

NEIL ABERCROMBIE GOVERNOR

SHAN S. TSUTSUI

STATE OF HAWAII OFFICE OF THE DIRECTOR

DEPARTMENT OF COMMERCE AND CONSUMER AFFAIRS

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

JO ANN M. UCHIDA TAKEUCHI

TO THE SENATE COMMITTEES ON HEALTH AND COMMERCE AND CONSUMER PROTECTION

TWENTY-SEVENTH LEGISLATURE Regular Session of 2014

Tuesday, January 28, 2014 8:30 a.m.

TESTIMONY ON SENATE BILL NO. 2054 - RELATING TO HEALTH.

TO THE HONORABLE JOSH GREEN AND ROSALYN BAKER, AND MEMBERS OF THE COMMITTEES:

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 the bill, and submits the following comments on this bill:

This bill requires health insurers, mutual benefit societies, and health maintenance organizations to cover the treatment of autism spectrum disorders.

The addition of new coverage may trigger §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 provided in the state's qualified health plan.

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



1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813

Phone/TTY: (808) 949-2922 Toll Free: 1-800-882-1057 Fax: (808) 949-2928

E-mail: info@hawaiidisabilityrights.org Website: www.hawaiidisabilityrights.org

THE SENATE THE TWENTY-SEVENTH LEGISLATURE REGULAR SESSION OF 2014

Committee on Health
Committee on Commerce and Consumer Protection
Testimony in Support of S.B. 2054
Relating to Health

Tuesday, January 28, 2014, 8:30 A.M. Conference Room 229

Chair Green, Chair Baker and Members of the Committees:

The Hawaii Disability Rights Center testifies in support of this bill.

The purpose of the bill is to require health insurance plans to provide coverage for autism spectrum disorders. This is a very important bill and this coverage is very 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 **approximately half the states in the country currently mandate some insurance coverage for autism.** Therefore, this would seem to be an approach to addressing this problem which has received broad support.

Thank you for the opportunity to testify in support of this measure.



An Independent Licensee of the Blue Cross and Blue Shield Association

January 28, 2014

The Honorable Josh Green, Chair Senate Committee on Health The Honorable Rosalyn H. Baker, Chair Senate Committee on Consumer Protection and Commerce

Re: SB 2054 - Relating to Health

Dear Chair Green, Chair Baker and Members of the Committees:

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 2054, which, would require health plans to provide coverage for services for autism spectrum disorders (ASD). HMSA certainly is empathetic to the intent of this Bill. However, as we noted during the last legislative session, we continue to be concerned that the Legislature and the community need more and clearer information about the consequences of such a mandate.

The 2012 Legislature, in fact, did attempt to gain that knowledge by adopting HCR 177, HD2, SD1, directing the Legislative Reference Bureau (LRB)study of the impacts of mandating insurance coverage for the diagnosis and treatment of ASD. The LRB submitted that report, "Autism Spectrum Disorders and Mandated Benefits Coverage in Hawaii" to the 2013 Legislature

Unfortunately, the LRB report is inconclusive with regard to many of its findings, including the financial impact and the impact of the Affordable Care Act (ACA) on such a mandate. The LRB instead offers recommendations including:

- Should the Legislature want more certainty with respect to the cost of a mandate, it may consider commissioning an independent actuarial analysis.
- Should the Legislature want more accurate information concerning the costs of the mandate to the Med-QUEST and EUTF systems, it may require the agencies to commission studies of their own.
- The Legislature needs to ensure Applied Behavioral Analysis network adequacy, especially for ASD patients on the Neighbor Islands.

While providing services for persons with ASD is important, we need to emphasize that, pursuant to the ACA, the cost of providing these services under a new mandate will not be a charge to the issuers, but must be borne by the State. And, that applies to plans sold both through and outside of the health insurance exchange. It is important that the Legislature clarifies the financial impact of a coverage mandate for those services on the community and the health care system. Consequently, the Legislature may wish to consider pursuing some or all of the additional studies recommended by the LRB.

Thank you for the opportunity to offer our comments on SB 2054.

Sincerely,

Jennifer Diesman
Vice President

Government Relations

From: mailinglist@capitol.hawaii.gov

To: <u>HTHTestimony</u>

Cc: michael.wasmer@autismspeaks.org

Subject: Submitted testimony for SB2054 on Jan 28, 2014 08:30AM

Date: Monday, January 27, 2014 8:15:33 AM

Attachments: SB 2054and2578.Wasmer.20140127waddendum.pdf

SB2054

Submitted on: 1/27/2014

Testimony for HTH/CPN on Jan 28, 2014 08:30AM in Conference Room 229

Submitted By	Organization	Testifier Position	Present at Hearing	
Michael Wasmer	Autism Speaks	Support	Yes	1

Comments: Mihoko Ito or Gary Slovin will be presenting this testimony in person on behalf of Autism Speaks

Please note that testimony submitted <u>less than 24 hours prior to the hearing</u>, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

January 27, 2014

Senator Rosalyn Baker Chair, Senate Committee on Commerce and Consumer Protection

Senator Josh Green Chair, Senate Committee on Health

State Capitol 415 South Beretania St Honolulu, HI 96813

Re: SB 2054 and SB 2578; Relating to Health. Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder treatments.

Dear Chairs Baker, Green and Members of the Committee,

I am Mike Wasmer, Associate Director 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 leading role in most of the now 34 states that have enacted autism insurance reform laws.

In previous sessions, Autism Speaks has testified to this joint 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 the first to enact autism insurance reform laws; and the long term cost savings and fiscal imperative of autism insurance reform.

While the general concept of SB 2054 an SB 2578 is similar, the details of these two bills are very different. I would like to address our position on each bill separately.

Re: In Support of SB 2054

Except for the effective dates, SB 2054 appears to be essentially identical to SB 668 SD2 HD1 from the 2013 legislative session. Based upon our discussions with other stakeholders and State agencies in last year's hearings and over the interim we encourage the committee to pass SB 2054 with the attached amendments which clarify:

- 1) that nothing in the bill shall be construed to require the proposed coverage in Medicaid plans;
- to which private insurance markets the proposed coverage applies without triggering an obligation for the State to defray the cost of benefits under the Affordable Care Act;
- that coverage for ABA shall include the services of personnel who work under the supervision of the Board Certified Behavior Analyst (BCBA) or the licensed psychologist overseeing the program;
- 4) and what the practice of ABA excludes.

Please refer to the attached addendum for details of these proposed amendments and several technical corrections.

Re: In Opposition to SB 2578

While we support mandatory coverage for the treatment of autism, SB 2578 does not propose a *meaningful* benefit. Furthermore, as the bill is written the State of Hawaii would be required to defray the cost of benefits in some plans. Also, SB 2578 does not acknowledge numerous stakeholder concerns raised in previous hearings on this issue.

SB 2578 does not provide meaningful coverage for autism

SB 2578 proposes that benefits be limited to individuals with autism under the age of 6 years. The Centers for Disease Control and Prevention (CDC) report that most children with autism are not diagnosed until after 4 years of age. Factors that impact the average age of diagnosis include family income, ethnicity and severity of the disorder. Children from low income families are diagnosed 0.9 years later than those with incomes greater than 100% of the poverty level. African American children are diagnosed 1.5 years later than white children. (Mandell 2002 and 2005). The CDC reports the average age of diagnosis for individuals who are less severely impacted by autism is 6 years 3 months i.e., <u>after</u> the age cap on services proposed by SB 2578.

The requirements of service providers qualified to deliver ABA as proposed by SB 2578 are very unclear and could result in significant problems with provider capacity. Most ABA programs rely on a tiered service delivery model in which the ABA consultant (e.g., a BCBA or licensed psychologist) uses carefully trained and well-supervised behavioral technicians to assist in delivery of medically necessary treatment. All of the existing 34 State autism insurance laws recognize this tiered service delivery model and provide for the reimbursement of behavioral technicians (or, "supervisees"). Delivery of ABA would be significantly compromised under SB 2578 because it does not allow for reimbursement for ABA provided by supervisees.

SB 2578 would trigger an obligation to defray costs of proposed benefits under the ACA SB 2578 proposes that benefits be required in *all* individual and group health benefit plans. Section 1311(d)(3) of the Patient Protection and Affordable Care Act (ACA) requires States to defray the cost of state-mandated benefits in "qualified health

plans" that exceed that State's essential health benefits (EHB). A qualified health plan (QHP) is a small group or individual health plan providing coverage for plan years 2014 or later that has been certified as meeting the standards established in Section 1301 of the ACA.

None of the benchmark options for Hawaii included coverage for ABA for autism. As a result, *ABA for autism is not an EHB for the State of Hawaii*. The legislature cannot require coverage for ABA in qualified health plans without triggering the obligation to defray the cost of this benefit. In contrast, language in SB 2054 addresses this issue by exempting qualified health plans from coverage.

SB 2578 does not address stakeholder concerns raised last session

SB 668 SD2 HD1 was debated in multiple committee hearings last session. Over the course of these hearings significant stakeholder concerns were raised and addressed with consensus amendments. For example, amendments were added to allow for coverage provided by social workers. Also, the definition of ABA was amended to clarify the distinction between services provided by qualified ABA providers and other allied health professionals. None of the stakeholder issues addressed by SB 668 SD2 HD1 (and SB 2054) are included in SB 2578.

The prevalence of autism as reported by the Centers for Disease Control and Prevention (CDC) is now 1:88. This represents a 1000 fold increase in the past forty years. Autism is an epidemic and a public health crisis. The time to act is now. Please support passage of SB 2054 with the attached proposed amendments.

Thank you for your consideration of my comments,

Michael L. Wasmer, DVM, DACVIM Associate Director, State Government Affairs Autism Speaks

14617 South Garnett St.
Olathe, KS 66062
816-654-3606
michael.wasmer@autismspeaks.org



Addendum to Wasmer testimony in Support of SB 2054

Please consider making the following amendments to SB 2054:

page 1, line 13 and page 8, line 4

"January July 1, 2014, shall provide to the policyholder and"

page 1, insert after line 18 and page 8, insert after line 9

"Nothing in this section shall be construed to require such coverage in a medicaid plan."

page 2, beginning on line 2 and page 8, beginning on line 11

"... regarding the coverage required by this section.

The notice shall be in writing and prominently positioned in any literature or correspondence sent to policyholders and shall be transmitted to policyholders within calendar year 2015 2014 when annual information is made available to members or in any other mailing to members, but in no case later than December 31, 2015.2014.

c) Individual coverage for behavioral health treatment provided under this section shall be subject to a maximum benefit of \$50,000 per year and a maximum lifetime benefit of \$300,000, but shall not be subject to any limits on the number of visits to an autism service provider. After December 31, 2016, 2015, the insurance commissioner, on an annual basis, shall"

page 3, line 9 and page 9, line 19

"deductible, and coinsurance provisions for <u>substantially all</u> other medical"

page 3, beginning on line 18 and page 10, beginning on line 8

"(g) Except for inpatient services, if an individual is receiving treatment for autism spectrum disorders, an insurer may request a review of that treatment not more than once every twelve months unless the insurer and the individual's licensed physician, psychiatrist, psychologist, clinical social worker, or registered nurse practitioner agree that a more frequent review is necessary. Any such agreement regarding the right to review a treatment plan more frequently shall apply only to a particular insured being treated for autism spectrum disorder by a licensed physician, psychiatrist, psychologist, clinical social worker, or nurse practitioner. The cost of obtaining any review shall be borne by the insurer."

page 4, beginning on line 8 and page 10, beginning on line 20 Delete old subsection (i) and replace with new subsection (i) as follows:

"(i) Nothing in this section shall apply to accident-only,

Addendum to Wasmer testimony in Support of SB 2054

specified disease, hospital indemnity, qualified health plans as defined in section 1301 of the Patient Protection and Affordable Care Act, Medicare supplement, disability income, long-term care, or other limited benefit hospital insurance policies."

page 5, beginning on line 3 and page 11, beginning on line 15 Delete old subsection (I) and replace with new subsection (I) as follows:

"(I) If an individual has been diagnosed as having a pervasive developmental disorder or autism spectrum disorder, then that individual shall not be required to undergo repeat evaluation upon publication of a subsequent edition of the Diagnostic and Statistical Manual of Mental Disorders to remain eligible for coverage under this section."

page 5, after line 11 and page 12, after line 2

Insert new subsection (m) as follows:

"(m) Coverage for applied behavior analysis shall include the services of the personnel who work under the supervision of the Board Certified Behavior Analyst or the licensed psychologist overseeing the program."

page 5, line 12 and page 12, line 3

"(m) (n) As used in this section, unless the context clearly requires otherwise:"

page 5, beginning on line 19 and page 12, line 10

"relations relationship between environment and behavior. The practice of applied behavior analysis expressly excludes psychological testing, diagnosis of a mental or physical disorder, neuropsychology, psychotherapy, cognitive therapy, sex therapy, psychoanalysis, hypnotherapy, and long-term counseling as treatment modalities."

page 6, beginning on line 19 and page 13, beginning on line 9

"Pharmacy care" means medications prescribed by a licensed physician or registered nurse practitioner and any health-related services that are deemed medically necessary to determine the need for or effectiveness of the medications.

page 7, beginning on line 9 and page 13, beginning on line 21

"Treatment for autism spectrum disorders" includes the following care prescribed or ordered for an individual diagnosed with an autism spectrum disorder by a licensed physician.

Addendum to Wasmer testimony in Support of SB 2054

psychiatrist, psychologist, licensed clinical social worker, or registered nurse practitioner if the care is determined to be medically necessary:"

page 15, line 4

"maintenance organization on or after January 1, July 1, 2014."

page 15, after line 6

Insert new SECTION 8 as follows:

"SECTION 8. If any provision of this Act, or the application thereof to any person or circumstances, is held invalid, the invalidity does not affect other provisions or applications of the Act that can be given effect without the invalid provision or application, and to this end the provisions of this Act are severable."

page 15, line 7

"SECTION 8. SECTION 9 This Act shall take effect upon its approval. on July 1, 2014"

From: Oren Chikamoto
To: HTHTestimony

Subject: SB 2054, Relating to Health

 Date:
 Monday, January 27, 2014 7:59:12 AM

 Attachments:
 SB 2054 - Autism (age 21).pdf

Measure: SB 2054

Date of Hearing: 1/28/14 Time of Hearing: 8:30 am.

Testifier: American Council of Life Insurers

Position: Comment

Oren T. Chikamoto. Esq.
Law Offices of Oren T. Chikamoto
A Limited Liability Law Company
1001 Bishop Street, Suite 1750
American Savings Bank Tower
Honolulu, Hawaii 96813
Tel: (808) 531-1500

Tel: (808) 531--1500 Fax: (808) 531-1600

E Mail: otc@chikamotolaw.com

This message is from the law firm of Law Offices of Oren T. Chikamoto, a Limited Liability Law Company, and contains information which may be confidential and legally privileged. If you have received this message in error, you are strictly prohibited from reading it and from disclosing or using its contents in any manner, and you should immediately delete it. The unauthorized disclosure or use of confidential or privileged information inadvertently transmitted to you may result in criminal and/or civil liability.

Circular 230 Compliance Statement: To comply with requirements imposed by U.S. Treasury Regulations, we inform you that unless otherwise expressly stated, any U.S. federal tax advice contained in this communication (including any attachments) is not intended or written to be used, and cannot be used, for the purpose of (1) avoiding penalties that may be imposed on the taxpayer or (2) promoting, marketing, or recommending to another party any transaction or matter addressed in this communication.

TESTIMONY OF THE AMERICAN COUNCIL OF LIFE INSURERS COMMENTING ON SENATE BILL 2054, RELATING TO HEALTH

January 28, 2014

Via e mail: hthtestimony@capitol.hawaii.gov

Honorable Senator Josh Green, Chair Committee on Health Honorable Senator Rosalyn Baker Committee on Commerce and Consumer Protection State Senate Hawaii State Capitol, Conference Room 229 415 South Beretania Street Honolulu, Hawaii 96813

Dear Chair Green, Chair Baker and Committee Members:

Thank you for the opportunity to comment on SB 2054, relating to Health.

Our firm represents the American Council of Life Insurers ("ACLI"), a Washington, D.C., based trade association with more than 300 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 twenty-five (225) ACLI member companies currently do business in the State of Hawaii; and they represent 92% of the life insurance premiums and 90% of the annuity considerations in this State.

As drafted, SB 2054 requires all insurers subject to its provisions to provide coverage for autism spectrum disorders.

Section 2 of the bill would amend Article 10A of Hawaii's Insurance Code (relating to Accident and Health or Sickness Insurance) to include a new section to require that "[e]ach individual or group accident and health or sickness insurance policy, contract, plan or agreement . . . shall provide to the policyholder and individuals under twenty-one years of age covered under the plicy, contract, plan, or agreement, coverage for . . . treatment of autism spectrum disorders." (Page 1, lines 9-18).

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

In 2010, Hawaii enacted HRS §431:10A-102.5, relating to Limited benefit health insurance which states in relevant part:

Except as provided . . . elsewhere in this article, when use in this article, the terms "accident insurance", "health insurance", or sickness insurance" shall not include

an accident-only, specified disease, hospital indemnity, long-term care, disability, dental, vision, Medicare supplement, or other limited benefit health insurance contract that pays benefits directly to the insured or the insured's assigns and in which the amount of the benefit paid is not based upon the actual costs incurred by the insure.

However, SB 2054, as drafted, mandates autism spectrum disorders coverage for "each individual or group accident and health or sickness insurance policy, contract, plan or agreement". ACLI submits that the intent and purpose of this bill is to require only health insurers to provide coverage for autism spectrum disorders – not insurers issuing limited benefit health insurance contracts.

In order to dispel any confusion as to what this bill is intended to cover, ACLI suggests that the new section proposed to be added to §431: 10A (on page 2 beginning on line 10) be amended as follows:

§431: 10A- Autisim spectrum disorders; benefits and coverage; notice: definitions. (a) Subject to the provisions of HRS §431:10-A-102.5, E[e]ach individual or group accident and health or sickness insurance policy, contract, plan, or agreement, issued or renewed in this State [etc.].

Again, thank you for the opportunity to comment on SB 2054.

LAW OFFICES OF OREN T. CHIKAMOTO

A Limited Liability Law Company

Oren T. Chikamoto

1001 Bishop Street, Suite 1750

Honolulu, Hawaii 96813 Telephone: (808) 531-1500 Facsimile: (808) 531-1600

E mail: otc@chikamotolaw.com

Committee on Health Senator Josh Green, Chair Senator Rosalyn H. Baker, Vice Chair

Committee on Commerce and Consumer Protection Senator Rosalyn H. Baker, Chair Senator Brian T. Taniguchi, Vice Chair

Tuesday, January 28, 2014 / 8:30 am Conference Room 229, Hawai'i State Capitol

Dear Senators Green and Baker,

My name is Amanda N. Kelly and I am a professional who works with children and families affected by autism. I am writing to you because I want to talk about SB2054: Luke's Law, and how it will benefit children and families with autism.

In 1999, while enrolled in my undergraduate program, I came across a flyer advertising the need for therapists to work with a 2-year-old child diagnosed with an autism spectrum disorder. Though I was enrolled in an education program, not much was known at the time regarding the disorder, nor which treatments might be effective. When my advisor gave me a less than satisfactory answer to "what is autism", I decided to meet with the family and learn for myself. When I met with the family, it was clear that their son had struggles that other typically developing children did not. He was unable to speak clearly and he would often exhibit aggressive or self-injurious behavior in attempts to communicate. It was heartbreaking to say the least. After meeting with the family and learning of their dedication to help their son and their commitment to educate and train the therapists, I agreed to join their team. I received my initial training in applied behavior analysis (ABA) through a company who sent a consultant (from New York to West Virginia) every six weeks. While the child and family made great progress, obtaining and maintaining quality treatment became too much of a financial burden for the family, and after two and a half years, they were forced to discontinue funding his services. Unfortunately, this is not an isolated situation. As a matter of fact, 15 years later, in 2014, families in 17 of the 50 United States are still without the support they need from their communities, state legislators and insurance companies.

After graduating with my Bachelors in Elementary Education in 2002, I decided to make a shift in my career. Rather than becoming an elementary school teacher, I began to look for employment as an ABA therapist. In order to obtain employment as a therapist, I relocated from West Virginia to Massachusetts. In January 2003, I began working at a now nationally recognized, day and residential treatment facility for children, adolescents and young adults with autism and other related neurological disorders. I learned a great deal during my time in private and

residential settings. However, my passion remained in helping children succeed in their neighborhood schools, local communities, and home settings.

In 2005, I completed coursework and a national examination to become a Board Certified assistant Behavior Analyst (BCaBA). The following year, I began my masters program at Simmons College in Behavioral Education and in 2008, I obtained certification as a Board Certified Behavior Analyst (BCBA). I was impressed --floored actually at the progress I observed children and teens to make when they received properly implemented ABA services. In 2013, I successfully defended my dissertation, *Effects of presession pairing on challenging behaviors for children with autism*, and graduated with my PhD in Behavior Analysis, also from Simmons College in Boston, Massachusetts.

Over the past 15 years in the field, I have obtained experience working in-homes, as well as in private and public schools, integrated centers and residential facilities. For the past four years in Boston I served as the Coordinator of ABA Consultation Services for a public school collaborative, where I was responsible for coordinating school and home-based behavior consultation services for 10-member and several non-member public school districts. During my time as coordinator, I witnessed several positive changes in regards to treatment for individuals with autism. Public schools began employing BCBA's full-time and granting in-home, carry over support for families, which resulted in many children being able to remain successfully in their neighborhood schools and at home with their families and friends.

Hawai'i is not the first state to grapple with the potential consequences of enacting autism insurance reform. Although Massachusetts was one of the first states to submit an act relative to insurance coverage for individuals with autism (ARICA), we were the $23^{\rm rd}$ state to pass and enact such legislation, when we finally did so in 2010. It was an exhausting process, yet very worthwhile in the end. Hawai'i has the benefit of observing and learning from the experience of other states that have successfully enacted and enforced legislation, which covers ABA treatments for children, teens and adult diagnosed with autism (Massachusetts legislation has no dollar or age cap).

I moved to Hawai'i last year, after obtaining my PhD for two reasons: the weather (of course) and (more seriously) the need for experienced individuals who are dedicated and experienced in advocating for individuals and families affected with autism. At present, I have been on this island for four short months. Yet, in this time I have come in contact with many children, families and professionals in need of support. Presently, I am employed as a Clinical Supervisor at Malama Pono Autism Center (MPAC) in Mililani where I am charged with providing supervision and consultation to behavior technicians, lead instructors, and parents across clinic, school, and in-home settings. Unfortunately, the individuals who I have been able to service are limited to those who have military (TRICARE) insurance or those who are financially strong enough to privately pay for treatment. This seems unnatural and in direct contradiction to the "Aloha Spirit" that permeates every other aspect of

life on the island. In what way does it make sense that children of military families can receive necessary services, but Hawaiians and local children and families cannot?

Briefly, I would like to address some misconceptions of those who oppose the passage of the current bill.

- ABA is not solely an educational treatment. It is considered to be a medically necessary, empirically validated treatment approach for children diagnosed with autism (and other related disorders). Public schools on island are not equipped to fully meet the needs of children with autism, as clearly evidenced by the recent ruling by Administrative Law Judge Haunani Alm, regarding the abuse at Kipapa Elementary in Mililani. http://www.Hawai'inewsnow.com/story/24391699/charges-of-cover-up-in-mililani-abuse-case
- ABA is not new, nor is it a passing fad. Applied behavior analysis is a science of evidenced-based interventions that have been substantiated by over 1,000 research studies. ABA been backed by the US Surgeon General, American Academy of Pediatrics, American Psychological Association, Autism Society of America and National Institute of Mental Health http://appliedbehaviorcenter.com/ABAEndorsements.htm.
- ABA is effective for individuals from birth to death. There is NO evidence that would support ABA as an intervention ONLY for young children with autism. For a list of common misconceptions and rebuttals, please visit http://www.behaviorbabe.com/commonmisconceptions.htm.

I would like to extend my sincerest gratitude to you for introducing and supporting Luke's Law: SB2054. I appreciate your time and thank you and the committee for hearing my point of view of why you, and all of Hawaii's legislators should vote to pass Luke's Law: SB2054.

Respectfully,

Amanda N. Kelly, PhD, BCBA-D

Clinical Supervisor, Malama Pono Autism Center

Vice President, Hawai'i Association for Behavior Analysis

www.behaviorbabe.com

Behaviorbabe@yahoo.com



BEHAVIOR ANALYSIS NO KA OI. INC

560 N. Nimitz Hwy, Suite 114B, Honolulu, Hawai'i 96817, Ph. (808) 591-1173, Fx :(808) 591-1174

Senator Josh Green, Senator Rosalyn H. Baker, and Members of the Committee, thank you for the opportunity to submit testimony supporting SB2054 which would mandate health insurers to fund treatments for individuals on the autism spectrum. I am a Clinical Psychologist and a Board Certified Behavior Analyst (BCBA) with more than 20 years of experience working with individuals with developmental disabilities. I am currently the President and Clinical Director of Behavior Analysis No Ka Oi, Inc. a clinic that primarily serves children on the autism spectrum.

I was born and raised in Honolulu, Hawaii and moved to California to complete my undergraduate degree. As a college freshman looking for a part time job, I responded to a parent's ad to work with a "6 year old nonverbal boy with autism." When I first met this boy, he engaged in aggressive behaviors, needed help with most of his self-help skills such as brushing his teeth and toileting and could not communicate verbally. The parents paid privately for a consultant who taught me behavioral principles. Approximately a year later, this boy dressed, toileted, and brushed his teeth independently, learned to do his homework on the computer, and used pictures to communicate. Because of this experience, I became very passionate about learning how to effectively teach individuals with autism as I quickly realized that this 6 year old child taught me more about understanding behavior then any professor in my psychology classes.

After graduating with my bachelor's degree, I called the President of the Hawaii Autism Society inquiring about jobs in the field of autism. He informed me that there were very few people in Hawaii with expertise in the area of autism and that if I really wanted to learn more about effective treatments in autism that it was best that I stay on the mainland. I took his advice, and researched and discovered that Applied Behavior Analysis (ABA), a scientific study of human behavior, was the only evidenced-based intervention in the field of autism. I decided to pursue my doctorate in Psychology with an emphasis in Behavior Analysis.

While in graduate school, I was given the opportunity to see first-hand how applied behavior analysis has impacted the lives of children and adults on the autism spectrum. Nonverbal children were able to develop language and sustain friendships with peers. Adults living in institutions were given opportunities to reside independently and work competitive jobs.

After approximately 10 years of schooling and training on the mainland, I moved back home to Hawaii to fulfill my dream of opening up a clinic to teach local families the power of applied behavior analysis and the impact it would have on children diagnosed with an autism spectrum disorder. I was discouraged that the Hawaii insurance carriers did not provide treatments for individuals with an autism spectrum disorder. One insurance carrier informed me that they only provide treatment for the families to "cope" with the diagnosis, which as you can imagine, was horrifying from a provider's perspective.

Currently, my clinic primarily works with military families since Tricare insurance is the only Hawaii insurance carrier that provides treatment in ABA. We also work with several local families who pay privately to ensure their child receive ABA. I know of several families who have had to mortgage their homes or relocate to the mainland just to receive ABA.

In conclusion, I urge you to support SB2054 that mandates health insurance coverage for autism spectrum disorders. SB2054 provides access to quality health care for those on the autism spectrum without forcing families to decide to relocate to the mainland, mortgage their homes or forego crucial services.

Thank you for the opportunity to submit testimony on this very important bill.

Christine Kim Walton, Ph.D., BCBA-D

President/Clinical Director, Behavior Analysis No Ka Oi, Inc.

From: <u>mailinglist@capitol.hawaii.gov</u>

To: <u>HTHTestimony</u>
Cc: <u>bburdt3@gmail.com</u>

Subject: Submitted testimony for SB2054 on Jan 28, 2014 08:30AM

Date: Sunday, January 26, 2014 11:03:45 PM

Attachments: <u>Luke"s Law.docx</u>

SB2054

Submitted on: 1/26/2014

Testimony for HTH/CPN on Jan 28, 2014 08:30AM in Conference Room 229

Submitted By	Organization	Testifier Position	Present at Hearing	
Brian Burdt	Individual	Support	No	

Comments:

Please note that testimony submitted <u>less than 24 hours prior to the hearing</u>, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

January 26, 2014

Hawaii State Capitol 415 South Beretania St. Honolulu, HI 96813

Dear Legislators,

My wife Emily and I strongly support passage of Bill SB 2054 "Luke's Law" which will provide insurance coverage for services for children on the autism spectrum which are not currently covered.

We have a daughter with asperger's syndrome. She is now 14 and a freshman at Roosevelt High School in special education classes. Since she was a toddler her asperger conditions made her very hard to parent, especially her opposition. Like many parents, we have been through a whole battery of medical professionals, different medications, and school Individualized Education Programs since she was 7. We are completely exhausted!

In August 2013 we started her at an autism clinic where her primary services are in Applied Behavioral Analysis. Since then she has shown slow but steady progress. In her session last week with the psychologist, we actually saw her sit down for a rather lengthy 45 minutes where she continuously made eye contact, listened actively and was attentive and engaged in the discussion. Our daughter didn't agree with everything that the psychologist was saying, but did participate in an adult manner. We have never seen that before and for the first time are genuinely encouraged. We understand that Applied Behavior Analysis can result in improved behavior which should transfer into adulthood.

These services run about \$1,200 per month, not an insignificant sum for us. None of it is covered by our HMSA insurance. We have another younger child to raise as well.

Children on the autism spectrum can become a huge drain on families, society, and themselves when they become adults. However if provided appropriate services as children, they can lead productive lives as adults. There is that saying "It is much easier to build a child, than fix an adult!".

We urge you to pass Bill SB 2054 so that children on the autism spectrum can get what they need the most – a chance in life. Thank you.

Calvert Chun 1054-A Alewa Drive Honolulu, HI 96817 Cell: 808-421-7996 Dear Senators Green and Baker,

My name is Carla Schmidt, I am an assistant professor at the University of Hawaii-Manoa in the Departments of Special Education and the Center on Disability Studies. I am also a board certified behavior analyst (BCBA-D) and President of the Hawaii Association of Applied Behavior Analysis (HABA). My work and research focuses on the use of Applied Behavior Analysis (ABA) with individuals with Autism Spectrum Disorders.

I am writing to you because I want to talk about SB2054/Luke's Law and how it will benefit children and families with autism. The field of ABA has over 40 years of research to support its use and is now considered the gold standard of treatment for the autism population. I have worked with families of children with Autism for the past ten years and have seen first hand the benefits of providing treatment based on ABA. For families of children with Autism, ABA treatment is essential and has the potential to change lives. The recommended dosage of ABA treatment is between 20-40 hours per week, depending on the severity of the Autism diagnosis. If paid out of pocket this treatment is extremely expensive for families. No child with Autism in the State of Hawaii should go without proper treatment due to its expense. Each child with Autism should have the opportunity to excel to his or her full potential, in order to ensure this; access to ABA treatment is imperative. SB2054/Luke's Law can help facilitate this. I thank you for your time and for hearing my point of view on why you should pass SB2054/Luke's Law.

Respectfully,

Carla Schmidt, Ph.D., BCBA-D University of Hawaii-Manoa carlats@hawaii.edu From: <u>mailinglist@capitol.hawaii.gov</u>

To: <u>HTHTestimony</u>

Cc: <u>d.simmons1982@yahoo.com</u>

Subject: Submitted testimony for SB2054 on Jan 28, 2014 08:30AM

 Date:
 Sunday, January 26, 2014 11:42:44 PM

 Attachments:
 SB2054-Luke"s Law Testimony.docx

SB2054

Submitted on: 1/26/2014

Testimony for HTH/CPN on Jan 28, 2014 08:30AM in Conference Room 229

Submitted By	Organization	Testifier Position	Present at Hearing
Dana Simmons	Individual	Support	No

Comments:

Please note that testimony submitted <u>less than 24 hours prior to the hearing</u>, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

The Committee on insurance Reform 415 South Beretania St Honololu, Hi. 96813

RE Insurance Reform for Autism Coverage SB2054

Dear legislators

I am writing in response to the recent action taken by Hawaii legislators with the introduction of SB668 and HB721. As a friend of children with special needs, I am pleased with the progress they are making to join the other 33 states that have chacted into law requirements for insurers to provide coverage for the treatment of autism.

As you are aware, the incident rates of autism confinue to climb (CDC estimates 1 in 88 people are on the autism spectrum) and as such likely impact a good percentage of your constituent hase. According to a 2006 Harvard study by health economist Michael Ganz, the direct costs to raise a drukt with autism to age 22 are more than \$500,000 (and that's in 2003 dultars!). Ganz estimated that families also, indirectly, lose almost \$160,000 in income across their child's first 22 years, on average, as parents must scale back on work to care for their child. The most staggering number though is this one. Over the course of a person with autism's lifetime, the total cost to society—of treatments, care and the lost work potential of both the person with autism and their caregivers—is more than \$3 million. During a time of great economic concern, your action to offer lamities with options to reduce these costs is needed. Research has proved the dramatic difference early diagnosis. ABA therapy, and coordinated intervention has on children with autism and other special needs.

Your leadership is needed now more than ever and I hope I can count on you to keep this issue at the forefront of the legislative agenda. Hook kniward to seeing Hawaii added to the list of 33 states with autism insurance coverage reform

Sincerely,

Your Voting Constituent

Som Faye Noves

Dear Legislators,

I strongly support passage of Bill SB 2054 "Luke's Law" which will provide insurance coverage for services for children on the autism spectrum which are not currently covered.

I am a Behavior Therapist, who is currently studying to be a Behavior Analyst. I have worked in the field of ABA for a short two years, but have seen so much progress and amazing discoveries that it feels like much longer. When I first began working in Applied Behavior Analysis, I really did not fully understand it's benefits, yet. My workplace did an amazing job of training me and showing me the ways in which we can really help children and families work toward goals, that they did not think possible before, with scientifically-proven, uncomplicated methods that are constantly being evaluated and re-evaluated to measure their effectiveness. If it is not effective, we change it until it is.

In the two years I have been in ABA, I have seen children walk through our office door with no communication system at all, severe self-injurious behavior, severe aggression, and/or very little to no "life skills." I have been amazed when these very same children were speaking or signing within months, and have looked at their comprehensive graphs to see the dramatic reduction in self-injury and aggression. I have heard the excited stories of parents who tell me about the word their previously uncommunicative child said yesterday, or how he/she walked into a store and actively chose a sandwich (a skill he/she did not previously have.) For these reasons and more, I have enrolled to get my Master's degree in ABA. I want to change lives, and ABA does that.

Moreover, ABA, to my knowledge, is the only scientifically-proven treatment method for autism by the Surgeon General, and I have seen it work with my own eyes. I believe that all families should have access to effective, proven treatment, regardless of economic standing.

Respectfuly, Gillienne Nadeau From: <u>mailinglist@capitol.hawaii.gov</u>

To: <u>HTHTestimony</u>

Cc: <u>usuhsdoc2008@gmail.com</u>

Subject: Submitted testimony for SB2054 on Jan 28, 2014 08:30AM

Date: Monday, January 27, 2014 7:02:38 AM

Attachments: SB 2054 Support Letter.pdf

SB2054

Submitted on: 1/27/2014

Testimony for HTH/CPN on Jan 28, 2014 08:30AM in Conference Room 229

Submitted By	Organization	Testifier Position	Present at Hearing	
John Coleman	Individual	Support	No	

Comments: The purpose of this written testimony is to provide support for SB 2054. My name is John C. Coleman, M.D. I currently serve as an active duty military physician. Autism Spectrum Disorders are found in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), as a legitimate medical diagnosis. I would like to provide a logical medical analogy to clarify why I strongly support this bill. If another medical diagnosis like hypertension (high blood pressure) is diagnosed but remains untreated the prognosis becomes very poor. It is a fact untreated hypertension leads to severe cardiovascular incidents such as heart attack and stroke, as well as other severe chronic medical problems like renal failure and blindness. The cost of treating these severe ailments far outweighs that of treating the hypertension initially. The same is true of not treating individuals, particularly children with autism. It additional to being the moral and ethical decision to provide treatment for individuals with autism, it will ultimately reduce the financial burden on the State of Hawaii. Treatment will ensure that individuals have the best chance of being self-supportive and productive members of society in the great state of Hawaii. One of the treatment modalities, Applied Behavior Analysis (ABA) can specifically target goals such as education and social deficiencies, and achieving skills for employment and independent living. I am not just a physician that understands that there are research proven treatment modalities for autism such as ABA, but I am also am the father of two autistic boys. We are blessed to have insurance that covers our sons' therapy, but there are many autistic children and individuals in Hawaii without any healthcare coverage. I personally know the effectiveness of ABA therapy for Autism, as after completing a General Surgery Internship I completed a Post Graduate Certificate Program in Applied Behavior Analysis from Penn State. I have personally seen the results in my 23 month old son, as well as my 10 year old son. You have an awesome opportunity to greatly improve the future prognosis of individuals in Hawaii diagnosed with autism spectrum disorders while simultaneously reducing the increased state financial burden that will logically occur without treatment.

Please note that testimony submitted <u>less than 24 hours prior to the hearing</u>, improperly identified, or directed to the incorrect office, may not be posted online or

distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

Senator Josh Green, Chair

Senator Rosalyn H. Baker, Vice Chair

COMMITTEE ON COMMERCE AND CONSUMER PROTECTION

Senator Rosalyn H. Baker, Chair

Senator Brian T. Taniguchi, Vice Chair

NOTICE OF HEARING

DATE:

Tuesday, January 28, 2014

TIME:

8:30AM

PLACE: Conference Room 229

Dear Senator Green and Senator Baker,

The purpose of this written testimony is to provide support for SB 2054. My name is John C. Coleman, M.D. I currently serve as an active duty military physician. Autism Spectrum Disorders are found in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5), as a legitimate medical diagnosis. I would like to provide a logical medical analogy to clarify why I strongly support this bill. If another medical diagnosis like hypertension (high blood pressure) is diagnosed but remains untreated the prognosis becomes very poor. It is a fact untreated hypertension leads to severe cardiovascular incidents such as heart attack and stroke, as well as other severe chronic medical problems like renal failure and blindness. The cost of treating these severe ailments far outweighs that of treating the hypertension initially. The same is true of not treating individuals, particularly children with autism. It additional to being the moral and ethical decision to provide treatment for individuals with autism, it will ultimately reduce the financial burden on the State of Hawaii. Treatment will ensure that individuals have the best chance of being self-supportive and productive members of society in the great state of Hawaii. One of the treatment modalities, Applied Behavior Analysis (ABA) can specifically target goals such as education and social deficiencies, and achieving skills for employment and independent living.

I am not just a physician that understands that there are research proven treatment modalities for autism such as ABA, but I am also am the father of two autistic boys. We are blessed to have insurance that covers our sons' therapy, but there are many autistic children and individuals in Hawaii without any healthcare coverage. I personally know the effectiveness of ABA therapy for Autism, as after completing a General Surgery Internship I completed a Post Graduate Certificate Program in Applied Behavior Analysis from Penn State. I have personally seen the results in my 23 month old son, as well as my 10 year old son.

You have an awesome opportunity to greatly improve the future prognosis of individuals in Hawaii diagnosed with autism spectrum disorders while simultaneously reducing the increased state financial burden that will logically occur without treatment.

Very Respectfully,

John C. Coleman, M.D.

Committee on Health
Senator Josh Green, Chair
Senator Rosalyn H. Baker, Vice Chair

Committee on Commerce and Consumer Protection Senator Rosalyn H. Baker, Chair Senator Brian T. Taniguchi, Vice Chair

Tuesday, January 28, 2014 / 8:30 am Conference Room 229, Hawai'i State Capitol

Dear Senators Green and Baker,

My name is Lara Bollinger and I am a professional who works with children with autism. I am writing to you because I want to talk about **SB2054 / Luke's Law** and how it will benefit children and families with autism.

I first got involved in the field of autism and Applied Behavior Analysis about 15 years ago when I signed up to be a counselor at a camp for students with disabilities. I had no idea that choice would change the course of my life and I'm so glad it did! Over these past 15 years, I have seen what a positive difference ABA can make in the lives of those affected by autism and other developmental disabilities.

I have seen an 11-year old, whose parents were told he would never talk or be toilet trained, learn to do both. I've seen students with severe challenging behaviors able to overcome these, learn to communicate their wants and needs, and transition into much less restrictive settings. I've seen young adults learn to brush their teeth, make a sandwich, and learn some basic vocational tasks that could help them gain more independence and a job in the future. I've seen young children say their first words and then take off with an explosion of language. I've seen students learn academic skills at a pace that far exceeds that of their typically developing peers. The difference for all of these students was Applied Behavior Analysis.

Without access to Applied Behavior Analysis services, I've seen many families struggle with how to best educate and help their child. I've worked with families coming into ABA for the first time and seen the difference it can make in their child's and family's life. I've seen the joy in a parent's eyes when a child says their first words, asks their parent a question for the first time, or shows their parent any of the new skills they have learned.

ABA is research based and driven. Techniques used are those that have been proven effective. Access to these services should not be only for the rich. Providing access for all children and families through insurance reform is a step that so many other states have already taken. This access can change the lives of countless children and families.

Thank you for your time and for hearing my point of view of why you should vote to pass SB2054 / Luke's Law.

Respectfully,

Lara Bollinger, M.S.Ed., BCBA Autism Behavior Consulting Group lara@autismbehaviorconsulting.com 808-277-7736 From: <u>mailinglist@capitol.hawaii.gov</u>

To: <u>HTHTestimony</u>

Cc: <u>lynhowe1946@yahoo.com</u>

Subject: *Submitted testimony for SB2054 on Jan 28, 2014 08:30AM*

Date: Friday, January 24, 2014 7:43:10 PM

SB2054

Submitted on: 1/24/2014

Testimony for HTH/CPN on Jan 28, 2014 08:30AM in Conference Room 229

Submitted By	Organization	Testifier Position	Present at Hearing
Lyn Howe	Individual	Support	No

Comments:

Please note that testimony submitted <u>less than 24 hours prior to the hearing</u>, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

From: <u>mailinglist@capitol.hawaii.gov</u>

To: <u>HTHTestimony</u>
Cc: <u>kawasakimb@aol.com</u>

Subject: Submitted testimony for SB2054 on Jan 28, 2014 08:30AM

Date: Saturday, January 25, 2014 10:07:25 AM

SB2054

Submitted on: 1/25/2014

Testimony for HTH/CPN on Jan 28, 2014 08:30AM in Conference Room 229

Submitted By	Organization	Testifier Position	Present at Hearing	
Mary Kawasaki	Individual	Comments Only	No	

Comments: Page 4 line one replace 'registered nurse practitioner" with the correct term 'advanced practice registered nurse' please do this throughout the document

Please note that testimony submitted <u>less than 24 hours prior to the hearing</u>, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

Do not reply to this email. This inbox is not monitored. For assistance please email webmaster@capitol.hawaii.gov

Committee on Health Senator Josh Green, Chair Senator Rosalyn H. Baker, Vice Chair

Committee on Commerce and Consumer Protection
Senator Rosalyn H. Baker, Chair
Senator Brian T. Taniguchi, Vice Chair

Tuesday, January 28, 2014 / 8:30 am Conference Room 229, Hawai'i State Capitol

Dear Legislators,

My name is Nedelka Martinez. I'm a recently graduated Board Certified Behavior Analyst (BCBA). I have worked with children and families of those individuals diagnosed with developmental disabilities for several years now. I've had all my clinical experience in the state of Florida. I have moved to Hawaii to fill the need for more behavior analysts on the island. I am one of the lucky individuals who can genuinely say they love their job. I am fiercely passionate about the services I provide to my clients and their families.

I stumbled into the field after a presentation I saw during my undergraduate degree. I feel forever grateful for that day. I have worked with many families and have not only shared in their joys but also their struggles. It is a beautiful thing to see the look in a parent's eyes when they hear their child communicate for the first time or make eye contact while having a conversation with them. In the same breath I can tell you that it is heart breaking to see how heavily it weighs on families when they see their child self-injuring themselves and feel completely helpless. I can go on and go on about the joys and struggles I've witnessed while in this field, but at the end of the day what really matters is that there is something that can be done, and that something is Applied Behavior Analysis.

Applied Behavior Analysis is rooted in research. The field only uses those procedures that have been shown to work time and time again. ABA has the ability to change people's lives in significant ways. No person diagnosed with a disability should have to do without it because of their economic capabilities. I urge you to look at the facts and all that can be accomplished if ABA is approved by insurance companies.

Respectfully,

Nedelka Martinez, MS, BCBA

Nedella Washing

To Senator Josh Green, Senator Rosalyn H. Baker, Senator Brian T. Taniguchi:

My name is Sara Sato and I am Board Certified Behavior Analyst (BCBA). I have a Masters Degree in Special Education, Severe Disabilities/Autism Specialization from the University of Hawaii at Manoa and have been working with individuals with disabilities for 15 years. I have worked in Hawaii and San Francisco as an Educational Assistant, Skills Trainer, Behavior Therapist, Special Education Teacher, and Behavior Analyst. Working with individuals with Autism is my passion and I wholeheartedly support SB 2054.

I clearly remember the first child I ever met with Autism. He was a preschool boy named "Ben", with long, black hair and had no vocal language. Ben cried often, engaged in aggression towards others, and was self-injurious. However, when it was time for recess he sought me out and sat next to me on top of the play structure. When it was time to nap, he would bring his face right up to mine, and rub his eye brows against mine. Ben's mannerisms and interactions with me were so fascinating and from that point on I eagerly wanted to work with children on the spectrum.

As a Skills Trainer working for a DOE contracted company, I participated in trainings about Autism, Challenging Behavior, and Data Collection. I had the opportunity to work with numerous children with Autism and other disabilities under the direction of Behavioral Supervisors and teachers. In this setting, I saw how intensive, structured programs using the principles of Applied Behavior Analysis (ABA) truly benefitted the children. The students gained academic skills, their challenging behavior decreased, and they became more independent. At the same time I witnessed other children's programs that were less structured and intensive, and saw how these children were stagnant in their growth.

In 2009 I was fortunate enough to begin working for Behavior Analysis No Ka Oi, an ABA company lead by Christine Walton, Ph.D, BCBA-D. Dr. Walton has significant training in the field of ABA from some of the leaders in the field. She spent countless hours training me, attending every session I had with our clients at first, carefully ensuring that we were providing the best services we could. I immediately saw significant improvements in all of the children we serviced. We worked with children that would spit at others, bite, head lock, engage in self-injury, scream, and flop to the ground. Children who were non-vocal, those who would only engage in echolalia, or ones who would imitate TV shows all day long. Through the systematic procedures that we implemented, through parent and teacher training, and through consistent and daily work with our clients, they all made incredible progress. I felt so gratified to do this work and took tremendous pride in helping these individuals and their families.

After this experience I moved to San Francisco and was determined to gain more opportunities in ABA. I also had my mind set on becoming a Board Certified Behavior Analyst (BCBA). This involved taking 5 post-graduate courses that were extremely rigorous, accumulating 1500 hours of supervision hours from a BCBA, and taking a comprehensive exam with a less than 40% pass rate. I was fortunate enough to find employment with an incredible company in San Francisco and gained countless experiences as a Program Supervisor and Behavior Analyst, working in homes and schools in the Bay Area. It was there that I also accumulated many of my supervision hours and passed the BCBA exam.

In San Francisco I was amazed at the structure of the DOH and DOE systems. When a child was diagnosed with Autism, they were allowed to have intensive ABA services from time of diagnosis until at least Kindergarten, focusing on early intervention. I saw how having these intensive services from the

moment they were diagnosed until becoming school age had a tremendous impact on their lives. It was amazing to work with children who were non-vocal to being able to fully communicate their wants and needs and eventually be rescinded from special education. To meet with parents who were in tears when we would start services and then have tears of gratitude when hearing their children talk for the first time.

Being back in Hawaii, I am blessed once again to be working for Behavior Analysis No Ka Oi, in the role of a Behavioral Specialist. I supervise Behavior Tutors to work with children with Autism, design their programs, and provide parent training. This position is difficult, time consuming, and stressful. But each day I come to work, I hear a child speak a new word or a parent tells me their child is listening to them more. I am helping individuals each day reach their highest potential. I am so proud of what I do and I want nothing more than to continue to help as many individuals with Autism as I possibly can.

Thank you for your time in reading this,

Sara Sato, M.Ed., BCBA

<u>Committee on Health</u> Senator Josh Green, Chair Senator Rosalyn H. Baker, Vice Chair

Committee on Commerce and Consumer Protection Senator Rosalyn H. Baker, Chair Senator Brian T. Taniguchi, Vice Chair

Tuesday, January 28, 2014 / 8:30 am Conference Room 229, Hawai'i State Capitol

Dear Senators Green and Baker.

My name is Sheena Garganian and I am a professional who works with children and families affected by autism. I am writing to you because I want to talk about SB2054: Luke's Law, and how it will benefit children and families with autism.

I was first introduced to applied behavior analysis in 2010 by accepting a position as behavior interventionist (therapist/tutor) who works with children with autism ranging in ages from 2 to 13 years old in Colorado. One of the first clients I worked with demonstrated deficits in communication and social skills as well as engaged in aggressive behaviors that further impacted him from learning and acquiring the skills to improve in those areas of need. Being new to the field, I honestly was not sure how ABA would decrease those behaviors (fecal smearing, biting and hitting others) of this child. Over a short period of time, this client made significant process and there was apparent reduction in those behaviors. That was one of many experiences that helped me understand how ABA helped and how it can shape the behaviors, whether it is a behavior to increase or a behavior to decrease. Aside from the research stating the effectiveness of behavior analysis, for me, it was just plain obvious—based on my interactions with each child I work with. In that same year, I pursued further education in behavior analysis and received my certification in 2013 as a Board Certified Behavior Analysis. Prior to behavior analysis, I have 10 years experience working with the mental health population, particularly adolescent girls ranging from 13 to 18 years old and adults in transition from psychiatric hospital to residential health care facility ranging from 18 to 75 years old. I hear myself saying, "if I only knew then, what I know now..." because behavior analysis would have been extremely beneficial to that population as well. The only prevalent issue is that behavior analysis is not widespread or accessible. Unfortunately, this is not an isolated situation. In 2014, families in 17 of the 50 United States are still without the support they need from their communities, state legislators and insurance companies.

I moved to Hawaii last year and, in my short time here, see the lack of services that are available to individuals with Autism. Previous states have endured the struggles that Hawaii is now experiencing, though support from the community, families, and

professionals have made remarkable impact on enacting autism insurance reform. I am employed as a Clinical Supervisor at Malama Pono Autism Center (MPAC) in Mililani where I am responsible in providing supervision and consultation to behavior clinicians (therapist/tutor), lead clinicians, and parents across several settings (in-home, center, and school). At this time, we are able to provide services to families in the military (Tricare) and to families with the ability to pay for treatment (private pay). We met many families who were looking for ABA services, though their insurance does not cover that service or the out-of-pocket expense was too high.

My colleague and I would like to address a few misconceptions about ABA. ABA is not solely an educational treatment. It is considered to be a medically necessary, empirically validated treatment approach for children diagnosed with autism (and other related disorders). Public schools on island are not equipped to fully meet the needs of children with autism, as clearly evidenced by the recent ruling by Administrative Law Judge Haunani Alm, regarding the abuse at Kipapa Elementary in Mililani. (http://www.Hawai'inewsnow.com/story/24391699/charges-of-coverup-in-mililani-abuse-case). ABA is not new, nor is it a passing fad. Applied behavior analysis is a science of evidenced-based interventions that have been substantiated by over 1,000 research studies. ABA been backed by the US Surgeon General, American Academy of Pediatrics, American Psychological Association, Autism Society of America and National Institute of Mental Health (http://appliedbehaviorcenter.com/ABAEndorsements.htm). ABA is effective for individuals from birth to death. There is NO evidence that would support ABA as an intervention ONLY for young children with autism. For a list of common misconceptions and rebuttals, please visit (http://www.behaviorbabe.com/commonmisconceptions.htm.)

I would like to extend my sincerest gratitude to you for introducing and supporting Luke's Law: SB2054. I appreciate your time and thank you and the committee for hearing my point of view of why you, and all of Hawaii's legislators should vote to pass Luke's Law: SB2054.

Respectfully,

Sheena Garganian, M.S. BCBA Clinical Supervisor, Malama Pono Autism Center Legislative Chair, Hawaii Association of Behavior Analysis (HABA)