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TO THE SENATE COMMITTEE ON WAYS AND MEANS

TWENTY-SEVENTH LEGISLATURE
Regular Session of 2014

Thursday, February 20, 2014
9:00 a.m.

WRITTEN COMMENTS ONLY

TESTIMONY ON SENATE BILL NO. 2054, S.D. 1 – RELATING TO HEALTH.

TO THE HONORABLE DAVID Y. IGE, 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.

NEIL ABERCROMBIE
GOVERNOR

PATRICIA MCMANAMAN
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STATE OF HAWAII
DEPARTMENT OF HUMAN SERVICES
P. O. Box 339
Honolulu, Hawaii 96809-0339

February 20, 2014

TO: The Honorable David Y. Ige, Chair
Senate Committee on Ways and Means

FROM: Barbara Yamashita, Deputy Director

SUBJECT: **S.D. 2054, S.D. 1 - RELATING TO HEALTH**

Hearing: Thursday, February 20, 2014; 9:00 a.m.
Conference Room 211, 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 autism spectrum disorders.

The DHS appreciates the S.D. 1 of this bill 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, these standards will trigger the application of these services to Medicaid eligible children under the Early & Periodic Screening, Diagnosis & Treatment (EPSDT) requirements for the more than 100,000 children in our Medicaid program.

Further, the DHS supports the intent of the coverage, but believes that this is largely a fiscal question that would need to be funded by the Legislature because of the anticipated Medicaid coverage that would be required. Should ABA be covered in Medicaid, the DHS estimates a projected total cost of $135 million to serve children up to age 19 years, of which $24.9 million would be DHS' cost, including federal funds, that will need to be appropriated by the Legislature.

The Department of Human Services conducted a study, between legislative sessions, on the cost of Medicaid coverage of applied behavioral analysis (ABA) to treat autism. While the population effect size of ABA is unclear, research has focused on children younger than 6 years of age and as children grow older, ABA treatment hours generally diminish. Should ABA be covered in Medicaid, the DHS estimates its annual total cost would be $24.3 million to serve children up to 6 years of age, of which approximately half would be federally funded. This measure would create a new standard of care and in effect defines applied behavioral analysis (ABA) as being medically necessary. These factors would result in Medicaid being required to cover ABA under Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) requirements. The Hilopa'a Project completed a comprehensive analysis that was utilized by the DHS and is included as an attachment to our testimony.

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, DHS would be responsible for accessing federal matching funds for the DOH and the DOE services for Medicaid qualified children.

Summary of the potential annual costs of covering ABA in Medicaid

	# Medicaid Children	Total Service Hours*	Total Cost** $ Millions	DOH***		DOE***		DHS	
				%	$ 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

* 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

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]

[1]http://summaries.cochrane.org/CD009260/early-intensive-behavioral-intervention-eibi-for-increasing-functional-behaviors-and-skills-in-young-children-with-autism-spectrum-disorders-asd

This bill states that ABA is evidence-based, but evidence-based experts would disagree because there is not good quality evidence of effectiveness.

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.

[2]http://www.uspreventiveservicestaskforce.org/uspstf13/speechdelay/spchfinalresplan.htm

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 Hawaii 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 Hawaii for 2012 - 303,818

1.3. Total estimated children in Hawaii 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 identifiable 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's early 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, self-injurious 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. EI services are currently authorized to meet the childs total need across settings
  4.1.2. EI 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
4.2. Services are provided by DOE Special Education
  4.2.1. DOE services are currently 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 DOE
    4.2.2.1. DOE federal mandate does not include addressing in home interventions
    4.2.2.2. 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 state plan only benefit should be nominal
  4.2.4. DOE should have a higher success rate in properly claiming for these services as it is new and the ABA providers are much more meticulous in charting than 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 ASD		81	86	108	122	123	121	112	91	91	89	82	86	78	67	60	44	25
DOE Dev. Delay		527	648	621														
EIABA Services	224																	
Counts	224	608	734	729	122	123	121	112	91	91	89	82	86	78	67	60	44	25

Total Number of Children Targeted for Services											
AGE	**<3**	**3**	**4**	**5**	**6**	**7**	**8**	**10**	**14**	**16**	**19**
Combined DOE and DOH	224	608	734	729	122	123	121	91	86	67	25
% Medicaid	47%	47%	47%	47%	47%	47%	47%	47%	47%	47%	47%
Projection	105	286	345	343	57	58	57	43	40	31	12
Total	1,377										

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
3-6	1,145	Direct Service	30	40	1,374,000		80%	274,800
		Supervision	3	40	137,400			27,480
		Assessment	3	10	34,350			6,870
		Parent Training	1	9/mo	10,305			2,061
6-8	244	Direct Service	3	40	29,280		80%	5,856
		Supervision	3	10	7,320			1,464

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
		Assessment & Parent Training	1	9/mo	2,196			439

Focused ABA Services					
Age	# of Projected Medicaid Children	Service	Hours per child per cycle	% SPED	Total Hours Not Carved Out: DHS
7	58	Direct Service	120	80%	1,392
		Supervision	12	80%	139
		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

S E A C
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Phone: 586-8126 Fax: 586-8129
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February 20, 2014

Senator David Ige, Chair
Committee on Ways and Means
State Capitol
Honolulu, HI 96813

RE: SB 2054, SD1 - RELATING TO HEALTH

Dear Chair Ige and Members of the Committee,

The Special Education Advisory Council (SEAC), Hawaii's State Advisory Panel under the Individuals with Disabilities Education Act (IDEA), appreciated the opportunity to provide **comments only** regarding SB 2054. SD 1 that proposes to mandate health insurance coverage for the diagnosis and treatment of autism spectrum disorders (ASD).

SEAC has been active over the last number of years in advising the Department of Education on appropriate educational supports for students who are on the Autism spectrum. Numerous evidence-based studies have shown us that the early identification and amelioration of the complex communication, social and behavioral needs of these children has a significantly positive impact on academic and behavioral goals.

SEAC has also been active in the last three years with a variety of key stakeholders who have collectively acknowledged the critical need for mandated insurance coverage in Hawaii to identify children with Autism Spectrum Disorders and provide timely and evidenced-based interventions to improve their health, academic and life outcomes. Should continued discussion on this legislation be sought, we offer our expertise and availability.

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

Respectfully,

Ivalee Sinclair, Chair

UNITE HERE!
LOCAL 5 HAWAII

Eric Gill, Financial Secretary-Treasurer *Hernando Ramos Tan, President* *Godfrey Maeshiro, Senior Vice-President*

February 18, 2014

Sen. David Ige, Chair, Committee on Ways and Means
Sen. Michelle Kidani, Vice Chair, Committee on Ways and Means

Members of the Committee on Ways and Means

Re: Testimony in support of re: SB 2054, SD1

Chair Ige and Committee Members:

UNITE HERE, Local 5 represents over 10,000 workers in the hotel, restaurant and health care industries in Hawai'i. Over 1,700 of our members work at Kaiser Permanente, where they strive to provide good, quality care for all Kaiser patients. We firmly believe that providing insurance coverage of autism spectrum disorders is vital to the health of our community. For that reason, we appreciate the committee's consideration of this bill and **Local 5 strongly supports the passage of SB 2054.**

Over the last several months, Local 5 members have spoken with one another and with members of the community about the need to pass this bill. We have gone out into our communities and talked to our neighbors about it. In a short time, we have gathered over 700 signatures from those who support coverage of ABA treatment for people with autism (you can see the petition here: http://bit.ly/MGAFIE).

As society's awareness of these disorders has increased, our knowledge of how to effectively treat them has grown. It would be an understatement to say that autism makes life more challenging for those who have it and for their families. Their struggle can significantly impact their quality of life, and in many cases even more so because of the additional costs of autism treatment. The cost of raising children is already high, but the cost of raising children with autism can be tremendous. If we fail to address this, many people with autism may go without appropriate treatment – this comes at an even greater cost, both to families and to society as a whole. Families have shouldered the significant additional burden of paying out of pocket for autism treatment for far too long.

One in 88 children is now diagnosed with an autism spectrum disorder according to the U.S. Centers for Disease Control. These are our 'ohana. Treatment can make a real difference in their lives. No one should have to choose between putting food on the table and providing the health care their children need to become functioning members of society. You have before you today the opportunity to help change the future of Hawai'i for our keiki by providing health care coverage for those that need it most.

Please pass SB 2054.

Attachment: The petition signed by well over 700 community members can be viewed at: http://bit.ly/MGAFIE

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Government Relations

Written Testimony of Phyllis Dendle

For decision making before:
Senate Committee on Ways and Means
The Honorable David Y. Ige, Chair
The Honorable Michelle N. Kidani, Vice Chair

February 20, 2014
9:00 am
Conference Room 211

SB 2054 SD1 RELATING TO HEALTH

Chair Ige, and committee members, thank you for this opportunity to provide testimony on SB 2054 SD1which 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:

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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 15, 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- The bill limits the ability of health plans to contract with providers based on the needs of their patients and the availability of providers by requiring that insurers not contract with more licensed psychologists than board certified behavior analysts. It also provides no licensing for these new providers. We have provided licensing language in our attached draft.

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 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

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.

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 l0A to be appropriately designated and to read as follows:

"**§431:10A- Autism spectrum disorders benefits and coverage; 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 non-restorative 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 at least as many board-certified behavior analysts in their provider network as there are qualified licensed psychologists in their network of approved providers of applied behavior analysis.~~

~~(l) 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) 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 service provider" means any person, entity, or group that 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:

(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.

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

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

~~"Psychiatric care" means direct or consultative services provided by a licensed psychiatrist.~~

~~"Psychological care" means direct or consultative services 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,

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

~~(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:

"**§432:1 Autism spectrum disorders benefits and coverage; 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 non-restorative 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 at least as many board-certified behavior analysts in their provider network as there are qualified licensed psychologists in their network of approved providers of applied behavior analysis.~~

~~(l) 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) 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 service provider" means any person, entity, or group that 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:

(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.

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

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

~~"Psychiatric care" means direct or consultative services provided by a licensed psychiatrist.~~

~~"Psychological care" means direct or consultative services 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, psychologist, licensed clinical social worker, or nurse practitioner if the care is determined to be medically necessary:

~~(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. Section 453, Hawaii Revised Statutes, 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

(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, 2014.

HMSA Blue Cross Blue Shield of Hawaii

An Independent Licensee of the Blue Cross and Blue Shield Association

February 20, 2014

The Honorable David Y. Ige, Chair
The Honorable Michelle N. Kidani, Vice Chair
Senate Committee on Ways and Means

Re: SB 2054, SD1 – Relating to Health

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

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 2054, SD1, 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, SD1, 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, SD1.

Sincerely,

Jennifer Diesman
Vice President
Government Relations

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

DATE: Thursday, February 20, 2014
TIME: 9:00 a.m.
PLACE: Conference Room 211

TO:
COMMITTEE ON WAYS AND MEANS
Senator David Y. Ige, Chair
Senator Michelle N. Kidani, Vice Chair

FROM: Hawaii Medical Association
Dr. Walton Shim, MD, President
Dr. Linda Rasmussen, MD, Legislative Co-Chair
Dr. Ron Keinitz, 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.

HAWAII DISABILITY RIGHTS CENTER

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

THE SENATE
THE TWENTY-SEVENTH LEGISLATURE
REGULAR SESSION OF 2014

Committee on Ways and Means
Testimony in Support of S.B. 2054, S.D.1
Relating to Health

Thursday, February 20, 2014, 9:00 A.M.
Conference Room 211

Chair Ige 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.

February 20, 2014

Senator David Y. Ige, Chair
Senator Michelle N. Kidani, Vice Chair
Senate Committee on Ways and Means

State Capitol
415 South Beretania St
Honolulu, HI 96813

Re: Comments in Strong Support of SB 2054, SD1. Relating to Health. *Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder treatments.*

Dear Senators Ige and Kidani, and Members of the Committee,

Thank you for the opportunity to submit comments in strong support of SB 2054, SD1.

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.

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

Updated information as it relates to the cost of required coverage for the treatment of autism comes from the Missouri Department of Insurance's Feb 1, 2014 annual report to the legislature, "Insurance Coverage for Autism Treatment & Applied Behavior Analysis.[1]" (*The executive summary of the MO report is attached.*) The report shows that after 3 years of implementation of their autism insurance law, the cost of the autism benefit remains **less than 0.2% of total claims costs** and states that "it is very unlikely that [this cost] will have any appreciable impact on insurance premiums."

[1] https://insurance.mo.gov/consumers/autismFAQ/documents/2014AutismReport.pdf

The prevalence of autism as reported by the Centers for Disease Control and Prevention (CDC) is now 1:88. This represents a 1,000-fold increase in the past forty years. SB 2054, SD 1 provides access to medically necessary care for individuals with autism and saves the State millions of dollars in special education costs and long-term adult disability services. Please support passage of SB 2054, SD1.

Thank you for your consideration of my comments,

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

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

AUTISM SPEAKS
It's time to listen.

Annual Report
to the
Missouri Legislature

Insurance Coverage for Autism Treatment & Applied Behavior Analysis

Statistics Section
Feb. 1, 2014

DIFP

Jeremiah W. (Jay) Nixon
Governor

Department of Insurance,
Financial Institutions &
Professional Registration

John M. Huff
Director

Executive Summary

This is the third annual report to the Missouri General Assembly related to insurance coverage for autism treatment and applied behavioral analysis (ABA). The findings of the first annual report reflected the fact that 2011 was a transitional year during which much of the infrastructure necessary to deliver the mandated benefits was developed. As expected, data show that the benefits of the mandate were more fully realized in 2012 and on into 2013, while the costs as a percent of overall health care costs remained negligible.

1. **Coverage.** All insureds in the small and large group markets were covered for autism and ABA therapy by 2012. In both 2012 and 2013, a much lower proportion, less than one-third, received similar coverage in the individual market, including individually underwritten association coverage. A few large providers of individual insurance coverage extended autism / ABA coverage to all of their insureds. However, Missouri statute requires only an offer of autism and ABA benefits, and most insurers do not provide it as a standard coverage. For those insurers that do not provide the coverage as a standard benefit, only a negligible number of insureds purchased the optional autism rider.

2. **Number impacted.** The number of individuals receiving covered treatment in 2013 for an autism-related condition equaled 3,070, up from 2,508 in 2012. This amounts to 1 in every 431 insureds, up from 1 in 548 insureds in 2012. The ratio ranged from 1 / 1,312 in the individual market to 1 / 372 in the large group market. These figures are consistent with estimates in the scientific literature of treatment rates.[1]

3. **Licensure.** The first licenses for applied behavior analysis were issued in Missouri in December 2010. As of mid-January 2013, 218 licenses had been issued, and an additional 41 persons obtained assistant behavior analyst licenses. Of these, 181 behavior analyst licenses were still active, as were 23 assistant behavior analyst licenses.

4. **Claim payments.** Between 2011 and 2013, claim costs incurred for autism services increased from $4.3 million to $8.3 million, of which $3.8 million was directed to ABA services. These amounts represent 0.2 percent and 0.09 percent of total claims incurred, consistent with initial projections produced by the DIFP.[2] For each member month of autism coverage, total autism-related claims amounted to 48 cents, while the cost of ABA treatment amounted to 22 cents.

[1] While the CDC estimates that the prevalence of autism is significantly higher than 1 in 372, autism presents with a high degree of variability. Not all such individuals will benefit from, or seek, treatment specifically targeted at autism.

[2] The DIFP estimated that the mandate would produce additional treatment costs of between 0.2 percent and 0.8 percent. The analytical assumptions associated with the lower-end of the estimate range appear to be validated by the claims data presented in this report.

5. **Average Monthly Cost of Treatment.** For each individual diagnosed with an autism spectrum disorder (ASD) who received treatment at some point during 2013, the average monthly cost of treatment across all market segments was $255, of which $118 consisted of ABA therapies. The average, of course, includes individuals with minimal treatment as well as individuals whose treatments very likely cost significantly more.

6. **Impact on Premiums.** While costs associated with autism-related treatment have risen over the prior two years, the fact that these costs represent just two-tenths of one percent of overall claim costs makes it very unlikely that they will have any appreciable impact on insurance premiums. However, because the DIFP has no authority over health insurance rates and does not receive rate filings, a more exact assessment of the impact of the mandate on rates cannot be provided.

7. **Self-Funded Plans.** This study focuses upon the licensed insurance market (i.e. those entities over which the DIFP has regulatory jurisdiction). Many employers provide health insurance by "self-insuring," that is, by paying claims from their own funds. Such plans are governed under the federal Employee Retirement Income Security Act (ERISA), and states have little jurisdiction over private employers that choose to self-fund. The Missouri statute does extend the autism mandate to the Missouri Consolidated Health Care Plan (MCHCP), which covers most state employees, as well as all self-funded local governments and self-insured school districts.

The advocacy group Autism Speaks maintains a list of self-funded private employers that have chosen to voluntarily provide coverage of autism and ABA therapy to their employees. Among this group are many of the most recognizable "high-tech" companies, including Microsoft, Intel, Adobe, Cisco, IBM, Apple, Yahoo and E-Bay. From the health care field are the Mayo Clinic and Abbott Laboratories. Additional companies come from a variety of sectors, from Home Depot to Wells Fargo. More recently, JP Morgan Chase & Co, GM, Chrysler, United Technologies Corp. and American Express have announced that they will begin offering the coverage. Because the DIFP lacks jurisdiction over private self-funded employers, the number of Missourians receiving autism benefits under private self-funded plans is unknown.

The DIFP encourages readers to check with their employer that may be self-insured to determine if coverage for autism treatments, including ABA, is included in their health benefit plan. Autism Speaks created a "Tool Kit" for employees of self-funded plans to approach their employers about adding benefits to their company health plan. The Self-Funded Employer Tool Kit can be found at http://www.autismspeaks.org/sites/default/files/docs/gr/erisa_tool_kit_9.12_0.pdf.

Hawaii Association of Health Plans

February 20, 2014

The Honorable David Y. Ige, Chair
The Honorable Michelle N. Kidani, Vice Chair

Committee on Ways and Means

Re: SB 2054 SD1 – Relating to Health

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

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

HAHP appreciates the opportunity to provide testimony on SB 2054 SD1 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 "State must assume (the) 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) directly to the qualified health plan in which such individual is enrolled; 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,

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 18022 (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) directly to the qualified health 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.

WAYS AND MEANS COMMITTEE
David Y. Ige, Chair
Michelle N. Kidani, Vice Chair

Thursday, February 20, 2014, 9:00 AM
Hawai'I State Capitol
415 South Beretania Street

Dear Chair Ige and Vice Chair Kidani,

My name is Amanda N. Kelly and I am a professional who works with children and families affected by autism. I am writing to you because I want to talk about HB2174: Luke's Law, and how it will benefit children and families with autism.

In 1999, while enrolled in my undergraduate program, I came across a flyer advertising the need for therapists to work with a 2-year-old child diagnosed with an autism spectrum disorder. Though I was enrolled in an education program, not much was known at the time regarding the disorder, nor which treatments might be effective. When my advisor gave me a less than satisfactory answer to "what is autism", I decided to meet with the family and learn for myself. When I met with the family, it was clear that their son had struggles that other typically developing children did not. He was unable to speak clearly and he would often exhibit aggressive or self-injurious behavior in attempts to communicate. It was heartbreaking to say the least. After meeting with the family and learning of their dedication to help their son and their commitment to educate and train the therapists, I agreed to join their team. I received my initial training in applied behavior analysis (ABA) through a company who sent a consultant (from New York to West Virginia) every six weeks. While the child and family made great progress, obtaining and maintaining quality treatment became too much of a financial burden for the family, and after two and a half years, they were forced to discontinue funding his services. Unfortunately, this is not an isolated situation. As a matter of fact, 15 years later, in 2014, families in 16 of the 50 United States are still without the support they need from their communities, state legislators and insurance companies.

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

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

Analysis, also from Simmons College in Boston, Massachusetts.

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

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

I moved to Hawai'i last year, after obtaining my PhD for two reasons: the weather (of course) and (more seriously) the need for experienced individuals who are dedicated and experienced in advocating for individuals and families affected with autism. At present, I have been on this island for four short months. Yet, in this time I have come in contact with many children, families and professionals in need of support. Presently, I am employed as a Clinical Supervisor at Malama Pono Autism Center (MPAC) in Mililani where I am charged with providing supervision and consultation to behavior technicians, lead instructors, and parents across clinic, school, and in-home settings. Unfortunately, the individuals who I have been able to service are limited to those who have military (TRICARE) insurance or those who are financially strong enough to privately pay for treatment. This seems unnatural and in direct contradiction to the "Aloha Spirit" that permeates every other aspect of life on the island. In what way does it make sense that children of military families can receive necessary services, but Hawaiians and local children and families cannot?

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

- ABA is not solely an educational treatment. It is considered to be a medically necessary, empirically validated treatment approach for children diagnosed with autism (and other related disorders). Public schools on island are not equipped to fully meet the needs of children with autism, as clearly evidenced by the recent ruling by Administrative Law Judge Haunani Alm, regarding the abuse at Kipapa Elementary in Mililani. http://www.Hawai'inewsnow.com/story/24391699/charges-of-cover-up-in-mililani-abuse-case

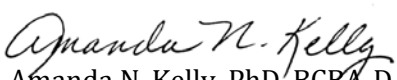
- ABA is not new, nor is it a passing fad. Applied behavior analysis is a science of evidenced-based interventions that have been substantiated by over 1,000

research studies. ABA been backed by the US Surgeon General, American Academy of Pediatrics, American Psychological Association, Autism Society of America and National Institute of Mental Health http://appliedbehaviorcenter.com/ABAEndorsements.htm.

- ABA is effective for individuals from birth to death. There is NO evidence that would support ABA as an intervention ONLY for young children with autism. For a list of common misconceptions and rebuttals, please visit http://www.behaviorbabe.com/commonmisconceptions.htm.

I 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: HB2174 (with an obvious amendment to the effective date of 2050).

Respectfully,



Amanda N. Kelly, PhD, BCBA-D
Vice President, Hawai'i Association for Behavior Analysis
Clinical Supervisor, Malama Pono Autism Center

www.behaviorbabe.com
Behaviorbabe@yahoo.com

From: Amy Wiech
To: WAM Testimony
Subject: SB Bill 2054- "Luke"s Law" in support-Mahalo!!!!
Date: Wednesday, February 19, 2014 7:01:32 AM

February 19, 2014

Dear Ways and Means Committee,
I am writing a 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 children and families affected by Autism here in Hawaii. I have made Hawaii my home since the 1995 prior to starting 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. I became Board Certified in Behavior Analysis in 2004. Currently, I am a PhD candidate at UH, defending my dissertation on Evidence Based Professional Development for teachers on March 7 of this year. 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. WeI 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, M.Ed., BCBA, PhD Candidate Defending on March 7, 2014
CEO of ABC Group
Board Certified Behavior Analyst #1-04-1581
HABA Member
808-637-7736
Amy@autismbehaviorconsulting.com

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

Sent from Amy's iPad

From: mailinglist@capitol.hawaii.gov
To: WAM Testimony
Cc: starsister2000@yahoo.com
Subject: *Submitted testimony for SB2054 on Feb 20, 2014 09:00AM*
Date: Tuesday, February 18, 2014 10:00:25 PM

SB2054
Submitted on: 2/18/2014
Testimony for WAM on Feb 20, 2014 09:00AM in Conference Room 211

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.

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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

February 18, 2014

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

Dear Senators,

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. Our daughter didn't agree with everything that the professional was saying, but did participate in an adult manner. We have never seen that before and for the first time are genuinely encouraged. We understand that Applied Behavior Analysis can result in improved behavior which should transfer into adulthood.

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

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

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

Calvert Chun
1054-A Alewa Drive
Honolulu, HI 96817
Cell: 808-421-7996

From: Christine Walton
To: WAM Testimony
Subject: In Support of SB 2054
Date: Wednesday, February 19, 2014 6:09:09 AM

Dear Members of the Ways and Means 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.

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.

Christine Walton, Ph.D., BCBA-D
Behavior Analysis No Ka Oi, Inc.
Executive Director
Phone: (808) 591-1173
Fax: (808) 591-1174
Website: hawaiibehavioranalysis.com

From: mailinglist@capitol.hawaii.gov
To: WAM Testimony
Cc: dakrekel4@gmail.com
Subject: Submitted testimony for SB2054 on Feb 20, 2014 09:00AM
Date: Wednesday, February 19, 2014 9:22:44 AM

SB2054
Submitted on: 2/19/2014
Testimony for WAM on Feb 20, 2014 09:00AM in Conference Room 211

Submitted By	Organization	Testifier Position	Present at Hearing
Deborah Krekel	Individual	Comments Only	No

Comments: COMMITTEE ON WAYS AND MEANS Senator David Y. Ige, Chair Senator Michelle N. Kidani, Vice Chair Thursday, February 20, 2014 9:00am Conference Room 211 Hawai'i State Capitol Dear Senators Ige and Kidani, My name is Deborah Krekel and I am a parent of a child with autism and a professional who works for a non-profit organization that supports children and families with disabilities. I am writing to you in hopes that you will hear my comments and consider the benefits and impact that SB2054: Luke's Law will have on children and families in Hawaii affected by autism. Since 2008 when my son Robert Kanoa was diagnosed with autism my hopes and dreams were shattered. I emerged myself in research and connected with other families all in the hopes that I could find some way to help my child. I only wanted what every parent wants for their child a chance for Kanoa to be healthy, happy and live an independent and meaningful life. Through hard work a supportive family and maybe just the pure tenacity of a mom on a mission, I discovered what was the only know evidence based practice to help children with autism. Because my spouse was active duty military a the time we were able to access an Autism Demonstration Project that allowed our son Kanoa to receive ABA services. For about 6 months we saw the light at the end of the tunnel. Our son was thriving, learning and my husband and I began to believe that he had a chance. Then after 20 years of service my husband retired from active duty and suddenly our access to these services that were helping our son turn a corner were cut short. The access to these services was at the time only for active duty military and their families. We had no choice but to look to the public schools for services because we could not afford the costly private service our son Kanoa needed. For the next 4 years we fought tooth and nail to try to get appropriate services that would help our son. Although the schools made a valiant effort the fact remains that there is no school in the State of Hawaii that can deliver, sustain or implement what was needed for my son to succeed. They simply to do not have enough properly trained personnel nor the capacity within the DOE to deliver ABA services to meet the needs of my son and others like him. Fortunately in the Fall of 2013 we once again were able to access ABA services through our military insurance because the law had recently changed to include retirees. Once again with access to this care our son Kanoa is thriving again. Sadly for many family who are not military they have no access to these very costly services. I have seen so many children and families who

like Luke will never have the opportunity to receive proper treatment, will never be independent or be able to live out their hopes and dreams. This is nothing short of an injustice. Our system is failing these children. This should not be a matter of the haves and the have nots. By passing Luke's Law you are giving all these children who can learn, who do have hopes and dreams an opportunity to contribute to our society and lead happy, healthy productive lives. Isn't that what any parent wants for their children? In closing I would like to briefly address some misconceptions of those who oppose the passage of the current bill. - ABA is not solely an educational treatment. It is considered to be a medically necessary, empirically validated treatment approach for children diagnosed with autism (and other related disorders). Public schools on island are not equipped to fully meet the needs of children with autism, as clearly evidenced by the recent ruling by Administrative Law Judge Haunani Alm, regarding the abuse at Kipapa Elementary in Mililani. http://www.Hawai'inewsnow.com/story/24391699/charges- of-cover-up-in-mililani-abuse-case - ABA is not new, nor is it a passing fad. Applied behavior analysis is a science of evidenced-based interventions that have been substantiated by over 1,000 research studies. ABA been backed by the US Surgeon General, American Academy of Pediatrics, American Psychological Association, Autism Society of America and National Institute of Mental Health http://appliedbehaviorcenter.com/ABAEndorsements.htm. - ABA is effective for individuals from birth to death. There is NO evidence that would support ABA as an intervention ONLY for young children with autism. For a list of common misconceptions and rebuttals, please visit http://www.behaviorbabe.com/commonmisconceptions.htm. I would like to extend my sincerest gratitude to you for considering support of Luke's Law: SB2054. I appreciate your time and thank you and the committee for hearing my point of view of why you, and all of Hawaii's legislators should vote to pass Luke's Law: SB2054. Respectfully, Deborah A. Krekel, MSCP

From: kekino73
To: WAM Testimony
Subject: Luke"s Law"/SB 2054
Date: Tuesday, February 18, 2014 11:36:58 PM

Testimony,
I have been servicing children diagnosed with autism for the past 16 years in the state of hawaii. Through the years (since the DOH held clinical and financial responsibility for special education) I have witnessed a steady decline in the quality of educational and therapeutic services for children with ASD. Continued budget cuts and a quality reduction in services have increased each child's chances of falling behind. Departments such as the D.O.E. Have reduced the minimum qualifications to work with our children with ASD in an ill attempt to financially and clinically match competent services such as contract agencies specializing in Applied Behavior Analysis and Autism. There are limited alternatives in the state of Hawaii. With the help of insurance, our children and their families will be light years closer to competent and qualified services in all environments. Insurance will allow for increased quality through social skills groups, individual therapy, family planning and education, and more. Just as important, through insurance reform, services throughout the island will be held at a competent level insuring quality education and therapy for all individuals diagnosed with Autism.

Thank You,
Fred Yuen M.S., BCBA

2/19/14

To: Ways and Means Committee

Re: 2054 SD1

Aloha,

I am writing in support of this bill. Speaking of bills, we keep getting them in our mail, regarding Luke's care!

Last week we got a statement from Kapiolani for $13,000.00 for Luke to have oral surgery. Luke had the surgery due to his inability to sit with his mouth open in a dentist's chair due to his Autism. If he had ABA therapy at say $60.00 an hour for a 100 hours it would be less than half that amount! He most likely could sit in the dentist's office!

We paid the anesthesiologist bill already and now face the dentist bill which is over $500.00 due to the fact we needed to choose a composite material because we don't know the effects of metal and autism.

I haven't even included the time needed to take off of work to do this for him. This is Luke's first cavity. I am sure there are more to come; even as diligent as we are with his oral care. I am scared daily for my family's financial future. I worry often and am pre-occupied with what is needed for him and what can we do/not do.

Emotionally seeing Luke with a tube keeping his airway open and buzzers all around as he had his surgery was debilitating enough and now all the bills……! We need the help of what this bill will do for Luke and our family. All the families need this help! The constituents in this state need this help now so that the end when these kids are adults is not such a burden to this state! This is a medical condition that was not chosen by us. My husband and I never smoked, drank, or did drugs! Our son was born this way. He needs your help! You are the difference in all our lives as well as the lives of those around these families!

Please feel free to contact me with any questions you may have. I have to work during the hearing tomorrow, I cannot afford a day off right now. You have my support! Can I count on yours?

Respectfully submitted,

Gerilyn Pinnow (Luke's Mom)

From: mailinglist@capitol.hawaii.gov
To: WAM Testimony
Cc: mendezj@hawaii.edu
Subject: *Submitted testimony for SB2054 on Feb 20, 2014 09:00AM*
Date: Tuesday, February 18, 2014 10:51:58 AM

SB2054
Submitted on: 2/18/2014
Testimony for WAM on Feb 20, 2014 09:00AM in Conference Room 211

Submitted By	Organization	Testifier Position	Present at Hearing
Javier Mendez-Alvarez	Individual	Support	No

Comments:

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From: mailinglist@capitol.hawaii.gov
To: WAM Testimony
Cc: kmbradler@gmail.com
Subject: Submitted testimony for SB2054 on Feb 20, 2014 09:00AM
Date: Wednesday, February 19, 2014 7:13:03 AM

SB2054
Submitted on: 2/19/2014
Testimony for WAM on Feb 20, 2014 09:00AM in Conference Room 211

Submitted By	Organization	Testifier Position	Present at Hearing
Kathleen Bradler	Individual	Comments Only	No

Comments: As a behavior analyst who has worked on Maui and Oahu, I see the great need for behavior analysis, especially early intervention,in Hawaii's special needs population. Please pass this legislation.

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.

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Dear Senators Ige and Kidani, and members of the Ways and Means 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

From: Malia Cox
To: WAM Testimony
Subject: Sb2054
Date: Wednesday, February 19, 2014 8:30:58 AM

Aloha committee members,

I'm sure the lawyers and legal supporters will give you all sorts if reasons to support the bill.

My reasons are just as a mom trying to get the best treatment for my daughter.

My family is occasionally eligible for Tricare when my husband is deployed. During those times I will do treatments, run tests that aren't covered by Kaiser. It seems like the military has a better appreciation for the types of treatments, therapies, tests, that will help heal our ASD children and are willing to support pursuit of them financially through Tricare.

We have seen tremendous gains that have resulted in better health (and spill into improved classroom functioning & better socialization) after each treatment that wasn't covered by kaiser. Persistent problems are not a pervasive issue. For example, our daughter no longer needs to take mirlax everyday prescribed to treat symptoms rather than fixing the problem. One of the issues causing the problem were some particularly bad bacteria/ fungi found based on tests requested by her non-kaiser MD in her gut that were treated for using antibiotic/anti fungal prescriptions.

I urge you to support improved insurance coverage for ASD. In the long run it may even reduce the States burden as children functioning improves so that they may not need as many classroom supports.

Mahalo for your consideration.
Malia Cox
835-9068

Sent from my iPhone

From: Monica Gotreau
To: WAM Testimony
Subject: "Luke"s Law"/SB 2054.
Date: Wednesday, February 19, 2014 7:54:16 AM

To: Senate Committee on Ways and Means and Whom it M Concern

I am a Board Certified Behavior Analyst (BCBA) and owner of my company, Monica Gotreau BCBA LLC, practicing exclusively on the Island of Oahu. My company provides Applied Behavioral Analysis (ABA) treatment to children and adolescents with a primary emphasis on early intervention services (12-36 months of age). "Luke's Law"/SB 2054", is a critical necessity for those affected by Autism Spectrum Disorders. Without very early intervention and on-going services by trained and skilled Behavior Analysts, life can be overwhelming if not tragic for child and family. ABA Treatment works and offers the best hope for growth and best symptom control.

We strongly support "Luke's Law"/SB 2054". When passed, we will enthusiastically participate as a treatment service provider for the citizens of Hawaii. Please provide those affected with Autism Spectrum Disorders the proven and necessary treatment they deserve.

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COMMITTEE ON WAYS AND MEANS
Senator David Y. Ige, Chair
Senator Michelle N. Kidani, Vice Chair

Thursday, February 20, 2014, 9:00 AM
Conference Room 211, State Capitol
415 South Beretania Street

Dear Senators Ige and Kidani,

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

I was first introduced to applied behavior analysis in 2010 by accepting a position as behavior interventionist (therapist/tutor) who works with children with autism ranging in ages from 2 to 13 years old in Colorado. One of the first clients I worked with demonstrated deficits in communication and social skills as well as engaged in aggressive behaviors that further impacted him from learning. 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, whether it is a behavior to increase or a behavior to decrease. Aside from the research stating the effectiveness of behavior analysis, it was just plain obvious 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)

TO THE SENATE COMMITTEES ON HEALTH AND
COMMERCE AND CONSUMER PROTECTION
TWENTY-SEVENTH LEGISLATURE
Regular Session of 2014
Thursday February 20, 2014
8:30 a.m.
TESTIMONY ON SENATE BILL NO. 2054 –
RELATING TO HEALTH.

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

My name is Stacey E. Kuhn. My life has been profoundly impacted by individuals with Autism, on both a personal and professional level. With Autism prevalence rates so high, it would be difficult to find someone who has not been impacted by this disorder. Along with having friends who have children with Autism, I am a Board Certified Behavioral Analyst, who has been providing services to children with autism since 1995.

I am writing to express my support for SB2054/Luke's Law, and how it will benefit children diagnosed with Autism Spectrum Disorder.

In July 2013, I moved Hawaii, from Pennsylvania. PA is one of many states that has an Autism insurance law in place. The positive impact this support has made in the community has been significant. Children who previously could not access evidenced based therapy services are now able to access these services, and parents no longer have to fear how they will be able to find treatment for their child. Applied Behavioral Analysis is an effective, empirically proven treatment, which has helped children with ASD display

remarkable improvement. In my years working with children with Autism, I have witnessed children with no communication skills begin to talk, behaviors which prohibited families and children from engaging in the community dissipate and lives begin to be rebuilt because a child and their family were no longer held prisoner to Autism.

I strongly support allowing children in Hawaii access to these services, and this high quality level of care. Thank you for taking the time to read my thoughts on why you should pass SB2054/Luke's Law.

Respectfully,

Stacey E Kuhn, MS, BCBA
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From: Taffy Perucci
To: WAM Testimony
Subject: Support for SB 2054, SD1
Date: Wednesday, February 19, 2014 12:11:43 AM

Aloha Senator Ige and members of the Senate Committee on Ways and Means

I am writing to you in regards to SB 2054, SD1. I support this bill.

I am writing as an individual and a provider. I have attended some of the hearings on the bill as it has passed through the house and the senate and would like to add a few comments in regards to concerns that have come up in other committees.

I have been a school psychologist for almost 13 years and have worked in California, North Carolina and Hawaii. I loved being a state employee in all instances and value the work of public school teachers, administrators and the parents and students that form the communities around the schools. School psychologists help children and youth succeed academically, socially, behaviorally, and emotionally. They collaborate with educators, parents, and other professionals to create safe, healthy. School Psychologists Work with Students and their families to identify and address learning and behavior problems that interfere with school success, evaluate eligibility for special education services and support students' social, emotional, and behavioral health. School Psychologists work with teachers to identify and resolve academic barriers to learning and design and implement student progress monitoring systems. They also design and implement school wide academic and behavioral interventions and support effective individualized instruction for all children to succeed. School Psychologists work with administrators to collect and analyze data related to school improvement, student outcomes, and accountability requirements. School Psychologists like many in the educational setting are experts at their trade and I was proud to have been in their ranks for many years.

With all the benefits and expertise that can be found in the school setting, they have very naive understanding of Applied Behavior Analysis (ABA) which is the accepted standard of care for treating children and adults who have been identified as having Autism. For myself, it was not apparent until I began my studies towards coursework that would one day allow me to sit for my certification with the Behavior Analysts Certification Board. Schools are experts in things like common core standards, Hawaii State-Wide Assessment (HSA), differentiated instruction and a list of requirements and expectations that they try and meet daily. Previous bills have attempted to shrug the burden off of the state and community providers and on to the schools at an arbitrary age. Based on my years of having been a public employee, schools, teachers and classrooms are not prepared to carry the burden of being the only source of support for families that are coming apart at their seams behind closed doors. Schools are not trained in the medical treatment of ABA and are only now beginning to receive training based on behavior principles and how they can be applied in the educational setting. In my 5 ½ years working in Central district, which covered 42 schools, I never observed a school that did ABA as defined in the applied behavior analysis research. No further proof is needed on how unprepared schools are than looking at the court documents and video from Kipapa Elementary in Central District where students with Autism were physically and emotionally traumatized. This is only the only case and the current bill on seclusion and restraints (HB1796_HD1) has stemmed from mistreatment and abuse in this very vulnerable population.

I often tell parents that come to our private agency for ABA treatment who are angry and frustrated with the system that the schools have some very good teachers that are skilled in their craft. However, their craft is teaching children how to succeed academically. They are woefully unprepared to continue to solely accept the burden for caring for all of the needs that the families and not having the tools nor the training to do it. I support SB 2054, SD1. I support it because

frankly it is the right thing to do.

Taffy Perucci, MS
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