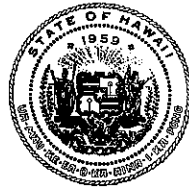


NEIL ABERCROMBIE
GOVERNOR OF HAWAII



GARY L. GILL
ACTING DIRECTOR OF HEALTH

STATE OF HAWAII
DEPARTMENT OF HEALTH
P.O. Box 3378
HONOLULU, HAWAII 96801-3378

In reply, please refer to:
File:

**Senate Committees on Health and
Commerce and Consumer Protection**

SB 2054, Relating to Health

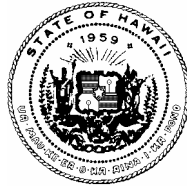
**Testimony of Gary L. Gill
Acting Director of Health**

January 28, 2014

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

6 **Fiscal Implications:** The Department recognizes that this bill impacts insurance rates for all citizens.
7 The cost for families with children with autism is significant. The National Institute of Health has
8 reported that one third of families with children with autism expend more than three percent of their
9 annual income on autism therapies. For some families with children with autism, extreme behaviors
10 create a great financial burden on families that can create major family stress and financial crisis.
11 Intensive treatment for autism for children does ameliorate challenging behaviors and lessens the life
12 long dependency upon Medicaid Home and Community Based personal assistance. The fiscal
13 implications to the Department of Health are lowered costs of long term care.

14 Thank you for this opportunity to testify.



STATE OF HAWAII
DEPARTMENT OF HUMAN SERVICES

P. O. Box 339
Honolulu, Hawaii 96809-0339

January 28, 2014

TO: The Honorable Josh Green, M.D., Chair
Senate Committee on Health

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

FROM: Patricia McManaman, Director

SUBJECT: **S.B. 2054 - RELATING TO HEALTH**

Hearing: Tuesday, January 28, 2014; 8:30 a.m.
Conference Room 229, 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.

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

Should ABA be covered in Medicaid, the DHS estimates a projected total cost of \$135 million to serve children up to age 19 years, of which \$24.9 million would be DHS' cost, including federal funds.

The Department of Human Services conducted a study, between legislative sessions, on the cost of Medicaid coverage of applied behavioral analysis (ABA) to treat autism. While the

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

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

Table. Summary of the potential annual costs of covering ABA in Medicaid

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

* Assumes an average of 1.5 cycles per year for 6-19 year olds
 ** Assumes \$75/hr reimbursement for direct services and \$100/hr for supervision, assessment and parent training; approximately half of cost would be federally funded
 *** Additional funding may not be necessary if these programs already cover the service

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

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

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

The U.S. Preventive Services Task Force (USPSTF) is considered the gold standard for clinical preventive services, and under the Affordable Care Act, insurers must cover services that receive an A or B recommendation by the USPSTF without requiring a co-payment. A recommendation of C would mean that there is evidence of benefit, but the benefit is small and the service is not routinely recommended to be provided; a recommendation of I would mean that there is insufficient evidence, i.e. that the service is

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>
AN EQUAL OPPORTUNITY AGENCY

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>
AN EQUAL OPPORTUNITY AGENCY

ABA Utilization Projection for Hawai'i 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 Health Early Intervention Section (DOH/EI) receiving ABA services, and Department of Education Special Education (DOE) who an eligibility of Autism or Developmental Delay – 3,486
 - 1.4.1. Since the two numbers are so close, this projection will utilize the number reflecting identifiable children, the DOH, DOE combined number
- 1.5. Studies show there is no higher prevalence of ASD in children who are Medicaid eligible than those who are not
- 1.6. Using 3-month continuous eligibility for 90 days, 154,000 children are in the state Medicaid program, which equates to 47% of the 0-18 population
- 1.7. Applying the 47% to the total children served – 1,624

2. Treatment

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

3. Projection Assumptions

- 3.1. Not all children will require the same level of high intensity
- 3.2. Comprehensive Intensive ABA services would be made available age 0-8
 - 3.2.1. Literature indicates intensive services on general population is 0-6
 - 3.2.2. Extended to age 8 due to health literacy for parent involvement and ability to provide stimulation rich environment to support services

3.3. Focused ABA services would be made available 8-19

3.3.1. Literature indicates service provision should be individualized and made available

3.3.2. For this exercise, the following tiered structure is proposed to be able to make some assumptions

3.3.2.1. Preventive Planning and Intervention

3.3.2.1.1. Preventive Planning and Intervention would be provided to identify early emerging problems as well as anticipated intervention needs to “pre-plan” for upcoming events which would require skilled intervention (e.g., preparing for puberty, etc.)

3.3.2.1.2. Prevention Planning and Intervention would be made available at the following regularly scheduled intervals

3.3.2.1.2.1. Age 7 (i.e., for children not already receiving comprehensive intensive ABA)

3.3.2.1.2.2. Age 10

3.3.2.1.2.3. Pre-puberty (i.e., could identify a stage in puberty, Stage 2)

3.3.2.1.2.4. Age 14

3.3.2.1.2.5. Age 16

3.3.2.1.2.6. Age 19-20

3.3.2.2. Targeted Assessment and Treatment

3.3.2.2.1. Targeted Assessment and Treatment would be 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 developed and implemented

3.3.2.2.2.2. Targeted Assessment 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 child's total need across settings

4.1.2. EI service numbers are included in the estimate

4.1.3. EI ABA services should be included to the matrix to draw down federal dollars

4.1.4. There should not be a need to provide more hours beyond what is provided by EI

4.2. Services are provided by DOE Special Education

4.2.1. DOE services are currently authorized to meet the child's education needs in the school setting

4.2.2. There will be a need to provide services beyond what is provided by DOE

4.2.2.1. DOE federal mandate does not include addressing in-home interventions

4.2.2.2. Unable to direct all children through DOE unlike EI

4.2.3. 80-100% of the child's need could be provided by the DOE, and what remains as a state plan only benefit should be nominal

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

- 4.3. The service is typically supervised by a Board Certified Behavior Analyst (BCBA)
 - 4.3.1. Tricare reimburses this at \$125.00/hour
 - 4.3.2. BCBA's 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%	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

Comprehensive Intensive ABA Services								
Age	# of Projected Medicaid Children	Service	Hours per child per week	Weeks per year	Total Hours for all	% DOH/EI	% SPED	Total Hours Not Carved Out: DHS
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
		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 BCBA's

OFFICE OF INFORMATION PRACTICES

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To: Senate Committees on Health and on Commerce and Consumer Protection

From: Cheryl Kakazu Park, Director

Date: January 28, 2014 at 8:30 a.m.
State Capitol, Conference Room 229

Re: Testimony on S.B. No. 2054
Relating to Health

Thank you for the opportunity to submit testimony on this bill. The Office of Information Practices (“OIP”) takes no position on the substance of this bill, which would require health insurers to provide coverage for autism spectrum disorders. OIP is testifying to ask for clarification of two references to chapter 92, HRS, at bill page 2, line 18, and bill page 9, line 9.

Both references require the Insurance Commissioner to “post notice of and hold a public meeting pursuant to chapter 92.” Part I of chapter 92, HRS, the Sunshine Law, does deal with public meetings, but it does not set generic standards for holding a single public meeting. Rather, it applies to “boards,” which are defined therein, and sets requirements not just for when a meeting must be open to the public and how to give notice, but also for when board members can communicate outside a meeting, what must be included in minutes, enforcement, and related matters. It is thus not possible for a single government official to “hold a public meeting pursuant to chapter 92” because the Sunshine Law’s provisions are written to apply to a body of members that exists and regularly meets over a period of time.

A more appropriate standard to reference might be section 91-3(a), which sets out requirements for an agency to post notice of and hold a public hearing on proposed administrative rules. Alternatively, if this Committee still prefers to reference the Sunshine Law, OIP would suggest at least rephrasing the references as follows so that there is no implication that the Insurance Commissioner is expected to fully follow a set of requirements designed for deliberative bodies: “hold a public hearing that is publicly noticed as described in section 92-7 and is open to public attendance and testimony as described in section 92-3.”

Thank you for the opportunity to testify.



STATE OF HAWAII
STATE COUNCIL
ON DEVELOPMENTAL DISABILITIES
919 ALA MOANA BOULEVARD, ROOM 113
HONOLULU, HAWAII 96814
TELEPHONE: (808) 586-8100 FAX: (808) 586-7543
January 28, 2014

The Honorable Josh Green, M.D., Chair
Senate Committee on Health
and

The Honorable Rosalyn H. Baker, Chair
Senate Committee on Commerce and Consumer Protection
Twenty-Seventh Legislature
State Capitol
State of Hawaii
Honolulu, Hawaii 96813

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

SUBJECT: SB 2578 and SB 2054 – RELATING TO HEALTH

The State Council on Developmental Disabilities (DD) **SUPPORTS THE INTENT of SB 2578 and SB 2054.** The bills require 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 mirrors SB 668 SD2 HD1 that was deferred in Conference Committee on April 26, 2013, and carried over to the 2014 Regular Session. These bills reflect the work and consensus of a large stakeholder group. SB 2054 provides comprehensive coverage of services, including well-baby and well-child screening diagnosis and evidence-based treatment for individuals under 21 years of age.

SB 2578 proposes to provide coverage for only behavioral health treatment for insurers under six years of age. We are aware that the Affordable Care Act includes screening, diagnosis and treatment of autism, as well as providing habilitation services. As noted in SB 2578, behavioral health treatments such as applied behavior analysis specific to the treatment of autism, may have not been covered as habilitative services. We feel at minimum, behavioral health treatments should be covered for individuals.

The Honorable Josh Green, M.D.
The Honorable Rosalyn H. Baker
Page 2
January 28, 2014

The Council acknowledges that SB 2578 and SB 2054 are a work in progress in addressing the needs of individuals with autism spectrum disorders to receive covered treatment and the concerns of insurers regarding costs to cover treatment. We strongly encourage continued discussions with the stakeholder group to flesh out the specific provisions of each bill. We respectfully recommend that both bills be combined and prefer that SB 2054 be the vehicle to move forward during this legislative session.

Thank you for the opportunity to provide testimony supporting the intent of SB 2578 and SB 2054.

Sincerely,



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



J. Curtis Tyler III
Chair

Testimony of Phyllis Dendle

Before:

Senate Committee on Health
The Honorable Josh Green, Chair
The Honorable Rosalyn H. Baker, Vice Chair

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

January 28, 2014
8:30 am
Conference Room 229

SB 2054 RELATING TO HEALTH

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

Kaiser Permanente Hawaii has concerns with how this bill is written and urges the committee to instead consider SB2578.

Our first concern is that this bill reflects **none of the recommendations of either the Legislative Auditor or the Legislative Reference Bureau**. Both studies were done as requested by the legislature and the auditor's study recommended against passing this mandate. The LRB made specific recommendations based on the effect of the proposed language in the draft bill and what would need to be done prior to passing such a bill.

We also want to explain our concerns about specific language in this bill.

Age-This bill sets the upper limit of coverage at 21 years of age. While some states set the age limit of 21 many are set younger than that. Several states focus their resources on young children who, research indicates, may benefit from services described in the bill.

Screening and diagnosis-Screening and diagnosis are already covered services under existing law. At Kaiser Permanente we follow the guidelines of the American Academy of Pediatrics on identification and evaluation of children to diagnose those with autism spectrum disorders. When these children are identified they are linked to the State Department of Health early intervention services and as the child grows they are linked to the Department of Education both of whom currently provide services to children with autism as well as children with other developmental issues.

Maximum dollar limits-We appreciate the intention of the drafters of this bill to create some financial certainty to health plans by placing a dollar limit per year and per lifetime. However, we are concerned that 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 limit. We are concerned that this bill might pass with the limits listed but there could be rulings in the future which would require coverage with no limits.

Also, this dollar limit is only for "behavioral health treatment" and the bill specifically says this must be in addition to any coverage for other care, treatment, intervention, or service. The actual cost of care could easily exceed the proposed dollar figures.

Habilitative treatment-ACA already requires coverage of habilitative treatment and in Hawaii the definition of habilitative treatment is very similar to the definition of rehabilitative treatment. There is no need to include this in this bill since it is already required.

Review of treatment- The bill would permit a health plan to review the treatment of a covered individual not more than once every twelve months. This is not in the best interest of the patient. All other medical treatments are subject to regular review to determine if the treatment is beneficial. It is essential for all medical care, including what is being required in this bill, to be based on what is medically necessary. If the individual is not improving it may be the wrong treatment or it may be the wrong provider. Under the circumstances described in the bill an individual could languish for a year making no improvement before the health plan would be able to evaluate the patient's progress.

There is no requirement for the prescribing provider to have oversight to this care once

prescribed. There is also no requirement that services provided be in line with evidence-based research and be provided to consistent standards.

Coordination of care- This bill does not clearly delineate the responsibilities between health plans and providers and the Departments of Health and Education. The schools are required to provide a range of services to students under federal disability and special education laws. This bill could set up circumstance where individuals are shuffled back and forth because it is not clear who is responsible for what services. This is similar to what was experienced before the Felix consent decree.

Who's covered- As written, this bill sets up two different levels of care based on whether the plan is gotten through the health insurance exchange or outside of the exchange. Those in the exchange would not be covered for this mandate according to this bill. It is important to note that changes due to ACA no longer permit the state to exempt itself in this way. Will Medicaid be required to pay for all of the same services to the same degree as commercial insurance? What will be the impact be on the EUTF?

Who can provide the service- The bill limits the ability of health plans to contract with providers based on the needs of their patients and the availability of providers by requiring that insurers not contract with more licensed psychologists than board certified behavior analysts.

Appropriate diagnosis- The bill does not permit a health care provider to diagnose a patient using the most current diagnostic information available in the DSM-V but instead requires that any individual diagnosed at any time with autism spectrum disorder not be reevaluated based on update critieria under any circumstances.

Definitions - Autism Spectrum Disorder-the term “pervasive developmental disorders” is not used in the most current Diagnostic and Statistical Manual of Mental Disorders. Individuals previously so diagnosed now are diagnosed as having autism spectrum disorder.

Autism Service provider-places no professional requirements on who may provide services. There is no certification or licensure requirement.

These are serious matters that need to be addressed and corrected. We urge the committee to hold this bill and consider instead SB 2578 which corrects these problems.

Thank you for your consideration.



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

January 27, 2014

TO: Senator Green and Senator Baker

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,

The Autism Society of Hawaii (ASH) **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.

ASH **suggests:**

1) increasing the age from 21 to age 26

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 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.



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www.autismhi.org (808) 394-7320 autismhi@gmail.com

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,

William Bolman
President

From: mailinglist@capitol.hawaii.gov
To: [HTHTestimony](#)
Cc: robertscottwall@yahoo.com
Subject: Submitted testimony for SB2054 on Jan 28, 2014 08:30AM
Date: Monday, January 27, 2014 7:39:09 PM

SB2054

Submitted on: 1/27/2014

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

Submitted By	Organization	Testifier Position	Present at Hearing
Scott Wall	Community Alliance for Mental Health	Support	No

Comments: to: Senate Health and Consumer Protection committees Aloha Sen.'s Baker, Green, and the members of their committees, On behalf of the Consumer Alliance for Mental Health along with United Self Help offer our support for SB2054. We feel that the Autism Spectrum deserves the respect and support that the rest of Mental Health received from the ACA. Scott Wall VP/Legislative Advocate Community Alliance for Mental Health

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

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COMMUNITY CHILDREN'S COUNCIL OF HAWAII
1177 Alakea Street • B-100 • Honolulu • HI • 96813
TEL: (808) 586-5363 • TOLL FREE: 1-800-437-8641 • FAX: (808) 586-5366

January 27, 2014

Senator Josh Green, Chair
Senator Rosalyn H. Baker, Vice-Chair
Chairs of the Health Committee – State Capitol

RE: SB2054 – Relating to Health

Health; Insurance; Mandatory Health Coverage; Autism Spectrum Disorders (ASD)

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

The 17 Community Children's Councils (CCCs) **strongly support** SB2054. We agree that children with ASD benefit academically, socially and behaviorally from early diagnosis and treatment utilizing evidence-based interventions, such as applied behavior analysis. The 17 Community Children's Councils (CCCs) have been involved for the past several years in providing input to the development of this bill. We firmly urge the passage of this bill.

The 17 Community Children's Councils (CCCs) are community-based bodies comprised of parents, professionals in both public and private agencies and other interested persons who are concerned with specialized services provided to Hawaii's students. Membership is diverse, voluntary and advisory in nature. The CCCs are in rural and urban communities organized around the Complexes in the Department of Education.

Thank you for the opportunity to testify if there are any questions or you need further information please contact us at 586-5370

Sincerely yours

Tom Smith, Co-Chair

Jessica Wong-Sumida, Co-Chair

(Original signatures are on file with the CCCO)

UNITE HERE!

LOCAL 5 HAWAII

Eric Gill, Financial Secretary-Treasurer

Hernando Ramos Tan, President

Godfrey Maeshiro, Senior Vice-President

January 27, 2014

Sen. Josh Green, Chair, Committee on Health
Sen. Rosalyn Baker, Chair, Committee on Commerce and Consumer Protection and
Vice Chair, Committee on Health
Sen. Brian Taniguchi, Vice Chair, Committee on Commerce and Consumer Protection

Members of the Committee on Health
Members of the Committee on Commerce and Consumer Protection

Re: Testimony in support of re: SB 2054

Chairs Green and Baker and Committee Members:

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

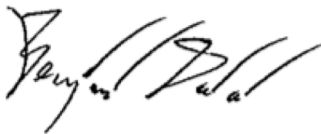
Over the last several months, Local 5 members have spoken with one another and with members of the community about the need to pass this bill. We have gone out into our communities and talked to our neighbors about it. In a short time, we have gathered over 700 signatures from those who support coverage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

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

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

Please pass SB 2054.

Sincerely,



Benjamin Sadoski
UNITE HERE, Local 5



HILOPA'A

Family to Family Health Information Center

Date: January 27, 2014

To: COMMITTEE ON HEALTH
Senator Josh Green, Chair
Senator Rosalyn H. Baker, Vice Chair

To: COMMITTEE ON CONSUMER PROTECTION
Senator Rosalyn H. Baker, Chair
Senator Brian T. Taniguichi, Vice Chair

Fr: Leolinda Parlin, State Coordinator for Family Voices of Hawai'i

Re: **Support the Intent** – SB 2054 – RELATING TO HEALTH

On behalf of Family Voices of Hawai'i, I support the intent of SB 2054 and offer comments for consideration. Family Voices/Hilopa'a Family to Family Health Information Center continues to support mandated coverage for services to individuals within the Autism Spectrum. There are 4 Autism related measures between the House and the Senate, in addition to the drafts in Conference Committee. I will summarize my recommendations based up the language of each bill.

Section 3(j) – Background Check

Consider as stated in SB 2578 a uniform guideline for background check requirements and guidelines. SB 2578 references Med-QUEST requirements for direct support workers.

Section 5 – Benefits and Coverage

Autism screening and well child visits are already a part of the Affordable Care Act and apply to plans inside as well as outside of the exchange, as it is part of the Preventive benefit requirement.

We look forward to working together on developing a final measure across all of the chambers and stake holder groups.

Thank you for your time and consideration.

Dear Senators Green and Baker,

My name is Anne Lau and I direct a clinic for children with autism with ABC Group. I am writing to you because I want to talk about **SB2054 / Luke's Law** and how it will benefit children and families with autism.

I started working in this field 10 years ago. I was hired by a woman who had gotten Applied Behavior Analysis (ABA) services for her child by suing the Windward school district for many years. Her son had learned how to talk and was, at that time, back in public school in a general education class. She worked with other families to get intensive services for their children- in the only way that seemed possible, by suing school districts.

I saw hundreds of families come through our center- they cashed in their savings to pay for treatment during the administrative hearings. Families went into battle with school districts, who became the apparent enemy- for in fact, they could not provide the intensive ABA program that would help these children. I read testimony of teachers lying, made-up data, schools and parents attacking each other and forever ruining their relationships.

The children in our clinic were all receiving 40 hours per week of ABA treatment. This was the number of hours that had been shown in multiple scientific studies to produce the best outcomes for children with autism. Out of the hundreds of children that I worked with, 90% were not able to maintain services for much more than one year. There were three children that I can remember who were under 5 years old when treatment started and received treatment for over three years. Two of these children benefited enough to go back to public school in general education classes. These families felt that their children had been recovered. While that is a controversial word, I personally also agree.

In the present day, I primarily work with military families- because they have insurance coverage and can receive ABA services without creating enemies at school. It is still very clear however that schools are not providing what is needed.

I hope with this bill, children will be able to receive the treatment they need.

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

Respectfully,

Anne Lau, M.Ed. NCC, BCBA

(808) 393-7206

Our son was diagnosed at the age of two and a half with Autism Spectrum Disorder (ASD). Since then our family has endured struggles that may have been avoided had we have been given additional and autism specific medical treatments. Upon his initial diagnosis we immediately started in home therapy, due to the fact that free state services (HKISS and Easter Seals) were only provided until age three. Once he turned three we were transitioned to the local school system hoping that he would get extensive service, only to find that since Autism isn't formally recognized as a disability, our son would only be receiving mild speech therapy. In the years since we've had several altercations at home and school that we strongly agree could have been avoided if our son had been given the proper medical attention. There are various behaviours and medical conditions that are directly related to (ASD), in our case I think lack of communication and delay in social emotional skills had the most profound effect on our family, and are not easily treated without Autism specific therapy. During his first year at preschool our son was not only lost on several occasions, but suffered a mild concussion from a fall on the playground, which was misdiagnosed due to his inability to communicate. Additionally for almost two years he suffered from sleep apnea, experiencing ten respiratory obstruction episodes every hour. This was also misdiagnosed as sleep anxiety which was said to be a typical for those with Autism Spectrum Disorder, but later turned out to be a severe case of sleep apnea due to respiratory obstruction. During our family's two year journey in figuring out what was causing our child to wake screaming from his sleep ten to fifteen times per night, we were instructed by his pediatrician to continue to give him blood pressure medication to lower his heart rate which would in turn help him relax. It wasn't until the medicine no longer continued to work, we were referred to a sleep specialist. Even then, because his lack of communication it took another six months of testing and after we refused to give our then 4 year old a childrens trial dosage of xanax, it was discovered he had sleep apnea. Today after three and a half years of board of education services our little guy is now six years old and in kindergarden. Although he has made some progress in many areas, his development is still significantly stunted. He mainly functions on a level equivalent to a 18-36 month old. My family and I are certain that if he had been given Autism specific therapy instead of targeting individual behaviors he would be further along in his developmental progression. As with any child there is a window of opportunity for growth and development, but without the necessary tools it is impossible to make substantial progress. I strongly believe autism specific therapy funded by medical insurance is the only way individuals and families impacted by autism will ever be able to attain life changing services that are desperately needed. My family and I strongly support SB.2054 in favor of insurance companies to provide funding for autism specific therapy.

January 27, 2014

House Committee on Finance
SB 2054 Relating to Health

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

Thank you for the opportunity to testify on SB 2054. My name is Brandon Letoto and I am in strong support of this measure.

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 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 50 American children. That number shows a steep increase from 1 in 88 just last year. With your help these children can be given the opportunities that they deserve.

Having a child with autism is very challenging and the cost of medical care and therapies is just one of the many hurdles that families must overcome. Currently 34 other states have Insurance Mandates for Autism Spectrum Disorder and Hawai'i effected children are long overdue for some relief. By passing this bill, you will help ease some of the financial struggles that these children and their families face and provide a brighter future for tomorrow.

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

From: mailinglist@capitol.hawaii.gov
To: [HTHTestimony](#)
Cc: jflash007@gmail.com
Subject: Submitted testimony for SB2054 on Jan 28, 2014 08:30AM
Date: Tuesday, January 28, 2014 10:41:47 AM

SB2054

Submitted on: 1/28/2014

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

Submitted By	Organization	Testifier Position	Present at Hearing
Jack Little	Individual	Support	No

Comments: Aloha, I am a parent of a 10 year old boy with Autism. We have had many problems with insurance coverage for my son's Autism needs even though I work for the State and have family HMSA PPO health insurance. Please support meaningful autism insurance reform Please support SB.2054 with the amendments proposed by Autism Speaks. Thanks, Jack Little

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

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

Jerry Bump
3248 Lamaloa Place
Honolulu, HI 96816

January 27, 2014

Senate Committees on Health and Commerce & Consumer Protection

Hearing: January 28, 2014, 8:30 a.m., Conference Room 229

Re: Testimony in Strong Support of SB 2054 – Relating to Health

Dear Chairs Green and Baker and Members of the Committees,

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

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 my wife and I do not feel they are staffed and funded to provide the proper therapies my son needed.

My son is now six years old and we have spent thousands of dollars for speech, medical, and behavioral therapies not covered by our health insurer. The therapies we have been able to provide has been helpful, but so much more was needed for our son during these early years.

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.

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

Mahalo,
Jerry Bump

Aloha Members of the Luke's Law Committee,

Thank you for your time today to consider this important piece of legislation. I am a practicing Board Certified Behavior Analyst on Maui and I highly support this bill. Research tells us that ABA is the only demonstrated therapy that makes significant and positive changes in the treatment of autism. Higher efficacy of treatment leads to more positive outcomes for the individual children and their families, as well as our community. States that have passed similar legislation see an increase in children with autism who have the opportunity to receive quality, ABA early intervention are successful in the general education, which gives them the opportunity to learn with their peers and ultimately contribute successfully in academic and vocational opportunities.

I have been told that a concern with this bill is that there are not enough BCBA practitioners in the state to support the requirements of the bill. I have been in positions to hire BCBA's in Hawaii for the past 5 years, I can assure the committee that there is a waiting list for BCBA's to move to this state. The hindrance for them to come is the lack of jobs. Passing legislation like Luke's Law would certainly bring more of these professionals to work with families and children in need.

Thank you for your time,

Rachel Huckfeldt, M.S., BCBA

**Testimony to the Senate Committee on Health and Committee on Commerce
and Consumer Protection
Tuesday, January 28, 2014 at 8:30 A.M.
Conference Room 229, State Capitol**

RE: SENATE BILL 2054 RELATING TO HEALTH

Chairs Green and Baker, Vice Chairs Baker and Taniguchi, and Members of the Committees:

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

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

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

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

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

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

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

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

Dear Senators Green and Baker,

My name is Taffy Perucci and I am deeply concerned about families that most need help cannot access it. I am writing to you because I want to talk about SB2054 / Luke's Law and how it will benefit children and families with autism.

In 2000 I graduated from the University of California San Diego ready to take on the world. A job that would change my life soon found me and I started a career in helping children by taking a position as a teacher's assistant in a special school for behaviorally disordered children in San Diego. While there, I learned how to work with children, decreasing the behaviors that impacted their lives through the use of Applied Behavior Analysis (ABA). At the time, I didn't know the value of the training I was receiving, but every day I knew that I was fortunate.

During my time at that school, I entered graduate school and eventually completed my Master's degree in School Psychology. I studied how children learn and how that learning can be greatly impacted through developmental and environmental influences. In my studies I learned how to provide needed supports for their learning and modifications to their work as well as teaching teachers how to do the same. I had worked in Hawaii for the Department of Education in Central District as a School Psychologist. I left that career of almost 10 years after it became clear that the children and teachers that needed help the most, simply could not get it. The level of behavioral support in the educational setting is to maintain the child's safety, minimize the behaviors and to the greatest extent possible, get them to pass high stakes tests like HSA so that Antiquate Yearly Progress (AYP) could be made and the school would maintain its standing. Skills however that are not taught as part of HSA are daily living skills like brushing teeth, bathing, doing laundry, preparing food. Skills like learning to work in a group, learning how to apologize, show interest in others and how to make friends, was not taught. Education and school were for reading, writing and arithmetic and those that couldn't keep up with common core, just fell further behind.

So this past spring, when I was offered the opportunity to lead a new business and open an autism center, I jumped at the chance. Here I was, 13 years into my career in working with children, and having almost completed my coursework to become a Board Certified Behavior Analyst (BCBA), and this opportunity found me. After all I had seen, I was steed fast in creating a place that families could heal, hope was found and as our name says, to 'take good care' of our families. At the Malama Pono Autism Center we have given families hope, that had lost hope. Parents that were told that their child would never have meaningful friendships have found that it can happen with the right treatment (ABA). With our motivated and well trained staff, we see every day that children who were once thought to be a burden, and children who had such low expectations of themselves and others have made progress. Meaningful progress that can be tracked through the behavioral sciences. Unlike other fields of counseling or even my own previous one as a School Psychologist, behavior analytic work is hard science that can be measured, replicated,, tested and

used to make meaningful treatment decisions to change lives.

We have one child in particular that has been with us since we opened. He was 28 months when we started and he used no words, minimal sounds, no gestures and he cried as a way to communicate. Last week, I saw him in the center and he can say 'hi', 'ball', 'mom' and 48 more words or gestures were in his chart. His mom has on a regular basis cried because she was hopeless before we started treatment. Another parent, whose husband is deployed sent an urgent email to me at 7:30 at night. I called her knowing something was going on. She was in her car, in her garage at a loss with how to manage her 11 year old child with Autism. That mother had a lifeline to reach out to. She has a team of professionals that can support that family through the road ahead. But these families shouldn't be the only ones.

I had the opportunity to be a professional Co-Chair for the Children's Community Council (CCC), which is part of the Department of Education, and we meet monthly to share resources and try to support the community. A few months ago a mother came to the meeting and she brought her 5 year old son with Autism. She held him in her lap while he played with her phone, flickered his hands in front of his face and made odd noises. This mother had recently moved to Mililani and wanted to know where she could get more help. She needed more help at home and had been recently divorced and was clearly stressed and overwhelmed. In that meeting, was the current principle of a special school that is only given when parents file due process, the branch chief for department of health and a staff member who works with the complex assistant superintendent. This mother only learned at that meeting that the department of health had no help as they do not 'cover Autism' and the special school was not available as she would have to sue the DOE first. Then she learned from Malama Pono that she did not have the right insurance card nor could she afford treatment. Her child, who needed specialized treatment could not access it because they were not military who are the only ones on island with a medical plan that covers ABA. That boy is no different than the one who came to us not speaking. His mother is no different from the mother that reached out to her lifeline while still in her garage and needed hope that the baby steps were in the right direction.

I think kids with autism should have ABA services. Hope is possible for all families if Hawaii passes Luke's Law. With ABA, all children in Hawai'i can be a success story.

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

Respectfully,

Taffy Perucci, MS
Clinical Director of Malama Pono Autism Center
Mother of two children who could have been that 1 in 88 children with Autism.
808-226-1155
Taffyp@mpautism.org