STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
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March 19, 2014

The Honorable Angus McKelvey, Chair
House Committee on Consumer Protection
Twenty-Seventh Legislature
State Capitol
State of Hawaii
Honolulu, Hawaii 96813

Dear Representative McKelvey and Members of the Committee:

SUBJECT: SB 2054 SD3 HD1– RELATING TO HEALTH

The State Council on Developmental Disabilities (DD) **SUPPORTS SB 2054 SD3 HD1.** The bill requires health insurers, mutual benefit societies, and health maintenance organizations to provide health care coverage and benefits for autism spectrum disorders (ASD).

According to the U.S. Centers for Disease Control and Prevention, about 1 in 88 children have been identified with ASD. That rate is anticipated to significantly increase in the next decade. With this alarming rate, it is imperative that children with ASD are provided with early diagnosis and treatment. Evidence-based practice shows that early identification and treatment results in overall improved outcomes for children with ASD. Moreover, services provided early on may decrease or minimize long-term services and supports needed as the child becomes an adult and through the individual's lifetime

SB 2054 SD3 HD1 provides comprehensive coverage of services, including well-baby and well-child screening diagnosis and evidence-based treatment for individuals with ASD under nine years of age. Without intensive behavioral therapy the cost of services to support an individual with ASD only increases throughout the individual's lifetime. Whereas, children with ASD provided with intensive behavior therapy, such as "applied behavior analysis" learn meaningful skills of interacting and coping, essentially increasing their independence and preparing them for adulthood. Through early identification and intervention, the cost of services would significantly decrease and an individual's independence increases throughout their adult years.

Thank you for the opportunity to provide testimony **supporting SB 2054 SD3 HD1.**

Sincerely,

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

J. Curtis Tyler, III
Chair

NEIL ABERCROMBIE
GOVERNOR OF HAWAII

LINDA ROSEN, M.D., M.P.H.
DIRECTOR OF HEALTH

STATE OF HAWAII
DEPARTMENT OF HEALTH
P.O. Box 3378
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In reply, please refer to:
File:

House Committee on Consumer Protection & Commerce

SB 2054, SD3, HD1, Relating to Health

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

March 19, 2014

Department's Position: The Department supports this bill requiring insurers to provide autism therapeutic coverage which improves the long term outcomes for persons with autism and reduces the burden of care on their families. Intensive behavioral interventions provided for children are evidenced based and a recognized best practice. Children with these interventions achieve better outcomes in socialization, employment and exhibit less challenging behaviors as they become adults.

Fiscal Implications: The Department recognizes that this bill impacts insurance rates for all citizens. The cost for families with children with autism is significant. For some families with children with autism, extreme behaviors create a great financial burden on families that can create major family stress and financical crisis. Intensive treatment for autism for children does ameliorate challenging behaviors and lessens the life long dependency upon Medicaid Home and Community Based personal assistance. The fiscal implications to the Department of Health are lowered costs of long term care.

The Department defers to the Department of Human Services on the fiscal implication to their Medicaid programs.

Thank you for this opportunity to testify.

TESTIMONY BY KALBERT K. YOUNG
DIRECTOR, DEPARTMENT OF BUDGET AND FINANCE
STATE OF HAWAII
TO THE HOUSE COMMITTEE ON CONSUMER PROTECTION & COMMERCE
ON
SENATE BILL NO. 2054, S.D. 3, H.D. 1

March 19, 2014

RELATING TO THE HEALTH

Senate Bill No. 2054, S.D. 3, H.D. 1, proposes to require all health insurers, mutual benefit societies, and health maintenance organizations to provide health care coverage and benefits for the diagnosis and treatment of autism spectrum disorders to individuals under nine years of age. Maximum benefits for behavioral health treatment provided may be limited to $50,000 per year and a maximum lifetime benefit of $300,000 for the individual, but shall not be limited as to the number of visits to an autism service provider.

Although H.D. 1 narrows the age of eligibility, as we noted in our testimony during the 2013 Legislative Session with regards to similar measures, the Department of Budget and Finance (Department) has strong concerns pertaining to the following:

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

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

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

We defer to the Insurance Commissioner in regards to the impact of SB 2054, S.D. 3, H.D. 1, upon Article 10A of the State of Hawaii Insurance Code.

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

NEIL ABERCROMBIE
GOVERNOR

PATRICIA MCMANAMAN
DIRECTOR

BARBARA A. YAMASHITA
DEPUTY DIRECTOR

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

March 19, 2014

TO: The Honorable Angus L.K. McKelvey, Chair
House Committee on Consumer Protection and Commerce

FROM: Patricia McManaman, Director

SUBJECT: **S.B. 2054, S.D.3, Proposed H.D.2 - RELATING TO HEALTH**

Hearing: Wednesday, March 19, 2014; 2:10 p.m.
Conference Room 325, 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 for children under nine years of age; exempts the Medicaid plans from the coverage requirements; requires the Legislative Reference Bureau to perform an actuarial analysis to estimate the costs of providing autism spectrum disorder benefits.

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

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

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

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

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, and cost may be greater if expected to provide to non-Medicaid covered children too.

Certain individuals may benefit from ABA, but whether the population of individuals with autism has a clinically significant benefit is unclear. Most studies have evaluated the effectiveness of ABA in children younger than 6 years old with autism, and the treatment intervention was typically no less than 20 hours per week of ABA. A 2012 Cochrane systematic review concluded:

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

In addition, a 2012 report completed by RAND found:

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

This bill states that ABA is evidence-based, but evidence-based experts would disagree because the quality of evidence of effectiveness is low.

[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

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 Hawai i Medicaid program.

1. Prevalence

1.1. National statistics indicate 1:88 children have Autism Spectrum Disorder (ASD), ranging in intensity from classic autism to Asperger s Syndrome

1.2. Population of children 18 and under in Hawai i for 2012 - 303,818

1.3. Total estimated children in Hawai i with an ASD – 3,452

1.4. Total children served by Department of Heath Early Intervention Section (DOH/EI) receiving ABA services, and Department of Education Special Eduation (DOE) who an eligibility of Autism or Developmental Delay – 3,486

1.4.1. Since the two numbers are so close, this projection will utilize the number reflecting identifyable children, the DOH, DOE combined number

1.5. Studies show there is no higher prevalence of ASD in children who are Medicaid eligible than those who are not

1.6. Using 3-month continuous eligibility for 90 days, 154,000 children are in the state Medicaid program, which equates to 47% of the 0-18 population

1.7. Applying the 47% to the total children served – 1,624

2. Treatment

2.1. Evidence shows that the most effective use of ABA are in the child 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 currenty authorized to meet the child s education needs in the school setting

4.2.2. There will be a need to provide services beyond what is provided by 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 statel plan only benefit should be nominal

4.2.4. DOE should have a higher success rate in properly claiming for these services as it s new and the ABA providers are much more meticulous in charting that other DOE therapists

4.3. The service is typically supervised by a Board Certified Behavior Analyst (BCBA)

4.3.1. Tricare reimburses this at $125.00/hour

4.3.2. BCBAs typically do not provide the 1:1 direct, hands on service

4.4. The direct service is typically provided by a paraprofessional behavior technician

4.4.1. Tricare reimburses this at $50.00/hour and $75.00/hour based upon provider credential

4.5. There does not appear to be uniformity in rates between DOE/DOH-EI/DOH-DD/MR

5. Projection

Step 1: Establish a child count

Total Number of Children																	
AGE	<3	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
DOE 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
		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

Focused ABA Services					
Age	# of Projected Medicaid Children	Service	Hours per child per cycle	% SPED	Total Hours Not Carved Out: DHS
		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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March 19, 2014

Representative Angus L.K. McKelvey, Chair
Committee on Consumer Protection & Commerce
State Capitol
Honolulu, HI 96813

RE: SB 2054, SD 3, HD 1 - RELATING TO HEALTH

Dear Chair McKelvey and Members of the Committee,

The Special Education Advisory Council (SEAC), Hawaii's State Advisory Panel under the Individuals with Disabilities Education Act (IDEA), **strongly support**s SB 2054, SD 3, HD 1 and the proposed HD 2 that mandates health insurance coverage for the diagnosis and treatment of autism spectrum disorders (ASD).

SEAC's main concern with the current language in this legislation is that services are only offered through age nine. It has been our experience that children over the age of nine and teenagers can still receive great benefit from Applied Behavioral Analysis (ABA) and other evidence-based treatments. We therefore request that your commiittee consider extending the benefits to include students from age ten through high school.

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, as well as ongoing targeted supports, has a significantly positive impact on academic and behavioral goals.

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

kawakami3-Benigno

From: Louis Erteschik <Louis@hawaiidisabilityrights.org>
Sent: Tuesday, March 18, 2014 2:45 PM
To: CPCtestimony
Subject: FW: SB2054 Autism Ins and SB2469 Telehealth

We support this measure,and prefer the prior version that did not have an age cap on the provision of services.

Louis Erteschik, Esq.
Executive Director
Hawaii Disability Rights Center

_____

SB 2054, SD3, HD1<http://www.capitol.hawaii.gov/session2014/Bills/SB2054_HD1_.pdf>
(HSCR960-14)<http://www.capitol.hawaii.gov/session2014/CommReports/SB2054_HD1_HSCR960-14_.pdf>
Status<http://www.capitol.hawaii.gov/measure_indiv.aspx?billtype=SB&billnumber=2054&year=2014>

RELATING TO HEALTH.
Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder treatments. Effective July 1, 2050.

HLT, CPC, FIN

COMMITTEE ON CONSUMER PROTECTION & COMMERCE

Rep. Angus L.K. McKelvey, Chair
Rep. Derek S.K. Kawakami, Vice Chair

Wednesday, March 19, 2014, 2:10 PM
Conference Room 325, State Capitol
415 South Beretania Street

Dear Chair McKelvey, Vice Chair Kawakami and members of the Committee:

My name is Dr. Amanda N. Kelly and I am a professional who works with children and families affected by autism. I am writing to you because I want to talk about **SB2054**: Luke's Law and why you should support this very important initiative, and **reinstate the age cap at age 21**.

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

I have earned my Master and Doctoral degree in behavior analysis and over the past 15 years I have gained experience working with several hundred children diagnosed with autism in multiple treatment settings, throughout various states. I consider myself an expert in the treatment of children with autism and in ABA. However, I do not consider myself an expert in legislation or with writing or interpreting insurance policies. I respectfully defer to you for your guidance on those matters and respectfully request that you consider my insight into areas that are within my realm of expertise.

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

1. Children with autism often have difficulty learning through exposure to typical social settings, which can be extremely damaging to their social development (Koegel, 1998; Smith, 2001).

2. There is no cure for autism, but it is a treatable condition (NCSL, 2012). In order to address these potential deficits, children with autism generally require explicit instruction to learn to attend to relevant stimuli in their environment (Drash & Tudor, 1993).

3. Evidence exists that early intensive interventions guided by behavior analytic principles produce substantial benefits for children with autism, as outlined in comprehensive reviews (Rimland, 1994; Rogers, 1998).

4. There have been long-term, positive effects achieved with intensive behavioral intervention (Lovaas, 1987; McEachin, Smith, & Lovaas, 1993; Smith, 1995).

5. Specifically, procedures based on applied behavior analysis (ABA) are recommended for children diagnosed with autism (National Research Council, 2001; Surgeon General, 1999).

6. In addition, over the past 30 years, several thousand published research studies have documented the efficacy of applied behavior analysis across a wide range of populations, interventionists, settings, behaviors, and AGE SPAN (NRC, 2001; MADSEC, 2000; Surgeon General, 1999).

7. Cost-benefit estimates suggest significant cost-aversion or cost-avoidance may be possible with early intensive behavioral intervention (EIBI). This model estimates that cost savings could range from $187,000 to $203,000 per child for ages 3-22 years and from $656,000 to $1,082,000 per child for ages 3-55 years (Jacobson, Mulick, & Green, 1998).

8. Applied behavior analysis is the science of systematically studying variables that influence behavior (Sulzer-Azaroff, Mayer, & Wallace, 2012) and is the methodology that generates the most effective outcomes for individuals with autism (Zager, 2005).

9. Behavior analytic teaching procedures include strategies based on positive reinforcement to increase academic and social skills (e.g., Jones, Feeley, & Takacs, 2007; Tarbox, Ghezzi, & Wilson, 2006), extinction to reduce challenging behavior (e.g., Neidert, Iwata, & Dozier, 2005; Waters, Lerman, & Hovanetz, 2009), and prompting strategies to teach new skills (e.g., Fisher, Kodak, & Moore, 2007; Kurt & Tekin-Iftar, 2008).

10. Typically, 25 to 40 hours per week of intensive behavior intervention is recommended for children with autism (Leaf & McEachin, 1999; Lord & McGee, 2001; Green, 1996; Myers & Johnson, 2007).

11. A Centers for Disease Control study in the April autism supplement of the Journal of Developmental and Behavioral Pediatrics, released May 10, 2006, found that the average age of initial evaluation of children later diagnosed with an autism spectrum disorder was 4 years of age but the average age of diagnosis was 5 years, 1 month, a 13 month delay. The study data was collected from the Metropolitan Atlanta Developmental Disabilities Surveillance Program 2000 (MADDSP). *See attachment.*

12. Diagnosis of Aspergers Syndrome is often later, between ages 10-12. Diagnosis can be tricky as there is a lack of a standardized diagnostic screening for the disorder. According to the National Institute of Neurological Disorders and Stroke, physicians look for the presence of a primary group of behaviors to make a diagnosis such as abnormal eye contact, aloofness, failure to respond when called by name, failure to use gestures to point or show, lack of interactive play with others, and a lack of interest in peers.

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

1. 34 states currently provide insurance mandates for autism spectrum disorders (ASD): Alabama, Alaska, Arizona, Arkansas, California, Colorado, Connecticut, Delaware, Florida, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Massachusetts, Michigan, Missouri, Montana, Nevada, New Hampshire, New Jersey, New Mexico, New York, Oregon, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, Virginia, West Virginia, and Wisconsin (ASHA, 2014).

2. Most of the legislation to provide coverage for autism has been enacted in the last four years (NCSL, 2012).

3. Board Certified Behavior Analysts (BCBA's) do not have to be licensed in order to receive reimbursement for treating individuals with autism.

    a. Ohio specifically has adopted the Behavior Analyst Certification Board (BACB) requirements for service providers and has developed certification at the state level.

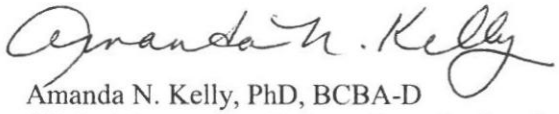
    b. In North Carolina, BCBA's practice is restricted and must be overseen by Licensed Psychologists, which has actually prohibited children and families from receiving access to effective treatment. The current practice contributes to the fact that NC does not have current autism legislation (Green, 2014).

4. A study in 2006 by the Harvard School of Public Health estimated that it costs $3.2 million to take care of an individual with autism over his or her lifetime and that it costs society an estimated $35 billion each year to care for all individuals with autism (NCSL, 2012).

5. Two years after requiring coverage, seven states saw monthly premiums rise by 31 cents on average per member, according to figures collated by Autism Speaks. In Arizona's second year of mandated coverage, autism-related claims totaled about $389,000 — less than 10 percent of the $4,900,000 that the legislature forecast in last March (Reuters, 2013).

I appreciate your time and thank you and the committee for hearing my point of view. I hope data and facts, rather than merely opinions and impressions, will be the guiding force that will lead you –and all of Hawaii's legislators, to **vote to pass Luke's Law: SB2054 and reinstate the age cap at 21 years**.

Respectfully,



Amanda N. Kelly, PhD, BCBA-D
Clinical Supervisor, Malama Pono Autism Center
2014 Vice President, Hawai'i Association for Behavior Analysis
Behaviorbabe, www.behaviorbabe.com

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CENTERS FOR DISEASE CONTROL AND PREVENTION

Press Release

For Immediate Release:
May 10, 2006

Contact: Centers for Disease Control and Prevention
Division of Media Relations
(404) 639-3286

Thirteen Month Delay Between Evaluation and Autism Diagnosis in Children

Children with autism spectrum disorders (ASDs) may experience a 13-month delay before they are diagnosed. A study in the April autism supplement of the Journal of Developmental and Behavioral Pediatrics released today, found that children diagnosed in metropolitan Atlanta were initially evaluated at an average of 4 years of age but were not diagnosed with an ASD until an average of 5 years 1 month. The study also found much variability in both, with an age range of 1 year 4 months to 8 years 6 months old for initial evaluation, and an age range of 1 year 5 months to 8 years 8 months old for actual diagnosis.

The study data, collected from the Metropolitan Atlanta Developmental Disabilities Surveillance Program 2000 (MADDSP), did not explore reasons for the 13-month delay. However, the study found that most children were first diagnosed with other conditions, such as language delay or general developmental delay.

"Although this study draws upon data from the metro Atlanta area, it serves as an important indicator of the nationwide challenges of diagnosing autism, particularly more mild cases," said Dr. José Cordero, director of CDC's National Center on Birth Defects and Developmental Disabilities. "The real public health challenge is to educate doctors on the signs of autism and to encourage use of standardized diagnostic instruments that better identify symptoms relevant to ASD and help distinguish ASD from other developmental delays or disorders."

According to the study, a 13-month delay in ASD diagnosis existed for both boys and girls and across racial/ethnic classification. While children with more severe symptoms of autism were evaluated and diagnosed almost two years earlier than children with milder symptoms, they were not evaluated until an average of 3½ years old and were not diagnosed with an ASD until an average of 4½ years old. Previous research indicates that parents of children with an ASD report began to have concerns about their child's development between 1 and 2 years of age.

Amanda Kelly

Seventy-six percent of the children diagnosed with an ASD were identified at medical facilities such as hospitals and clinics, and 24 percent were identified at schools. The study's researchers found that 70 percent of healthcare professionals did not use a standardized diagnostic instrument when assigning the first ASD diagnosis.

ASDs are lifelong neuro-developmental disorders characterized by early onset of social, communication, and behavioral problems, which are present before 3 years of age. Early identification of ASDs leads to earlier entry into intervention programs that can help improve developmental outcomes. It is important for parents and healthcare professionals to recognize early symptoms of ASDs. It is also important that children with identified delays be administered routine developmental and autism-specific screenings. CDC designed the "Learn the Signs, Act Early" campaign to educate parents and professionals on the early signs of autism and other developmental disorders. For more information, visit www.cdc.gov/actearly.

To obtain a full copy of the article, visit the Journal of Developmental and Behavioral Pediatrics' Web site at www.jrnldbp.com.

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DEPARTMENT OF HEALTH AND HUMAN SERVICES

Amanda Kelly

Hawaii Behavioral Health

March 18, 2014

TO: Chair McKelvey, Vice-Chair Kawakami and Members of the Committee,

RE: SB2054 – RELATING TO HEALTH
Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for treatment of autism spectrum disorders.

Dear Chairs Green and Baker, Vice-Chair Taniguchi and Members of the Committee,

Hawaii Behavioral Health (HBH) **supports** the passage of bill SB2054, which provides for treatment of autism spectrum disorder through speech therapy, occupational therapy, and physical therapy, and applied behavior analysis.

HBH suggests **a tired approach** to benefits and following New Hampshire's lead which allows benefits up to $36,000 per year for a age twelve and under but decreases that amount to $27,000 per year for a child ages thirteen to twenty one. This tiered approach emphasizes the need for early intensive therapy while constraining the overall costs associated with treating a child with ASD. Eight (8) states have a tiered approach..

HBH has provided services for over 20 years to students exhibiting social, communication and behavioral challenges under IDEA. HBH is one of Hawaii's largest and most experienced provider of autism support services to the Department of Education (DOE) currently and is a provider of Early Intervention Services to the Department Health serving well over one thousand families and youth annually from offices in Honolulu, Hilo, Kona, Maui and Kauai, providing them with an array of educational and social services.

HBH is accredited by the Commission on Accreditation of Rehabilitation Facilities (CARF) and licensed as a Child Placing Organization by the Department of Human Services and is proud to serve Hawaii's families throughout the islands through contracts with a variety of state agencies.

Thank you for considering our testimony,
Carla Gross
Chief Operating Officer

AUTISM SOCIETY
Improving the Lives of All Affected by Autism
Hawaii

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

March 18, 2014

TO: Senator Green and Senator Baker

RE: SB2054 SD3 HD1 – RELATING TO HEALTH
Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for treatment of autism spectrum disorders.

Dear Chair McKelvey, Vice-Chair Kawakami and Members of the Committee,

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

1) Lowering the yearly maximum benefit as the child gets older

For example, Connecticut allows benefits up to $50,000 per year for a child under the age of nine but decreases that amount to $35,000 per year for a child ages nine to twelve and to $25,000 per year for a child ages thirteen to fourteen. This tiered approach emphasizes the need for early intensive therapy while constraining the overall costs associated with treating a child with ASD. Eight (8) states have a tiered approach.

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

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

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

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

Fact 3: This worrisome increase in the autism is mostly a new social condition - what we know about the symptoms and causes show that society has not faced this condition before, which is why we are so unprepared. Because of this there has been a dramatic increase in research by the federal government and many private groups such as Autism Speaks. As a physician who formerly treated polio and childhood leukemia, I am thrilled at the wonderful advances this research has produced in the neuroscience of autism, and look forward to its eventual control. However promising this sounds, we are still stuck with an unknown number of years of an extremely expensive condition.

Fact 4: What we do know about causes and treatment is that autism is a neurologic condition in which the inner connections in the brain are miswired. This is a physical fact, so it does not respond to the usual medical treatments like medications and surgery. The reason for this is that the brain is a different organ than the heart, lungs, kidneys, etc. Brain function is based on our experience with the environment. Thus, correction of miswiring requires corrective changes in the child's life experience. These changes require intensive exposure to positive, corrective social behavior and language experience. This is why medical insurance has previously not covered these social and language treatments, seeing them as 'habilitative'. However, current neuroscience, genetics and brain imaging all point to the benefits of the kind of behavioral and social-language treatments that SB668 is proposing. There is also abundant evidence-based data showing that these treatments are effective and do reduce long-term impairment. What's important is that the earlier autism is diagnosed and given effective treatment, the better is the outcome and the less the financial impact on families and the state.

Fact 5: The reason that universal insurance coverage is for autism treatments is so important is the fact that it involves all social and ethnic groups (indeed in my own personal experience working as a consultant for the World Health Organization, autism is as common in Asia, India, the Near East and Europe as it is in Hawaii and the United States). Thus insurance needs to be broad-based. Fortunately, the experience of 30+ other states shows that autism insurance causes a very small increase in insurance costs given the broad base of the condition. I might add a side comment, that the reason for the increase in federal and private research is that the numbers of grandchildren of congressional legislators and wealthy private donors who have developed autism.

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

Thank you for considering our testimony,

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William Bolman
President

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

DATE: Wednesday, March 19, 2014
TIME: 2:10 PM
PLACE: Conference Room 325

TO:
COMMITTEE ON CONSUMER PROTECTION & COMMERCE
Rep. Angus L.K. McKelvey, Chair
Rep. Derek S.K. Kawakami, Vice Chair

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

RE: SB 2054 RELATING TO HEALTH

Position: Support

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

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

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

Hawaii Association of Health Plans

March 19, 2014

The Honorable Angus L.K. McKelvey, Chair
The Honorable Derek S.K. Kawakami, Vice Chair

Committee on Consumer Protection and Commerce

Re: SB 2054 SD3 HD1 – Relating to Health

Dear Chair McKelvey, Vice Chair Kawakami, 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 SD3 HD1 which requires health plans to provide coverage for autism and related services to individuals up to age 9 years. 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.

Chamber of Commerce HAWAII
The Voice of Business

Testimony to the House Committee on Consumer Protection and Commerce
Wednesday, March 19, 2014 at 2:10 P.M.
Conference Room 325, State Capitol

RE: SENATE BILL 2054 SD3 HD1 RELATING TO HEALTH

Chair McKelvey, Vice Chair Kawakami, and Members of the Committee:

The Chamber of Commerce of Hawaii ("The Chamber") **cannot support** SB 2054 SD3 HD1, which requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder treatments.

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

We appreciate the intent of the bill to help those with autism spectrum disorders. However, the Chamber has several concerns with the bill.

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

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

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

Thank you for the opportunity to testify.

1132 Bishop Street, Suite 402 • Honolulu, Hawaii 96813 • Phone: (808) 545-4300 • Facsimile: (808) 545-4369

March 19, 2014

The Honorable Angus L.K. McKelvey, Chair
The Honorable Derek S.K. Kawakami, Vice Chair
House of Representatives Committee on Consumer Protection and Commerce

RE: Support of the Intent of SB 2054, SD3, HD1 - Relating to Health.

Dear Representative McKelvey, Representative Kawakami and Members of the Committee:

For more than 60 years, Easter Seals Hawaii has provided exceptional, individualized, family-centered services to empower infants, children, youth and adults with disabilities or special needs to achieve their goals and live independent fulfilling lives. Easter Seals Hawaii is a statewide CARF accredited organization with 15 facilities from Waimea, Kauai to Hilo, Hawaii providing a variety of programs including Autism Services. These services include Applied Behavior Analysis /Verbal Behavior-Based Therapy, Speech/Language Pathology, Assessment, Training, Education and Consultation.

Easter Seals Hawaii strongly supports mandated coverage for services to individuals within the Autism Spectrum and therefore supports the intent of SB 2054, SD3, HD1 and offers the following recommendations:

1. Amend section 3(a), page 1, lines 10- 17, remove "individuals under nine years of age and insert "individuals under 15 years of age". To read, "Each individual or group accident and health or sickness insurance policy, contract plan or agreement issued or renewed in this State after December 31, 2015, shall provide to the policyholder and **individuals under 15 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." The Center for Disease Control states that the average individual with Autism Spectrum Disorder (ASD) does **not** receive a diagnosis of ASD until age six. Autism service providers in Hawaii estimate that children in Hawaii are diagnosed even later than age six. Increasing the age cap to 15 years old would allow for the lag in diagnosis and also provide services up to high school.

2. Amend Section 3, page 1, lines 15-17 – Benefits and Coverage
   Autism screening and well child visits are covered as part of the Preventive benefit requirement of the Affordable Care Act.

3. Amend section 3(j), page 4, lines 14-16 - Background Check
   Adopt a uniform standard for background check requirements and guidelines which references Med-QUEST requirements for direct support workers.

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

Thank you for your time and consideration.

Respectfully,

Christopher E. Blanchard
President & CEO
Easter Seals Hawaii

UNITE HERE!
LOCAL 5 HAWAII

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

March 18, 2014

Rep. Angus McKelvey, Chair, Committee on Consumer Protection & Commerce
Rep. Derek Kawakami, Vice Chair, Committee on Consumer Protection & Commerce
Members of the Committee on Consumer Protection & Commerce

Re: Testimony re: SB 2054, SD1

Chair McKelvey 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. While we support the intent of this bill and earlier versions of it, we do not support limiting the mandated coverage to children under nine years of age. The original bill would have mandated coverage for children up to age 21, and we should continue to push for that standard. This treatment can potentially change people's lives permanently for the better – we should not give up on them in their key developmental stages just to save a few dollars.

Over the last year, 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 autism has increased, our knowledge of how to effectively treat it 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 an amended SB 2054 that does not cap mandated coverage at age 9.

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

1516 South King Street • Honolulu, Hawaii • 96826-1912 • Phone (808) 941-2141 • Fax (808) 941-2166 • www.unitehere5.org

House Committee on Consumer Protection and Commerce
March 19, 2014
2:10 p.m. HST

Representative Angus L.K. McKelvey, Chair
Representative Derek S.K. Kawakami, Vice Chair
State Capitol
415 South Beretania St
Honolulu, HI 96813

Re: In Support of SB 2054 SD3 HD1
Relating to Health. Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder treatments.

Dear Chair McKelvey, Vice Chair Kawakami and Members of the Committee,

I am Mike Wasmer, Associate Director for State Government Affairs at Autism Speaks and the parent of a child with autism. Autism Speaks is the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Our state government affairs team has played a role in most of the now 34 states that have enacted autism insurance reform laws. Autism Speaks is pleased to submit testimony in strong support of SB 2054 SD3 HD1 ("Luke's Law").

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

The House Committee on Health amended the age cap on coverage for treatment of autism in SB 2054 SD3 from 21 years to 9 years. We encourage the House Committee on Consumer Protection and Commerce to restore the age cap to 21 years. Autism is a lifelong condition. While more intense "comprehensive" ABA therapy to address multiple treatment goals is most commonly prescribed at a younger age, "focused" ABA therapy to address isolated maladaptive behaviors may be required at times throughout the lifespan. Recognizing this fact, the median age cap on ABA in the 34 other states that have passed autism insurance laws is 21 years. Seven states impose no age cap on coverage for ABA (*please see attached, "A Discussion of Age Caps on Coverage of ABA for Autism"*). Due to the fact that treatment intensity decreases with age, a higher age cap would have a negligible impact on cost of the benefits (*see Table 1 below*).

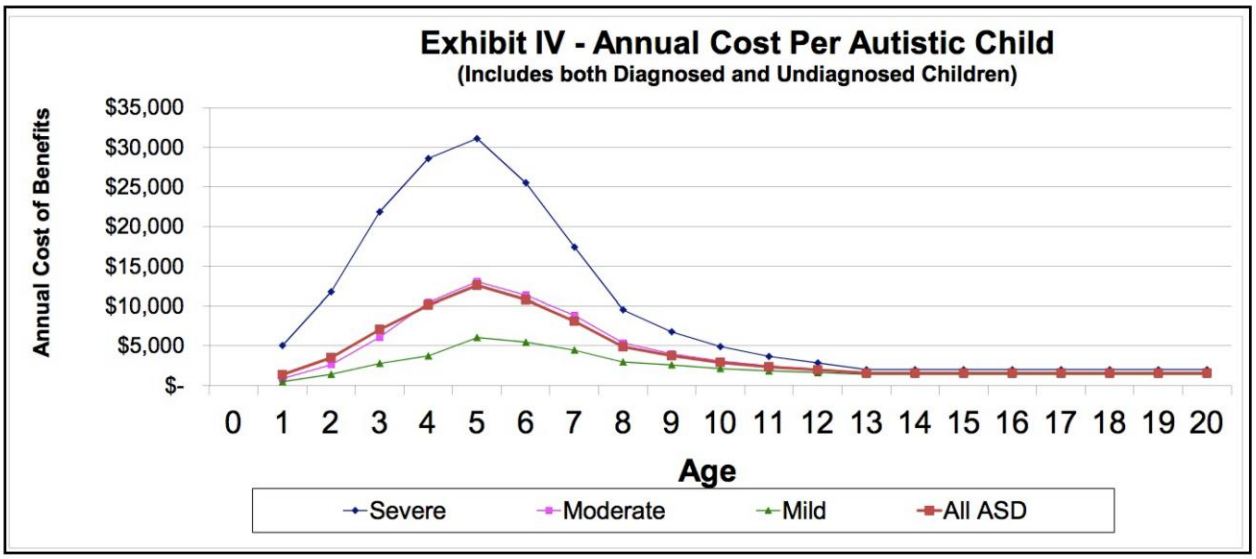

Table 1. Average annual cost of autism benefits by age and severity of autism; from *"Actuarial Cost Estimate: Hawaii Senate Bill 2054 SD1"* prepared by Oliver Wyman Actuarial Consulting, Inc. at http://bit.ly/1qteypb)

While SB 2054 SD3 HD1 does not require coverage for ABA in Medicaid plans, the potential cost of requiring such coverage has been raised during debate of this issue. Oliver Wyman Actuarial Consulting, Inc. has analyzed in detail the cost impact of SB 2054 and the potential impact to Medicaid plans in "Actuarial Cost Estimate: Hawaii Senate Bill 2054 SD1."[1] (*See* http://bit.ly/1qteypb.) Oliver Wyman's middle estimate for the State of Hawaii to extend benefits to the Medicaid program would be $4,059,000, with approximately half of that cost being matched by the Federal government. A February 11, 2014 estimate prepared by Hawaii's Department of Human Services was considerably higher. The primary difference between the two estimates appears to be due to the assumptions made in analyzing the total number of children in the Medicaid program who would be covered by the benefit. A detailed discussion of the differences between the two estimates is found in the report.

There is a minor technical error in the definition of "board certified behavior analyst" on page 6 (lines 16-18) and page 13 (lines 9-11). Please consider amending the definition to read as follows:

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

[1] Please note that the proposed terms of coverage in SB 2054 SD1 are identical to those proposed by SB 2054 SD3 HD1 except for the lower age cap in SB 2054 SD3 HD1

Thank you for considering my comments. We encourage the committee to pass SB 2054 SD 3 HD1 with the restored age cap of 21 years and the amendment to the definition of “board certified behavior analyst”.

Respectfully submitted,

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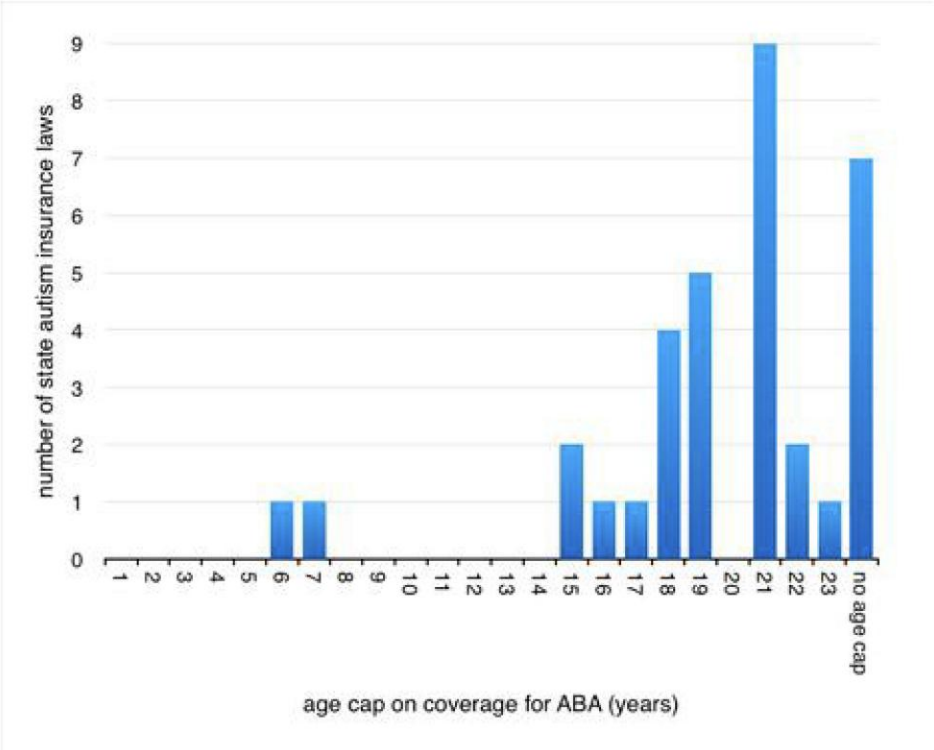
AUTISM SPEAKS
It's time to listen.

A Discussion of Age Caps on Coverage of ABA for Autism

Thirty four (34) other States currently require insurance coverage for ABA for autism. Age caps in these state laws range from 6 years to *no age cap* on ABA. Over 80% of State autism insurance laws impose an age cap on ABA of 18 years or older. The most common age cap on coverage for ABA is 21 years of age (9 states). Seven states impose no age cap on coverage for ABA.



Proponents of imposing an age cap on coverage for ABA frequently assert that ABA is either not effective past a certain age or not indicated past a certain age. Neither assertion is accurate. While most research on ABA for autism examines comprehensive ABA therapy in younger children, the attached report highlights extensive research that demonstrates the efficacy of focused ABA therapy for individuals with autism between 5 and 21 years of age. (Larsson, 2012)

When ABA therapy is provided early and with the prescribed intensity, the number of treatment goals (and therefore treatment intensity) decreases with age. However, the fact that older individuals with autism are generally prescribed less intensive ABA does not reflect diminished medical necessity of the therapy. In fact, if left untreated by ABA, maladaptive behaviors often associated with autism such as pica (i.e. eating non-food items), self injurious behavior, aggression and elopement can result in serious physical disability or death. Therefore, Autism Speaks opposes age caps on coverage for ABA for autism.

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Applied Behavior Analysis (ABA) for Autism: What is the Effective Age Range for Treatment?

Eric V. Larsson, Ph.D., L.P., B.C.B.A.-D. (2012)

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

"Within each reviewed study, at least one dependent variable suggested a reduction in anxiety following implementation of CBT." (page 60).

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

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

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

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

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

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

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

"Results of the present study, in which single-subject designs were used to examine the functional properties of SIB in 152 individuals, indicated that social reinforcement was a determinant of SIB in over two thirds of the sample, whereas nonsocial (automatic) consequences seemed to account for about one fourth of the cases." (page 234).

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

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

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

Eikeseth and colleagues, in 2007, used the following cut-off:

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

"The largest gain was in IQ; the behavioral treatment group showed an increase of 25 points (from 62 to 87) compared to 7 points (from 65 to 72) in the eclectic treatment group." (page 269).

"in the behavioral treatment group, all correlations among intake age and outcome measures and changes were nonsignificant, with r(12) ranging from –.40 to .46. Thus, age was not reliably associated with outcome or amount of change for this group." (page 273).

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

Mudford and colleagues, in 2001, reported the following cut-off:

"By the age of 4 years, 71% of the sample had started EIBI. At the ages of 5, 6 and 7 years, the corresponding cumulative figures were 91%, 97% and 100%." (page 177).

Mudford, O.C., Martin, N.T., Eikeseth, S., & Bibby, P. (2001). Parent-managed behavioral treatment for preschool children with autism: Some characteristics of UK programs. Research in Developmental Disabilities, 22, 173-182.

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

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

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

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

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

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

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

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

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

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

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Belchic, J.K., & Harris, S.L. (1994). The use of multiple peer exemplars to enhance the generalization of play skills to the siblings of children with autism. *Child and Family Behavior Therapy, 16,*1-25.

Bellini, S., & Akullian, J. (2007). A Meta-Analysis of Video Modeling and Video Self-Modeling Interventions for Children and Adolescents with Autism spectrum disorders. *Exceptional Children*, 73, 261-284.

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

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

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March 18th, 2014

Dear Consumer Protection and Commerce Committee,

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

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

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

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

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

Respectfully,

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

Amazing Behaving, LLC.
Solutions for Challenging Behavior

Joshua H Fouts PhD, BCBA-D
amazingbehaving@gmail.com
(808) 295-2453

March 18th, 2014

Dear Committee on Consumer Protection & Commerce:

My name is Joshua Fouts, and I am a Board Certified Behavior Analyst who has been providing behavior analysis services to families for the past 15 years. I am writing to support SB2054/Luke's Law. The purpose of my testimony is to let you know just how important behavior analysis, which is commonly referred to as ABA (applied behavior analysis), is to individuals with autism and other developmental disabilities, their families, and their communities.

As a scientifically validated approach to understanding behavior, and how the environment affects it, ABA is widely recognized as a safe and effective treatment for autism. A treatment that can foster basic skills such as looking, listening and imitating, as well as complex skills such as reading, conversing and understanding another person's perspective. Not only does ABA address important academic skills, but it addresses *all* of the other *necessary* skills needed for an individual to be successful in the classroom, at home, and in the community. With ABA an individual can:

- Sit at their desk, pay attention, and complete their work
- Transition from desk, to play ground, and make friends
- Leave school, walk home safely, and avoid potential dangers (i.e. cars, strangers, peers, etc.)
- Ride their bike to soccer practice, contribute to a team, and keep a high level of health and exercise
- Catch the bus to work, identify they could be late, and make a cell call to their job
- Make plans with their friends, drive their car without using a cell phone, and wear their seat belt

As you can see, ABA is used to help individuals acquire many, many different types of skills. Without this essential treatment, individuals with autism and other developmental disabilities will continue to fall short in language skills, self-help skills, play skills, social skills, community skills, and many other functional life skills.

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

Respectfully,

Joshua H Fouts PhD, BCBA-D
Behavior Analyst and Director
Amazing Behaving LLC

COMMITTEE ON CONSUMER PROTECTION AND COMMERCE
Rep. Angus McKelvey, Chair
Rep. Derek Kawakami, Vice Chair

Wednesday, March 19, 2014, 2:10 PM
State Capitol, 415 South Beretania Street
Conference Room 325

Dear Representative McKelvey, Kawakami, and Members of the Consumer Protection and Commerce Committee,

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

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

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

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

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

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

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

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

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

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

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

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

Christine Kim Walton, Ph.D., BCBA-D
President/Clinical Director, Behavior Analysis No Ka Oi, Inc.

Fantasea

March 12, 2014

Dear Senators, Representatives, and Committee Members,

I am the owner of KJN Corporation, a small business in Hawaii, and I am writing to ask you to support SB2054, Luke's Law. Currently in Hawaii, children with autism are not covered under medical insurance therefore families are forced to incur the cost of expensive treatments.

I have been a small business owner for over 20 years, and I have been faced with incurring increasing insurance premiums through the years. While every business owner does not like to see premiums increase, I understand the increase is small and I also understand the impact this bill will have on the state and will likely reduce costs long term. In addition, working parents are often forced to leave their jobs or take time off in order to support their children at home. I believe that as the prevalence of autism increases, more and more employees will need to make difficult choices about remaining employed or taking time off to care for their children. The disruption in business operations because of employee turnover, low morale and repeated leaves is unquantifiably high.

Studies show that, with proper intervention such as Applied Behavior Analysis, almost 50% of children with autism make substantive gains and may enter first grade indistinguishable from their peers.

As a business owner, I support SB2054. At some point we need to balance what is right to simply looking at the costs.

Sincerely,

Jeong Nam Kim
President KJN Corporation

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kawakami3-Benigno

From: Amy Wiech <amy@autismbehaviorconsulting.com>
Sent: Tuesday, March 18, 2014 2:25 PM
To: CPCtestimony
Subject: Fwd: SB Bill 2054- "Luke's Law" in support-Mahalo!!!!

March 18, 2014

Dear Consumer Protection 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. I recently successfully defended 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 Analyst s. The impetus for starting ABC Group was to provide high quality ABA services with integrity, fidelity and compassion for families affected by autism. We have to remember that they DID NOT choose Autism; but Autism chose them. We would like to be able to offer our services beyond the military insurance, and beyond only those who can afford the treatment privately.

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

If Data driven and developmentally appropriate programs developed by Board Certified Behavior Analysts in correlation with appropriate assessment tools, and the programs delivered with fidelity, intensity and duration by well trained behavior technicians, the terminal outcomes can be life changing as well as socially significant. These services are medically necessary, and result in kids first learning to learn, then learning to talk, learning to tolerate aversive stimuli, learning self help skills (eating, brushing teeth, bathing, etc) leading to independence from caregivers, learning say "I love you mommy", become employed self supporting citizens of

Hawaii, and eventually becoming YOUR next door neighbor. And services should not be capped off at age 6, but allowed up into young adulthood. Teaching functional life skills to this population would certainly increase their independence and likely result in decreasing their reliance on others to care for them. In addition, would save the State millions in the long run.

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

We are also extending an invitation for you to visit our clinic in Aiea if you would like to experience high quality ABA treatment in action with kids, behavior technicians, and supervisors. You can see how we assess, collect data and visually analyze the data daily in order to make treatment decisions which are individualized. Please feel free to contact me for a personal tour. We would be very proud to show you quality ABA services in action at ABC Group and demonstrate to you what hard work goes into a program with fideli ty 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, PhD., BCBA
CEO of ABC Group
Board Certified Behavior Analyst #1-04-1581
HABA Member
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http://www.facebook.com/pages/Autism-Training-Solutions/103558586786

"If the student hasn't learned, the teacher hasn't taught."- Sig Englemann

"Children with Autism are not learning disabled, they are teaching challenged!" - Dr. Vincent Carbone

"In God We Trust - All Others Bring Data!"
- W. Edwards Deming

If you want to be happy for an hour, take a nap.
If you want to be happy for a day, go fishing.
If you want to be happy for a month, go on a honeymoon.
If you want to be happy for a year, inherit a fortune.
If you want to be happy for a lifetime, teach children with disabilities.
Adapted from a Chinese Proverb-Unknown Author

KAISER PERMANENTE®

Government Relations

Testimony of Phyllis Dendle

Before:

House Committee on Consumer Protection and Commerce
The Honorable Angus L.K. McKelvey, Chair
The Honorable Derek S. K. Kawakami, Vice Chair

March 19, 2014
2:10 pm
Conference Room 329

SB 2054 SD3 RELATING TO HEALTH

Chair McKelvey, and committee members, thank you for this opportunity to provide testimony on SB 2054 SD3HD1 which 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:

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.

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However, this is a violation of federal law. Federal mental health parity laws require that there be no coverage limits on mental health services which are not also on other health services. The federal Patient Protection and Accountable Care Act (ACA) prohibits any lifetime limits. The federal law will make it impossible for health plans to adhere to these limits.

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

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

Date-With the change in the date when health plans must have this in their contract to December 31, 2015 all of the other dates in the bill need to be updated. For example the notice requirement should be changed to 2016.

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 Autism 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 9. By this time individuals would be eligible for services through the Department of Education.

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

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

Thank you for your consideration.

Proposed amendments to SB2054 SD3
Red with strike-through to be removed.
Blue and highlighted 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 10A 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 after December 31, 2015, shall provide to the policyholder and individuals under nine 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.~~ 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 non-grandfathered plans in the individual an small group markets that are required to include essential health benefits under the Patient Protection and Affordable Care Act, Public Law 111-148 as amended, or to Medicare supplement,accident-only, specified disease, hospital indemnity, disability income, long-term care, or other limited benefit hospital insurance policies.

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

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

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

"Applied behavior analysis" means the evidence-based design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior. The practice of applied behavior analysis expressly excludes psychological testing, diagnosis of a mental or physical disorder, neuropsychology, psychotherapy, cognitive therapy, sex therapy, psychoanalysis, hypnotherapy, and long-term counseling as treatment modalities.

~~"Autism 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.

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

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

"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 after December 31, 2015, shall provide to the policyholder and individuals under nine 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.~~ 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 non-grandfathered plans in the individual an small group markets that are required to include essential health benefits under the Patient Protection and Affordable Care Act, Public Law 111-148 as amended, or to Medicare supplement,accident-only, specified disease, hospital indemnity, disability income, long-term care, or other limited benefit hospital insurance policies.

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

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

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

"Applied behavior analysis" means the evidence-based design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior. The practice of applied behavior analysis expressly excludes psychological testing, diagnosis of a mental or physical disorder, neuropsychology, psychotherapy, cognitive therapy, sex therapy, psychoanalysis, hypnotherapy, and long-term counseling as treatment modalities.

~~"Autism 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.

~~"Board certified behavior analyst" means a behavior analyst credentialed by the Behavior Analyst Certification Board as a board certified analyst.~~

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

~~"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."~~

~~(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-116.2,431:10A-116.5, 431:10A-116.6, 431:10A-119, 431:10A-120, 431:10A-121, 431:10A-122, 431:10A-125, 431:10A-126, ~~431:10A-122, [and] 431:10A-116.2,~~ and 431:10A- and chapter 431M."

SECTION 6. Notwithstanding section 432D-23, Hawaii Revised Statutes, the coverage and benefits 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 after December 31, 2015. SECTION 7. 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 8. Statutory material to be repealed is bracketed and stricken. New statutory material is underscored.

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

COMMITTEE ON CONSUMER PROTECTION & COMMERCE
REPRESENTATIVE ANGUS L.K. MCKELVEY, CHAIR
REPRESENTATIVE DEREK S.K. KAWAKAMI, VICE CHAIR

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

Tuesday, March 18, 2014

Greetings Chair McKelvey, Vice-Chair Kawakami, and other esteemed Representatives of the House Committee on Consumer Protection and Commerce.

In regards to **SB 2054, SD3, HD1** that requires health insurers, mutual benefit societies, and health maintenance organizations to provide health care coverage and benefits for autism spectrum disorders, I am **in support** of this bill as it addresses a serious need for coverage that private insurers should bear and the Department of Education cannot.

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

Several things need to be made clear about SB2054, SD3, HD1:

First, the Department of Education follows an educational model, not a clinical model, and thus is not in a position to provide the intensive applied behavioral analysis services to address the needs of the children and adolescents with Autism Spectrum Disorder (ASD). As the focus of the DOE's educational model is academic, not social/emotional, the Individualized Education Plans developed for students with ASD focus on managing behavior to promote access to educational content. The parents of many of these students with ASD who seek and obtain the services of skilled psychologists and Board Certified Behavior Analysts (BCBAs) do so because their children with ASD are not receiving services from the DOE that address pragmatic speech, social reciprocity, theory of mind deficits, and other hallmark features of ASD that, while perhaps not germaine to traditional academics, will most certainly impact future employability, social and professional opportunities, etc. In the past, the DOE provided ESY (extended school year) support services to address these concerns, but by and large, these services have been cut from almost every case with which I am or have been involved. I respectfully ask you to request of the DOE data reflecting the percentage of children qualifying for SPED under the category "Autism" who receive or have received ESY services over the past 10 years. I am confident you will see that this percentage has steadily DECREASED (just as the prevalence rate of Autism has increased).

Second, I believe a provision needs to be added to the bill that clarifies the nature of supervision for skills trainers/tutors. The Board that oversees BCBAs is currently revising their training requirements such that by the end of 2014, all BCBAs would need to complete a supervision requirement that includes a competency exam for supervision. I respectfully request that language be included in the final version of the bill that specifies that all BCBAs providing supervision need to have completed supervision training and passed the competency exam to be a supervisor.

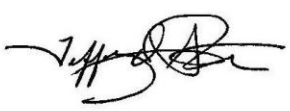
Third, I believe the wording of Section 3 (m) needs to be amended as follows (addition underlined): "Coverage for applied behavior analysis shall include the services of the personnel who work under the supervision of the board certified behavior analyst of the licensed psychologist overseeing the program, however, the personnel who work under the supervision of the board certified behavior analyst or psychologist overseeing the program shall not be eligible to bill for their services, independently." If this is inferred, I withdraw my recommended amendment.

Fourth, it is critical that the age provision include children beyond the age of 9. The average age of identification is about 6 years. Research has shown a considerable discrepancy in age of identification as a function of such factors as symptom severity ethnicity and socioeconomic status where less severe, poorer and minority children are identified significantly later than other children with Autism (Daniels & Mandell, 2013). In addition, ABA services targeting such significant concerns as pragmatic speech, social reciprocity, and theory of mind need to be addressed over the course of years, not months, as they tend to be the most difficult to ameliorate, but critical, nonetheless, and treatable with ABA (e.g., Pivotal Response Treatment).

Fifth, I have changed my opinion regarding the need for BCBAs to be licensed in the State prior to being eligible for insurance reimbursement. The reasons for this change of opinion are: First, there is a precedent in that Certified Substance Abuse Counselors can bill insurance companies for substance abuse treatment. Second, I've been communicating with Dr. Christine Walton, a psychologist and BCBA-D here in Hawai'i, about BCBA certification and reading up on the requirements. I am convinced they are very well-trained and capable of providing at least as high level services to children and adolescents with ASD as CSACs are capable of providing high level services to those with substance dependence and abuse problems.

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

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



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

HOUSE COMMITTEE ON CONSUMER PROTECTION AND COMMERCE
Rep. Angus L.K. McKelvey, Chair
Rep. Derek S.K. Kawakami, Vice Chair

Wednesday, March 18, 2014, 2:10 P.M.
Conference Room 325, State Capitol
415 South Beretania Street

Dear Representatives McKelvey and Kawakami,

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

One of the first clients I worked with demonstrated deficits in communication and social skills as well as engaged in aggressive behaviors that further impacted him from learning. Being new to the field, I honestly was not sure how ABA would decrease those behaviors (fecal smearing, biting and hitting others) of this child. Over a short period of time, this client made significant process and there was apparent reduction in those behaviors. That was only one of many experiences that helped me understand how ABA helped and how it can shape behaviors. Aside from the research stating the effectiveness of behavior analysis, it was clearly evident based on my interactions with each child I work with. In that same year, I decided to pursue further education in behavior analysis and received my certification in 2013 as a Board Certified Behavior Analyst. Prior to behavior analysis, I have 10 years experience working with the mental health population, particularly adolescent girls ranging from 13 to 18 years old and adults in transition from psychiatric hospital to residential health care facility ranging from 18 to 75 years old. I hear myself saying, "If I only knew then, what I know now…" because behavior analysis would have been extremely beneficial to that population as well. The only prevalent issue is that behavior analysis is not widespread or accessible. Unfortunately, this is not an isolated situation.

As you have read from the ages indicated above, applied behavior analysis (ABA) can be effective in working with individuals of all ages. However, research shows that skill development programs that are provided at a young age foster better outcomes and can often reduce the likelihood of more severe or dangerous behaviors later in life (Mays Institute, 2014). While early intervention has shown significant progress for children up to 3-4 years of age, many children are not diagnosed until the age of 6, especially with children who are "high functioning" (i.e. Asperger's) are usually diagnosed between the ages of 8-10. Ages 8 and older is also a critical time in a child's life as they start to face other challenges (social, academics, daily living) that is not appropriate to teach a child below the age of 8. I support the amendment to provide services up to age 21.

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. We have a growing number of clients ages 10 and older with varying levels of need. Part of what we do is to help teach the skills they require as they enter middle or high school, especially the transition into teen and adulthood.

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)

March 18, 2014

March 10, 2014

Capping the age at 9 is not realistic and does not help most families. The age should be at least 21.
This is a serious social problem and cannot be addressed with a "band-aid" solution. Thank you.

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

Dear Representatives and Committee Members:

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

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

In August 2013 we started her at an autism clinic where her primary services are in Applied Behavioral Analysis. Since then she has shown slow but steady progress. In a recent session with her ABA professional we actually saw her sit down for a rather lengthy 45 minutes where she continuously made eye contact, listened actively and was attentive and engaged in the discussion. We have never seen that before and for the first time are genuinely encouraged. We understand that Applied Behavior Analysis can result in improved behavior which should transfer into adulthood.

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

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

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

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

Rep. Angus L.K. McKelvey, Rep. Kawakami and Members of the Committee:

Please accept my testimony in strong support of SB2054, Luke's Law. I am the mother of a severely autistic son who is now 6 years old. With intensive ABA, Ryan has learned to speak simple sentences, ask for what he wants and needs, and is making great progress academically and socially. I shudder to think where he would be today without this treatment.

Beyond the personal cost to Hawaii's families, is the cost that is currently being passed on to the State and its taxpayers by overburdening Hawaii's schools to provide what is essentially therapy for a medical condition. In the current scenario, parents and families, our schools and all our citizens bear the financial cost of autism. Only health insurers get away without contributing. This isn't fair and it isn't right.

Please do the right thing and support SB2054.

Thank you.

Sincerely,

Janet Edghill

March 18, 2014

Attention:
Rep. Angus L.K. McKelvey, Chair

Rep. Derek S.K. Kawakami, Vice Chair

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

I clearly remember the first child I ever met with Autism. He was a preschooler named "Ben", with flowing, black hair and had the longest eyelashes I have ever seen. Ben cried often, engaged in aggression towards others, was self-injurious and completely non-vocal. When I first started working with him, I struggled to figure him out. I never knew what he wanted and constantly felt helpless: I wanted to help and I just didn't know how! However, when it was time for recess he sought me out and sat next to me on top of the play structure. When it was time to nap, he would bring his face right up to mine, and rub his eye brows against mine. Ben's mannerisms and interactions with me were so fascinating, I was intrigued and wanted to learn as much as I could about Autism.

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

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

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

Supervisor and Behavior Analyst, working in homes and schools in the Bay Area. It was there that I also accumulated many of my supervision hours and passed the BCBA exam.

In San Francisco I was amazed at the structure of the DOH and DOE systems. When a child was diagnosed with Autism, they were allowed to have intensive ABA services from time of diagnosis until at least Kindergarten, focusing on early intervention. I saw how having these intensive services from the moment they were diagnosed until becoming school age had a tremendous impact on their lives. It was amazing to work with children who were non-vocal to being able to fully communicate their wants and needs and eventually be rescinded from special education. To meet with parents who were in tears when we would start services and then have tears of gratitude when hearing their children talk for the first time.

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

Thank you for your time in reading this,

Sara Sato, M.Ed., BCBA

March 18, 2014

House Committee on Consumer Protection & Commerce
SB 2054 Relating to Health

Chair Angus, Vice Chair Kawakami, and Members of the Committee:

Thank you for the opportunity to testify on SB 2054. My name is Brandon Letoto and I strongly support the intent of this bill. However I am very concerned with recent amendments to limit the age to individuals under 9 instead of those under 21.

My wife Lori and I are the proud parents of six year old twin boys, Luke and Troy. Our son Luke was diagnosed with Autism Spectrum Disorder PDD-NOS around the age of 2. Since then, we have been to many Doctors visits and therapy sessions. Many of which are not covered by medical insurance.

Our son Luke is considered nonverbal and we send him to weekly speech therapy services at O'ahu Speech Therapy. Our families out of pocket cost for this is $100 an hour. Additionally, Luke takes daily supplements which add another $100 to our monthly bills. We also have our son on a special gluten free, casein free diet. The cost of this special diet is another cost that many families with autistic children face. We would like to implement more therapy sessions such as ABA but the cost of such services seem so out of reach.

We also have our son see Dr. John Green from Oregon. He specializes in biomedical treatment for autistic individuals. These services include prescription drugs and other treatments that could possibly help our son. Every visit to see Dr. Green is an out of pocket expense, since insurance does not cover it. This includes labs, meds, visits, etc. Biomedical Physicians are very expensive and has put another financial burden on our family.

I believe that passing this bill will increase Luke's chances of thriving by allowing him to receive more therapy and treatments that could help him to "recover" from his autism diagnosis. Like every parent, they have dreams for their child. My dream for Luke is that one day he will not only be able to function independently but also be a contributing member of society. There are thousands of children who have been diagnosed with autism in Hawai'i and the statistics are showing that this number is on the rise. The Centers for Disease Control and Prevention has reported that Autism Spectrum Disorders affect 1 in 88 American children and in boys the percentage is even greater. With your help these children can be given the opportunities that they deserve.

The recent amendment to narrow the eligibility for treatment to individuals under 9, rather than individuals under 21 years of age is very troublesome and alarming. Our son is 6 and our journey with him has just begun. Much more is needed to help him thrive and reach his full potential. Capping this age so early in a child's development just doesn't make sense. Our children will need help well past age 9 and putting an age limit for these proposed health services should be taken off the table. Enacting this age restriction will severely weaken this bill.

Having a child with autism is very challenging and the cost of medical care and therapies are just some of the many hurdles that families must overcome. Currently 34 other states have Insurance Mandates for Autism Spectrum Disorder and Hawai'i's children are long overdue for some relief. By passing this bill without the age restrictions, you will help ease some of the financial struggles that these children and their families face but most importantly you will be helping to provide a brighter future for tomorrow.

Thank you for your time and consideration,
Brandon M. Letoto
45-501 Apapane St.
Kaneohe, HI 96744

Derrick K. Abe, O.D.
1441 Kapiolani Blvd., Suite #805
Honolulu, HI 96814
PH: (808) 946-6136
FAX: (808) 943-6236

March18, 2014

Dear Chair McKelvey, Vice Chair Kawakami and Members of the Consumer Protection and Commerce Committee,

I am a small business owner in Hawaii, and I am writing to ask you to support SB2054, Luke's Law. As you know, children with autism in Hawaii currently aren't covered under most medical insurances.

I have been a small business owner for 11 years, and I understand the impact of high insurance premiums. However, I am also aware of the impact of autism on families in Hawaii, and there is simply no comparison between the struggles. Families with autism struggle daily – emotionally and financially – to provide for their children. Our state should act to relieve some of the financial burden on these families who did nothing to deserve their dire situations. The increase in cost that the insurance industry will pass on to small businesses is truly minuscule (0.2 percent, based on experience in other states) and is simply not a valid reason to turn our backs on children with autism.

Studies show that, with proper intervention, almost 50% of children with autism make amazing gains and can enter first grade indistinguishable from their peers. If left untreated, or if the child receives less than the recommended level of intervention as prescribed by his physician, these children are sometimes subject to a lifetime of state services over the course of their lifetime.

Please support SB2054. Not only does it make good fiscal sense for our state, it is morally and ethically the right thing to do.

Mahalo,

Derrick K. Abe, O.D.

To: Representative Angus McKelvey From: Geri Pinnow (Luke's Mom)

Re: In Support of Luke's Law SB2054

Got Chance?

According to data kids with autism are bullied due to their non-social norms to the point where they are physically ill. We actually don't even need to look at the published data. We can look into Luke's eyes and he can tell you firsthand what it is to be bullied to the point where you throw up because you don't have the ability to tell someone! When did this type of bullying start? When Luke was 13 and in middle school! He needs a chance from this legislation to finally help him!

We often give people in our wonderful state a first and second chance to get it right. Our kids just need a first chance!

Luke ***wants*** to go to college. He has a plan unlike some other kids who are fully supported yet we can't help him? Why? Because he doesn't have a right to medical supports that other kids have?

As it is right now Luke will have cost the state in skills trainer supports over a million dollars when he graduates high school. Now X that by 1 in 88! It didn't have to be and it doesn't have to continue!! I can only imagine what Luke will cost in benefits in Disability when he graduates! Again X that by 1 in 88. It doesn't have to be! We can change it!

I am not only his Mother, I am a tax paying citizen for many years in Hawaii and I can tell you I do not want to pay higher taxes for these kids in the years to come when I know this can be alleviated at 32 cents a premium!

Luke entered public school in preschool and was 18 months behind. He is graduating middle school in May and is now 6 years behind! I hear people testify that when the kids are school age the D.O.E. takes over. Why is Luke so far behind then? Our schools are not medical institutions, our teachers are not trained or equipped for this epidemic, the D.O.E. is not equipped now and the way 'it stands' in the future. If they were Luke would have received therapy and not be 6 years behind! No more smokescreens and no more passing the buck! Please promise **Luke** and **ALL** keiki….."**Ya**, **Got Chance!**"

Jerry Bump
3248 Lamaloa Place
Honolulu, HI 96816

March 18, 2014

House Committee on Consumer Protection and Commerce

Hearing: March 19, 2014, 2:10 p.m., Conference Room 325

Re: Testimony in Support of SB 2054, SD 3, HD 1 – Relating to Health

Dear Chair McKelvey, Vice Chair Kawakami and Members of the Committee,

Aloha and thank you for the opportunity to submit testimony in favor of SB 2054, SD 3, HD 1.

First, let me say that the most recent amendment to limit the services to age 8 or below, I do not agree with. There are many kids, including my son, who will fall between the cracks with such an age limit. Please reconsider amending the age back to under 21.

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

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

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

Please do the right thing for all of Hawaii's keiki and pass SB 2054, SD 3, HD 1.

Mahalo,
Jerry Bump

Committee on Consumer Protection & Commerce
Wednesday, March 19, 2014
Conference Room 325
State Capitol
415 South Beretania St

Dear Representatives McKelvey and Kawakami, and members of the Committee on Consumer Protection and Commerce:

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.

As a practitioner, I have worked with many teen and adult clients. While many believe that ABA is specifically beneficial for early-intervention, treating younger children, ABA is beneficial across the lifespan. There is a significant body of research that demonstrates the effectiveness of ABA for older children, treating the occurrence of challenging behavior, improving communication, and teaching self-help skills, community safety, and job skills just to name a few.

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

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

kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, March 18, 2014 1:55 PM
To: CPCtestimony
Cc: dakrekel4@gmail.com
Subject: Submitted testimony for SB2054 on Mar 19, 2014 14:10PM

SB2054
Submitted on: 3/18/2014
Testimony for CPC on Mar 19, 2014 14:10PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Kanoa Krekel	Individual	Oppose	Yes

Comments: I appreciate the intent; however, oppose age cap at 9 years.

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kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, March 18, 2014 1:57 PM
To: CPCtestimony
Cc: starsister2000@yahoo.com
Subject: Submitted testimony for SB2054 on Mar 19, 2014 14:10PM

SB2054
Submitted on: 3/18/2014
Testimony for CPC on Mar 19, 2014 14:10PM in Conference Room 325

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

Comments: I strongly support Luke's Law and feel it is particularly important to cover children of all ages. I have known many older children, ages 9-18, that have benefited from ABA services and truly hope Hawaii will do what is right to assist children with autism.

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kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, March 18, 2014 1:58 PM
To: CPCtestimony
Cc: dakrekel4@gmail.com
Subject: Submitted testimony for SB2054 on Mar 19, 2014 14:10PM

SB2054
Submitted on: 3/18/2014
Testimony for CPC on Mar 19, 2014 14:10PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Deborah Krekel	Individual	Oppose	Yes

Comments: I appreciate the intent. However, I oppose the age cap at 9 years.

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COMMITTEE ON CONSUMER PROTECTION & COMMERCE

Rep. Angus L.K. McKelvey, Chair
Rep. Derek S.K. Kawakami, Vice Chair

Wednesday, March 19, 2014, 2:10 PM
Conference Room 325, State Capitol
415 South Beretania Street

Dear Chair McKelvey, Vice Chair Kawakami and members of the Committee:

My name is Will Parker and I am teenager with autism and I live in Massachusetts. I am writing to you because I want to talk about applied behavior analysis (ABA) and how it benefits people with autism.

When I was younger I had difficulty with managing my behavior and controlling my temper. It was hard for my family and me. Due to this issue I even had to go to a different school. At this new school, I worked with a Board Certified Behavior Analyst (BCBA) who helped my family and me with my challenges. My behaviors were confusing and frustrating for my entire family. My BCBA came to my house and walked me through the steps of how to behave and learn better. I learned about behaviorism and B.F. Skinner. This helped me control myself at school and home. I was even invited to present about my experiences at the Massachusetts ABA Conference in 2012.

If I didn't have ABA therapy, my behaviors would probably have gotten worse and become more intense. If I didn't learn how to control my behavioral outbursts I might have gotten into trouble with the police. With the help of my family and my BCBA, we were able to treat, not cure my autism. Even though I am doing so much better, I still work with a BCBA today. I learn something new all of the time.

With the help of ABA therapy, I learned to control my outbursts, but I also learned to how to ride a bike, tie my shoes, and make friends. I also have a better relationship with my mom and dad and I'm a good big brother.

I think kids with autism should have ABA services. I think it would be cool if Hawaii passes *Luke's Law* to allow this to happen. With ABA, kids in Hawaii can be a success like me.

Thank you for your time.

Respectfully,

Will Parker

Will Parker
Massachusetts

APRIL 9, 2014, 2:10 PM

HOUSE COMMITTEE ON CONSUMER PROTECTION & COMMERCE
REP. ANGUS L.K. MCKELVEY, CHAIR
REP. DEREK S.K. KAWAKAMI, VICE CHAIR

S.B. 2054, SD3, HD1

SUBMITTING IN STRONG SUPPORT OF S.B. 2054,
ALSO KNOWN AS "LUKE'S LAW"

TESTIMONY OF:

Christopher M. Letoto

Chair McKelvey, Vice Chair Kawakami, and Members of the House of Representatives Committee on Consumer Protection and Commerce, I write in strong support of Luke's Law, S.B. 2054.

I have personally been touched by this disorder with my nephew who also happens to be named Luke Letoto, so I hope that this is a great sign that "Luke's Law" will be passed. He is the most amazing, loving, smart and happy young boy, but being diagnosed with autism he deserves a chance to receive autism-related psychiatric, psychological, pharmaceutical and therapeutic care. I pray and hope that someday he will be able to function and interact the same way that we all take for granted every day. He deserves to have the type of care and treatment that can help him grow up into an amazing man and member of our Hawaii community. We must stop pushing this issue to the side and address it with understanding and action. Additionally, I know of four other families who have children diagnosed with autism and they are all boys. This is a serious problem and we have to put in place the proper funding to get these children the help and support they deserve and require. Just imagine if this was your child and I know that you will make the right decision in support of Luke's Law.

Being involved in Hawaii's health care insurance industry and finance, I believe it is a fundamental human right that all residents of Hawaii are provided with access to quality health care. And we can do this by requiring coverage for the treatment of autism spectrum disorders.

At the last hearing there was recent discussion on capping services at an early age, but how can we put an age restriction on when a child should stop receiving treatment or services? Would we stop sending a young child to school that isn't learning at the same rate as others, or do we find solutions to ensure that all children get the help they need in spite of their learning capacity? The answer is the latter because children learn at different rates and have different capabilities to grasp knowledge. Children with autism typically have the capacity to learn and grow, but they need to be supported in a different way, much like the way we treat children with other special needs. To say you no longer can continue to receive treatment once you reach the age of 8 or 9 is a disservice to the entire program and to all the hard work and effort we would have put into helping these children with autism spectrum disorder. If any child has the capacity and willingness to continue to learn and grow, we should not hesitate to offer them the necessary care and support they deserve.

It is a fact that autism prevalence figures are growing and it's the fastest growing serious developmental disability in the U.S. Autism now affects 1 in 88 children and 1 in 54 boys, with boys nearly five times more likely than girls to have autism. Financially, autism costs a family $60,000 a year on average and this disorder currently only receives less than 5% of the research funding of many less prevalent childhood diseases. Currently, many families struggle to help their children because medical insurance carriers do not cover autism related services. We have to start making decisions that help foster the learning and growth of our children that live here in Hawaii. And by taking action now, we can help change the lives of so many children that need our love and support, by passing Luke's Law.

Thank you for your consideration.

Sincerely, Christopher M. Letoto, MBA

kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, March 18, 2014 2:36 PM
To: CPCtestimony
Cc: scannerchief@yahoo.com
Subject: Submitted testimony for SB2054 on Mar 19, 2014 14:10PM

SB2054
Submitted on: 3/18/2014
Testimony for CPC on Mar 19, 2014 14:10PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Christopher Toyama	Individual	Support	No

Comments: please start autism insurance

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kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, March 18, 2014 4:31 PM
To: CPCtestimony
Cc: info@swamwine.com
Subject: *Submitted testimony for SB2054 on Mar 19, 2014 14:10PM*

SB2054
Submitted on: 3/18/2014
Testimony for CPC on Mar 19, 2014 14:10PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Jill Shiroma	Individual	Support	No

Comments:

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kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, March 18, 2014 7:43 PM
To: CPCtestimony
Cc: alicekamaka@gmail.com
Subject: Submitted testimony for SB2054 on Mar 19, 2014 14:10PM

SB2054
Submitted on: 3/18/2014
Testimony for CPC on Mar 19, 2014 14:10PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Donovan Keliiaa	Individual	Support	Yes

Comments: I will provide verbal testimony at the hearing, I am still working on my testimony. Thank you very much for the opportunity to testify

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From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, March 18, 2014 9:03 PM
To: CPCtestimony
Cc: paulakomarajr@yahoo.com
Subject: *Submitted testimony for SB2054 on Mar 19, 2014 14:10PM*

SB2054
Submitted on: 3/18/2014
Testimony for CPC on Mar 19, 2014 14:10PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Paul A. komara, Jr.	Individual	Support	No

Comments:

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March 19, 2014

Dear Committee Members,

My name is Brandi Chew, PhD and I am a licensed psychologist working in the state of Hawaii. I am writing to you because I want to talk about **SB2054 / Luke's Law** and how it will benefit children and families with autism.

Many families with special needs children spend months, even years, seeing numerous providers while waiting for a diagnosis. Once they receive a diagnosis they often find themselves navigating complex medical and educational systems and jumping through bureaucratic hoops to access adequate care for their child. It seems to be a cruel and unusual punishment that after all that – these families are often denied the services that research has shown to be most effective because of the cost of these services and the insurance companies' unwillingness to cover those costs. These evidence-based interventions not only provide effective treatment for these children – they offer hope as well; hope of developmental progress, long-term well-being, and greater independence in adulthood.

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

Respectfully,

Brandi Chew, PhD

LATE

HOUSE OF REPRESENTATIVES

STATE OF HAWAII
STATE CAPITOL
HONOLULU, HAWAII 96813

Testimony for the House Committee on Consumer Protection and Commerce

Regarding Senate Bill No. 2054 SD 3 HD 1, Relating to Health

Committee Hearing on March 19, 2014 at 2:10 p.m.
Hawaii State Capitol, 415 South Beretania Street, Conference Room 325

Dear Chair McKelvey, Vice-Chair Kawakami, and Members of the House Committee on Consumer Protection and Commerce:

Thank you for this opportunity to testify in STRONG SUPPORT to SB 2054 SD 3 HD 1.

The intent of this bill is to afford families coverage for autism spectrum disorders so that these children are provided with the resources necessary to treat and improve their conditions.

Please see the attached letter and response from the Department of Education, where the department has provided specific information on costs for autism spectrum disorder services paid for by the State.

Thank you again for the opportunity to provide this testimony.

Respectfully submitted by: Della Au Belatti
State Representative, District 24

Representative Della Au Belatti
District 24 • Makiki, Tantalus, Papakolea, McCully, Pawaa, Manoa
Hawaii State Capitol, Room 331 • 415 South Beretania Street • Honolulu, Hi 96813
Tel: (808) 586-9425 • repbelatti@capitol.hawaii.gov

LATE

HOUSE OF REPRESENTATIVES

STATE OF HAWAII
STATE CAPITOL
HONOLULU, HAWAII 96813

Mrs. Kathryn Matayoshi
Superintendent of Education
Hawaii State Department of Education
1390 Miller Street
Honolulu, HI 96813

Re: Request for Department of Education Expenditure Reports

Dear Superintendent Matayoshi:

The affordability of and access to autism services continues to be a concern of legislators and families with students diagnosed with autism spectrum disorder. To help understand the cost of autism services to our State budget, can the Department of Education provide the following information of monies spent by the Department over the last ten years, aggregated annually for:

(1) All children who received IEP services for the last ten years;

(2) All children diagnosed with autism spectrum disorders who received IEP services for the last ten years; and

(3) A complex area breakdown for both categories requested above if it is possible to develop such a breakdown.

I would greatly appreciate your cooperation with the gathering of this information as this will help us with our deliberations and decision-making on a number of measures before us during the 2014 legislative session. Thank you for your time and consideration.

Sincerely,

Della Au Belatti
Chairperson, State House Committee on Health
Hawaii State Capitol, Room 331
(808) 586-9425
repbelatti@capitol.hawaii.gov

Representative Della Au Belatti
District 24 • Makiki, Tantalus, Papakolea, McCully, Pawaa, Manoa
Hawaii State Capitol, Room 331 • 415 South Beretania Street • Honolulu, HI 96813
Tel: (808) 586-9425 • repbelatti@capitol.hawaii.gov

NEIL ABERCROMBIE
GOVERNOR

KATHRYN S. MATAYOSHI
SUPERINTENOENT

STATE OF HAWAI'I
DEPARTMENT OF EDUCATION
P.O. BOX 2360
HONOLULU, HAWAI'I 96804

OFFICE OF THE SUPERINTENDENT

March 18, 2014

The Honorable Della Au Belatti
House Committee on Health
The Twenty-seventh State Legislature
State Capitol, Room 331
Honolulu, Hawaii 96813

Dear Representative Belatti:

Thank you for meeting yesterday with Deputy Superintendent Ronn Nozoe to discuss educational services provided by the Hawaii State Department of Education (DOE) to students diagnosed with autism spectrum disorder.

In response to your letter received on February 27, 2014, attached please find our answers to the questions posed in your letter as well as the question you posed to Mr. Nozoe at yesterday's meeting.

Should you have any questions or require further information of clarification, please do not hesitate to contact Deputy Nozoe at (808) 586-3316.

Mahalo for your continued support of the Department, and commitment and dedication to Hawaii's keiki.

Very truly yours,

Kathryn S. Matayoshi
Superintendent

KSM:itk

Attachment

c: Mr. Ronn Nozoe, Deputy Superintendent
Office of Fiscal Services
Office of Curriculum, Instruction and Student Support

ATTACHMENT

LATE

Monies spent by the Department of Education over the last ten years, aggregated annually for:

1. ***All children who received IEP services for the last ten years:***

School Year	Estimated SPED expenditures (w/o transportation and fringe*)
2003-04	$ 331,851,652
2004-05	$ 334,487,366
2005-06	$ 344,052,476
2006-07	$ 369,622,438
2007-08	$ 410,006,514
2008-09	$ 419,988,412
2009-10	$ 372,168,903
2010-11	$ 361,356,341
2011-12	$ 348,715,831
2012-13	$ 349,637,135
*B&F	

2. ***All children diagnosed with autism spectrum disorder who received IEP services for the last ten years:***
(Please note that this is an updated table from that presented to you at our meeting on March 17, 2014.)

School Year	*Total No. of Autism students	**Autism specific programs
2003-04	770	$ 33,083,414
2004-05	868	$ 32,901,409
2005-06	960	$ 37,398,903
2006-07	1018	$ 35,692,086
2007-08	1108	$ 41,075,113
2008-09	1185	$ 44,506,249
2009-10	1268	$ 40,697,413
2010-11	1298	$ 42,356,495
2011-12	1390	$ 38,135,663
2012-13	1474	$ 37,467,606

*Number of students with autism, ages 3-21, as reported to the U.S. Department of Education.
**Total expenditures for autism specific programs. NOTE: This total does not include general and federal fund expenditures for services applicable to all SPED students such as school-based services, service testing/monitoring, speech/language services, psychological services, occupational/physical therapy, counseling, skilled nursing, mental health services, transition services, and diagnostic services. For the Department to include such costs would require a manual review of each IEP.

3. ***A complex area breakdown for both categories requested above if it is possible to develop such a breakdown.*** We apologize for our inability to provide this information as such data is gathered statewide rather than by complex areas.

4. ***The amount of general and federal funds received for SPED services:***
If we may respond by providing the average amount of annual funds received by the Hawaii State Department of Education based on the last three school years (SY2010-11 to SY2012-13), as follows:
   - General funds $313.9 million
   - Federal funds $40.6 million

To: Rep. Angus L.K. McKelvey, Chair

Committee on Consumer Protection & Commerce

LATE

Wednesday, March 19, 2014

THE AUTISM (YES) MOVEMENT

FOR SB2054

My story by Donovan Keliiaa

I was a kid with autism and had a hard time in school. I was bullied and teased a lot. I had to change schools four times because the kids would not stop bullying me. I tried hard not to act up in school so others would like me, but the kids didn't care and make me ~~pee myself so I could~~ go home. No one helped me at school. When I got home I would explode. My parents would fight, they got divorced. They could not get help for me because the school said it didn't happen there. My senior year things changed, I was manager of the football team, and no one knew I had autism, the players helped me. I met CJ Tausaga who taught me a thing called HOPE and what it stands for is Helping Others Pursue Excellence. That's why the players helped me if I worked my butt off. That is why I am here today. Because I want to give HOPE to the kids with Autism. This Bill will help them. No kid should have to go through what I went through. No family should. I had a good senior year but then that was it. For 10 years I stayed home, gained 200 pounds, became a diabetic and started to get frustrated and violent put my sister through hell and had to move out of my moms house 2 and a half years ago. I remembered HOPE, the DD Division gave me HOPE 24 hours every day and I worked my butt off. Now I have my own apartment. I wrote to Assistive Technology Resource Center for a laptop and they gave me one so I could get a job and I now work making menus for a lunch truck. I lost 75 pounds and I do not have to take insulin for my diabetes. But if I had the training when I was a kid on how to cope and make friends, my life would have been much better today. Please say YES to SB 2054! Start the YES MOVEMENT TODAY! Don't wait another day or year. Don't make kids with autism piss themselves to get help! Remove from the bill the part to have an audit thing, excuse me to say this but that is BULLSHIT! Tripler and other states can tell you how much it costs to help a kid with autism. The DD Division can tell you the cost of an adult who didn't get the help, like me. On my good days, it costs $600 from the Waiver for daily supports on my anxiety days $900 a day because more staff have to help me. I also have to take medications for diabetes and coping, see a psychiatrist and psychologist monthly. When I was in High School I took a multivitamin only now I take 12 pills a day. My total cost comes to an average of $20,000 a month. The math is easy, it costs a lot more money to support an adult then it does to help a kid. Not only more money but also the cost of breaking a kids heart. My heart was broken and I still have nightmares over it. GIVE THESE KIDS HOPE! Please HELP OTHERS PERSUE EXCELLENCE START THE YES MOVEMENT TODAY BY SAYING YES TO SB 2054 and start it by July 1, 2014.

Thank you so very much for letting me give HOPE through testimony for all the kids with autism.

HMSA

Blue Cross Blue Shield of Hawaii

An Independent Licensee of the Blue Cross and Blue Shield Association

LATE

March 19, 2014

The Honorable Angus L.K. McKelvey, Chair
The Honorable Derek S.K. Kawakami, Vice Chair
House Committee on Consumer Protection and Commerce

Re: SB 2054, SD3, HD2 – Relating to Health

Dear Chair McKelvey, Chair Kawakami and Members of the Committee:

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on SB 2054, SD3, HD1 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, with the exception of Sections 6 and 7 of the Bill, HMSA opposes this legislation.

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. We believe it is critical to have a financial analysis of the cost of providing coverage for screening, diagnosis, and treatment of autism spectrum disorders as required by this Bill, including an estimate of the cost benefits provided, and the cost impact if this Bill were applied to the Hawaii Medicaid market.

HMSA supports Sections 6 and 7 of this Bill that provides for the Legislative Reference Bureau to commission an independent actuarial analysis of the impact of covering these services.

In light of the provision for the actuarial study, we believe the other sections of the Bill are premature. The Legislature should not adopt legislation mandating this coverage until it fully understands its financial impact. It only should be considered after the Legislature receives the actuarial analysis mandated under Sections 6 and 7 of this Bill.

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 the Bill attempts to shield the State from bearing the cost burden – it does not do so. Section 431:10A (i) states:

> Nothing in this section shall apply to non-grandfathered plans in the individual and small group markets that are required to include essential health benefits under the Patient Protection and Affordable Care Act, Public Law 111-148, as amended, or to the Medicare supplement, accident-only, specified disease, hospital indemnity, disability income, long-term care, or other limited benefit hospital insurance policies.

This section would not successfully carve out the mandate's application to small group markets due to the Hawaii Prepaid Health Care Act (PHCA). The new mandated coverage for autism spectrum disorder would be incorporated into the prevalent plan. All business plans would undergo price adjustment to accommodate this mandate, and small businesses would not be exempted from the PHCA... As written, the exemption language written in this section is irrelevant.