

PATRICIA MCMANAMAN DIRECTOR

BARBARA A. YAMASHITA DEPUTY DIRECTOR

STATE OF HAWAII DEPARTMENT OF HUMAN SERVICES P. O. Box 339

Honolulu, Hawaii 96809-0339

March 12, 2014

- TO: The Honorable Della Au Belatti, Chair House Committee on Health
- FROM: Barbara A. Yamashita, Deputy Director
- SUBJECT: S.B. 2054, S.D.2 RELATING TO HEALTH

Hearing: Wednesday, March 12, 2014; 8:30 a.m. Conference Room 329, State Capitol

PURPOSE: The purpose of this bill is to require health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for treatment of autism spectrum disorders subject to a maximum benefit of \$50,000 per year and a maximum lifetime benefit of \$300,000. This bill would also exempt the Medicaid plans from the coverage requirements.

DEPARTMENT'S POSITION: The Department of Human Services (DHS) provides the following comments for consideration regarding the provision of services autism spectrum disorders.

The DHS appreciates the language which would exempt Medicaid plans from providing services for autism spectrum disorders required by this bill. However, once these services are established as the standard of care, those standards will trigger the application of these services to Medicaid eligible children under the Early & Periodic Screening, Diagnosis and Treatment (EPSDT) requirements for the more than 150,000 children in our Medicaid program.

AN EQUAL OPPORTUNITY AGENCY

Further, the DHS supports the intent of the coverage, but believes that this is a largely fiscal question that would need to be funded by the legislature because of the anticipated Medicaid coverage that would be required. The Hilopa'a Project completed a comprehensive analysis that was utilized by the DHS and is included as an attachment to our testimony. Should ABA be required to be covered by Medicaid, the DHS estimates a projected total cost of \$135 million to serve Medicaid children up to age 19 years (see Summary of potential annual costs below), of which \$24.9 million would be DHS' cost, including federal funds that will need to be appropriated by the Legislature.

In Hawaii, the Department of Health (DOH) Early Intervention Program provides services to Medicaid beneficiaries ages 0-3 years who met eligibility criteria, and the Department of Education (DOE) Special Education program provides services during the school day for children beginning at age 3 years. The DHS would be responsible for services provided outside of the school day and for services not covered by DOE. While the DOH and the DOE would be responsible for funding the state share of the services, the DHS would be responsible for accessing federal matching funds for the DOH and the DOE services for Medicaid qualified children.

	# Medicaid	Total Service	Total Cost**	DOI	H***	DOI		D	HS
	Children	Hours*	\$ Millions	%	\$ M	%	\$ M	%	\$ M
0-3	105	138,969	\$10.7	100%	\$10.7	0%	\$0	0%	\$0
3-6	1,145	1,556,055	\$121.3	0%	\$0	80%	\$97.6	20%	\$24.3
6-19	428	40,011	\$3.2	0%	\$0	80%	\$2.0	20%	\$0.6
Total	1,573	1,630,575	\$135.2		\$10.7		\$99.6		\$24.9

Summary of the potential annual costs of covering ABA in Medicaid

* Assumes an average of 1.5 cycles per year for 6-19 year olds

** Assumes \$75/hr reimbursement for direct services and \$100/hr for supervision, assessment and parent training; approximately half of cost would be federally funded

*** Additional funding may not be necessary if these programs already cover the service, and cost may be greater if expected to provide to non-Medicaid covered children too.

Certain individuals may benefit from ABA, but whether the population of individuals

with autism has a clinically significant benefit is unclear. Most studies have evaluated the

effectiveness of ABA in children younger than 6 years old with autism, and the treatment

intervention was typically no less than 20 hours per week of ABA. A 2012 Cochrane systematic

review concluded:

Early intensive behavioral intervention (EIBI) is one of the most widely used treatments for children with autism spectrum disorder (ASD). The purpose of our review was to examine the research on EIBI. We found a total of five studies that compared EIBI to generic special education services for children with ASD in schools. Only one study randomly assigned children to a treatment or comparison group, which is considered the 'gold standard' for research. The other four studies used parent preference to assign children to groups. We examined and compared the results of all five studies. A total of 203 children (all were younger than six years old when they started treatment) were included in the five studies. We found that children receiving the EIBI treatment performed better than children in the comparison groups after about two years of treatment on tests of adaptive behavior (behaviors that increase independence and the ability to adapt to one's environment), intelligence, social skills, communication and language, autism symptoms, and quality of life. The evidence supports the use of EIBI for some children with ASD. However, the quality of this evidence is low as only a small number of children were involved in the studies and only one study randomly assigned children to groups [emphasis added].¹

In addition, a 2012 report completed by RAND found:

[S]tudies of UCLA/Lovaas-based interventions report greater improvements in cognitive performance, language skills, and adaptive behavioral skills than broadly defined eclectic treatments available in the community. **However, strength of evidence is currently low.** Further, not all children receiving intensive intervention demonstrate rapid gains, and many children continue to display substantial impairment.

This bill states that ABA is evidence-based, but evidence-based experts would disagree

because the quality of evidence of effectiveness is low.

The U.S. Preventive Services Task Force (USPSTF) is considered the gold standard for clinical preventive services, and under the Affordable Care Act, insurers must cover services that receive an A or B recommendation by the USPSTF without requiring a co-payment. A recommendation of C would mean that there is evidence of benefit, but the benefit is small and the service is not routinely recommended to be provided; a recommendation of I would mean that there is insufficient evidence, i.e. that the service is not evidence-based. The USPSTF is currently developing an evidence report and recommendation on screening for autism spectrum disorders. The report will evaluate the effectiveness of screening for children ages 12-36 months and of treatment for children ages 0 to 12 years.²

Thank you for the opportunity to testify on this measure.

¹http://summaries.cochrane.org/CD009260/early-intensive-behavioral-intervention-eibi-for-increasingfunctional-behaviors-and-skills-in-young-children-with-autism-spectrum-disorders-asd ²http://www.uspreventiveservicestaskforce.org/uspstf13/speechdelay/spchfinalresplan.htm AN EQUAL OPPORTUNITY AGENCY

ABA Utilization Projection for Hawaii Medicaid

The following assumptions serve as the basis for projecting utilization of Applied Behavior Analysis services for the children enrolled in the Hawai i Medicaid program.

1. Prevalence

- 1.1. National statistics indicate 1:88 children have Autism Spectrum Disorder (ASD), ranging in intensity from classic autism to Asperger s Syndrome
- 1.2. Population of children 18 and under in Hawai i for 2012 303,818
- 1.3. Total estimated children in Hawai i with an ASD 3,452
- 1.4. Total children served by Department of Heath Early Intervention Section (DOH/EI) receiving ABA services, and Department of Education Special Eduation (DOE) who an eligibility of Autism or Developmental Delay – 3,486
 - 1.4.1. Since the two numbers are so close, this projection will utilize the number reflecting identifyable children, the DOH, DOE combined number
- 1.5. Studies show there is no higher prevalence of ASD in children who are Medicaid eligible than those who are not
- 1.6. Using 3-month continuous eligibility for 90 days, 154,000 children are in the state Medicaid program, which equates to 47% of the 0-18 population
- 1.7. Applying the 47% to the total children served 1,624

2. Treatment

- 2.1. Evidence shows that the most effective use of ABA are in the child searly years
- 2.2. Studies indicate for a child under the age of 3, between 25-30 hours a week of services ramping up to potential 40 hours a week at age 3 show significant improvement these hours of services are across settings
- 2.3. For children over the age of 3, the general practice is to front load the intensive hours of treatment during the younger years and taper off the hours
- 2.4. As children grow older, the need for ABA services may be required to address targeted maladaptive behaviors triggered by puberty, emerging co-morbidities, as well as significant transitions
- 2.5. Typical utilization patterns (which have anecdotally been shared) indicate that families do not utilize all the hours that are authorized, as the rigor of an intensive program is quite difficult on families
- 2.6. ABA services would include 1) Assessment, 2) Plan Development, 3) Direct 1:1 service, 4) Service Supervision, and 5) Family Training
- 2.7. Ratio of supervision hours to direct service is 1:10
- 2.8. Current service provision of Assessments in the DD/MR Waiver are 30 hours to complete assessment, develop report, plan and provide initial family training

3. Projection Assumptions

- 3.1. Not all children will require the same level of high intensity
- 3.2. Comprehensive Intensive ABA services would be made available age 0-8
 - 3.2.1. Literature indicates intensive services on general population is 0-6

- 3.2.2. Extended to age 8 due to health literacy for parent involvement and ability to provide stimulation rich environment to support services
- 3.3. Focused ABA services would be made available 8-19
 - 3.3.1. Literature indicates service provision should be individualized and made available
 - 3.3.2. For this exercise, the following tiered structure is proposed to be able to make some assumptions
 - 3.3.2.1. Preventive Planning and Intervention
 - 3.3.2.1.1. Preventive Planning and Intervention would be provided to identify early emerging problems as well as anticipated intervention needs to "pre-plan" for upcoming events which would require skilled intervention (e.g., preparing for puberty, etc.)
 - 3.3.2.1.2. Prevention Planning and Intervention would be made available at the following regularly scheduled intervals
 - 3.3.2.1.2.1. Age 7 (i.e., for children not already receiving comprehensive intensive ABA)
 - 3.3.2.1.2.2. Age 10
 - 3.3.2.1.2.3. Pre-puberty (i.e., could identify a stage in puberty, Stage 2)
 - 3.3.2.1.2.4. Age 14
 - 3.3.2.1.2.5. Age 16
 - 3.3.2.1.2.6. Age 19-20
 - 3.3.2.2. Targeted Assessment and Treatment
 - 3.3.2.2.1. Targeted Assessment and Treatment would utilized on an as need basis to address behaviors that affect health and safety of the individuals or others (e.g., aggression, selfinjurious behaviors, etc.) as well as behaviors that restrict the setting of the individual (e.g., eloping, masturbating in public, property destruction, etc.)
 - 3.3.2.2.2. It is difficult to project the frequency of the service
 - 3.3.2.2.2.1. Frequency and intensity should diminish if the proposed preventive planning and intervention service could be develop and implemented
 - 3.3.2.2.2.2. Targeted Asssessment and Treatment may overlap the Preventive Planning and Intervention or defer the need for the service, so assumption would be to not include a quantity for this measure

4. Service Provision

- 4.1. Services are provided by DOH/Early Intervention Program (EI)
 - 4.1.1. El services are currently authorized to meet the childs total need across settings
 - 4.1.2. El serve numbers are included in the estimate
 - 4.1.3. EI ABA services should be included to the matrix to draw down federal dollars
 - 4.1.4. There should not be a need to provide more hours beyond what is provided by EI AN EQUAL OPPORTUNITY AGENCY

- 4.2. Services are provided by DOE Special Education
 - 4.2.1. DOE services are currenty authorized to meet the child s education needs in the school setting
 - 4.2.2. There will be a need to provide services beyond what is provided by DOE4.2.2.1. DOE federal mandate does not include addressing in home interventions4.2.2.2. Unable to direct all children through DOE unlike EI
 - 4.2.3. 80-100% of the child s need could be provided by the DOE, and what remains as a statel plan only benefit should be nominal
 - 4.2.4. DOE should have a higher success rate in properly claiming for these services as it s new and the ABA providers are much more meticulous in charting that other DOE therapists
- 4.3. The service is typically supervised by a Board Certified Behavior Analyst (BCBA)
 - 4.3.1. Tricare reimburses this at \$125.00/hour
 - 4.3.2. BCBAs typically do not provide the 1:1 direct, hands on service
- 4.4. The direct service is typically provided by a paraprofessional behavior technician
 - 4.4.1. Tricare reimburses this at \$50.00/hour and \$75.00/hour based upon provider credential
- 4.5. There does not appear to be uniformity in rates between DOE/DOH-EI/DOH-DD/MR

5. Projection

Step 1: Establish a child count

	Total Number of Children																	
AGE	<3	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
DOE		81	86	108	122	123	121	112	91	91	89	82	86	78	67	60	44	25
ASD																		
DOE		527	648	621														
Dev.																		
Delay																		
EIABA	224																	
Services																		
Counts	224	608	734	729	122	123	121	112	91	91	89	82	86	78	67	60	44	25

2011		1							1						1
Delay															
EIABA	224														
Services															
Counts	224	608	8 734	4 729	122	123	121	112	91	91	89	82	86	78	6
					·										
			Total	Numbe	er of Ch	ildren	Targe	eted fo	r Se	rvices	5	512			
AGE		<3	3	4	5	6	7	8	;	10	14	Ł	16	19	
Combined	1 2	24	608	734	729	122	123	3 1	21	91	8	36	67	2	$\overline{5}$
DOE and															

Combined	224	608	134	129	122	123	121	91	86	67	20
DOE and											
DOH											
%	47%	47%	47%	47%	47%	47%	47%	47%	47%	47%	47%
Medicaid											
Projection	105	286	345	343	57	58	57	43	40	31	12
Total	1,377						0				

Step 2: Establish a base for 100% participation and utilization

Comprehensive Intensive ABA Services

Age	# of Projected Medicaid Children	Service	Hours per child per week	Weeks per year	Total Hours for all	% DOH/ EI	% SPE D	Total Hours Not Carved Out: DHS
0-3	105	Direct Service	30	40	126,336	100%		0
		Supervision	3	40	12,633			0
		Direct Service	30	40	1,374,000			274,800
3-6	1,145	Supervision	3	40	137,400		80%	27,480
30	1,140	Assessment	3	10	34,350		0070	6,870
		Parent Training	1	9/mo	10,305			2,061
		Direct Service	3	40	29,280			5,856
6-8	244	Supervision	3	10	7,320		80%	1,464
6-8 244		Assessment & Parent Training	1	9/mo	2,196		0070	439

	Focused ABA Services								
Age	# of Projected Medicaid Children	Service	Hours per child per cycle	% SPED	Total Hours Not Carved Out: DHS				
		Direct Service	120	80%	1,392				
7	58	Supervision	12	80%	139				
	00	Assessment & Parent Training	30	20%	1,392				
10	43	Direct Service	120	80%	1,032				
		Supervision	12	80%	103				
		Assessment & Parent Training	30	20%	1,032				
14	40	Direct Service	120	80%	960				
		Supervision	12	80%	96				
		Assessment & Parent Training	30	20%	960				
16	31	Direct Service	120	80%	744				
		Supervision	12	80%	74				
		Assessment & Parent Training	30	20%	744				
19	12	Direct Service	120	80%	288				
		Supervision	12	80%	29				
		Assessment & Parent Training	30	20%	288				

Step 3: Apply other factors against the base

Other factors could include:

- Participation rate, 100% of the services will not be utilized, in general
- Start up rate, service utilization would "ramp" up over a longer period of time
- Credentialing, as the Autism Bill currently is written, provision is not made for the technician level of direct service which is a majority of the hours. The bill only supports qualified licensed providers and BCBAs



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

TO THE HOUSE COMMITTEE ON HEALTH

TWENTY-SEVENTH LEGISLATURE Regular Session of 2014

> Wednesday, March 12, 2014 8:30 a.m.

TESTIMONY ON SENATE BILL NO. 2054, S.D. 3 - RELATING TO HEALTH.

TO THE HONORABLE DELLA AU BELATTI, 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 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 comments on this matter.

KEALI`I S. LOPEZ DIRECTOR

JO ANN M. UCHIDA TAKEUCHI DEPUTY DIRECTOR NEIL ABERCROMBIE GOVERNOR OF HAWAII





STATE OF HAWAII DEPARTMENT OF HEALTH P.O. Box 3378 HONOLULU, HAWAII 96801-3378 LINDA ROSEN, M.D., M.P.H. DIRECTOR OF HEALTH

> In reply, please refer to: File:

House Committee on Health

SB 2054, SD3, Relating to Health

Testimony of Linda Rosen, M.D., M.P.H. Director of Health

March 12, 2014

Department's Position: The Department strongly supports this bill. Requiring insurers to provide 1 autism therapeutic coverage improves the long term outcomes for persons with autism and reduces the 2 burden of care on their families. Intensive behavioral interventions provided for children are evidenced 3 4 based and a recognized best practice. Children with these interventions achieve better outcomes in socialization, employment and exhibit less challenging behaviors as they become adults. 5 **Fiscal Implications:** The Department recognizes that this bill impacts insurance rates for all citizens. 6 The cost for families with children with autism is significant. The National Institute of Health has 7 reported that one third of families with children with autism expend more than three percent of their 8 annual income on autism therapies. For some families with children with autism, extreme behaviors 9 create a great financial burden on families that can create major family stress and financical crisis. 10 Intensive treatment for autism for children does ameliorate challenging behaviors and lessens the life 11 long dependency upon Medicaid Home and Community Based personal assistance. The fiscal 12 implications to the Department of Health are lowered costs of long term care. 13 Thank you for this opportunity to testify. 14

TESTIMONY BY KALBERT K. YOUNG DIRECTOR, DEPARTMENT OF BUDGET AND FINANCE STATE OF HAWAII TO THE HOUSE COMMITTEE ON HEALTH ON SENATE BILL NO. 2054, S.D. 3



March 12, 2014

RELATING TO THE HEALTH

Senate Bill No. 2054, S.D. 3, proposes to require all health insurers, mutual benefit societies, and health maintenance organizations to provide health care coverage and benefits for the diagnosis and treatment of autism spectrum disorders up to the age of twenty one. Maximum benefits for behavioral health treatment provided may be limited to \$50,000 per year and a maximum lifetime benefit of \$300,000 for the individual, but shall not be limited as to the number of visits to an autism service provider.

As we noted in our testimony during the 2013 Legislative Session with regards to similar measures, the Department of Budget and Finance (Department) has strong concerns pertaining to the following:

- These types of measure will limit an insurance carrier's ability to control both the appropriateness of care and costs by mandating coverage for specific types of disorders;
- This measure tends to increase the overall costs of health insurance and will thereby lead to higher insurance premiums that must be borne by both the employees and employers and other payers;

- An independent actuarial analysis of the respective cost impacts as a result
 of this mandate is prudent but has not been conducted to determine the
 potential cost impacts on both the Med-Quest and the Hawaii Employer Union
 Health Benefit Trust Fund (EUTF) program as was recommended in the 2013
 study that was conducted by the State of Hawaii Legislative Reference
 Bureau.
- With regard to the EUTF, active State employees are currently paying up to 50 percent of their health insurance and some employees are finding it increasingly difficult to afford health insurance coverage for themselves and their dependents. Hence, while this measure may benefit a certain insured group, any increase to the overall cost of health insurance premiums impacts all of the insured groups and their employers.

Furthermore, given the difficulty in diagnosing this disorder and the significant degree of treatment required, any insurance mandate for coverage is sure to correlate to higher premium costs charged by providers throughout the state. The Department would advise that the Legislature consider the socialized cost impact of mandating such coverage on all citizens that have health or medical insurance. As a business organization, the State of Hawaii, expends more than \$550 million per year on its portion of health insurance for State employees. Increases to health insurance premium costs – for whatever reason – will also increase taxpayer costs in the form of added cost of state government.

We defer to the Insurance Commissioner in regards to the impact of SB 2054, S.D. 3 upon Article 10A of the State of Hawaii Insurance Code.

Thank you for the opportunity to provide testimony on this important measure.

-2-



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 12, 2014

The Honorable Della Au Belatti, Chair House Committee on Health Twenty-Seventh Legislature State Capitol State of Hawaii Honolulu, Hawaii 96813

Dear Representative Belatti and Members of the Committee:

SUBJECT: SB 2054 SD3 - RELATING TO HEALTH

The State Council on Developmental Disabilities (DD) **SUPPORTS SB 2054 SD3.** The bill requires health insurers, mutual benefit societies, and health maintenance organizations to provide health care coverage and benefits for autism spectrum disorders (ASD).

According to the U.S. Centers for Disease Control and Prevention, about 1 in 88 children have been identified with ASD. That rate is anticipated to significantly increase in the next decade. With this alarming rate, it is imperative that children with ASD are provided with early diagnosis and treatment. Evidence-based practice shows that early identification and treatment results in overall improved outcomes for children with ASD. 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

SB 2054 SD3 provides comprehensive coverage of services, including well-baby and well-child screening diagnosis and evidence-based treatment for individuals with ASD under 21 years of age. Without intensive behavioral therapy the cost of services to support an individual with ASD only increases throughout the individual's lifetime. Whereas, children with ASD provided with intensive behavior therapy, such as "applied behavior analysis" learn meaningful skills of interacting and coping, essentially increasing their independence and preparing them for adulthood. Through early identification and intervention, the cost of services would significantly decrease and an individual's independence increases throughout their adult years.

Thank you for the opportunity to provide comments supporting SB 2054 SD3.

Sincerely,

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

J. Curtis Tyler, III Chair



HAWAII MEDICAL ASSOCIATION 1360 S. Beretania Street, Suite 200, Honolulu, Hawaii 96814 Phone (808) 536-7702 Fax (808) 528-2376 www.hmaonline.net

DATE:

TO: <u>COMMITTEE ON HEALTH</u> Rep. Della Au Belatti, Chair Rep. Dee Morikawa, Vice Chair

FROM: Hawaii Medical Association Dr. Walton Shim, MD, President Dr. Linda Rasmussen, MD, Legislative Co-Chair Dr. Ron Kienitz, DO, Legislative Co-Chair Dr. Christopher Flanders, DO, Executive Director Lauren Zirbel, Community and Government Relations

RE: SB 2054 RELATING TO HEALTH

Position: Support

This measure requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for treatment of autism spectrum disorders.

HMA finds that treatment of autism spectrum disorders is medical necessary and as such supports this measure, which would ensure that autism treatment is covered by insurance.

Thank you for introducing this bill and for the opportunity to provide testimony.



Government Relations

Testimony of Phyllis Dendle

Before: House Committee on Health The Honorable Della Au Belatti, Chair The Honorable Dee Morikawa, Vice Chair

> March 12, 2014 8:30 am Conference Room 329

SB 2054 SD3 RELATING TO HEALTH

Chair Belatti, and committee members, thank you for this opportunity to provide testimony on SB 2054 SD3which would mandate expanded insurance coverage for people with autism spectrum disorders.

Kaiser Permanente Hawaii supports the intent of this measure but has concerns and suggests amendments.

Attached to this testimony is a detailed revision of the bill that we request you use to replace what is in this bill.

Because this bill is based on last year's proposal and many of the things in it are already covered under the federal Accountable Care Act it is necessary to streamline the bill to be clear on what is being covered. Also it is important to remember that any and all additional mandates increase the cost of health care so care must be taken to balance wants and needs. This is particularly important this year because federal law and regulations requires the state to pay for additional mandates they pass now. Even with that said we urge the legislature to assure that if they are going to provide these benefits for some under commercial insurance that they also assure that it is available to all in and out of the health connector and including Medicaid and EUTF.

While we have many concerns with the bills in the way they are written I will just highlight a few that are corrected in the attached draft:

711 Kapiolani Blvd Honolulu, Hawaii 96813 Telephone: 808-432-5210 Facsimile: 808-432-5906 Mobile: 808-754-7007 E-mail: phyllis.dendle@kp.org **Date**—the date of July 1, 2014 on page one line 12 and page 8 line 8 are too early for the health plans to comply with. It is necessary with all additional benefits that health plans have the opportunity to figure out the cost of the additional benefits and add this cost to the premiums. It will also be necessary to locate and employ appropriate providers. The earliest we could effectively do this is with plans that start after December 31, 2015. However, if the state is prepared to pay for these benefits July 1, 2014 we would do our best to assure treatment was provided to individuals to whom it is prescribed.

Maximum dollar limits-We appreciate the intention of the drafters of this bill to create some financial certainty to health plans by placing a dollar limit per year and per lifetime. However, this is a violation of federal law. Federal mental health parity laws require that there be no coverage limits on mental health services which are not also on other health services. The federal Patient Protection and Accountable Care Act (ACA) prohibits any lifetime limits. The federal law will make it impossible for health plans to adhere to these limits.

Who's covered- As written the state is attempting to exempt itself from paying for services under Medicaid, and, in or out of the exchange as required by federal law. If this mandated benefit is too expensive for the state to pay for then it is too expensive to thrust on businesses.

Who can provide the service- Board certified behavior analysts are not licensed health care providers in the state of Hawaii. We have provided licensing language in our attached draft. For all services that are paid for by health plans the providers should be licensed to assure the protection of the consumers who use their services. In this case these providers can actually go into people's homes to provide services. Licensing the providers of ABA services improves the safety of the users of these services.

AS AMENDED this proposal focuses on providing coverage for services that are not otherwise covered or provided. It also focuses on assuring that it provides these services at the best possible time when the highest number of individuals could benefit. It solves the concerns we have about assuring the safety of patients by requiring the providers act and be treated like other medical professionals.

This amended bill specifically seeks to provide coverage for applied behavioral analysis. The research that is available including the March 2, 2012 actuarial cost Kaiser Permanente Hawaii

estimate done by Oliver Wyman at the request of Autisim Speaks shows that the ABA utilization and therefore costs peak at age 5. From there utilization falls off dramatically through age 8 when it drops to almost no usage. This bill proposes to have health insurance pay for coverage up to age 6 when individuals become eligible for services through the Department of Education.

This would mean that there would be assistance for families when they need it most, when it would do the most good but would also limit the expected increase in costs to the state and to businesses which are required to pay for mandated benefits.

We urge the legislature to move forward this version of the mandate that solves the many problems with this bill.

Thank you for your consideration.

Proposed amendments to SB2054 SD3

Red with strike-through to be removed.

Blue to be inserted.

Black to remain from original draft.

RELATING TO HEALTH.

BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF HAWAII:

SECTION 1. The purpose of this Act is to ensure the provision of quality health care for all Hawaii residents by requiring coverage of treatment for autism spectrum disorders.

The legislature finds that appropriate screening can determine whether an individual as young as one year old is at risk for autism and demonstrates that early treatment improves outcomes. Autism Speaks, an autism science and advocacy organization, estimates that one out of every eighty-eight children is diagnosed with some form of autism. Autism Speaks stresses the importance of recognizing the early signs of autism and seeking early intervention services. The legislature further finds that the federal Affordable Care Act has improved the availability of screening, diagnosis, and treatment of autism. For example, habilitative services would permit individuals with autism to access ongoing services in speech, occupational, and physical therapy when their physician prescribes it. However, behavioral health treatments such as applied behavior analysis specific to the treatment of autism have not been covered as habilitative services. The purpose of this Act is to require health insurance to provide coverage for behavioral health treatment of autism spectrum disorders when it is prescribed by an individual's physician and provided by trained professionals, at the time it will most benefit the individual. This treatment shall be covered by health insurance up to the age of six when the individual with autism may receive services as required by federal law from the department of education.

Kaiser Permanente Hawaii

Page 5

SECTION 2. This Act shall be known and may be cited as "Luke's Law".

SECTION 3. Chapter 431, Hawaii Revised Statutes, is amended by adding a new section to article 10A to be appropriately designated and to read as follows:

"<u>§431:10A-</u><u>Autism spectrum disorders benefits and coverage;</u> notice; definitions. (a) Each individual or group accident and health or sickness insurance policy, contract, plan, or agreement issued or renewed in this State on or after July 1, 2014, shall provide to the policyholder and individuals under twenty-one years of age covered under the policy, contract, plan, or agreement coverage for the screening, including well-baby and well-child screening, diagnosis, and evidence based treatment of autism spectrum disorders. Nothing in this section shall be construed to require such coverage in a medicaid plan.

after December 31, 2015, shall provide to individuals under six years of age covered under the policy, contract, plan, or agreement, coverage for behavioral health treatment of autism spectrum disorders.

(b) Every insurer shall provide written notice to its policyholders regarding the coverage required by this section. The notice shall be prominently positioned in any literature or correspondence sent to policyholders and shall be transmitted to policyholders within calendar year 2014 2016 when annual information is made available to members or in any other mailing to members, but in no case later than December 31, 2014 2016.

(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, 2015, the insurance commissioner, on an annual basis, shall adjust the maximum benefit for inflation using the medical care component of the United States Department of Labor Consumer Price Index for all urban consumers; provided that the commissioner may post notice of and hold a public meeting pursuant to chapter 92 before adjusting the maximum benefit. The commissioner shall publish the adjusted maximum benefit annually no later than April 1 of each calendar year, which shall apply during the following calendar year to health insurance policies subject to this section. Payments made by an insurer on behalf of a covered individual for any care, treatment, intervention, or service other than behavioral health treatment shall not be applied toward any maximum benefit established under this subsection.

(d) (c) Coverage under this section may be subject to copayment, deductible, and coinsurance provisions of an accident and health or sickness insurance policy, contract, plan, or agreement that are no less favorable than the copayment, deductible, and coinsurance provisions for substantially all other medical services covered by the policy, contract, plan, or agreement.

(e) This section shall not be construed as limiting benefits that are otherwise available to an individual under an accident and health or sickness insurance policy, contract, plan, or agreement. (f) Coverage for treatment under this section shall not be denied on the basis that the treatment is habilitative or nonrestorative in nature.

(g) Except for inpatient services, if an individual is receiving treatment for autism spectrum disorders, an insurer may request a review of that treatment. The cost of obtaining any review shall be borne by the insurer.

(h) (d) This section shall not be construed as reducing any obligation of the State to provide services to an individual under an individualized family service plan, an individualized education program, or an individualized service plan.

(i) (e) Nothing in this section shall apply to accident-only, 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. (j) Insurers shall include in their network of approved autism service providers only those providers who have cleared criminal background checks as determined by the insurer.

(k) Insurers shall include board-certified behavior analysts in their provider network.

(1) 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.

(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.

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

"Applied behavior analysis" means the evidence-based design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the 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.

<u>"Autism service provider" means any person, entity, or group that</u> provides treatment for autism spectrum disorders.

"Autism spectrum disorders" means any of the pervasive developmental disorders or autism spectrum disorders as defined by the most recent edition of the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM).

"Behavioral health treatment" means evidence based counseling and treatment programs, including applied behavior analysis, that are:

Kaiser Permanente Hawaii

SB2054 SD3

Page 8

- (1) Medically necessary <u>Necessary</u> to develop, maintain, or restore, to the maximum extent practicable, the functioning of an individual; and
- (2) Provided or supervised by a board-certified behavior analyst or by a licensed psychologist so long as the services performed are commensurate with the psychologist's formal university training and supervised experience.; provided that all providers of services regardless of their licensure or certification shall demonstrate they meet the same criminal history and background check standard as required by the department of human services Med-QUEST division.

<u>"Board certified behavior analyst" means a behavior analyst</u> credentialed by the Behavior Analyst Certification Board as a board certified analyst.

"Diagnosis of autism spectrum disorders" means medically necessary assessments, evaluations, or tests conducted to diagnose whether an individual has an autism spectrum disorder.

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

<u>"Psychiatric care" means direct or consultative services provided</u> by a licensed psychiatrist.

<u>Psychological care" means direct or consultative services</u> provided by a licensed psychologist.

"Therapeutic care" means services provided by licensed speech pathologists, registered occupational therapists, licensed social workers, licensed clinical social workers, or licensed physical therapists.

"Treatment for autism spectrum disorders" includes the following care behavioral health treatment; and habilitative services as defined by the state for the benchmark benefit package in the health insurance exchange; that are prescribed or ordered for an individual with an autism spectrum disorder by a licensed physician, psychiatrist, Page 9

(1) Behavioral health treatment;

(2) Pharmacy care;

(3) Psychiatric care;

(4) Psychological care; and

(5) Therapeutic care."

SECTION 4. Chapter 432, Hawaii Revised Statutes, is amended by adding a new section to article 1 to be appropriately designated and to read as follows:

"<u>§432:1</u> <u>Autism spectrum disorders benefits and coverage;</u> notice; definitions. (a) Each individual or group accident and health or sickness insurance policy, contract, plan, or agreement issued or renewed in this State on or after July 1, 2014, shall provide to the policyholder and individuals under twenty-one years of age covered under the policy, contract, plan, or agreement coverage for the screening, including well-baby and well-child screening, diagnosis, and evidence based treatment of autism spectrum disorders. Nothing in this section shall be construed to require such coverage in a medicaid plan.

after December 31, 2015, shall provide to individuals under six years of age covered under the policy, contract, plan, or agreement, coverage for behavioral health treatment of autism spectrum disorders.

(b) Every insurer shall provide written notice to its policyholders regarding the coverage required by this section. The notice shall be prominently positioned in any literature or correspondence sent to policyholders and shall be transmitted to policyholders within calendar year 2014 2016 when annual information is made available to members or in any other mailing to members, but in no case later than December 31, 2014 2016.

(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, 2015, the insurance commissioner, on an annual basis, shall adjust the maximum benefit for inflation using the medical care component of the United States Department of Labor Consumer Price Index for all urban consumers; provided that the commissioner may post notice of and hold a public meeting pursuant to chapter 92 before adjusting the maximum benefit. The commissioner shall publish the adjusted maximum benefit annually no later than April 1 of each calendar year, which shall apply during the following calendar year to health insurance policies subject to this section. Payments made by an insurer on behalf of a covered individual for any eare, treatment, intervention, or service other than behavioral health treatment shall not be applied toward any maximum benefit established under this subsection.

(d) (c) Coverage under this section may be subject to copayment, deductible, and coinsurance provisions of an accident and health or sickness insurance policy, contract, plan, or agreement that are no less favorable than the copayment, deductible, and coinsurance provisions for substantially all other medical services covered by the policy, contract, plan, or agreement.

(e) This section shall not be construed as limiting benefits that are otherwise available to an individual under an accident and health or sickness insurance policy, contract, plan, or agreement. (f) Coverage for treatment under this section shall not be

denied on the basis that the treatment is habilitative or nonrestorative in nature.

(g) Except for inpatient services, if an individual is receiving treatment for autism spectrum disorders, an insurer may request a review of that treatment. The cost of obtaining any review shall be borne by the insurer.

(h) (d) This section shall not be construed as reducing any obligation of the State to provide services to an individual under an individualized family service plan, an individualized education program, or an individualized service plan.

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

(j) Insurers shall include in their network of approved autism service providers only those providers who have cleared criminal background checks as determined by the insurer.

(k) Insurers shall include board-certified behavior analysts in their provider network.

(1) 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.

(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.

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

"Applied behavior analysis" means the evidence-based design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the 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.

"Autism spectrum disorders" means any of the pervasive developmental disorders or autism spectrum disorders as defined by the most recent edition of the American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders (DSM).

Kaiser Permanente Hawaii

Page 12

"Behavioral health treatment" means evidence based counseling and treatment programs, including applied behavior analysis, that are:

- (1) Medically necessary Necessary to develop, maintain, or restore, to the maximum extent practicable, the functioning of an individual; and
- (2) Provided or supervised by a board-certified behavior analyst or by a licensed psychologist so long as the services performed are commensurate with the psychologist's formal university training and supervised experience, ; provided that all providers of services regardless of their licensure or certification shall demonstrate they meet the same criminal history and background check standard as required by the department of human services Med-QUEST division.

<u>"Board certified behavior analyst" means a behavior analyst</u> <u>eredentialed by the Behavior Analyst Certification Board as a board</u> <u>certified analyst.</u>

"Diagnosis of autism spectrum disorders" means medically necessary assessments, evaluations, or tests conducted to diagnose whether an individual has an autism spectrum disorder.

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

<u>Psychiatric care means direct or consultative services provided</u> by a licensed psychiatrist.

<u>"Psychological care" means direct or consultative services</u> provided by a licensed psychologist.

"Therapeutic care" means services provided by licensed speech pathologists, registered occupational therapists, licensed social workers, licensed clinical social workers, or licensed physical therapists.

"Treatment for autism spectrum disorders" includes the following care behavioral health treatment; and habilitative services as defined by the state for the benchmark benefit package in the health insurance

SB2054 SD3

Page 13

- (1) Behavioral health treatment;
- (2) Pharmacy care;
- (3) Psychiatric care;
- (4) Psychological care; and
 - (5) Therapeutic care."

SECTION 5. Section 432D-23, Hawaii Revised Statutes, is amended to read as follows:

"\$432D-23 Required provisions and benefits. Notwithstanding any provision of law to the contrary, each policy, contract, plan, or agreement issued in the State after January 1, 1995, by health maintenance organizations pursuant to this chapter, shall include benefits provided in sections 431:10-212, 431:10A-115, 431:10A-115.5, 431:10A-116, 431:10A-116.5, 431:10A-116.6, 431:10A-119, 431:10A-120, 431:10A-121, 431:10A-125, 431:10A-126, 431:10A-122, [and] 431:10A-116.2, and 431:10A- and chapter 431M."

SECTION 6. <u>Section 453, Hawaii Revised Statutes</u>, is amended to add the a new part as follows:

[§453 -] Application for licensure of behavior analysts and certified behavior analyst assistant. (a) An applicant shall be issued a license by the department if the applicant provides satisfactory evidence to the department that the applicant is qualified for licensure pursuant to the requirements of this chapter and meets the following qualifications:

(1) is of good moral character and conducts his or her professional activities in accordance with accepted professional and ethical standards, including:

(a) compliance with the BACB Professional Disciplinary and Ethical Standards and the BACB Guidelines for Responsible Conduct for Behavior Analysts; and

Page 14

(b) completion of a state approved criminal background check and/or jurisprudence examination; and

(2) (a) for a Licensed Behavior Analyst applicant:

(i) file an application with the department;

(ii) have received an education, including a Master's or Higher Degree from a Program registered by the Department or determined by the department to be the substantial equivalent, thereof, in accordance with the Commissioner's regulations;

(iii) have experience in the practice of applied behavior analysis satisfactory to the department in accordance with the Commissioner's regulations;

(iv) has passed the Board Certified Behavior Analyst ("BCBA") examination; and

(v) maintains active status as a Board Certified Behavior Analyst.

(b) for a Licensed Assistant Behavior Analyst applicant:

(i) file an application with the department;

(ii) have received an education, including a Bachelor's or Higher Degree from a Program registered by the Department or determined by the department to be the substantial equivalent, thereof, in accordance with the Commissioner's regulations;

(iii) have experience in the practice of applied behavior analysis satisfactory to the department in accordance with the Commissioner's regulations;

(iv) has passed the has passed the Board Certified Assistant Behavior Analyst ("BCABA") examination;

(v) maintains active status as a Board Certified Assistant Behavior Analyst; and (vi) provides proof of ongoing supervision by a Licensed Behavior Analyst who is a current Board Certified Behavior Analyst in a manner consistent with the Behavior Analyst Certification Board's requirements for supervision of Board Certified Assistant Behavior Analysts.

SECTION 6. Notwithstanding section 432D-23, Hawaii Revised Statutes, the coverage and benefit for autism spectrum disorders to be provided by a health maintenance organization under section 5 of this Act shall apply to all policies, contracts, plans, or agreements issued or renewed in this State by a health maintenance organization on or after July 1, 2014.

SECTION 7. If any provision of this Act, or the application thereof to any person or circumstance, 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.

SECTION 8. Statutory material to be repealed is bracketed and stricken. New statutory material is underscored.

SECTION 9. This Act shall take effect on July 1, 2050 2014.

House Committee on Health March 12, 2014, 8:30 a.m. Room 329

Representative Della Au Belatti, Chair Representative Dee Morikawa, Vice Chair State Capitol 415 South Beretania St Honolulu, HI 96813

Re: In Strong Support of SB 2054 SD3

Relating to Health. Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder treatments.

Dear Chair Belatti, Vice Chair Morikawa 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 role in most of the now 34 states that have enacted autism insurance reform laws. Autism Speaks is pleased to submit testimony in strong support of SB 2054 SD3.

In testimony presented to this committee earlier this session (January 31, 2014 re: HB 2174) we provided an overview of autism spectrum disorders and our national experience with autism insurance legislation. Please refer to this testimony for 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. SB 2054 SD3 would require coverage for medically necessary treatment including ABA for individuals with autism.

While SB 2054 SD3 does not require similar coverage in Medicaid plans, the potential cost of requiring such coverage has been raised during debate of this issue. Oliver Wyman Actuarial Consulting, Inc. has analyzed in detail the cost impact of SB 2054 and the potential impact to Medicaid plans in *"Actuarial Cost Estimate: Hawaii Senate Bill 2054 SD1."*¹ See <u>http://bit.ly/1qteypb</u>. Oliver Wyman's middle estimate for the State of Hawaii's to extend benefits to the Medicaid program would be \$4,059,000, with approximately half of that cost being matched by the Federal government. A February 11, 2014 estimate prepared by Hawaii's Department of Human Services was considerably higher. The primary difference between the two estimates appears to be

^[1] Please note that the proposed terms of coverage in SB 2054 SD1 are identical to those proposed by SB 2054 SD3

due to the assumptions made in analyzing the total number of children in the Medicaid program who would be covered by the benefit. A detailed discussion of the differences between the two estimates is found in the report.

SB 2054 SD3 exempts "qualified health plans" (QHPs) as defined by the Affordable Care Act from required coverage because ABA is not an essential health benefit (EHB) in Hawaii and such coverage would trigger an obligation to the state to defray the cost of the benefit. The U.S. Department of Health and Human Services has further clarified that, except for "grandmothered" plans, they would not allow differences in benefits offered between QHPs and non-QHPs.² Therefore, even though the state would not be required to defray the cost of benefits offered in non-QHPs that exceed the essential health benefits, SB 2054 SD3 cannot require coverage for ABA in this market. Please consider the following amendment to subsection (i) in both Sections 431:10A and 432:1-which addresses this issue:

(i) Nothing in this section shall apply to accident-only, specified disease, hospital indemnity, qualified health plans as defined in section 1301 of the Patient Protection and Affordable Care Act, Public law 111-148, as amended, medicare supplement, disability income, long-term care, or other limited benefit hospital insurance policies.

(i) Nothing in this section shall apply to nongrandfathered plans in the individual and small group markets that are required to include essential health benefits under the Patient Protection and Affordable Care Act or to Medicare supplement, accident-only, specified disease, hospital indemnity, disability income, long-term care, or other limited benefit hospital insurance policies.

Section 6 of SB 2054 SD1 was amended to remove reference to section 432D-23, Hawaii Revised Statutes. However there was no explanation provided for this change in Standing Committee Report No. 2651. Please consider replacing this reference pending clarification of the amendment.

SECTION 6. Notwithstanding section 432D-23, Hawaii Revised Statutes, the coverage and benefit for autism spectrum disorders to be provided by a health maintenance organization under section 5 of this Act shall apply to all policies, contracts, plans, or agreements issued or renewed

² A "**grandmothered**" plan refers to a non-QHP that does not comply with certain market reforms required in this market by the ACA (e.g., inclusion of EHB). Grandmothered plans (or transitional renewal plans) are allowed under a transitional U.S. Dept. of HHS policy if the plans were in effect on October 1, 2013.

in this State by a health maintenance organization on or after July 1, 2014.

Thank you for considering my comments. We encourage the committee to pass SB 2054 SD 3 with the above amendments.

Respectfully submitted,

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

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





March 12, 2014

The Honorable Della Au Belatti, Chair The Honorable Dee Morikawa, Vice Chair

Committee on Health

Re: SB 2054 SD3 – Relating to Health

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

My name is Rick Jackson and I am Chairperson of the Hawaii Association of Health Plans ("HAHP") Public Policy Committee. HAHP is a non-profit organization consisting of nine (9) member organizations:

AlohaCare	MDX Hawai'i
Hawaii Medical Assurance Association	'Ohana Health Plan
HMSA	University Health Alliance
Hawaii-Western Management Group, Inc.	UnitedHealthcare
Kaiser Permanente	

Our mission is to promote initiatives aimed at improving the overall health of Hawaii. We are also active participants in the legislative process. Before providing any testimony at a Legislative hearing, all HAHP member organizations must be in unanimous agreement of the statement or position.

HAHP appreciates the opportunity to provide testimony on SB 2054 SD3 which requires health plans to provide coverage for autism and related services. We would like to raise your attention to the Affordable Care Act (ACA), which includes a provision that would require the State to bear costs associated with this mandate. We have attached the relevant ACA provisions for your review.

Under the ACA "a State may require that a qualified health plan offered in such State offer benefits in addition to the essential health benefits specified under section 18022(b) of this title." We believe that this Bill proposes a mandate that exceeds the current benefits offered in qualified health plans.

Further, if a State offers such a new mandated benefit, the "<u>State must assume (the) cost.</u> A <u>State shall</u> <u>make payments</u>—(I) to an individual enrolled in a qualified health plan offered in such State; or (II) on behalf of an individual described in subclause (I) <u>directly to the qualified health plan in which such</u> <u>individual is enrolled</u>; to defray the cost of any additional benefits described in clause."

HAHP believes that this autism mandate would require the State of Hawaii to do something it has never done before; pay for a health benefit plan mandate via payments made through a State Agency (i.e. Department of Accounting and General Services, Department of Commerce and Consumer Affairs, etc.) using State appropriated funds directly to individuals or, more likely, to health plans.

We believe that the State and especially this Committee should consider these new requirements arising from the ACA as it addresses any new mandated benefit.

Thank you for the opportunity to provide testimony.

Sincerely,

Cuhand m fack_

Rick Jackson Chair, Public Policy Committee

42 U.S. CODE § 18031 - AFFORDABLE CHOICES OF HEALTH BENEFIT PLANS

(3) Rules relating to additional required benefits

(A) In general

Except as provided in subparagraph (B), an Exchange may make available a qualified health plan notwithstanding any provision of law that may require benefits other than the essential health benefits specified under section <u>18022</u> (b) of this title.

(B) States may require additional benefits

(i) In general Subject to the requirements of clause (ii), a State may require that a qualified health plan offered in such State offer benefits in addition to the essential health benefits specified under section 18022 (b) of this title.

(ii) State must assume cost A State shall make payments-

(I) to an individual enrolled in a qualified health plan offered in such State; or

(II) on behalf of an individual described in subclause (I) <u>directly to the qualified health</u> plan in which such individual is enrolled;

to defray the cost of any additional benefits described in clause (i).

42 U.S. CODE § 18022 - ESSENTIAL HEALTH BENEFITS REQUIREMENTS

a) Essential health benefits package

In this title, ^[1] the term "essential health benefits package" means, with respect to any health plan, coverage that—

(1) provides for the essential health benefits defined by the Secretary under subsection (b);

(2) limits cost-sharing for such coverage in accordance with subsection (c); and

(3) subject to subsection (e), provides either the bronze, silver, gold, or platinum level of coverage described in subsection (d).

(b) Essential health benefits

(1) In general

Subject to paragraph (2), the Secretary shall define the essential health benefits, except that such benefits shall include at least the following general categories and the items and services covered within the categories:

(A) Ambulatory patient services.

(B) Emergency services.

(C) Hospitalization.

(D) Maternity and newborn care.

(E) Mental health and substance use disorder services, including behavioral health treatment.

(F) Prescription drugs.

(G) Rehabilitative and habilitative services and devices.

(H) Laboratory services.

(I) Preventive and wellness services and chronic disease management.

(J) Pediatric services, including oral and vision care.

(2) Limitation

(A) In general

The Secretary shall ensure that the scope of the essential health benefits under paragraph (1) is equal to the scope of benefits provided under a typical employer plan, as determined by the Secretary. To inform this determination, the Secretary of Labor shall conduct a survey of
employer-sponsored coverage to determine the benefits typically covered by employers, including multiemployer plans, and provide a report on such survey to the Secretary.



Testimony to the House Committee on Health Wednesday, March 12, 2014 at 8:30 A.M. Conference Room 329, State Capitol

RE: SENATE BILL 2054 SD3 RELATING TO HEALTH

Chair Belatti, Vice Chair Morikawa, and Members of the Committee:

The Chamber of Commerce of Hawaii ("The Chamber") **cannot support** SB 2054 SD3 Relating to Health.

The Chamber is the largest business organization in Hawaii, representing over 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. However, the Chamber has several concerns with the bill.

- The findings of the 2009 Auditor's report on similar legislation that has concerns on the enactment of a mandated benefit.
- Presently these services are already being offered by the Departments of Education and Health.
- The projected cost could be at least \$70 million per year if not more for private sector companies.

We strongly urge this committee to implement the recommendations of the Legislative Reference Bureau study requested by HCR 177, HD2, SD1 in 2012. Specifically the recommendation to commission an independent actuarial analysis which will help project the cost of this mandated benefit. Also, we highly suggest that the Legislature ask the affected agencies to conduct an analysis what would be the additional cost per this mandate. Based on testimony from some government agencies <u>it could cost the state and county governments at least an additional \$80 million per year</u>.

While we understand problems facing our community, we do not believe that business should be the group responsible for paying for this mandated benefit. Ninety percent of the cost of an employee's health care premium is paid for by the employer. Most employers would be unable to pass this new cost onto the consumer. Please keep in mind that this would be in addition to the already annual increase in health care premiums of 7-10% each year.

Thank you for the opportunity to testify.

ABC Group

AUTISM BEHAVIOR CONSULTING GROUP, INC.

www.AutismBehaviorConsulting.com

Committee on Health Rep. Della Au Bellati, Chair Rep. Dee Morikawa, Vice Chair

Dear Committee on Health,

My name is Anne Lau and I am the Clinical Director of the Autism Behavior Consulting Group clinic. I am writing to you because I want to talk about my support for HB 2054 / Luke's Law and how it will benefit children and families with autism.

I have been working in the field of Applied Behavior Analysis (ABA) for the last 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 parents cash in their life savings, sell their house, and go into nasty battles with school districts.

I have seen schools put in a terrible position of trying to prove that they can provide ABA, when in fact they are not equipped. Public schools cannot be expected to provide treatment for all disorders and diseases that occur in childhood. Imagine if schools were asked to treat leukemia! Some children have medical problems that supersede the need for compulsory education. Many children with autism lack the skills to benefit from school, yet they are required to attend instead of receive the treatment that they desperately need. This is a loss for them, a loss for the schools, and a loss for society.

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.

Thank you for your time and for hearing my point of view of why you should vote to pass HB 2054 / Luke's Law.

Respectfully,

Anne Lau, M.Ed. NCC, BCBA **Clinical Director**



vs: 10/2012

March 11th, 2014







March 11, 2014

TO: Representative Belatti

RE: SB2054 – RELATING TO HEALTH

Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for treatment of autism spectrum disorders.

Dear Chair Belatti, Vice-Chair Morikawa and Members of the Committee,

The Autism Society of Hawaii (ASH) **strongly supports** the passage of bill SB2054, which provides for treatment of autism spectrum disorder through speech therapy, occupational therapy, and physical therapy, and applied behavior analysis.

Autism continues to rise at an alarming rate, the most recent statistic from the Center for Disease Control citing <u>1 in 88 children</u> are affected; boys are a higher risk at 1 in 54. Harvard did a study showing the cost to be <u>\$3.2</u> <u>million dollars to take care of one autistic individual over their lifetime</u>. This can be significantly lowered with early identification and treatment. Despite having assessment tools that can <u>diagnose children as early as 12</u> to 18 months of age, the <u>average age of diagnosis is still a little over 4 years</u> this significantly impairs their ability to improve.

My name is Dr William Bolman. I am testifying as President of the Autism Society of Hawaii, and as a child psychiatrist specializing in the treatment of autism spectrum disorders for the past 15 years. Also, I am a retired Professor of Child Psychiatry at the John A. Burns School of Medicine, and in this role I try to stay current with research into the neuroscience of autism. What I would like to do is briefly summarize the present factual status of the autism spectrum disorders as it relates to insurance coverage.

<u>Fact 1:</u> In the past 20 years, the prevalence of autism has increased dramatically from 1 or 2 in 10,000 to 1 in 88, with a recent study by the Yale Child Study Center finding 1 in 38. The reasons for the increase are unknown, since the underlying causes are mostly unknown and appear to multiple in nature. We know that increased awareness accounts for about one-third of the increase, but the remaining two-thirds is genuine. One of the problems in determining the actual increase is we have tended to rely on routine data from physicians and educators which the Yale report shows will give us an underestimate of the issue. In my medical practice during the past 15 years, my case load started at 2 cases in 1990, and I now have several hundred. Most are still school-aged, but they are beginning to graduate high school, and encounter a marked absence of support services after leaving high school.

<u>Fact 2:</u> In addition to the dramatic increase in cases, combined with our ignorance of the causes and the degree of impairment autism causes, we are looking at a dramatic rise in the costs of life-long care for those affected by autism. The best estimate of the lifetime costs of autism (done by the Harvard School of Public Health) is \$3.2 million per person. If we take a conservative underestimate of just the number of young people I have seen who are likely to meet this cost due to the inadequacy of treatment (about 100), the cost will be



1600 Kapiolani Blvd. #620 Honolulu, HI 96814 www.autismhi.org (808) 394-7320 autismhi@gmail.com

about \$320,000,000. These costs are shared by parents and state agencies, but the majority of the costs are state based, as they arise between the years after the completion of schooling at age 21 and the 50+ years of dependent care.

<u>Fact 3:</u> This worrisome increase in the autism 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. As a physician who formerly treated polio and childhood leukemia, I am thrilled at the wonderful advances this research has produced in the neuroscience of autism, and look forward to its eventual control. However promising this sounds, we are still stuck with an unknown number of years of an extremely expensive condition.

<u>Fact 4:</u> What we do know about causes and treatment is that autism is a neurologic condition in which the inner connections in the brain are miswired. 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 miswiring 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 SB668 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.

<u>Fact 5:</u> The reason that universal insurance coverage is for autism treatments is so important is the fact that it involves all social and ethnic groups (indeed in my own personal experience working as a consultant for the World Health Organization, autism is as common in Asia, India, the Near East and Europe as it is in Hawaii and the United States). 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. I might add a side comment, that the reason for the increase in federal and private research is that the numbers of grandchildren of congressional legislators and wealthy private donors who have developed autism.

<u>To sum up</u>: The increase in autism is real, it is a medical-neurologic condition, it is expensive, it affects everyone, it can be partially treated successfully, and the experience with insurance coverage of other states show the cost is very manageable and cost-effective. Thank You.

Thank you for considering our testimony,



1600 Kapiolani Blvd. #620 Honolulu, HI 96814 www.autismhi.org (808) 394-7320 autismhi@gmail.com

William Bolman President



An Independent Licensee of the Blue Cross and Blue Shield Association



March 12, 2014

The Honorable Dell Au Belatti, Chair The Honorable Dee Morikawa, Vice Chair House Committee on Health

Re: SB 2054, SD3 – Relating to Health

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

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 2054, SD3, which, would require health plans to provide coverage for services for autism spectrum disorders (ASD), with the exception of certain plans. 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.

Both the State Auditor and the Legislative Reference Bureau have reviewed similar legislation in the past. The Auditor estimated the cost to cover services for autism spectrum disorders, including applied behavior analysis, to be \$1 billion. The Legislative Reference Bureau recommend the State to commission an independent actuarial analysis of the impact of covering these services, including impacts to the EUTF and to the MedQUEST Division.

Pursuant to the ACA, the cost of providing these services under a new mandate must be borne by the State. This requirement applies to plans sold both through and outside of the health insurance exchange. While SB 2054, SD3, attempts to shield the State from bearing the cost burden – it does not do so. All non-ACA plans provided by Hawaii's small businesses or purchased directly by individuals are not exempt in this proposed draft and, therefore, that cost must be picked-up by the State. As such, we also request an appropriation be included, and a process be developed in a State agency to administer the new benefit.

It still is important that the Legislature clarifies the potential financial impact of a coverage mandate for those services on both the State and the health care system. Consequently, the Legislature may wish to consider pursuing the additional study recommended by the LRB.

Thank you for the opportunity to offer our opposition to SB 2054, SD3.

Sincerely,

Jennifer Diesman Vice President Government Relations





March 12, 2014

The Honorable Della Au Belatti, Chair The Honorable Dee Morikawa, Vice Chair House of Representatives Committee on Health

RE: Support of the Intent of SB 2054, SD3 - Relating to Health.

Dear Representative Belatti, Representative Morikawa Members of the Committee:

For more than 60 years, Easter Seals Hawaii has provided exceptional, individualized, familycentered 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 2054, SD3 and offers the following recommendations:

- 1. Amend section 3(j), page 4, line 13 Background Check Adopt a uniform standard for background check requirements and guidelines which references Med-QUEST requirements for direct support workers.
- 2. Amend Section 3, page 1, lines 15-17 Benefits and Coverage Autism screening and well child visits are covered as part of the Preventive benefit requirement of the Affordable Care Act.

Easter Seals Hawaii appreciates the efforts of the Legislature to meet a critical need for services in our community. We would welcome the opportunity to work collaboratively with all of the interested parties to resolve these issues.

Thank you for your time and consideration.

Respectfully,

Christopher E. Blue church

Christopher E. Blanchard President & CEO Easter Seals Hawaii



HAWAII DISABILITY RIGHTS CENTER

1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813Phone/TTY:(808) 949-2922Toll Free:1-800-882-1057Fax:(808) 949-2928E-mail:info@hawaiidisabilityrights.orgWebsite:www.hawaiidisabilityrights.org

THE HOUSE OF REPRESENTATIVES THE TWENTY-SEVENTH LEGISLATURE REGULAR SESSION OF 2014

Committee on Health Testimony in Support of S.B. 2054, S.D.3 Relating to Health

Wednesday, March 12, 2014, 8:30 A.M. Conference Room 329

Chair Belatti and Members of the Committee:

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.

Community Alliance for Mental Health

Board of Directors

Anne Chipchase President

Robert Scott Wall Vice President

Brenda Kosky Secretary

William Lennox Treasurer

Susan King

Linda Takai

Randolph Hack

Gina Hungerford

To: House Committee on Health Re: SB 2054, SD 3,

Aloha Chair Belatti and the members of the committee,



March, 12, 2014

On behalf of the Community Alliance for Mental Health along with United Self Help we strongly support the passage of SB 2054, SD 3.

The great rise in the incidence of various illnesses in the Autism spectrum requires a greater investment by society in the study and treatment of Autism. These are members of our Ohana and the deserve out support.

Scott Wall VP/Legislative Advocate Community Alliance for Mental Health



Dear Legislators,

The Hawaii Association of School Psychologists (HASP) strongly supports HB2225, which requires insurance companies to provide coverage for autism spectrum disorder treatments. "School psychologists help children and youth succeed academically, socially, behaviorally, and emotionally. They collaborate with educators, parents, and other professionals to create safe, healthy, and supportive learning environments that strengthen connections between home, school, and the community for all students." –nasponline.org

Currently, this collaboration and continuum of services would only be possible in the state Hawaii for students with autism spectrum disorders that have access to federal insurance or private pay. As such, HASP encourages Hawaii's legislators to pass SB2054.

Respectfully,

Leslie Baunach, MA/CAS Hawaii Association of School Psychologists

Jerry Bump 3248 Lamaloa Place Honolulu, HI 96816

March 10, 2014

House Committee on Health

Hearing: March 12, 2014, 8:30 a.m., Conference Room 329

Re: Testimony in Support of SB 2054, SD 3 - Relating to Health

Dear Chair Bellati, Vice Chair Morikawa and Members of the Committee,

Aloha and thank you for the opportunity to submit testimony in favor of SB 2054, SD 3.

At 18 months, my son was diagnosed with an Autism Spectrum Disorder (ASD). As devastating as this was to us, we were shocked to find out that our health insurer would not cover any sort of therapy or treatments relating to his ASD. Instead, my family was directed to receive support from early intervention, DOH and eventually the DOE. We appreciate the help DOH and DOE have provided, but we do not feel they are staffed and funded to provide the proper therapies my son needs.

My son is now six years old and we have spent thousands of dollars for medical, speech, and behavioral therapies not covered by our health insurer. The DOE has stopped providing us services stating that his disability does not affect his academic performance. However, my son still needs social/behavioral therapies not covered by our insurer or provided by the DOE.

Currently, a majority of states specifically require insurers to provide coverage for the treatment of autism. Year after year, study after study, the Hawaii Legislature fails to help the struggling families. Let this be the year Hawaii stops the discrimination and requires health insurers' to provide the necessary treatment for this medical condition.

Please do the right thing for all of Hawaii's keiki and pass SB 2054, SD 3.

Mahalo, Jerry Bump

<u>COMMITTEE ON HEALTH</u> REPRESENTATIVE DELLA AU BELLATI, CHAIR REPRESENTATIVE DEE MORIKAWA, VICE CHAIR

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

Monday, March 10, 2014

In regards to **SB 2054, SD 1** that require health insurers, mutual benefit societies, and health maintenance organizations to provide health care coverage and benefits for autism spectrum disorders, <u>I am **in support**</u> of these bills as they address a serious need for coverage that private insurers should bear.

I am a psychologist who was raised here in Honolulu and I am a Past President of the Hawaii Psychological Association. I was fortunate to have received special training and internship experience to work with children on the Autism Spectrum and have provided expert witness testimony at Due Process hearings involving families seeking services from the Department of Education for their neurodevelopmentally disabled youth, including children on the Autism spectrum, for more than 10 years.

While I strongly support the intent of the measure, I am a little reticent to give a wholehearted endorsement as <u>I am concerned that those individuals providing applied</u> <u>behavior analysis under the supervision of a psychologist or BCBA would be</u> <u>reimbursable (Section 3 (m).</u> The BCBA should be the only non-licensed individual that should be permitted to be reimbursed by insurance companies.

Frankly, I would like there to be minimum requirements regarding training in the use of Applied Behavior Analysis and that providers be licensed in the State of Hawai'i. BCBAs should be able to provide services, but for the purpose of consumer protection, they should be under the supervision of a licensed psychologist or psychiatrist specializing in assessment and treatment of Autism Spectrum Disorders. That being said, I am willing to let that go since the DCCA does not seem to be as concerned as I. However, I feel I must draw a line with SECTION 3, (m) – "coverage....shall include the services of personnel under the supervision of a BCBA or the licensed psychologist overseeing the program." This seems irresponsible. BCBAs don't yet have a continuing education requirement and their newly minted supervision training curriculum doesn't even go into effect until the end of 2014. It's not even clear if BCBAs need to have had this supervision training to maintain their certification and there is no provision in the legislation that requires BCBAs to have undergone this training.

All this being said, I still believe that BCBAs should be held to the same level of accountability as other professionals in the field, including psychologists, psychiatrists, clinical social workers, mental health counselors, and marriage and family therapists, if they wish to be eligible for 3rd party reimbursement (i.e., insurance companies). It

seems the bills allow BCBAs to circumvent the law that governs other professionals with considerably more education (including terminal degrees in their fields).

Finally, as a "housekeeping" item, the term "licensed psychologist" can be replaced with "psychologist" as the license is inferred. One cannot refer to themselves as "psychologist" in this State without being licensed.

Thank you for the opportunity to provide my mana'o.

Jeffrey D. Stern, Psychologist Past President, Hawaii Psychological Association

Testimony

SB 2054

Aloha. I am a graduate student in the School of Social Work at the University of Hawaii at Manoa. I am testifying on Senate Bill 2054, which requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder treatments.

I am for this bill being passed as it is crucial for individuals with autism spectrum disorders to receive treatment. There are a number of agencies and treatments out there for families and individuals to access. However, often these services are not utilized because of how expensive they are. Autism can be assessed and diagnosed as early as 18 months. Studies show that the earlier treatment begins, the greater the chance of having an independently functioning adult able to live in the community despite having an autism spectrum disorder.

I was a behavioral therapist for children diagnosed with autism for only six months, and we strictly implemented ABA (Applied Behavioral Analysis). In the six months that I worked with five children and their families, I saw immense improvements. It was heart breaking to learn of many other individuals seeking services for their child or grandchild and being shut down by the financial barrier. If individuals can receive continual treatment from the time of their diagnosis (hopefully while they are children), they will stand a higher probability of leading independent lives and perhaps not requiring as much complex social services in their adult life. This would benefit the individual, their family and ultimately, the community as a whole. Mahalo for your consideration. Dear Committee Members,

This letter is in strong support of SB 2054.

I have worked with individuals with developmental disabilities for several years. I have been part of programs in the DOE, working in area high schools, and worked as a program supervisor for DOH-DD Waiver programs. While in my experience, I do believe people try their best to help individuals in the DOE and DOH-DD programs, there is something to be said for the difference in quality, progress, and overall improvement for the individual when the program is overseen by a Behavior Analyst (BCBA). Sadly, I have witnessed individuals with severe behavioral needs flounder in the system because they were not able to receive the proper behavioral assessment and systematic, data-based programming a BCBA would be able to provide. No parent should be forced to watch their child hurt themselves and suffer to participate in the most basic tasks, all the while knowing that there are quality services available, if only they had the money to pay for it or lived in one of the other 35 states that currently mandate insurance coverage for ABA. Hawaii is a state of aloha, that values respect and care for those that call these beautiful islands home—passing this bill allows us, as a state, to care for some of our most vulnerable citizens and ensure that every ohana is able to access quality care.

Please pass SB 2054 in this legislative session.

Sincerely,

Brian J. Burdt

morikawa2-Joanna

From: Sent: To: Subject: Rheena Lynne A. Campbell <rheenalynne@gmail.com> Monday, March 10, 2014 9:01 PM HLTtestimony SUPPORT for SB 2054

I support SB 2054 and ABA services for children with autism.

Rheena Lynne A. Campbell Behavioral Tnerapist March 10, 2014

Committee on Health Rep. Della Au Bellati, Chair Rep. Dee Morikawa, Vice Chair Hawaii State Capitol 415 South Beretania St. Honolulu, HI 96813

Dear Representatives and Committee Members:

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 a recent session with her ABA professional 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. 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

morikawa2-Joanna

From: Suzanne Egan <segan808@gmail.< th=""><th>com></th></segan808@gmail.<>	com>
Sent: Monday, March 10, 2014 11:50 PM	
To: HLTtestimony	
Cc: Louis Erteschik; Suzanne Egan	
Subject: Luke's_Law	

COMMITTEE ON HEALTH

Rep. Della Au Belatti, Chair Rep. Dee Morikawa, Vice Chair

Wednesday, March 12, 2014, 8:30 AM State Capitol, 415 South Beretania Street Conference Room 329

Dear Representatives Belatti and Morikawa,

My name is Suzanne Egan and I am the parent of a beautiful 5 year old boy 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.

We suspected that Julian had Autism when he was an infant, but our pediatrician and Early Intervention specialists told us to "wait and see." We were told that the DOE would evaluate him if warranted.

Once he transitioned to DOE/Kamiloiki Elementary, we were assertive about having him evaluated. We were told to "wait until we get to know your child better." Observations by unqualified DOE staff said his school behaviors were "not severe enough to warrant formal testing." Teachers are NOT doctors. Teachers are NOT Behavioral Analysts? Why are they given these jobs in our State?

By age three, we had secured his diagnosis. It was OBVIOUS to the private psychologist. We celebrated his diagnosis - FINALLY, we felt empowered! We had expected immediate responsiveness via Evidence Based Practice, particularly ABA. We were shocked to find that NOONE was responsive. NOONE was accountable.

Evaluation, after evaluation, NOONE was responsive:

Every professional we have ever seen, has recommended ABA therapy: Dr. Jennifer Takahashi, PsyD.; Dr. Brian Tanabe, Pediatrician, Straub; Dr. Mari Uehara, Developmental Behavioral Pediatrician, Kapiolani; Kiegan Blake, OTSI, Maui Child Development Center; Mary Marasovich, SLP, Oahu Speech; Drs. Tyson, Dunkin and Lipsitt, Psy Ds, LD and ADHD Center of Hawaii; Dr. Ryan Lee, MD, Nueropsycology, Shriners and the Renowned Kennedy-Krieger/John Hopkins Center for Autism. The refusal of the State of Hawaii to abide by the professional knowlege base and recommendation by both national and local expertise is a shockingly ignorant act, and one not only answerable to families and children, but to God Himself. The State is blatently, deliberatley, indifferntly, harming children.

Shame on you.

Julian could have been diagnosed as an INFANT! We have been pursuing Evidence Based Practice/ABA through Medical Insurance, DOE and DOH for almost 2 years now. Medical insurance has told us it's a DOH responsibility. DOH says its a DOE responsibility. DOE says its a medical issue, not an educational one. What a senseless loss of our child's precious critical developmental period. What a senseless burden on the children, families, the community and the state....so much WASTE.

This merry-go-round of service avoidence is a repulsive neglect. Our child, Julian, and many others like him, suffer. Julian's formative window is quickly closing. We missed the 3 1/2 year mark for establishing Intensive Early Intervention/ABA; 40 years of longitudinal research, recognized by the Surgeon General, shows a 47% success rate for recovery of Autism with this therapy. At age 5, we have only 1 year left to capitalize on what is left of the neuroplasticity of his brain.

Mother knows best. I know my child, and I KNOW that Julian can grow to be an independent, contributing member of society, with appropriate intervention. We have been told by the State Systems that Julian is low cognitive; that he is a "naive" child. But Independent experts across fields tell us how receptive he is, how teachable he is, how apparent it is that he will speak, given the right therapies. They are not convinced that he is "low cognitive." The state ignores the experts. We have listened to the experts.

Our extended family has stepped up to the plate. This past December, Julian began an Independent Behavioral ABA Program with Partington Behavioral Analysts. After just a couple of short months, he is a different child! All those things we were told he "couldn't learn"?he's learning! and quickly! He has play skills, social receptiveness, he is attending for up to 2 hours at a time, signing, matching, following a visual schedule. There are times that he connects so well, I genuinely believe that we can beat this Autism. We have a chance! MY SON HAS A CHANCE!

But we can't keep this up forever. The family has limited resources. My extended family is supporting Julian's therapy with the promise of reimbersement. We are positioned for due process with DOE via a private attorney, and a litigation with Medicaid via Hawaii Disability Rights. We must prevail - for the physical, psycological and financial health of our family. For my son's LIFE.

Our family's journey has been nothing short of devestating. And our crisis is not unique.

Who takes on the burden of family crisis, in this matter? Insurance companies, who support devestated mothers' clinical depressions, anxieties and other stress related problems; The Hawaii Department of Education, who will contine to invest time and money in due process cases, and who may be burdened with services through age 21, that could have been avoided via appropriate Early Interventions by those qualified; In our case, the Department of Education, who is also mother's employer, and who has supported months of sick leave related to evaluations, advocacy, and mother's stress related health problems; The Hawaii Department of Health - DD/ID, who may be supporting individuals through their adult lives unecessarily; Social Security, who may be supporting individuals through their adult lives unnecessarily; the Department of Human Services, who will support families driven below the poverty line by exhaustion of personal resources for therapies, and who will invest time and money in litigation; Medicaid, who will invest time and money in litigation; any State Department from which settlements may be incurred. Families, the community, insurance companies, the state, THE CHILDREN...all bear the unessesary burdens of the lack of access to absolutely necessary Intensive Interventions for Autism.

We are angry. But we are also humbly asking for your support today. Your decision today will significantly affect the health and welfare of Hawaii's children, and the State at large. BE WISE IN YOUR LEADERSHIP.

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

Respectfully,

Suzanne Egan 1151 Kahului Street Honlulu, Hawaii 96825

808-321-3072 segan808@gmail.com Aloha, My name is Patty Kaholokula and I am submitting my testimony in favor of SB 2054. I understand the importance of early diagnosis first hand. In early 2008 when I was 48 years old I was finally diagnosed with having dyslexia and ADHD. Growing up as a child when learning disabilities were not recognized and testing was not available, the classroom became extremely painful. I struggled, cried, kicked, screamed and prayed my way through school. By the time I finished 8th grade I was angry, ashamed and felt hopeless. I dropped out of school just 3 weeks into my freshmen year of high school. I was uneducated, barely able to read and write and facing poverty for the rest of my life.

Today, I'm now turning 59 years old and I am in the Masters Social Work program at the University of Hawaii at Manoa. I have a cumulative GPA of 3.50. I am also a member of the Nu Sigma Phi Alpha Honor Society. After being a guest speaker in April 2009 at the International Pacific Rim Conference On Learning Disabilities, I set a goal to help people with disabilities have a fair chance to succeed and learn they can accomplish their goals when headed in the right direction with the right help. My goal is to utilize my training and experience with children and adults diagnosed with behavioral and learning disorders. Because I was diagnosed I was able to get the help I needed to stop a dead-end cycle.

Jackie Robinson once said, "a life is not important except through the impact it has on other lives." By passing SB 2054, you can impact a child's life so they too can find their dream.

Mahalo

Patty Kaholokula



COMMITTEE ON HEALTH Rep. Della Au Belatti, Chair Rep. Dee Morikawa, Vice Chair

Wednesday, March 12, 2014, 8:30 AM State Capitol, 415 South Beretania Street Conference Room 329

Dear Representatives Belatti and Morikawa,

My name is Dr. 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 <u>SB2054: Luke's</u> <u>Law</u> and why you should <u>support this very important initiative</u>.

Applied behavior analysis (ABA) is an evidenced-based, empirically validated, scientifically proven methodology for improving the lives of children and families impacted by autism spectrum disorders (ASD). I have spent over a decade learning about ABA and focusing on how it can be employed to solve some of society's largest problems.

I have earned my Master and Doctoral degree in behavior analysis and over the years I have gained experience working with several hundred children diagnosed with autism in multiple treatment settings, throughout various states. I consider myself an expert in the treatment of children with autism and in ABA. However, I do not consider myself an expert in legislation or with writing or interpreting insurance policies. I respectfully defer to you for your guidance on those matters and respectfully request that you consider my insight into areas that are within my realm of expertise.

I would like to provide you with some **facts** pertaining to autism treatments based on applied behavior analysis (ABA).

- 1. Children with autism often have difficulty learning through exposure to typical social settings, which can be extremely damaging to their social development (Koegel, 1998; Smith, 2001).
- 2. There is no cure for autism, but it is a treatable condition (NCSL, 2012). In order to address these potential deficits, children with autism generally require explicit instruction to learn to attend to relevant stimuli in their environment (Drash & Tudor, 1993).
- 3. Evidence exists that early intensive interventions guided by behavior analytic principles produce **substantial benefits** for children with autism, as outlined in **comprehensive reviews** (Rimland, 1994; Rogers, 1998).
- 4. There have been long-term, positive effects achieved with intensive behavioral intervention (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Smith, 1995).
- Specifically, procedures based on applied behavior analysis (ABA) are recommended for children diagnosed with autism (National Research Council, 2001; Surgeon General, 1999).

- 6. In addition, over the past **30 years, several thousand published research studies** have documented the efficacy of applied behavior analysis across a wide range of populations, interventionists, settings, and behaviors (NRC, 2001; MADSEC, 2000; Surgeon General, 1999).
- 7. Cost-benefit estimates suggest significant cost-aversion or cost-avoidance may be possible with early intensive behavioral intervention (EIBI). This model estimates that cost savings could range from \$187,000 to \$203,000 per child for ages 3-22 years, and from \$656,000 to \$1,082,000 per child for ages 3-55 years (Jacobson, Mulick, & Green, 1998).
- 8. Applied behavior analysis is the science of systematically studying variables that influence behavior (Sulzer-Azaroff, Mayer, & Wallace, 2012) and is the methodology that generates **the most effective outcomes** for individuals with autism (Zager, 2005).
- 9. Behavior analytic teaching procedures include strategies based on positive reinforcement to <u>increase academic and social skills</u> (e.g., Jones, Feeley, & Takacs, 2007; Tarbox, Ghezzi, & Wilson, 2006), extinction to <u>reduce challenging behavior</u> (e.g., Neidert, Iwata, & Dozier, 2005; Waters, Lerman, & Hovanetz, 2009), and prompting strategies to <u>teach new skills</u> (e.g., Fisher, Kodak, & Moore, 2007; Kurt & Tekin-Iftar, 2008).
- 10. Typically, 25 to 40 hours per week of intensive behavior intervention is recommended for children with autism (Leaf & McEachin, 1999; Lord & McGee, 2001; Green, 1996; Myers & Johnson, 2007).

Additionally, I would like to share information pertaining to the coverage of ABA for treatment of ASD in other states.

- 34 states currently provide insurance mandates for autism spectrum disorders (ASD): Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, Virginia, West Virginia, and Wisconsin (ASHA, 2014).
- 2. Most of the legislation to provide coverage for autism has been enacted in the last four years (NCSL, 2012).
- 3. Board Certified Behavior Analysts (BCBA's) do not have to be licensed in order to receive reimbursement for treating individuals with autism.
 - a. Ohio specifically has adopted the Behavior Analyst Certification Board (BACB) requirements for service providers and has developed *certification* at the state level.
 - b. In North Carolina, BCBA's practice is restricted and must be overseen by Licensed Psychologists, which has actually prohibited children and families from receiving access to effective treatment. The current practice contributes to the fact that NC does <u>not</u> have current autism legislation (Green, 2014).

- 4. A study in 2006 by the Harvard School of Public Health estimated that it costs \$3.2 million to take care of an individual with autism over his or her lifetime and that it costs society an estimated \$35 billion each year to care for all individuals with autism (NCSL, 2012).
- Two years after requiring coverage, seven states saw monthly premiums rise by 31 cents on average per member, according to figures collated by Autism Speaks. In Arizona's second year of mandated coverage, autism-related claims totaled about \$389,000 — less than 10 percent of the \$4,900,000 that the legislature forecast in last March (Reuters, 2013).

I appreciate your time and thank you and the committee for hearing my point of view. I hope data and facts, rather than merely opinions and impressions, will be the guiding force that will lead you –and all of Hawaii's legislators, to <u>vote to pass Luke's Law: SB2054</u>.

Respectfully,

Amanda N. Kelly, PhD, BCBAD

Clinical Supervisor, Malama Pono Autism Center 2014 Vice President, Hawai'i Association for Behavior Analysis Behaviorbabe, <u>www.behaviorbabe.com</u>

References

American Speech-Language Hearing Association (ASHA), 2014: http://www.asha.org/Advocacy/state/States-Specific-Autism-Mandates/

Behaviorbabe (2014). www.behaviorbabe.com

Drash, P. W. & Tudor, R.M. (1993). A functional analysis of verbal delay in preschool children: Implications for prevention and total recovery. *The Analysis of Verbal Behavior, 11,* 19-29.

Fisher, W. W., Kodak, T., & Moore, J. W. (2007). Embedding an identity-matching task within a prompting hierarchy to facilitate acquisition of conditional discriminations in children with autism. *Journal of Applied Behavior Analysis, 40,* 489-499.

Green, G. (1996). Early behavioral intervention for autism: What does research tell us? In C. Maurice, G. Green, & S. C. Luce (Eds.), *Behavioral intervention for young children with autism* (pp. 181-194). Austin, TX: PRO-ED.

Green, G. (2014). Personal phone conversation.

Harvard School of Public Health, (2006) Press release: Autism has high costs to US Society. http://archive.sph.harvard.edu/press-releases/2006-releases/press04252006.html

Jacobson, J. W., Mulick, J. A., & Green, G. (1998). Cost-benefit estimates for early intensive behavioral intervention for young children with autism – general model and single state case. *Behavioral Interventions, 13,* 201-226.

Jones, E. A., Feeley, K. M., & Takacs, J. (2007). Teaching spontaneous responses to young children with autism. *Journal of Applied Behavior Analysis, 40,* 565-570.

Koegel, R. L., Camarata, S., Koegel, L. K., Ben-Tall, A., & Smith, A. E., (1998). Increasing speech intelligibility in children with autism. *Journal of Autism and Developmental Disorders, 28,* 241-251.

Kurt, O. & Tekin-Iftar, E. (2008). A comparison of constant time delay and simultaneous prompting within embedded instruction on teaching leisure skills to children with autism. *Topics in Early Childhood Special Education, 28,* 53-64.

Leaf, R. & McEachin, J. (1999). A work in progress: Behavior management strategies and curriculum for intensive behavioral treatment of autism. New York, NY: DRL Books.

Lord, C. & McGee, J. P. (2001). *Educating children with autism*. National Academy Press: Washington, DC.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55,* 3-9.

Maine Administrators of Services for Children with Disabilities (2000). *Report of the MADSEC Autism Task Force, Revised Edition.* Kennebec Centre, RR 2 Box 1856, Manchester, ME 04351, <u>http://www.madsec.org/docs/atf.htm</u>

McEachin, J.J., Smith, T., & Lovaas, O.I (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal of Mental Retardation*, *97(4)*, 359-372. <u>http://www.ncbi.nlm.nih.gov/pubmed/8427693</u>

Myers, S. M. & Johnson, C. P. (2007). Management of children with autism spectrum disorders. *Pediatrics, 120,* 1162-1182.

National Research Council. (2001). *Educating children with autism.* Washington, DC: National Academy Press.

National Conference of State Legislators (NCSL), 2012: http://www.ncsl.org/research/health/autism-and-insurance-coverage-state-laws.aspx

Neidert, P. L., Iwata, B. A., & Dozier, C. L. (2005). Treatment of multiply controlled challenging behavior with procedural variations of differential reinforcement. *Exceptionality*, *13*, 45-53.

Reuters, 2013: http://www.reuters.com/article/2013/12/16/us-usa-health-autism-idUSBRE9BF0H820131216

Rimland, B. (1994). Recovery from autism is possible. *Autism Research Review International, 8*, 3.

Rogers, S. J. (1998). Empirically supported comprehensive treatments for young children with autism. *Journal of Clinical Child Psychology*, *27*, 167-178.

Smith R. G, Iwata B. A, Goh H, Shore B. A. (1995). Analysis of establishing operations for selfinjury maintained by escape. *Journal of Applied Behavior Analysis, 28,* 515–535.

Smith, T. (2001). Discrete-trial instruction in the treatment of autism. *Focus on Autism and Other Developmental Disabilities, 16,* 86-92.

Sulzer-Azaroff, B., Mayer, G., & Wallace M. D. (2012). Behavior *Analysis for lasting change*, (2nd Ed.). Fort Worth: Holt-Rinehart-Winston.

Surgeon General. (1999). *Mental health: A report of the surgeon general.* Washington, DC: Department of Health and Human Services.

Tarbox, R. S. F., Ghezzi, P. M., & Wilson, G. (2006). The effects of token reinforcement on attending in a young child with autism. *Behavioral Interventions*, *21*, 155-164.

Waters, M. B., Lerman, D. C., & Hovanetz, A. N. (2009). Separate and combined effects of visual schedules and extinction plus differential reinforcement on challenging behavior occasioned by transitions. *Journal of Applied Behavior Analysis, 42*, 309-313.

Zager, D. (2005). Autism Spectrum Disorders Identification, Education, and Treatment. Mahwah, NJ: Lawrence Erlbaum Associates.

From: Sent:	mailinglist@capitol.hawaii.gov Monday, March 10, 2014 8:39 PM
To:	HLTtestimony
Cc:	starsister2000@yahoo.com
Subject:	*Submitted testimony for SB2054 on Mar 12, 2014 08:30AM*

SB2054

Submitted on: 3/10/2014 Testimony for HLT on Mar 12, 2014 08:30AM in Conference Room 329

Submitted By	Organization	Testifier Position	Present at Hearing
Bonnie Koba	Individual	Support	No

Comments:

Please note that testimony submitted less than 24 hours prior to the hearing, 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

Dear Representatives Belatti and Morikawa, and members of the Health Committee:

My name is Kristen Koba-Burdt and I am a Board Certified Behavior Analyst (BCBA) working with individuals with autism, writing in **support** of SB 2054.

For the last several years, I have worked with individuals on Maui and now, on Oahu. I have experienced first-hand the tremendous difference ABA services can make for individuals and families. Witnessing first-hand the significant improvements in an individual's ability to participate in the world around them and access a better quality of life motivated me to pursue graduate education and become a BCBA.

Sadly, many families are not able to access quality ABA programs because they have no financial means to pay for this type of therapy out-of-pocket. Some have implied that DOE and DOH-DD programs provide the same level of ABA services proposed in this bill; however, this is not the case. These programs are not currently structured in ways that support the implementation of effective, evidence-based service provision that individual's with autism so greatly need.

This lack of effective intervention for children of Hawaii has, in my opinion, led to greater expenses for the state. It's no secret that Hawaii spends a tremendous amount of money on Special Education services and on Department of Health- Developmental Disabilities Division Medicaid Waiver services. From the Felix decree to current Due Process suits, to the need for more intensive adult services due to severe deficits and behavioral challenges, the state spends money trying to address the challenges faced when the proper treatment is not readily available. The population of those affected by autism continues to grow and without effective ABA services, the cost to the state will continue to grow exponentially.

ABA offers the potential to change this trend. Research on ABA programming for individuals with autism has demonstrated a variety of desirable outcomes including increases in ability to communicate, treatment of eating and feeding problems, ability to perform functional self-help skills, treatment of sleep problems, treatment of eloping and wandering, and the treatment of self-injurious, aggressive, or other dangerous behaviors. Individuals with autism need access to evidence-based treatment and insurance reform is an absolutely necessary step in creating this change for Hawaii. I ask for your support in helping SB 2054/Luke's Law become a reality in this legislative session.

Thank you for your time and consideration,

Kristen Koba-Burdt, M.S., BCBA Marketing Chair-Hawaii Association for Behavior Analysis (HABA) kkburdt@gmail.com

HOUSE COMMITTEE ON HEALTH Rep. Della Au Bellati, Chair Rep. Dee Morikawa, Vice Chair

Wednesday, March 12, 2014, 8:30 AM Conference Room 329, State Capitol 415 South Beretania Street

Dear Representatives Bellati and Morikawa,

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 ABA therapist 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. 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 only one of many experiences that helped me understand how ABA helped and how it can shape behaviors. Aside from the research stating the effectiveness of behavior analysis, it was clearly evident based on my interactions with each child I work with. In that same year, I decided to pursue further education in behavior analysis and received my certification in 2013 as a Board Certified Behavior Analyst. 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. Part of my position now is not only to help the individual with Autism but also train the parents and caregivers the techniques and strategies to improve their quality of life in the home and community. I know that I am doing my job when I hear parents, family members, educators, and professionals say, "he/she is doing so well!" "I cannot believe how much he has learned!" "he talks now!" "he can use the bathroom all on his own!" "he's eating more AND can sit at the table without any problems!" "he's talking to his classmates!"

I moved to Hawaii last year and, in my short time here, I 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.

I would like to also mention that ABA is not solely an educational treatment, but medically necessary, evidence-based treatment approach for children diagnosed with autism. Schools are not fully equipped to meet the needs of children with autism. This is clearly indicated in 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 just another trend because of the prevalence of autism; it is a science of evidence-based interventions and is supported by organizations such as the US Surgeon General, American Academy of Pediatrics, American Psychological Association, and Autism Society of America, to name a few. (http://appliedbehaviorcenter.com/ABAEndorsements.htm). ABA is effective for individuals from birth to death.

I would like to state my support for 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.

Respectfully,

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



WEDNESDAY, March 12th at 8:30 am, SB 2054, SD 3.

Committee on Health Rep. Della Au Bellati, Chair Rep. Dee Morikawa, Vice Chair

Conference Room 329 State Capitol 415 Beretania Street

Dear Representatives Belatti & Morikawa,

My name is Brandi M. Picardal. I am the mother of a 4 year old Autistic child named Ethan. I am writing to you because I want to talk about SB 2054, SD3 and how this bill will affect our family and many other families in Hawaii.

Having a child with Autism is something I would not wish on anyone. As parents we try to find the silver lining in having a child with Autism, but the truth is not one parent who has a disabled child would ever chose to have a child with Autism.

Having a child with Autism is overwhelming and devastating to our families. Most children with Autism, like Ethan, have Co-Morbid medical conditions with their Autism. People do not understand that children with Autism do not only suffer from Social and Communication delays, but often suffer from Mitochondrial Dysfunction, Sensory Processing Disorder, Anxiety disorders, Immune disorders, Gastrointestinal dysfunction, Food Allergies and Seizures. I know this because my son, Ethan, has been diagnosed with almost all of these, as well as Maldigestion and Malabsorption.

Parents of children with Autism depend on insurance to help pay the overwhelming amount of therapies and medical treatments that our children need. As with most children with Autism, there are visits to the Neurologist, Psychologist, Gastroenterologist, Allergist, Developmental Pediatrician, Opthamologist, Audiologist, Speech Therapist, Occupational Therapist, MAPS trained physicians and the list goes on. Our kids need to have Evaluations done to see what their needs are and these evaluations are very costly. Even with insurance, we still are overwhelmed by copays. Families are forced to prioritize their child's needs because we are unable to pay for all the help our children need.

Ethan has so many therapy and medical bills that ABA therapy has never been an option. If SB2054, SD3 is passed, Ethan will be able to start ABA therapy. Why is this so important? ABA therapy is the single most proven therapy to help children with Autism. ABA therapy is the gold standard for Autism treatment.

Thank you for your time and for hearing why our family and so many families in Hawaii are counting on you to vote for SB2054, SD3 .

Respectfully,

Brandi M. Picardal 94-1415 Welina Lp. Apt. 8B, Waipahu, HI 96797 808-741-2283

3/11/14

To: House Committee on Health

Re: Luke's Law sb2054

I am tired. I don't know what to tell my Husband anymore. We need to help our son, Luke, who has Autism. Please give us some hope...please let me tell Luke and family that there is help for him on the horizon!

We have done what we can as a family. We love Luke unconditionally. We moved our family around 2 different islands chasing down services we could afford out of pocket. I try to work with his school (s) when he is misunderstood and bullied. I try to explain these things to Luke.

If we could only have services afforded to us from this bill we could help Luke with social and educational abilities. If we could get help through this bill Luke will cost so much LESS to this wonderful state.

If we could all get help through this bill I would be less tired as a teacher, teaching students who are not diagnosed, who are not getting services and who are taking up SO MUCH TIME away from ALL the students in the regular education class.

I meet so many people who are effected by Autism. They are always saying, "oh ya my Auntie's kid...." Or "My boyfriend's brother...." And this weekend it was the worker at Verizon (Luke love's phones and gravitates towards the phone section) who said his relative's Autism services have been cut and the family has no more money to continue.

For less than the cost of a postage stamp we could help everyone! Please help all of us by passing Luke's Law sb2054!

Respectfully Submitted,

Gerilyn Pinnow (Luke's Mom)

Committee on Health Rep. Della Au Bellati, Chair Rep. Dee Morikawa, Vice Chair

Conference Room 329 State Capitol 415 Beretania Street

March 10, 2014

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. I am writing this testimony to voice my wholehearted support for HB 2054 SD1.

I clearly remember the first child I ever met with Autism. He was a preschooler named "Ben", with flowing, black hair and had the longest eyelashes I have ever seen. Ben cried often, engaged in aggression towards others, was self-injurious and completely non-vocal. When I first started working with him, I struggled to figure him out. I never knew what he wanted and constantly felt helpless: I wanted to help and I just didn't know how! 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, I was intrigued and wanted to learn as much as I could about Autism.

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, parent and teacher training, and consistent, 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 witness a child call their mother, "Mama" for the first time or work on social interactions with teenagers. Each day I am helping individuals 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

Dear Representatives Belatti and Morikawa,

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). I am also an aunt to three children on the autism spectrum. 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.

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 Committee on Health Rep. Della Au Bellati, Chair Rep. Dee Morikawa, Vice Chair

Conference Room 329 State Capitol 415 Beretania Street

Dear Representatives,

My name is Dana Simmons and I am the aunt of an amazing nine year old boy with autism as well as a Board Certified assistant Behavior Analyst (BCaBA) currently working with children diagnosed with autism and developmental disabilities. 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 the past five years I have seen many families' lives changed by the application of Applied Behavior Analysis (ABA). I began working in this field approximately a year after receiving my undergraduate degree in Speech Pathology. I worked as a Speech-Language Pathologist Assistant (SLPA) for many months in California but took a job tutoring children with autism upon arriving in Hawaii. It took less than 6 months for me to realize that the work I was doing was so powerful that it could help many children learn at a rate higher than many in a regular education classroom. I did not need any convincing to immediately change my career path. Proof of the effectiveness of this treatment had been shown over and over again through me, many other technicians and Behavior Analysts applying the principles of Applied Behavior Analysis with a wide variety of children on the autism spectrum. I have worked harder to learn more, become certified and am currently enrolled in a master's program for ABA and autism. With this degree I hope to assist children, young adults and families with a wide variety of life challenges that come along with an autism diagnoses.

In the past, working as an SLPA, I felt that working with children with disabilities was my calling. I would go classroom to classroom pulling children to the side to work on particular sounds and language skills that they were having trouble with. At that time I had no knowledge of ABA and my efforts and advances with their progress were mediocre at best, this likely being typical with practices based on theory. I do not want to slander the ways of others but merely point out the changes that ABA has made in helping me help others. Armed with the scientifically proven procedures used in the application of ABA I have been able to assist children who were falling behind and have been considered "helpless" by many other professionals. I have worked with children who have been literally abused, likely because their teachers were frustrated by their own inability to communicate and have them follow instructions. Without ABA I would not have been able to assist those children in learning how to ask for what want and tell others what they need. Without ABA, it is likely that those children would never have had a voice. Most heartbreaking of all, I have watched my own nephew struggle with school and social skills for more than 5 years, due to a lack of funds to cover ABA services that have been proven to help him. He falls behind his peers in school every day, even with extra classroom aide. Living so far away from them, I see a family who needs a cohesive,

comprehensive program to assist not only my nephew, but his family in maintaining consistency that could ease all of their lives.

In my experience with ABA I have seen a child unable to speak any intelligible language, walk away from his specialized program nine months later and join his peers in a regular education classroom. I have seen children who scream, cry and hit others as a form of communication, learn to verbally ask for food and use the toilet on their own, after years of unsuccessful attempts at home. I have seen children learn math and reading at a rate higher than any typically developing child I know; all due to the application of ABA.

Applied Behavior Analysis has the potential to not only help diminish behaviors that interfere with learning but also to help individuals join their society and lead happier lives. ABA can be used in so many ways that will benefit children's lives, their family's lives, a teacher's ability to teach or a schools ability to educate. Through years of research, this has been proven. Please give our children in Hawaii the opportunity to be educated in ways that can help them lead more enriched lives. They are full of humor and brilliant ideas, given the chance they may just help change our world for the better someday.

I am more than willing to share a thousand more stories if you would like to contact me but I hope that you have also taken a moment to meet some of these beautiful children and see the difference ABA has made in their lives. If this bill is allowed to be put off until the year 2050, many of the children that need our help now will continue to fall behind their peers. My nephew will be 45 years old by then, and at that point a whole other world of help will be needed. I honestly thank you for your time and for hearing my point of view of why you should vote to pass HB2174 with amendments to take effect by 2015.

Respectfully,

Dana Simmons, BCaBA dana@autismbehaviorconsulting.com (228) 357-0840 <u>COMMITTEE ON HEALTH</u> Rep. Della Au Belatti, Chair Rep. Dee Morikawa, Vice Chair

Wednesday, March 12, 2014, 8:30 AM State Capitol, 415 South Beretania Street Conference Room 329

My name is Johanna Taylor and I am a Board Certified Behavior Analyst (BCBA) that has worked with individuals diagnosed with autism spectrum disorder (ASD) for over 10 years. I am writing in **support** of SB 2054.

Currently I am a doctoral student studying ASD and early intervention at the University of Pittsburgh in Pittsburgh, Pennsylvania. I was fortunate to work on Maui several years ago with individuals with ASD providing interventions that use applied behavior analysis (ABA). In pursuit of higher education, I returned to the mainland and will complete my PhD in April of 2014.

After graduation I am moving to Hawaii and intend to make the state my home. I have observed the monumental impact ABA based services can have on individuals with ASD and their families. It is clear that many families in Hawaii are not able to access quality ABA programs that can significantly change their children's lives because of the expense. Also, while the Department of Education and Department of Health Developmental Disabilities programs provide some level of service, it is often not nearly as intense as is needed for children to improve to the level where they will no longer need support later in life.

If individuals with ASD can have access to therapies that are grounded in ABA implemented by individuals trained in such evidence-based programs this will ultimately save the state money in the future. ABA is a treatment we know is effective that is more strongly supported than any other intervention method for individuals with ASD. A wealth of research exists supporting ABA based programming for treating challenging behaviors, eating and sleeping problems, inabilities to complete self-help tasks, communication deficits, wandering and eloping issues, and social skill problems that exist in individuals with ASD.

I am thrilled to be returning to Hawaii and look forward to supporting children with ASD and their families. Insurance reform is a necessary step towards providing effective services for individuals with ASD. I hope that you consider supporting SB 2054/Luke's Law in this legislative session.

Thank you,

Johanna P. Taylor, M.Ed., BCBA johannapatriciataylor@gmail.com

morikawa2-Joanna

From:
Sent:
To:
Subject:

Amy Wiech <amy@autismbehaviorconsulting.com> Monday, March 10, 2014 9:11 PM HLTtestimony In Support of Lukes Law 2054

Dear Committee on Health, Reps. Au Bellatti and Morikawa,

I am writing this letter in support of a bill to mandate health insurance providers here in Hawaii to provide services which are evidence based and scientifically supported called Applied Behavior Analysis or ABA.

Thank you for allowing me the opportunity to testify today, and over the past several years where I have testified before you both and other members of the Senate and House for at least the past three years regarding similar bills. I strongly believe it is about time to make it pono for child ren and families affected by Autism here in Hawaii. I have made Hawaii my home since 1995. I started my career in ABA over 20 years ago, while working with a 2 year old boy with autism, and have since worked with hundreds of children with the diagnosis 299.0.

I graduated from University of Hawaii in 2002 with my Masters in Special Education and concentration in Applied Behavior Analysis, and have just earned my PhD in Special Education-with an emphasis in Behavior Analysis. I became Board Certified in Behavior Analysis in 2004.

I have had many experiences within with schools, with teachers, families, and conducting training to various organizations including DOE and Early Intervention, and have seen well run ABA programs and those not so well run, producing not so optimal outcomes unfortunately.

After teaching in the DOE for 4 years, and realizing ABA was not being delivered with the integrity and fidelity it deserves, I started ABC Group in 2006 as a seed planted by my father, who used to employ men with developmental disabilities back in the 80s. We started as a small Kama'aina family owned company and have employed over 70 local staff members as behavior technicians, clinical supervisors, and Behavior Analysts. The impetus for starting ABC Group was to provide high quality ABA services with integrity, fidelity and compassion for families affected by autism. We have to remember that they DID NOT choose Autism; but Autism chose them. We would like to be able to offer our services beyond the military insurance, and beyond only those who can afford the treatment privately.

This bill would provide access to scientifically supported treatments which result in socially significant outcomes for individuals with ASD and their families, including children of Hawaiian ancestry. Not duplicating what the Department of Education cannot and has not been providing in terms of ABA treatment, this bill would follow in the footsteps of 33 other states, and save the State millions over the course of ones life (research to support this). And, would not increase premiums more then few cents per person (data from actuarial consulting firms).

If Data driven and developmentally appropriate programs developed by Board Certified Behavior Analysts in correlation with appropriate assessment tools, and the programs delivered with fidelity, intensity and duration by well trained behavior technicians, the terminal outcomes can be life changing as well as socially significant. These services are medically necessary, and result in kids first learning to learn, then learning to talk, learning to tolerate aversive stimuli, learning self help skills (eating, brushing teeth, bathing, etc) leading to independence from caregivers, learning say "I love you mommy", become employed self supporting citizens of Hawaii, and eventually becoming YOUR next door neighbor. And services should not be capped off at age 6, but allowed up into young adulthood. Teaching functional life skills to this population would certainly increase their independence and likely result in decreasing their reliance on others to care for them. In addition, would save the State millions in the long run.

In 2015, Behavior technicians will need to become Registered Behavior Technicians (RBTs) as directed by our governing board, the BACB, further increasing the standards of practice and training for those delivering front line interventions with integrity, given supervision by a Board Certified Behavior Analyst.

We are also extending an invitation for you to visit our clinic in Aiea if you would like to experience high quality ABA treatment in action with kids, behavior technicians, and supervisors. You can see how we assess, collect data and visually analyze the data daily in order to make treatment decisions which are individualized. Please feel free to contact me for a personal tour. We would be very proud to show you quality ABA services in action at ABC Group and demonstrate to you what hard work goes into a program with fidelity implemented by our talented staff!

We cannot afford to wait any longer to help our families affected by ASD. Please support this bill, and are doing our State a disservice by delaying these mandates. Lets not be the 50th state in Autism Insurance but be the 34th or 35th state!

Respectfully submitted, Mahalo palena 'ole,

Amy Smith Wiech, Ph.D., BCBA-D CEO of ABC Group Board Certified Behavior Analyst #1-04-1581 HABA Member 808-637-7736 (cell) Amy@autismbehaviorconsulting.com

Www.autismbehaviorconsulting.com (ABC Group) Www.autismtrainingsolutions.com

COMMITTEE ON HEALTH

Rep. Della Au Belatti, Chair Rep. Dee Morikawa, Vice Chair



Wednesday, March 12, 2014, 8:30 AM State Capitol, 415 South Beretania Street Conference Room 329

Dear Representatives Belatti and Morikawa,

My name is Grace Bunghanoy-Diama and I am a Board Certified Behavior Analyst. I have worked with children and families affected with autism for the past 14 years in Hawaii. 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 have seen the positive outcomes in utilizing Applied Behavior Analysis. When I first started off as a skills trainer 14 years ago, I had training on behavior modification but not on Applied Behavior Analysis. It wasn't until I attended a training on ABA and working with mentors with ABA experience that I witnessed firsthand how systematic, objective, and effective ABA has on children with autism. I remember working with a child with no vocal language and primarily communicating by gesturing or grabbing his mother to indicate what he wanted. If his mother did not know what he wanted, he would flop to the ground and engage in a tantrum. Within in a week of working with him, he was saying a few words and on his way to more functional communication. Of course, his parents were so happy to see his progress and gave them hope that their child could achieve so much more and reach his fullest potential.

I have also seen the struggles families go through with trying to obtain services for their child. Only a few families that I worked with were able to pay for services on their own but not with a lot of financial sacrifices. Most of my families cannot afford to pay for services and must rely on state assisted programs, if they are fortunate enough to be eligible. There is an abundance of literature that illustrates the effectiveness of utilizing ABA in reducing problem behaviors and increasing appropriate skills in communication skills, social skills, and ultimately a better learner. The positive impact of ABA not only impacts the child, but it trickles to the family and also to the community.

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

Respectfully,

Grace Bunghanoy-Diama, LSW, BCBA Bayada Habilitation, Clinical Manager gbunghanoy-diama@bayada.com

From: Sent:	mailinglist@capitol.hawaii.gov Tuesday, March 11, 2014 2:09 PM
To:	HLTtestimony
Cc:	blarrabeeduarte@hawaii.rr.com
Subject:	*Submitted testimony for SB2054 on Mar 12, 2014 08:30AM*



<u>SB2054</u>

Submitted on: 3/11/2014 Testimony for HLT on Mar 12, 2014 08:30AM in Conference Room 329

Submitted By	Organization	Testifier Position	Present at Hearing
Barbara Duarte	Individual	Support	No

Comments:

Please note that testimony submitted less than 24 hours prior to the hearing, 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

<u>COMMITTEE ON HEALTH</u> Rep. Della Au Belatti, Chair Rep. Dee Morikawa, Vice Chair



Wednesday, March 12, 2014, 8:30 AM State Capitol, 415 South Beretania Street Conference Room 329

Dear Representative Belatti, Morikawa and Members of the House Health Committee,

Thank you for the opportunity to submit testimony supporting SB2054, which would mandate health insurers to fund services 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 autism and other 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 in order to complete my undergraduate degree in Psychology. 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. I quickly realized that this 6 year old child taught me more about understanding behavior than any professor had 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, researched and discovered that Applied Behavior Analysis (ABA) 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 at West Virginia University.

While attending graduate school, I was given the opportunity to observe first-hand how applied behavior analysis had 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 coverage of treatments for individuals with an autism spectrum disorder. One prominent insurance carrier informed me that they only provide treatment for the families to "cope" with the diagnosis. Currently, my clinic primarily works with military families, since Tricare is the only Hawaii insurance carrier that provides treatment for ABA services. We also work with several local families who pay privately to ensure their child receive ABA services. I know of several families who have had to mortgage their homes or relocate to the mainland just to receive ABA, highlighting the social injustice in the denial of services for those on the autism spectrum.

I would like to address some comments discussed by my colleagues with regards to the profession of behavior analysts. The Behavior Analyst Certification Board (BACB) that oversees all behavior analysts is a nonprofit organization that was established in 1999 to meet needs identified by governments, consumers, funding sources, and behavior analysts to credential professional practitioners of applied behavior analysis (ABA). Its certification programs are accredited by the well-respected National Commission on Certifying Agencies of the Institute for Credentialing Excellence.

The BACB has conducted systematic job analysis studies involving thousands of professional behavior analysts to determine the degree, coursework, and experiential training required to practice ABA. It has also developed a psychometrically valid and reliable professional examination in behavior analysis. All of those requirements -- which parallel requirements for obtaining most valid professional credentials -- must be met to obtain BACB certification. The BACB has also established continuing education requirements for maintaining certification.

Additionally, the BACB has established Guidelines for Responsible Conduct of Behavior Analysts and Professional Disciplinary and Ethical Standards to protect consumers of ABA services. The latter are enforced by the BACB, which can impose sanctions on certificants who are found to have violating one of the standards. In other words, consumers and others do in fact have recourse if a BACB certificant engages in misconduct. The disciplinary standards, complaint form, review procedures, and disciplinary actions taken by the BACB to date are available at <u>www.bacb.com</u>, Ethics and Discipline.

Finally, the job analysis studies conducted by the BACB over the past 15 years have identified knowledge and competencies for practicing behavior analysis that are distinct from those required to practice clinical psychology and other professions. An ethical principle that is common to many professions requires professionals to practice within the boundaries of their competence and training. It follows that the practice of behavior analysis should be regulated and supervised by credentialed professional behavior analysts rather than members of other professions.

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.