NEIL ABERCROMBIE GOVERNOR OF HAWAII



STATE OF HAWAII DEPARTMENT OF HEALTH P.O. Box 3378 HONOLULU, HAWAII 96801-3378 GARY L. GILL ACTING DIRECTOR OF HEALTH

> in reply, please refer to: File:

Senate Committees on Health and Commerce and Consumer Protection

S.B. 2578, Relating to Health

Testimony of Gary L. Gill Acting Director of Health

January 28, 2014

Department's Position: The Department of Health supports the intent of S.B. 2578 to require health insurance to provide coverage for behavioral health treatment of autism spectrum disorders (ASD) when it is prescribed by an individual's physician and provided by trained professionals. This treatment shall be covered by health insurance up to the age of six.

5 **Fiscal Implications:** None to the Department.

6 **Purpose and Justification:**

S.B. 2578 amends Chapter 431, Hawaii Revised Statutes by providing a new section to article 10A to
provide benefits and coverage to insureds under six years of age diagnosed with an ASD coverage for
treatment of autism spectrum disorders.

The Department appreciates the importance of early diagnosis and treatment for ASD. This bill will allow best practice, evidence-based treatments such as Applied Behavioral Analysis (ABA) that has been shown to improve socialization and language of people, especially children with ASD. Treatment of ASD at an early age using ABA and/or other treatments will increase the opportunity for children and teens to develop the skills and functioning needed for adult life. Improved outcomes may lessen the

15 need for long-term supports when children with autism become adults.

Promoting Lifelong Health & Wellness

According to the U.S. Centers for Disease Control and Prevention, about 1 in 88 children have been
 identified with ASD. Research shows that early treatment services can greatly improve a child's
 development. Increasing the access of individuals to appropriate services, including through private

4 health insurance, will contribute to improved outcomes for individuals with ASD.

5 Thank you for this opportunity to testify.



PATRICIA MCMANAMAN DIRECTOR

BARBARA A. YAMASHITA DEPUTY DIRECTOR

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. 2578 - RELATING TO HEALTH Hearing: Tuesday, January 28, 2014; 8:30 a.m.

Conference Room 229, State Capitol

<u>PURPOSE</u>: 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 for children up to the age of 6 years.

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 \$132 million to serve children up to 6 years of age, of which \$24.3 million would be the DHS' cost, including federal funds.

The Department of Human Services conducted a study, between the 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 AN EQUAL OPPORTUNITY AGENCY 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 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.

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

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

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

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

*** Additional funding may not be necessary if these programs already cover the service

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

Evidence-based experts would disagree that ABA is evidence-based because there is not

good quality evidence of effectiveness.

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

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

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

2. Treatment

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

3. Projection Assumptions

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

- 3.3. Focused ABA services would be made available 8-19
 - 3.3.1.Literature indicates service provision should be individualized and made available
 - 3.3.2. For this exercise, the following tiered structure is proposed to be able to make some assumptions
 - 3.3.2.1. Preventive Planning and Intervention
 - 3.3.2.1.1. Preventive Planning and Intervention would be provided to identify early emerging problems as well as anticipated intervention needs to "pre-plan" for upcoming events which would require skilled intervention (e.g., preparing for puberty, etc.)
 - 3.3.2.1.2. Prevention Planning and Intervention would be made available at the following regularly scheduled intervals
 - 3.3.2.1.2.1. Age 7 (i.e., for children not already receiving comprehensive intensive ABA)
 - 3.3.2.1.2.2. Age 10
 - 3.3.2.1.2.3. Pre-puberty (i.e., could identify a stage in puberty, Stage 2)
 - 3.3.2.1.2.4. Age 14
 - 3.3.2.1.2.5. Age 16
 - 3.3.2.1.2.6. Age 19-20
 - 3.3.2.2. Targeted Assessment and Treatment
 - 3.3.2.2.1. Targeted Assessment and Treatment would utilized on an as need basis to address behaviors that affect health and safety of the individuals or others (e.g., aggression, 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.El serve numbers are included in the estimate
 - 4.1.3.EI ABA services should be included to the matrix to draw down federal dollars
 - 4.1.4. There should not be a need to provide more hours beyond what is provided by EI
- 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

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- 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.		527	648	621														
Delay																		
EIABA	224																	
Services																		
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

		Comp	rehensive I	ntensive A	ABA Services	3		
Age	# of Projected Medicaid Children	Service	Hours per child per week	Weeks per year	Total Hours for all	% DOH/ EI	% SPE D	Total Hours Not Carved Out: DHS
0-3	105	Direct Service	30	40	126,336	100%		0
		Supervision	3	40	12,633			0
		Direct Service	30	40	1,374,000			274,800
3-6	1,145	Supervision	3	40	137,400		80%	27,480
50	1,140	Assessment	3	10	34,350		0070	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

Age	# of Projected Medicaid Children	Compi Service	rehensive I Hours per child per week	ntensive A Weeks per year	ABA Services Total Hours for all	3 % DOH/ EI	% SPE D	Total Hours Not Carved Out: DHS
		Assessment & Parent Training	1	9/mo	2,196			439

		Focused ABA Serv	vices		
Age	# of Projected Medicaid Children	Service	Hours per child per cycle	% SPED	Total Hours Not Carved Out: DHS
		Direct Service	120	80%	1,392
7	58	Supervision	12	80%	139
1	50	Assessment & Parent Training	30	20%	1,392
10	43	Direct Service	120	80%	1,032
		Supervision	12	80%	103
		Assessment & Parent Training	30	20%	1,032
14	40	Direct Service	120	80%	960
		Supervision	12	80%	96
		Assessment & Parent Training	30	20%	960
16	31	Direct Service	120	80%	744
		Supervision	12	80%	74
		Assessment & Parent Training	30	20%	744
19	12	Direct Service	120	80%	288
		Supervision	12	80%	29
		Assessment & Parent Training	30	20%	288

Step 3: Apply other factors against the base

Other factors could include:

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



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

<u>RE:</u> SENATE BILL 2578 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 2578 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 tens of millions of dollars per year if not more for both government and 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.

We are sympathetic to the many families dealing with this issue. 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.



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,

Cabral

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

J. Curtis Tyler III Chair



Government Relations

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 2578 RELATING TO HEALTH

Chair Green, Chair Baker, and committee members, thank you for this opportunity to provide testimony on SB 2578 which would provide insurance coverage for people with autism spectrum disorders for behavioral health treatment.

Kaiser Permanente Hawaii supports this measure.

This bill addresses the concerns we have expressed with other mandates for treatment of autism spectrum disorder that have been heard and considered by the legislature. This proposal focuses on providing coverage for services that are not otherwise covered or provided. It also focusses 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 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 show that the ABA utilization and therefore costs peak at age 5. From there utilization falls off dramatically through age 8 when it drops to almost no usage. This bill proposes to have health insurance pay for coverage up to age 6 when individuals

711 Kapiolani Blvd Honolulu, Hawaii 96813 Telephone: 808-432-5210 Facsimile: 808-432-5906 Mobile: 808-754-7007 E-mail: phyllis.dendle@kp.org become eligible for services through the Department of Education.

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

We urge the legislature to move forward this version of the mandate for continued discussion.

Thank you for your consideration.

From:	mailinglist@capitol.hawaii.gov
To:	HTHTestimony
Cc:	autismhi@gmail.com
Subject:	Submitted testimony for SB2578 on Jan 28, 2014 08:30AM
Date:	Monday, January 27, 2014 9:37:03 AM
Attachments:	ASH Testimony SB2578.docx

<u>SB2578</u>

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
Jessica Wong-Sumida	Autism Society of Hawaii	Comments Only	Yes

Comments: William Bolman

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

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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: SB2578 - RELATING TO HEALTH

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

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

The Autism Society of Hawaii (ASH) supports the intent of the bill SB2578, 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 of treatment from 6 to 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.

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

<u>Fact 2:</u> In addition to the dramatic increase in cases, combined with our ignorance of the causes and the degree of impairment autism causes, we are looking at a dramatic rise in the costs of life-long care for those affected by autism. The best estimate of the lifetime costs of autism (done by the Harvard School of Public Health) is \$3.2 million per person. If we take a conservative underestimate of just the number of young people I have seen who are likely to meet this cost due to the inadequacy of treatment (about 100), the cost will be 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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<u>Fact 3:</u> This worrisome increase in the autism is mostly a new social condition - what we know about the symptoms and causes show that society has not faced this condition before, which is why we are so unprepared. Because of this there has been a dramatic increase in research by the federal government and many private groups such as Autism Speaks. As a physician who formerly treated polio and childhood leukemia, I am thrilled at the wonderful advances this research has produced in the neuroscience of autism, and look forward to its eventual control. However promising this sounds, we are still stuck with an unknown number of years of an extremely expensive condition.

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

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

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

Thank you for considering our testimony,

William Bolman President



S E A C Special Education Advisory Council 919 Ala Moana Blvd., Room 101 Honolulu, HI 96814 Phone: 586-8126 Fax: 586-8129 email: spin@doh.hawaii.gov

January 27, 2014

Senator Josh Green, M.D., Chair Senate Committee on Health Senator Rosalyn Baker, Chair Senate Committee on Commerce and Consumer Protection State Capitol Honolulu, HI 96813

RE: SB 2578 - RELATING TO HEALTH

Dear Chairs Green and Baker and Members of the Committees,

The Special Education Advisory Council (SEAC), Hawaii's State Advisory Panel under the Individuals with Disabilities Education Act (IDEA), **supports** SB 2578 with reservations.

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. We are very aware that the early identification and amelioration of the complex communication, social and behavioral needs of these children has a significantly positive impact on academic and behavioral goals.

SEAC has also been active in the last three years with a variety of key stakeholders who have collectively acknowledged the critical need for mandated insurance coverage to identify children with Autism Spectrum Disorders and provide timely and evidenced-based interventions to improve their health, academic and life outcomes. The consensus of the majority of these stakeholders is that evidence-based treatments for individuals with autism spectrum disorders is medically necessarily beyond six years of age. Therefore, we encourage further discussion at the earliest opportunity to resolve any differences prior to the end of the session. The time to act is now.

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

Respectfully,

when Suuren

Ivalee Sinclair, Chair Mandated by the Individuals with Disabilities Education Act

Special Education Advisory Council

Ms. Ivalee Sinclair, *Chair* Ms. Martha Guinan. *Vice Chair*

Ms. Brendelyn Ancheta Dr. Tammy Bopp Dr. Robert Campbell Ms. Deborah Cheeseman Ms. Annette Cooper Ms. Shari Dela Cuadra-Larsen, liaison to the Superintendent Ms. Jenny Gong Ms. Gabriele Finn Ms. Tami Ho Ms. Barbara Ioli Ms. Valerie Johnson Ms. Deborah Kobayakawa Ms. Bernadette Lane Ms. Shanelle Lum Ms. Dale Matsuura Ms. Stacey Oshio Ms. Zaidarene Place Mr. Kenneth Powell Ms. Barbara Pretty Ms. Kau'i Rezentes Ms. Melissa Rosen Dr. Patricia Sheehey Mr. Tom Smith Ms. Lani Solomona Dr. Daniel Ulrich Ms. Amy Weich Ms. Cari White Ms. Susan Wood

Jan Tateishi, Staff Susan Rocco, Staff



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: SB2578 - Relating to Health

Health; Insurance; Mandatory Health Coverage; Behavioral Health Treatment; Autism Spectrum Disorders (ASD). Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for treatment of autism spectrum disorders.

The 17 Community Children's Councils (CCCs) **support with reservation** SB2578. We agree that children with ASD benefit both academically, socially and behaviorally from early diagnosis and treatment utilizing evidence-based interventions, such as applied behavior analysis. These interventions are medically necessary for students with ASD beyond age six. Need more discussion to resolve the differences between SB2578 and SB2054. Empirical data needs to be collected immediately to support the determination of the appropriate age range for providing these services.

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 testimony 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)

From:	mailinglist@capitol.hawaii.gov
To:	HTHTestimony
Cc:	robertscottwall@yahoo.com
Subject:	Submitted testimony for SB2578 on Jan 28, 2014 08:30AM
Date:	Monday, January 27, 2014 7:35:33 PM

<u>SB2578</u>

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 & Consumer Protection Committees Alohs Sen.'s Green, Baker, and members of their committees, On behalf of the Community Alliance for Mental Health along with United Self Help we offer our support for SB2578. We feel that it is time that the Autism Spectrum of disorders received the coverage it deserves. Scott Wall VP/Legislative Advocate Community Alliance for Mental Health

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

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January 27, 2014

House Committee on Finance SB 2578 Relating to Health

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

Thank you for the opportunity to testify on SB 2578. My name is Brandon Letoto and I am in strong opposition of this bill.

I strongly oppose this measure. As a father of a six year old autistic child, i do not agree that the age cap of 6 years old is adequate. The age cap should be extended well into early adulthood to help care for these children and young adults' health. "Healthcare" should put a reasonable age limit on treatment of individuals. I strongly feel that having an age limit of 6 is unreasonable.

My wife and I have been paying out of pocket for medical expenses since my son was diagnosed with Autism Spectrum Disorder at the age of 2. These expenses include Physician visits, labs, meds, speech therapy, etc. This has put a huge financial burden on our family. Although my son is 6 and has experienced many gains we have a long road ahead of us, and will be traveling this road well past this year at his current age of 6.

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:	autismhi@gmail.com
Subject:	Submitted testimony for SB2578 on Jan 28, 2014 08:30AM
Date:	Monday, January 27, 2014 9:59:32 AM
Attachments:	HBH Testimony SB2578.doc

<u>SB2578</u>

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
Jessica Wong-Sumida	Individual	Comments Only	No

Comments: Carla Gross

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Hawaii Behavioral Health

January 27, 2014

TO: Senator Green and Senator Baker

RE: SB2578- 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 intent of bill SB2578, which provides for treatment of autism spectrum disorder through speech therapy, occupational therapy, and physical therapy, and applied behavior analysis. HBH suggests **increasing** the age from 21 to age 26.

HBH is a statewide leader in the provision of educational, behavioral health, and social services in Hawaii and provides a statewide system of integrated services to improve the educational, health, and safety outcomes for Hawaii's youth and families through innovative, community based, culturally competent and empirically supported programs.

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

<u>COMMITTEE ON HEALTH</u> Senator Josh Green, Chair Senstor Rosalyn H. Baker, Vice Chair

COMMITTEE ON CONSUMER PROTECTION AND COMMERCE

Senator Rosalyn H. Baker Chair Senator Brian T. Taniguchi, Vice Chair

Gabrielle D. Toloza, Psy.D. 40 Aulike St #411 Kailua, HI 96734

January 26, 2014

In regards to SB2578 and SB2054 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 strong favor of both of these bills as they address a very real and serious need for coverage that private insurers should provide.

SB2578 emphasizes the need for these services for children under the age of 6. There is ample research based evidence that supports the use of intensive behaviorally based treatment programs as an early intervention is efficacious; and that children can make notable gains in functional communication, self-regulation that can impact them as learners in there future years.

SB2054 emphasizes the need for services for individuals under the age of 21. This is equally essential, the needs of children and young adults on the spectrum persist through their lifespan, but with continued intensive behavioral interventions the severity of impact on an individual and their family, and ultimately society, can be notably reduced.

I have a very strong connection to the autism community. Since 2000 I have worked in some capacity as a 1:1 support person, behavioral specialist, behavioral consultant in schools and homes and most recently as a mental health professional in private practice. I am the founder of Creative Connections Foundation, a small non-profit established in 2009 that aims to improve the social, emotional and behavioral functioning of youth and adults affected by Autism and other neurodevelopmental conditions. I am also in private practice as co-owner of Hawaii Center for children and Families, where I perform psychoeducational evaluations and develop in-home behaviorally based programs for children with Autism and related conditions; as well as provide individual, group and family therapy to the individual and families affected by Autism. Some of these services cost money and are not commonly covered by insurers, yet they are necessary and effective at improving the current and future functioning of children with Autism.

Availability and access to quality programs outside of the public education system are limited, but more importantly they are costly due to the intensity and duration that is commonly needed to make improvements. Necessary supports and interventions that are proven effective must be sought and paid for privately by parents. Families with limited income are not able to afford these quality programs and therefore experience limited progress for their children and teens. This legislation would help to increase access to care for individuals under 21 who previously may not have received adequate support.

A common argument is that children's needs should be serviced within the school system, I personally believe that this is not only impossible but an unfair expectation on our educators.

There is ample research to support the need for intensive behaviorally based programs that are team based and comprehensive in nature, thereby including the home and community environment. Without the funding such as this legislation would provide, families are left to rely solely on the school system or pay out of pocket a tremendous amount and the school systems are left bearing a responsibility much larger than intended. Sharing the responsibility with private insurance and allowing trained professionals with sufficient experience and training the ability to properly service these clients is the logical choice.

The only concern these bills raise for me as a professional in the field is that the

Thank you for the opportunity to share my perspective

Sincerely

Gabrielle Toloza, Psy.D.

<u>SB2578</u>

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	Oppose	No

Comments: Please oppose SB2578 because: it does NOT offer meaningful autism insurance reform -- coverage would be capped at age 6; it would trigger a significant cost to the State; and it does not acknowledge Hawai'i stakeholder concerns raised on this issue last year Please support SB.2054 with the amendments proposed by Autism Speaks instead of this bill. Thanks, Jack Little

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<u>COMMITTEE ON HEALTH</u> SEN. JOSH GREEN, CHAIR SEN. ROSALYN H. BAKER, VICE CHAIR

COMMITTEE ON COMMERCE AND CONSUMER PROTECTION SEN. ROSALYN H. BAKER, CHAIR

SEN. BRIAN T. TANIGUCHI, VICE CHAIR

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

Monday, Janurary 27, 2014

SB2578 emphasizes the need for these services for children under the age of 6. There is ample empirical evidence that supports the use of intensive, behaviorally-based early intervention programs are efficacious; and that children can make notable gains in functional communication and self-regulation that can impact them as learners in their future years.

SB2054 emphasizes the need for services for individuals under the age of 21. This is equally essential, the needs of children and young adults on the spectrum persist through their lifespan, but with continued intensive behavioral interventions the severity of impact on an individual and their family, and ultimately society, can be notably reduced.

In regards to **SBs 2578 and 2054** that require health insurers, mutual benefit societies, and health maintenance organizations to provide health care coverage and benefits for autism spectrum disorders, <u>I am **in support**</u> of these bills as they address a serious need for coverage that private insurers should bear.

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

While I strongly support the intent of the measure, I am a little reticent to give a wholehearted endorsement as I am concerned with the scope of services granted to Board Certified Behavior Analysts given they are not licensed in the State of Hawaii and therefore would not be held accountable to the same degree as other providers who are licensed in the State. I would like there to be minimum requirements regarding training in the use of Applied Behavior Analysis and that providers be licensed in the State of Hawai'i. BCBAs should be able to provide services, but for the purpose of consumer protection, they should be under the supervision of a licensed psychologist or psychiatrist specializing in assessment and treatment of Autism Spectrum Disorders.

The reasons for this are twofold; if for some reason there is a complaint, there would be no recourse for consumers except through their insurance companies. Second, while competent and highly trained, BCBAs do not have the wider view of ASDs that doctoral level providers have.

Let's look at that more closely. Treatment of ASD is not just about the child, it's about the child in all of his/her contexts, including home (family), school, community, and peer group. In addition, it's about the child receiving team-based services from interdisciplinary teams, including but not limited to parents, teachers, occupational therapists, speech therapists, psychologists, psychiatrists, behavioral support specialists (e.g., BCBAs), parent/family advocates, skills trainers, and sometimes other family members, nutritionists, pediatricians, and audiologists. As a former MCH-LEND trainee (I received two certificates in maternal child health and neurodevelopmental disabilities while earning my Ph.D. in clinical psychology at the University of Hawaii), and as a current faculty mentor with the MCH-LEND program, I am acutely aware of the importance of interdisciplinary skills and understanding to provide the most appropriate and comprehensive treatment to children with ASD. In addition, I am acutely aware of the need to consider culture and diversity, comorbidity, and family resources as moderators of outcome. BCBAs do not have the training necessary to adopt these wider viewpoints, relying instead on a micro-analysis and fine-grained treatment approach, which, while demonstrably effective, should be supervised by someone with a broader, transdisciplinary, diversity-minded perspective. Simply put, the wording of the bill seems to put BCBAs in the position of "team leader," supervising others in the treatment of children and adolescents with ASD. They have neither the training nor the expertise to assume leadership and oversight of treatment beyond applied behavior analysis.

As for licensing, I believe BCBAs should be held to the same level of accountability as other professionals in the field, including psychologists, psychiatrists, clinical social workers, mental health counselors, and marriage and family therapists, if they wish to be eligible for 3rd party reimbursement (i.e., insurance companies). It seems the bills allow BCBAs to circumvent the law that governs other professionals with considerably more education (including terminal degrees in their fields).

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