smith, & Lovaas, 1993, Lovaas, 1987) that children with autism can make substantial gains with ABA, and those that are receiving intensive treatment, defined as 30-40 hours of treatment per week for several years, can in fact lose the symptoms of autism that would have prevented them from benefiting from a general education placement, gaining employment, and living as an independent adult. Autism is treatable and families should be able to rely on their health insurance to cover standard treatments that are recommended by their doctors.

This particular bill has several problems:

- This bill would not require treatment after age 11. There is NO clinical rational for limiting treatment services based on age. If anyone is saying otherwise, I would request for their references on this matter.
- The fiscal benefits, not to mention the benefits for the people surrounding a patient, are available for people of any age with severe problem behaviors. Applied Behavior Analysis services should be available when it is medically appropriate, as determined by a patients doctor.

Thank you for your time and for hearing my point of view of why you should amend SB 791

Respectfully, Anne Lau, M.Ed., BCBA Clinical Director Clinical Director



**E-mail:** info@autismbehaviorconsulting.com www.AutismBehaviorConsulting.com

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#### Testimony to the Senate Committee on Ways and Means Tuesday, March 3, 2015 at 9:05 A.M. Conference Room 211, State Capitol

#### **RE:** SENATE BILL 791 RELATING TO AUTISM SPECTRUM DISORDERS

Chair Tokuda, Vice Chair Kouchi, and Members of the Committee:

The Chamber of Commerce of Hawaii ("The Chamber") would like to **offer comments** on SB 791, which requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism diagnosis and treatment.

The Chamber is the largest business organization in Hawaii, representing about 1,000 businesses. Approximately 80% of our members are small businesses with less than 20 employees. As the "Voice of Business" in Hawaii, the organization works on behalf of members and the entire business community to improve the state's economic climate and to foster positive action on issues of common concern.

We appreciate the intent of the bill to help those with autism spectrum disorders. We also appreciate the advocates of this legislation fine tuning the bill from issues raised in prior hearings.

At the same time we have some concerns. First is the varied projected cost. While we recognize there were some different actuarial assumptions, the projected cost between the projections by Wakely and the projections by Oliver Wyman was over 50% more. This concerns us as no one has a clear idea of the true cost of this mandate.

Second is the timing of the mandate. It is our understanding that filings for the following year rates are submitted to Commissioner the prior spring. While the start date is blank, other dates suggest a timetable of next year. How will this work and how will employers see the increase in their premiums? In addition, what is the mechanism – both in process and appropriation – for the state's share to be paid for those businesses now covered under ACA that requires the state to pay for new mandates?

Third is the issue of licensure. The bill states that licensure will be handled by the Behavior Analyst Certification Board, Inc. We have some concerns that the state would allow an outside non-profit to designate approval for reimbursement. Also, this provision is at odds with the usual requirement of the Auditor to conduct a sunrise review of new licensed professions.

Lastly, as always, we have concerns on mandating new benefits. On average, ninety percent of the cost of an employee's health care premium is paid for by the employer.

Thank you for the opportunity to testify.





COMMITTEE ON WAYS AND MEANS Senator Jill N. Tokuda, Chair Senator Ronald D. Kouchi, Vice Chair

Hawaii State Capitol 415 South Beretania Street, Conference Room 211

Committee Chair, Vice Chair, and Committee Members,

#### I support the intent of SB791, with revisions.

My name is Amanda N. Kelly. I am a Board Certified Behavior Analyst at the Doctoral (BCBA-D™) level. I have been certified as a behavior analyst from the Behavior Analyst Certification Board (BACB™) for the past 10 years, and have been working with keiki with autism for the past 15.

#### Currently, I serve as:

- Executive Director, Keiki Educational Consultants, Inc. (Haleiwa, Hawai'i)
- K8 Counselor at Assets Elementary (Honolulu, Hawai'i)
- Adjunct Professor, University of West Florida's ABA online program
- Exam Prep Instructor, Global Autism Project (GAP)
- President, Hawai'i Association for Behavior Analysis (HABA)

#### First, a few facts:

- 1) Autism spectrum disorder (ASD) affects 1 in 68 children in the US, 1 in 54 boys
- 2) The only evidenced-based effective treatment is applied behavior analysis (ABA)
  - a. ABA is endorsed by the US Surgeon General, the American Academy of Pediatrics, the Center for Disease Control (CDC) and many other reputable agencies and experts.
  - b. ABA is recognized by the American Medical Association (AMA)
- 3) 38 States in the United States have passed meaningful Autism Insurance Mandates.
  - a. 12 States remain.
  - b. Hawai'i is the last democratic state remaining.
- 4) Behavior analysts are being reimbursed for their services as CERTIFIED professionals
  - a. Request for licensure have been used as stall tactics in many states
  - b. 18 states license behavior analysts and 1 state certifies (Ohio)
  - c. All states that require licensure, accept the BACB credentials
  - d. There is a current SB40/SD-3 that seeks to license Behavior Analysts. We are in favor of this piece of legislation.
- 5) Imposing age caps conflict with the mental health-parity law
  - a. Imposing dollar caps may conflict with intention of the affordable care act (ACA).
  - b. Medicaid has released a memo extending services through age 21.
  - c. There is long standing evidence of effectiveness of applied behavior analysis. When treatment is provided, results are obtained, across the life span (*see attached*).
  - d. Cutting services arbitrarily at any age, is both morally and fiscally reprehensible

The question no longer remains "will Hawai'i pass an autism insurance mandate" but "when will Hawai'i pass a autism insurance". We know it's the right thing to do, from a humanistic as well as a financial perspective. Waiting does damage to individuals affected with autism, their families, schools, and communities. Waiting misses valuable teaching opportunities. Waiting is something our keiki simply can't afford to do. I'm asking you to do what's right and #MalamaOurKeiki.

Many mahalos for the discussion on autism insurance reform in Hawai'i.

Sincerely,

Amanda N. Kelly, PhD, BCBA-D President, Hawai'i Association for Behavior Analysis

## Applied Behavior Analysis (ABA) for Autism: What is the Effective Age Range for Treatment? Eric V. Larsson, Ph.D., L.P., B.C.B.A.-D. (2012)

There is extensive research in the field of Applied Behavior Analysis (ABA) that shows the effectiveness of focused treatment of behavior disorders with children who suffer from autism who are between the ages of five to twenty-one.

In the research listed here, over 2,000 children and adolescents who were between the ages of five and twenty-one were documented as receiving effective ABA treatment.

In addition, the cost effectiveness of Early Intensive Behavioral Intervention (EIBI) for autism is also well documented. Much of the research emphasizes the need to treat the children at as young an age as possible, and this is certainly an important aspect of effective treatment. However, the following list of several hundred references also reports the clinically important impact of Applied Behavior Analysis (ABA) with children who are specifically *above* the age of seven.

For a child starting treatment at any age, the average length of intensive ABA treatment would be expected to be 3 years, and the range of medically necessary treatment durations has been shown to be from 18 months to 5 years of duration. Maximum cost effectiveness will be achieved when a competent authorization process involves evaluation of the child's response to treatment and prognosis every six months, as was typically done in the studies listed here. When applying such standards, the children would not automatically continue treatment indefinitely. Instead the intensity and duration would be tailored to each child's optimum effectiveness, by periodically evaluating each child's individual response to treatment, and thereby dramatically control costs by providing time-limited ABA for only so long as is medically necessary.

## These following studies reported meta-analyses of ABA treatment of children and adolescents with autism, between the ages of five and fifteen.

Reichow and Volkmar, in 2010, reported on 31 studies of children, aged four to fifteen, who benefited from ABA social skills training:

"The school-age category had the highest participant total of the three age categories (N = 291)." (page 156).

"Within the last 8 years, 66 studies with strong or acceptable methodological rigor have been conducted and published. These studies have been conducted using over 500 participants, and have evaluated interventions with different delivery agents, methods, target skills, and settings. Collectively, the results of this synthesis show there is much supporting evidence for the treatment of social deficits in autism." (page 161).

Reichow, B. & Volkmar, F.R. (2010). Social Skills Interventions for Individuals with Autism: Evaluation for Evidence-Based Practices within a Best Evidence Synthesis Framework. Journal of Autism and Developmental Disorders. 40, 149-166.

Bellini and colleagues, in 2007, reported the following age ranges of 155 children who benefited from ABA social skills training:

"21 studies involved preschool-age children, 23 involved elementary age children, and 5 studies involved secondary-age students." (page 158).

Bellini, S., Peters, J.K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. Remedial and Special Education, 28, 153-162.

## These following studies reported peer reviews of ABA treatment of children and adolescents with autism, between the ages of five and eighteen.

Brosnan and Healy, in 2011, reported on 18 studies of children aged three to 18, who received effective ABA treatment to reduce or eliminate severe aggressive behavior:

"All of the studies reported decreases in challenging behavior attributed to the intervention. Of the studies included, seven reported total or near elimination of aggression of at least one individual during intervention in at least one condition." (page 443).

"only four of the studies conducted follow-up assessments. However, each of these studies reported that treatment gains were maintained." (page 443).

Brosnan, J., & Healy, O. (2011). A review of behavioral interventions for the treatment of aggression in individuals with developmental disabilities. Research in Developmental Disabilities. 32, 437–446.

Lang, et al. in 2010, reported on nine studies which involved 110 children aged nine to 23, who received a variety of forms of behavior therapy for anxiety.

"Within each reviewed study, at least one dependent variable suggested a reduction

in anxiety following implementation of CBT." (page 60).

"CBT has been modified for individuals with ASD by adding intervention components typically associated with applied behaviour analysis (e.g. systematic prompting and differential reinforcement). Future research involving a component analysis could potentially elucidate the mechanisms by which CBT reduces anxiety in individuals with ASD, ultimately leading to more efficient or effective interventions." (page 53).

Lang, R., Regester, A., Lauderdale, S., Ashbaugh, K., & Haring, A. (2010). Treatment of anxiety in autism spectrum disorders using cognitive behaviour therapy: a systematic review. Developmental Neurorehabilitation, 13, 53–63.

Hanley, Iwata, and McCord in 2003, reported on 277 studies which involved 536 children and adults (70% of the studies included persons between the ages of 1 and 18, and 37% also included persons older than 18), who received functional analyses of problem behaviors. Of these, 96 percent were able to yield an analysis of the controlling variables of the problem behavior. The specific functional analysis of individual problem behaviors is crucial to the successful intervention with those behaviors.

"Large proportions of differentiated functional analyses showed behavioral maintenance through social-negative (34.2%) and social-positive reinforcement (35.4%). More specifically, 25.3% showed maintenance via attention and 10.1% via access to tangible items. Automatic reinforcement was implicated in 15.8% of cases." (pages 166-167).

Hanley, G., Iwata, B.A., & McCord, B.E. (2003). Functional analysis of problem behavior: A review. Journal of Applied Behavior Analysis, 36, 147-185.

Iwata and colleagues, in 1994, reported on the effective treatment of self-injurious behavior with 152 children, adolescents, and adults. In their sample, 39 were between the ages of 11 and 20, and 74 were 21 and older. The function of the self-injurious behavior could be identified in 95% of the persons, and in 100% of those cases an effective treatment could then be prescribed.

"Across all categories of intervention, restraint fading was the most effective, but its 100% success rate is misleading because it was always implemented in conjunction with another procedure. As single interventions, EXT (escape) had the highest success rate (93.5%); sensory integration and naltrexone had the lowest (0%)." (page 233).

"Results of the present study, in which single-subject designs were used to examine the functional properties of SIB in 152 individuals, indicated that social reinforcement was a determinant of SIB in over two thirds of the sample, whereas

nonsocial (automatic) consequences seemed to account for about one fourth of the cases." (page 234).

Iwata, B.A., Pace, G.M., et al. (1994). The functions of self-injurious behavior: An experimental-epidemiological analysis. Journal of Applied Behavior Analysis, 27, 215-240.

## The following studies reported age cut-offs *for initiating* EIBI up to the age of seven years (84 months) and completing treatment up to the age of twelve.

Several articles of note are highlighted that report the effectiveness of EIBI/ABA that was delivered to children who *started* treatment even up to the age of seven, and then continued treatment for up to five more years, up until the age of twelve, where still medically necessary. The range of age cut-offs in evidence-based EIBI studies were established for the purpose of controlled research, and were based upon a number of factors, such as available funding. They weren't meant to imply that autism was untreatable after those ages. Throughout the EIBI literature, the published range of such age cut-offs, for the purpose of research, was 48 to 84 months for the maximum age to *begin* receiving treatment, and then the subsequent duration of treatment was one to five years, lasting up to the age of twelve.

Eikeseth and colleagues, in 2007, used the following cut-off: "All referrals who met the following criteria were admitted to the study: (a) a diagnosis of childhood autism... (b) chronological age between 4 and 7 years at the start of treatment, (c) a deviation IQ of 50 or above... and (d) no medical conditions... that could interfere with treatment." (page 266).

"The largest gain was in IQ; the behavioral treatment group showed an increase of 25 points (from 62 to 87) compared to 7 points (from 65 to 72) in the eclectic treatment group." (page 269). "in the behavioral treatment group, all correlations among intake age and outcome measures and changes were nonsignificant, with r(12) ranging from -.40 to .46. Thus, age was not reliably associated with outcome or amount of change for this group." (page 273).

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2007). Outcome for children with autism who began intensive behavioral treatment between ages 4 and 7: A comparison controlled study. Behavior Modification, 31, 264-278.

Mudford and colleagues, in 2001, reported the following cut-off: "By the age of 4 years, 71% of the sample had started EIBI. At the ages of 5, 6 and 7 years, the corresponding cumulative figures were 91%, 97% and 100%." (page 177).

Mudford, O.C., Martin, N.T., Eikeseth, S., & Bibby, P. (2001). Parent-managed

behavioral treatment for preschool children with autism: Some characteristics of UK programs. Research in Developmental Disabilities, 22, 173-182.

Sallows and Graupner, in 2005, reported the following data for children who ranged up to the age of 8.5 years of age at the conclusion of treatment:

"Following 2 to 4 years of treatment, 11 of 23 children (48%) achieved Full Scale IQs in the average range, with IQ increases from 55 to 104, as well as increases in language and adaptive areas comparable to data from the UCLA project. At age 7, these rapid learners were succeeding in regular first or second grade classes, demonstrated generally average academic abilities, spoke fluently, and had peers with whom they played regularly." (page 433).

Sallows, G.O., & Graupner, T.D. (2005). Intensive Behavioral Treatment for Children With Autism: Four-Year Outcome and Predictors. American Journal on Mental Retardation, 110, 417-438.

Love, Carr and colleagues, in 2009, reported the following average ages of treatment in a comprehensive survey of nationwide ABA practices:

"Seventy-four percent (n = 153) of respondents reported that the *average* age of the children they served was between 2 and 5 (33% reported serving children who were 4-years old), and 26% (n = 55) reported an *average* client age of 6 or greater." (page 177).

Love, J.R., Carr, J.E., Almason, S.M., Petursdottir, A.I. (2009). Early and intensive behavioral intervention for autism: A survey of clinical practices. Research in Autism Spectrum Disorders, 3, 421-428.

## These additional 227 studies report the evidence base for ABA treatment of children who suffer from autism between the ages of five and twenty-one.

Baer, D. M., Peterson, R.F., & Sherman, J.A. (1967). The development of imitation by reinforcing behavioral similarity to a model. *Journal of the Experimental Analysis of Behavior*, 10, 405-416.

Baer, D.M. & Guess, D. (1971). Receptive training of adjectival inflections in mental retardates. *Journal of Applied Behavior Analysis*, 4, 129-139.

Baer, D.M. & Guess, D. (1973). Teaching productive noun suffixes to severely retarded children. *American Journal of Mental Deficiency*, 77 (5), 498-505.

Barbetta, P.M., Heron, T.E., & Heward, W.L., (1993). Effects of active student response during error correction on the acquisition, maintenance, and

- generalization of sight words by students with developmental disabilities. *Journal of Applied Behavior Analysis*, *26*, 111-120.
- Barbetta, P.M., Heward, W.L., & Bradley, D.M. (1993). Relative effects of whole-word and phonetic- prompt error correction on the acquisition and maintenance of sight words by students with developmental disabilities. *Journal of Applied Behavior Analysis*. *26*, 99-111.
- Belchic, J.K., & Harris, S.L. (1994). The use of multiple peer exemplars to enhance the generalization of play skills to the siblings of children with autism. *Child and Family Behavior Therapy*, *16*,1-25.
- Bellini, S., & Akullian, J. (2007). A Meta-Analysis of Video Modeling and Video Self-Modeling Interventions for Children and Adolescents with Autism spectrum disorders. *Exceptional Children*, 73, 261-284.
- Bellini, S., Peters, J.K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education*, 28, 153-162.
- Bernard-Opitz, V., Sriram, N., & Nakhoda-Sapuan, S. (2001). Enhancing social problem solving in children with autism and normal children through computer-assisted instruction. *Journal of Autism & Developmental Disorders*, 31, 377-384.
- Bibby, P., Eikeseth, S., Martin, N.T., Mudford, O.C., & Reeves, D. (2001). Progress and outcomes for children with autism receiving parent-managed intensive interventions. *Research in Developmental Disabilities*. 22, 425-447.
- Billingsly, F.F., & Neel, R.S. (1985). Competing behaviors and their effects on skill generalization and maintenance. *Analysis and Intervention in Developmental Disabilities*, *5*, 357-372.
- Blew, P.A., Schwartz, I.S., & Luce, S.C. (1985). Teaching functional community skills to autistic children using nonhandicapped peer tutors. *Journal of Applied Behavior Analysis*. 18, 337-342.
- Brown, F., Holvoet, J., Guess, D., & Mulligan, M. (1980). Individualized curriculum sequencing model (III): Small group instruction. *Journal of the Association for the Severely Handicapped*, 5, 352-367.
- Buggey, T., Toombs, K., Gardener, P., Cervetti, M. (2000). Training responding behaviors in students with autism: Using videotaped self-modeling. *Journal of Positive Behavior Interventions*, 1, 205-214.
- Burgess, R. L., Burgess, J. M., & Esveldt, K. C. (1970). An analysis of generalized

imitation. Journal of Applied Behavior Analysis, 3, 39-46.

Camarata, S. (1993). The application of naturalistic conversation training to speech production in children with speech disabilities. *Journal of Applied Behavior Analysis*, 26. 173-182.

Carr, E. G., Newsome, C. D., & Binkoff, J. A. (1980). Escape as a factor in the aggressive behavior of two retarded children. *Journal of Applied Behavior Analysis*, 13, 101-117.

Casey, L.O. (1978). Development of communicative behavior in autistic children: a parent program using manual signs. *Journal of autism & childhood schizophrenia*. 8, 45-59.

Celiberti, D.A., & Harris, S.L. (1993). Behavioral intervention for siblings of children with autism: A focus on skills to enhance play. *Behavior Therapy*, 24(4). 573-599.

Charlop, M.H. (1983). The effects of echolalia on acquisition and generalization of receptive labeling in autistic children. *Journal of Applied Behavior Analysis*. 16, 111-127.

Charlop, M.H., & Milstein, J.P. (1989). Teaching autistic children conversational speech using video modeling. *Journal of Applied Behavior Analysis*. 22, 275-286.

Charlop, M.H., & Trasowech, J.E., (1991). Increasing autistic children's daily spontaneous speech. *Journal of Applied Behavior Analysis*. *24*, 747-762.

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# THE SENATE THE TWENTY-SEVENTH LEGISLATURE REGULAR SESSION OF 2015

Committee on Ways and Means Testimony on S.B. 791 Relating to Autism Spectrum Disorders

Tuesday, March 3, 2015, 9:05 A.M. Conference Room 211

Chair Tokuda and Members of the Committee:

The purpose of the bill is to require health insurance plans to provide coverage for autism spectrum disorders. This is a very significant problem and this coverage seems appropriate for insurance policies. The whole point of insurance is to spread risk and cost among an entire population, so that disproportionate, catastrophic expenses are not heaped upon specific individuals or groups.

With that in mind, we need to realize that autism is occurring among children in epidemic proportions. According to current statistics, **one out of 110 children (1 out of 85 boys) are born with autism**. That is a staggering, alarming figure, as is the cost to those families and to society to care for these individuals over the course of their lives. It is estimated that the cost of caring for a single individual with autism for a lifetime is \$3 million. Evidence suggests that techniques such as applied behavioral analysis have been effective in mitigating or reducing or eliminating the effects of autism if used at an early age. While the treatments may seem costly in the short run, hundreds of thousands of dollars, if not millions, are saved over the course of a lifetime by the early utilization of treatments.

Further, while some services are supposed to be provided via the DOE under the Individuals With Disabilities Education Act, in reality, the DOE has done a very poor job of either educating or providing needed services to children with autism. Therefore, other means of providing coverage and services need to be addressed.



Inasmuch as autism is unfortunately becoming common and the costs are so high, insurance coverage is appropriate as a mechanism to spread the risk and cost amongst all of us. We note that an increasing number of states in the country currently mandate some insurance coverage for autism. Hawaii in fact is now in a smaller minority. Therefore, this would seem to be an approach to addressing this problem which has received broad support.

Moreover, we recently filed a class action lawsuit in Federal Court against the Department of Human Services to require them to cover applied behavioral analysis under the Medicaid EPSDT program. It now appears that in response to the Court case the Department has announced that it will begin to cover applied behavioral analysis services. In light of that it would seem anomalous to provide these services to our children on Medicaid and not require their provision to the children of families who are working and paying into their system of private health plan coverage.

Thank you for the opportunity to testify on this measure.



An Independent Licensee of the Blue Cross and Blue Shield Association

March 3, 2015

The Honorable Jill N. Tokuda, Chair The Honorable Ronald D.Kouchi, Vice Chair Senate Committee on Ways and Means

Re: SB 791 – Relating to Autism Spectrum Disorders

Dear Chair Tokuda, Vice Chair Kouchi and Members of the Committee:

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 791 which provides for coverage for autism spectrum disorder services. HMSA offers comments on this Bill.

HMSA is empathic to the concerns that this Bill seeks to address. While we, generally, have opposed coverage mandate legislation, we truly appreciate that this version of the Bill helps to alleviate many of the concerns we raised with previous drafts of the measure.

We further appreciate the Legislature's effort at trying to get a grasp on the financial impact of this mandate. As a result of Act 185, SLH 2014, the Insurance Commissioner commissioned an actuarial analysis of an autism spectrum disorder coverage statute. The actuary estimated that the financial impact of such a mandate to the commercial health insurance market in 2015 would be between \$17 to \$31 per member per year, or \$1.44 to \$2.56 per member per month.

With these numbers in hand, we believe a more informed decision may be made, and the potential consequence to members' premiums and the health care system may be better understood.

Thank you for the opportunity to testify on this measure.

Sincerely,

Jennifer Diesman Vice President

Government Relations

#### **COMMITTEE ON WAYS AND MEANS**

Senator Jill N. Tokuda, Chair Senator Ronald D. Kouchi, Vice Chair

Jeffrey D. Stern, Ph.D. Licensed Clinical Psychologist 1833 Kalakaua Ave. Suite 908 Honolulu, HI 96815

Monday, March 2, 2015

Honorable Chair Tokuda, Honorable Vice Chair Kouchi, and esteemed members of the Senate Committees on Ways and Means, in regards to **SB 791** that require health insurers, mutual benefit societies, and health maintenance organizations to provide health care coverage and benefits for autism spectrum disorders, <u>Hawaii Psychological Association is in support of this bill as it addresses a serious need for coverage that insurers in the State of Hawai'i should bear.</u>

My name is Jeffrey Stern, and I am a psychologist and a Past President of the Hawai'i Psychological Association (HPA), as well as the chair of the Children's Committee of HPA. I have been involved with the working committee that has been trying to resolve issues in this legislation for the last two years. It is not necessary to review facts and opinions as ample testimony has been submitted. Concerns regarding the increasing prevalence rate of ASD, similar laws passed in most other states, costs to society for covering and for not covering these services, arbitrary age restrictions not supported by research evidence, potential legal challenges associated with mental health parity law requirements, reevaluation requirements every time the DSM is updated, the need for and type of background checks providers should be subject to, have been delineated in testimony provided in previous years and this year by other testifying organizations and individuals. Hawai'i Psychological Association echoes these concerns.

Therefore, Hawaii Psychological Association offers what it hopes will be complementary testimony for consideration.

First, we have noticed that definitions for what constitutes treatment for Autism and what should not be considered autism treatment under this legislation are still not clearly delineated. Hawaii Psychological Association therefore recommends the following language. Please note the A(1) is currently the language in the proposed legislation while sections A(2), A(3) and B(1) are proposed additions:

- A. Practice of "Applied Behavior Analysis" means:
- (1) The design, implementation, and evaluation of instructional and environmental modifications based on scientific research and the direct observation and measurement of behavior and the environment to produce socially and clinically significant improvements in human behavior; (currently in the legislation)

- (2) Empirical identification of functional relations between behavior and environmental factors known as function assessment and analysis; and
- (3) Utilization of contextual factors, motivating operations, antecedent stimuli, positive reinforcement, and other consequences to assist individuals in developing new behaviors, increasing or decreasing existing behaviors, and emitting behaviors under specific environmental conditions.
- B. Practice of "Applied Behavior Analysis" does not include:
- (1) Psychological testing, diagnosis of a mental or physical disorder, neuropsychology, psychotherapy, cognitive therapy, cognitive-behavioral therapy, sex therapy, psychoanalysis, hypnotherapy, or counseling as treatment modalities.

Second, although Board Certified Behavior Analysts are recognized experts in Applied Behavior Analysis, the vast majority of research that has been and is being conducted and reported in the scientific literature has been directed and conducted by psychologists, not doctors of Board Certified Behavior Analysis. Not to seek the input of the Hawai'i\_Psychological Association in the development of this proposed legislation seems to suggest an attempt by some organizations to promote divisiveness where none should exist. Licensed BCBAs and appropriately trained and licensed ABA providers including psychologists, psychiatrists, nurse practitioners, clinical social workers, etc. stand to benefit from collaboration and inclusion in this legislation in that it will promote interdisciplinary exchange as well as a deeper understanding of and appreciation for the inextricable nature of the disciplines in the care of children with ASD and their families.

Third, the requirement that children be reevaluated every time a new edition of the DSM is published is potentially problematic in that the American Psychiatric Association intends to publish updates of the DSM much more regularly (Neimeyer, 2013). This would pose an undue burden on insurance companies as what constitutes Autism Spectrum Disorder is not likely to change in a meaningful manner in the coming year, but updates (e.g., DSM-5.1) are anticipated every few years.

Respectfully,

Jeffrey D. Stern, Ph.D.
Past President, Hawai'i Psychological Association



#### SEAC

## Special Education Advisory Council 919 Ala Moana Blvd., Room 101 Honolulu, HI 96814

Phone: 586-8126 Fax: 586-8129 email: spin@doh.hawaii.gov

March 3, 2015

#### **Special Education Advisory Council**

Ms. Ivalee Sinclair, *Chair* Ms. Martha Guinan. *Vice Chair* 

Ms. Brendelyn Ancheta

Dr. Tammy Bopp

Dr. Robert Campbell

Ms. Deborah Cheeseman

Ms. Annette Cooper

Ms. Shari Dela Cuadra-Larsen, liaison to the Superintendent

Ms. Gabriele Finn

Ms. Jenny Gong

Ms. Natalie Haggerty

Ms. Barbara Ioli

Ms. Valerie Johnson

Ms. Deborah Kobayakawa

Ms. Bernadette Lane

Ms. Dale Matsuura

Ms. Stacey Oshio

Ms. Zaidarene Place

Ms. Barbara Pretty

Ms. Kau'i Rezentes

Ms. Rosie Rowe

Dr. Patricia Sheehey

Mr. Tom Smith

Ms. Lani Solomona

Dr. Todd Takahashi

Dr. Daniel Ulrich

Dr. Amy Wiech

Ms. Jasmine Williams

Ms. Susan Wood

Amanda Kaahanui, Staff Susan Rocco, Staff Senator Jill N. Tokuda, Chair Committee on Ways and Means State Capitol Honolulu, HI 96813

RE: SB 791 - RELATING TO AUTISM SPECTRUM DISORDERS

Dear Chair Tokuda and Members of the Committee,

The Special Education Advisory Council (SEAC), Hawaii's State Advisory Panel under the Individuals with Disabilities Education Act (IDEA), **strongly support**s the intent of SB 719 that mandates health insurance coverage for the diagnosis and treatment of autism spectrum disorders (ASD).

SEAC's has several concerns with the current language in this legislation:

- 1) The first is that services are only offered through age ten. It has been our experience that children over the age of ten and young adults can still receive great benefit from Applied Behavioral Analysis (ABA) and other evidence-based treatments.
- 2) Our second concern is that this bill places an annual dollar cap on services to no more than \$30,000 per year. Using the per hour service rates cited in the Wakely actuarial study conducted in response to SB 2054, this cap would result in utilization rates of less than 30 hours per week. This utilization rate is less than optimal for many children on the autism spectrum based on current research.

In 1999 Hawaii's Child and Adolescent Mental Health Division began developing a tool for practitioners and families to use in determining appropriate psychosocial interventions for children and youth with emotional and behavioral disorders, including Autism Spectrum Disorders. It collected evidence from randomized clinical trials to determine which interventions were most effective in treating children and adolescents. That tool, called the *Blue* 



Testimony on SB 791 March 3, 2015 Page 2

*Menu*, has since been adopted by the American Pediatric Association and updated regularly. It notes that the best support for the treatment of Autism Spectrum Disorders is *intensive* behavior therapy (applied behavioral analysis), generally meaning 30-40 hours a week. This is especially true for young children with moderate to severe symptoms.

Based on these concerns, we respectfully request that your committees consider extending the benefits to include students through age twenty-one (the upper limit for IDEA eligibility) and removing the annual dollar cap for services. By offering children with Autism Spectrum Disorders access to early identification and amelioration of their complex communication, social and behavioral needs, as well as ongoing targeted supports, study after study has shown a significantly positive impact on academic and behavioral goals, as well as a reduction in their overall need for lifetime supports.

Thank you for this opportunity to provide comments. If you have any questions or concerns, please feel free to contact me.

Parla Smile

Ivalee Sinclair, Chair

### #MALAMAOURKEIKI



I am a concerned citizen in Hawai'i and I support Autism insurance. Hawai'i is 1 of 12 states that does not provide meaningful Autism insurance coverage. This needs to change! I support Autism insurance campaigns in Hawai'i, specifically House Bill 1108.

By signing below, I consent for my name and opinions to be submitted as public testimony.

Name	Signature	Date
Sandi Tahayama	SaideThoon	2/2/15
Patricia Kido	Patricia Kido	2/2/15
Jan Ohta	Santotal	2/2/15
Patricia Szupinura	Patricia Jakimena	2/2/15
Jenna Ham	tema sochall	sp/4
CANDI PONELL		2/3/15
Chrohne Vunchano	Manghun	2/3/15
Deburah Carter	Diboral & Contr	2/3/15
Verna Ling-Roche	Gen Sing	2/3/15
Mandakini Boode	Ill	213/15
Jodi Stein	July-	2/3/15
Michelle Mmerda	Mich	2/2/15
Corinne K. Thompson	Conneck. They	2/3/15
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Jag Pawloushi	Lay Pawlowshi	2-4-15
Tara Sesepasaa-Williams	75	2-3-15
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Katen Yamamoto	Xauepea	2/3/15
Carolyn Taguchi	July Colembia	2/3/15
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Gina Antonic	arch	2/3/2017
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#### #MALAMAOURKEIKI



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By signing below, I consent for my name and opinions to be submitted as public testimony.

Name	Signature	Date
Sharon Quitevis	Sharm Well	2/3/15
Lois Soto	For At	2/3/15
Arlene Sato	alenesato	2/3/15
Creoffrey Sato	the	2/3/15
Sara Safo	Sara Selo	2/3/15
Stephanie DeVrice	Spill	5 Feb 2015
JEREMIAH DEVRIES	C) Dale	5 FEB 2015
Shannon China	DOP_	0/6/16
Lindsay Jones	Trymy	2/5/15
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COMMITTEE ON WAYS AND MEANS
Senator Jill N. Tokuda, Chair
Senator Ronald D. Kouchi, Vice Chair

Conference Room 211

Hawaii State Capitol

415 South Beretania Street

Dear Chair Tokuda, Vice Chair Kouchi and members of the Committee,

My name is Johanna Taylor and I am a Board Certified Behavior Analyst (BCBA) living on the Big Island in the state of Hawaii. I am writing to encourage you to **support SB 791**.

I support SB 791 for several reasons. First, as a researcher and clinician I have observed the monumental impact services based in applied behavior analysis (ABA) have on individuals with ASD and their ohanas. A wealth of research exists supporting ABA, clearly demonstrating that it is the most effective intervention approach for individuals with ASD to improve IQ, language, academic performance, adaptive behaviors, challenging behaviors, and social behaviors (Myers and Johnson, 2007, p. 1164). Research has demonstrated that children with ASD can reach typical skill development if provided with services early in life because this is when the brain is the most malleable (Dawson et al., 2010). It is imperative that all children with ASD receive individualized ASA-based services from a young age so they can succeed later in life.

My second reason for supporting this bill is that I have observed the current climate for support for families of children with autism. Unfortunately, in the state of Hawaii, the supports for families of children with autism are extremely limited. Some children receive services through the Department of Education; however, it is clear that the programs are not necessarily individualized for children with autism, developed by a behavior analyst, or grounded in ABA. Therefore, in the cases I have observed, challenging behaviors increased as the child grew older, the level of service needed intensified, and the educational cost for the children grew exponentially over time. There is often little-to-no parent involvement or parent training; therefore, caregivers are unsure of how to deal with challenging behaviors in their child's natural environment. I have witnessed firsthand parents on the Big Island that are struggling to understand how to deal with challenging behaviors and how to appropriately teach their children; if this bill were to pass, parents would have options for support. The passing of this bill would empower families to help their children with autism using effective and evidence-based strategies.

My final reason for supporting SB791 is that currently on the Big Island there are very few individuals trained in behavior analysis. It is my belief that because there is no funding stream to cover services based in ABA, providers are unlikely to move to the island. The Big Island is a beautiful place to live and has a population larger than any other island outside of Oahu. The families here deserve to have appropriate supports so that their children can succeed and live a meaningful lives. If this bill were to pass, it is likely that more BCBAs would choose to move to the Big Island and make it their home as I have done.

Insurance reform is a necessary step towards providing effective services for individuals with ASD. I hope that you consider supporting 58791 in this legislative session.

Mahalo for providing me with the opportunity to submit testimony,

Johanna P. Taylor, PhD, BCBA Neighbor Island Representative Hawaii Association for Behavior Analysis

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03/03/2015

COMMITTEE ON WAYS AND MEANS

Senator Jill N. Tokuda, Chair

Senator Ronald D. Kouchi, Vice Chair

Conference Room 211

Hawaii State Capitol

415 South Beretania Street

Dear Chair Tokuda, Vice Chair Kouchi, and members of the committee,

Thank you for the opportunity to submit testimony on SB791 for **support with revisions**. My name is Kristen Koba-Burdt and I am Board Certified Behavior Analyst (BCBA). For several years, I have worked with individuals with autism on Maui, Oahu, and the Big Island. Similarly, I have submitted testimony and supported efforts to pass meaningful autism insurance reform in Hawaii, for several years. Each year, I've watched as more and more children receive insufficient or no early intervention services and enter the DOE far behind their peers. Sadly, this trend continues and children with autism slip farther and farther away from their neurotyipcal peers. As of today, 38 states, the District of Columbia, and the US Virgin Islands have all passed autism insurance reform and have helped the children of their area gain access to medically necessary treatment. **It's time to do the right Hawai'i.** 

While I appreciate the intent of SB791, **limiting services to age 11 does not meet the needs of our state**. As evidenced in the actuarial study commissioned from last year's bill, SB2054, children in Hawai'i are diagnosed on average after their 4<sup>th</sup> birthday. In my experiences, neighbor island children receive even later diagnosing and a significant delay or no access to services. I have worked with numerous children in intermediate and high school that have not yet acquired a functional way to communicate, are not able to perform activities of daily living independently, and need assistance round the clock for safety. These 13, 15, 17 and even 21 year old individuals with autism can, and do, benefit from Applied Behavior Analysis (ABA) services. I have seen first-hand clients make significant progress in their adolescent years. This progress not only improves the quality of life for the child, but also for their ohana. **Without appropriate services, beyond age 11, individuals with autism will exit the DOE and be** 

reliant on the state for the rest of their lives. Hawai'i's DOH DDD-Medicaid Waiver system is already stretched thin and the state does not have the capacity to handle the sheer volume of individuals that will need support and services. This number becomes exasperated by the fact that many of the individuals will enter the DOH-DDD system without having developed basic skills, requiring higher levels of staff support and training. As a former DOH-DDD Training and Consultation provider, I can attest that the current system is not equipped to deal with this higher level of need.

There are numerous service providers in this state that are ready and willing to provide medically necessary ABA services. It is important that the language of SB791 reflect the model of ABA services used around the world. Frontline staff, Registered Behavior Technician's (RBT) or skills trainers, need to also be listed as covered providers, if they are overseen by a BCaBA, BCBA, BCBA-D, or Psychologists with ABA in the scope of their practice. Additionally, it is crucial that credentials from the Behavior Analyst Certification Board (BACB) are accepted for a five year window following implementation and any additional requirements for providers be clearly detailed.

Autism rates have continued to soar. Currently 1 in 68 children are diagnosed with autism. The need for treatment has never been greater and it's important that this bill support an appropriate frequency and duration of treatment, which is why the dollar caps need to be removed. Children with autism can make significant gains, when allowed access to the appropriate level of treatment. Please allow Hawai'i children their right to effective treatment by removing the age and dollar caps.

Malama our keiki,

BURD

Kristen Koba-Burdt, M.S., BCBA

Vice-President, Hawaii Association for Behavior Analysis (HABA)

Behavioral Services Manager, BAYADA Habilitation—Maui

kkoba-burdt@BAYADA.com

2/5/2015

For the Senate Committee on Health and Committee on Commerce and Consumer Protection,

Children with Autism have been a part of my life for the past 15 years. I worked as a Skills Trainer for a little boy with Autism and never looked back. I have worked in several disciples as a Special Education Teaching Assistant to Developmental Specialist to a Behavior Analyst. I have always been passionate about improving the lives of children, particularly those with disabilities but it wasn't until I studied Behavior Analysis that I had the skills to help make significant and long lasting changes in children's lives. Applied Behavior Analysis (ABA) has given me the skills to teach children to become part of the world around them, to find the joy and happiness they deserve, and allow them to be live a life with as much independence as they can.

Now that myself, and a lot of other talented Behavior Analysts, have the skills and knowledge to teach children who are difficult to teach, not having the resources to do so is devastating. Insurance companies not covering effective treatment is detrimental to children's quality of life but also drastically affects the amount of resources that will be required to care for these children in the future without independent skills. Bills HB 1108 and SB 791 will give my children the chance to get evidence based treatment that is effective. Children with Autism deserve the chance to succeed and in my experience they need Applied Behavior Analysis to do so.

Thank you for your time and for hearing my point of view of why you should amend SB 791

Respectfully,

Kelly Deacon



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3/3/15
COMMITTEE ON WAYS AND MEANS
Senator Jill N. Tokuda, Chair
Senator Ronald D. Kouchi, Vice Chair

Conference Room 211
Hawaii State Capitol
415 South Beretania Street

My name is Sara Sato and I am Board Certified Behavior Analyst (BCBA). I have a Master's Degree in Special Education, Severe Disabilities/Autism Specialization from the University of Hawai'i at Manoa and have been working with individuals with disabilities for 15 years. I have worked in Hawai'i and San Francisco as an Educational Assistant, Skills Trainer, Behavioral Therapist, Special Education Teacher, and Behavior Analyst practicing Applied Behavior Analysis (ABA). I am writing this testimony to voice my support for SB791 which would mandate insurance coverage for children with Autism.

Today, about 1 in 68 children has been identified with Autism Spectrum Disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. There are numerous studies which show that Early Detection and Early Intervention are key in addressing the symptoms of ASD (Moore & Goodson, 2003; Peters-Scheffer, N., et. al, 2011, etc.). However, for individuals diagnosed with ASD and their families in Hawai'i, there are very limited state-funded options available for treatment. Families are left to accept the minimal amount of assistance provided by the State (sometimes only 1 therapy session per week); wait until their child reaches school age to seek Special Education Services; or are forced to pay out of pocket for intensive behavioral therapy which can cost between \$40,000 to \$60,000 per year and which only a very small percentage of residents can afford. Additionally, it is estimated to cost at least \$17,000 more per year to care for a child with ASD compared to a child without ASD. Costs include health care, education, ASD-related therapy, family-coordinated services, and caregiver time. For a child with more severe ASD, costs per year increase to over \$21,000. Taken together, it is estimated that total societal costs of caring for children with ASD were over \$9 billion in 2011 (Lavelle, et. al, 2014). It is unreasonable for the

citizens of Hawai'i to believe that families affected by ASD can bear the financial and emotional burden on their own.

If this bill is passed there will certainly be an increase in insurance premiums, however, there are studies to support cost-savings of Early Intensive Behavioral Intervention compared to Special Education Services (Chasson, G. S., 2007) and Early Intensive Behavioral Intervention and cost-savings over the lifespan of individuals with ASD (Peters-Scheffer, N., 2012). When we consider this research, it only makes logical and fiscal sense to mandate Hawai'i health insurers to cover the cost of treatment for ASD.

Nationwide there are 38 states which currently require private health insurers to cover the cost of ABA therapy. Let's make Hawai'i the 39<sup>th</sup> and show our local Ohana affected by Autism that there is hope. There is a way.

Sincerely,

Sara Sato

Sara Sato, M.Ed., BCBA

Legislative Co-Chair Hawaii Association for Behavior Analysis (HABA)

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3/3/15

#### **COMMITTEE ON WAYS AND MEANS**

Senator Jill N. Tokuda, Chair

Senator Ronald D. Kouchi, Vice Chair

Conference Room 211

Hawaii State Capitol

415 South Beretania Street

First name: Kathleen

Last name: Bradler

Affiliation: Hawaii Association for Behavior Analysis

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Email address: kmbradler@gmail.com

Message to Legislators:

Aloha, my name is Kathleen Bradler. I am a Board Certified Behavior Analyst living and working on the island of Oahu. I currently work with military families who received Applied Behavior Analysis at the age of diagnosis. Previously, I worked with local families on Maui who received minimal care at a much later age. The difference in outcomes is overwhelmingly apparent. I have seen first-hand what consistent, continuous Applied Behavior Analysis, created by a Board Certified Behavior Analyst, can do. For this reason, I support SB 791.

Sincerely,

Kathleen Bradler, M. Ed. BCBA

Good Morning Chair(s) and Committee Members of the Ways and Means,

Thank you for allowing me to submit testimony today. I am in support of the Autism Bill but with amendments to the age cap. I think it should follow the Medicaid age of 21.

Please allow me to demonstrate what this bill does for Luke.

We go to work every day paying our insurance to help with services for those who need. Children with Tricare need services. We take the money and help them. Great! We are helping Keiki! Children with Medicare need services. We take the money and help them. Fantastic! We are helping Keiki! Luke, our son, needs services we go to help him and we are told to go away that we are not eligible.

Luke is 14. Does he need help? Yes! Can he still be helped? Yes! As an example, Luke was lured across the street from his High School by some students. It is an extremely busy road. Luke went. He said to me after, "Mom, the cars wouldn't stop!" "They should stop!" Luke does not have the capabilities to cross the street on his own. If he could have access to services he could get the help he needs to navigate some of these dangerous situations.

Luke is liking a girl in his class. So appropriate behavior from a student that age would be? Well what does Luke do? He writes his life story, his genealogy on a paper, and wants to give it to her. He is offering this of himself. Socially appropriate? No! He needs the services to understand how to navigate socially and become an independent functional adult.

Are these services offered by the D.O.E.? No! We are told that his behavior needs consequences, write-ups for insubordination, and suspension. When in fact he needs people who are trained in helping him.

We are going back to work tomorrow, our insurance will be paid, the services will be replenished. When will Luke have access to services?

Do what is right! We are ALL counting on your help!

Respectfully submitted,

Gerilyn Pinnow M.Ed. (Luke's Mom)

To Managed Manage Committee
To: Ways and Means Committee
From: Luke Pinnow (age 14)
I need a new brain. My head hurts. It's not working. I don't know how to think.
Help me please!
(As told to me his Mom when we parked the car this morning. It was very heart breaking to not be able

to have an answer of help for him because we do not qualify through our insurance for help)