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TO THE HOUSE COMMITTEE ON CONSUMER PROTECTION & COMMERCE

TWENTY-SEVENTH LEGISLATURE
Regular Session of 2014

Monday, February 10, 2014
5:00 p.m.

TESTIMONY ON HOUSE BILL NO. 2174, H.D. 1 – RELATING TO HEALTH.

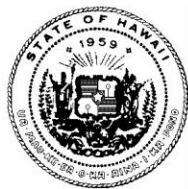
TO THE HONORABLE ANGUS L.K. McKELVEY, CHAIR, AND MEMBERS OF THE COMMITTEE:

My name is Gordon Ito, State Insurance Commissioner, testifying on behalf of the Department of Commerce and Consumer Affairs (“Department”). The Department takes no position on the bill, and submits the following comments:

This bill adds a new mandated health insurance benefit requiring health insurers, mutual benefit societies, and health maintenance organizations to cover the treatment of autism spectrum disorders.

Adding a new mandated coverage may trigger section 1311(d)(3) of the ACA, which requires states to defray the additional cost of benefits that exceed the essential health benefits in the state’s qualified health plan.

We thank the Committee for the opportunity to present testimony on this matter.



STATE OF HAWAII
DEPARTMENT OF HUMAN SERVICES

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

February 11, 2014, 2014

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

FROM: Patricia McManaman, Director

SUBJECT: **H.B. 2174, H.D. 1 - RELATING TO HEALTH**

Hearing: Monday, February 10, 2014; 5:00 p.m.
Conference Room 325, State Capitol

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

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

Even though this measure purports to exempt Medicaid plans from providing services for autism spectrum disorders required by this bill, once these services are established as the standard of care, these standards will trigger the application of these services to Medicaid eligible children under the Early & Periodic Screening, Diagnosis & Treatment (EPSDT)

requirements for the more than 100,000 children in our Medicaid program. Additionally, it creates health care disparities by virtue of economic class.

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's 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 DOE. While the DOH and the DOE would be responsible for funding the state share of the services, DHS would be responsible for accessing federal matching funds for the DOH and the DOE services for Medicaid qualified children.

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

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

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

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

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

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

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

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

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

Thank you for the opportunity to testify on this measure.

²<http://www.uspreventiveservicestaskforce.org/uspstf13/speechdelay/spchfinalresplan.htm>
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ABA Utilization Projection for Hawaii Medicaid

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

1. Prevalence

- 1.1. National statistics indicate 1:88 children have Autism Spectrum Disorder (ASD), ranging in intensity from classic autism to Asperger's Syndrome
- 1.2. Population of children 18 and under in Hawaii for 2012 - 303,818
- 1.3. Total estimated children in Hawaii with an ASD – 3,452
- 1.4. Total children served by Department of 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 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 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 serve numbers are included in the estimate

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

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

4.2. Services are provided by DOE Special Education

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

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

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

4.2.2.2. Unable to direct all children through DOE unlike EI

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

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

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

4.3.1. Tricare reimburses this at \$125.00/hour

4.3.2. 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	
6-8	244	Direct Service	3	40	29,280		80%	5,856	
		Supervision	3	10	7,320			1,464	

Comprehensive Intensive ABA Services								
Age	# of Projected Medicaid Children	Service	Hours per child per week	Weeks per year	Total Hours for all	% DOH/EI	% SPED	Total Hours Not Carved Out: DHS
		Assessment & Parent Training	1	9/mo	2,196			439

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

Step 3: Apply other factors against the base

Other factors could include:

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



Chamber of Commerce HAWAII

The Voice of Business

**Testimony to the House Committee on Consumer Protection and Commerce
Monday, February 10, 2014 at 5:00 P.M.
State Capitol - Conference Room 325**

RE: HOUSE BILL 2174, HD1 RELATING TO HEALTH

Chair McKelvey and Vice Chair Kawakami, and members of the committee:

The Chamber of Commerce of Hawaii ("The Chamber") **cannot support** HB 2174 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. Also the benefit caps in this bill may be impacted by ACA.

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 new ACA fees and taxes (4-5%) and the annual inflation based increase in health care premiums of 7-10% each year.

Thank you for the opportunity to testify.



HAWAII MEDICAL ASSOCIATION

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

DATE: Monday, February 10, 2014
TIME: 5:00 PM
PLACE: Conference Room 325

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

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

RE: HB 2174, HD1

Position: Support

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

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

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

Officers

*President - Walton Shim, MD President-Elect – Robert Sloan
Secretary - Thomas Kosasa, MD Immediate Past President – Stephen Kemble, MD
Treasurer – Brandon Lee, MD Executive Director – Christopher Flanders, DO*

HMSA



An Independent Licensee of the Blue Cross and Blue Shield Association

February 10, 2014

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

Re: HB 2174, HD1 – Relating to Health

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

The Hawaii Medical Service Association (HMSA) appreciates the opportunity to testify on HB 2174, HD1, which, would require health plans to provide coverage for services for autism spectrum disorders (ASD). HMSA certainly is empathetic to the intent of this Bill. However, as we noted during the last legislative session, we continue to be concerned that the Legislature and the community need more and clearer information about the consequences of such a mandate.

The 2012 Legislature, in fact, did attempt to gain that knowledge by adopting HCR 177, HD2, SD1, directing the Legislative Reference Bureau (LRB) study of the impacts of mandating insurance coverage for the diagnosis and treatment of ASD. The LRB submitted that report, "Autism Spectrum Disorders and Mandated Benefits Coverage in Hawaii" to the 2013 Legislature

Unfortunately, the LRB report is inconclusive with regard to many of its findings, including the financial impact and the impact of the Affordable Care Act (ACA) on such a mandate. The LRB instead offers recommendations including:

- Should the Legislature want more certainty with respect to the cost of a mandate, it may consider commissioning an independent actuarial analysis.
- Should the Legislature want more accurate information concerning the costs of the mandate to the Med-QUEST and EUTF systems, it may require the agencies to commission studies of their own.
- The Legislature needs to ensure Applied Behavioral Analysis network adequacy, especially for ASD patients on the Neighbor Islands.

While providing services for persons with ASD is important, we need to emphasize that, pursuant to the ACA, the cost of providing these services under a new mandate must be borne by the State. And, that applies to plans sold both through and outside of the health insurance exchange. It is important that the Legislature clarifies the financial impact of a coverage mandate for those services on the community and the health care system. Consequently, the Legislature may wish to consider pursuing some or all of the additional studies recommended by the LRB.

Thank you for the opportunity to offer our comments on HB 2174, HD1.

Sincerely,

A handwritten signature in black ink, appearing to read "JDiesman".

Jennifer Diesman
Vice President
Government Relations

COMMITTEE ON CONSUMER PROTECTION & COMMERCE

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

Monday, February 10, 2014, 5:00 PM
Conference Room 325, State Capitol
415 South Beretania Street

Dear Representatives McKelvey and Kawakami,

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

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

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

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



Analysis, also from Simmons College in Boston, Massachusetts.

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

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

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

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

- ABA is not solely an educational treatment. It is considered to be a medically necessary, empirically validated treatment approach for children diagnosed with autism (and other related disorders). Public schools on island are not equipped to fully meet the needs of children with autism, as clearly evidenced by the recent ruling by Administrative Law Judge Haunani Alm, regarding the abuse at Kipapa Elementary in Mililani.
<http://www.Hawai'inewsnow.com/story/24391699/charges-of-cover-up-in-mililani-abuse-case>
- ABA is not new, nor is it a passing fad. Applied behavior analysis is a science of evidenced-based interventions that have been substantiated by over 1,000

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

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

I appreciate your time and thank you and the committee for hearing my point of view of why you, and all of Hawaii's legislators should VOTE TO PASS Luke's Law: HB2174 (with an obvious amendment to the effective date of 2050).

Respectfully,


Amanda N. Kelly, PhD, BCBA-D

Clinical Supervisor, Malama Pono Autism Center
Vice President, Hawai'i Association for Behavior Analysis

www.behaviorbabe.com
Behaviorbabe@yahoo.com

Dear Representatives,

My name is Kristen Koba-Burdt and I am a Board Certified Behavior Analyst (BCBA) working with individuals with autism, writing in support of HB 2174.

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

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

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

ABA offers the potential to change this trend. Research on ABA programming for individuals with autism has demonstrated a variety of desirable outcomes including increases in ability to communicate, treatment of eating and feeding problems, ability to perform functional self-help skills, treatment of sleep problems, treatment of eloping and wandering, and the treatment of self-injurious, aggressive, or other dangerous behaviors. Individuals with autism need access to evidence-based treatment and insurance reform is an absolutely necessary step in creating this change for Hawaii. I ask for your support in helping HB 2174/Luke's Law become a reality in this legislative session.

Thank you for your time and consideration,

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

February 10, 2014
5:00 p.m.

House Committee on Commerce and Consumer Protection

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

State Capitol
415 South Beretania St
Honolulu, HI 96813

Re: In Support of HB 2174 HD 1; Relating to Health.

Dear Representatives McKelvey, Kawakami and Members of the Committee,

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

In previous sessions, Autism Speaks has testified to this committee in support of mandatory health insurance coverage for autism spectrum disorder including Applied Behavior Analysis (ABA). We have shared an overview of autism spectrum disorders and our national experience with autism insurance legislation. Our testimony has included a discussion of the epidemic increase in prevalence of autism; research documenting the efficacy of ABA therapy; actual claims data from states which were among the the first to enact autism insurance reform laws; and the long term cost savings and fiscal imperative of autism insurance reform. I am pleased to speak again today in strong support of HB 2174 HD 1, "Luke's Law."

Several issues that I would like to address this afternoon are 1) the impact of the Affordable Care Act on insurance coverage for autism and Luke's Law, 2) the assertion that ABA is an educational treatment, and 3) a discussion of age caps on ABA benefits for autism.

The Impact of the Affordable Care Act (ACA) on Insurance Coverage for Autism and Luke's Law

The ACA, Essential Health Benefits and Applied Behavior Analysis

The ACA requires that essential health benefits (EHB) be provided in all non-grandfathered plans in the individual and small group markets beginning in 2014. During congressional hearings on the ACA, the category of essential health benefits "mental health and substance use disorder services" was amended to "mental health

and substance abuse disorders, *including behavioral health treatment.*” In a letter to the Secretary of the U.S. Department of Health and Human Services (HHS), Senator Menendez stated that during the Senate Finance Committee’s discussion of this amendment “it was made explicitly clear that it was intended to cover the behavioral health services associated with autism treatments and therapies.”¹

However, the practical intent of this amendment was lost during implementation of the ACA when HHS issued guidance that the specific essential health benefits within the ten statutorily defined categories would not be established at the federal level but by a state-selected benchmark plan. Of the thirty four (34) states that have passed autism insurance laws that require coverage for ABA, twenty seven (27) states plus the District of Columbia are expected to include an ABA benefit in their EHB. None of the benchmark options identified for Hawaii included coverage for ABA for autism. As a result, ABA for autism is not an essential health benefit in Hawaii.

The autism community continues to advocate that ABA for autism be considered an essential health benefit in all 50 states as was intended by the Menendez amendment.

Coverage for ABA in Luke’s Law

In states such as Hawaii where ABA for autism is not an EHB, the ACA limits the markets in which a new ABA benefit can be required without triggering an obligation for the State to defray the cost of the benefit. Section 1311(d)(3) of the ACA requires States to defray the cost of state-mandated benefits in “**qualified health plans**” that exceed that State’s EHB. A qualified health plan (QHP) is a small group or individual health plan providing coverage for plan years 2014 or later that has been certified as meeting the standards established in Section 1301 of the ACA. The U.S. Department of Health and Human Services (HHS) has clarified that “state payment for state-required benefits only applies to QHPs.”²

In November 2013, HHS further clarified that except for “grandmothered” plans, they would not allow differences in benefits offered between QHPs and non-QHPs.³ Therefore, even though the State would not be required to defray the cost of benefits offered in non-QHPs that exceed EHB, Luke’s Law cannot require coverage for ABA in this market. (*See Table 1; attached*)

HB 2174 HB 1 includes a provision that insulates the State from ACA-related costs by excluding qualified health plans from the required coverage. Autism Speaks proposes

¹ Menendez, R. Letter to Secretary Kathleen Sebelius. 31 Jan. 2012 (see attached)

² Federal Register/Vol. 78, No. 37/Monday, February 25, 2013

³ A “**grandmothered**” plan refers to a non-QHP that does not comply with certain market reforms required in this market by the ACA (e.g., inclusion of EHB). Grandmothered plans (or transitional renewal plans) are allowed under a transitional U.S. Dept. of HHS policy if the plans were in effect on October 1, 2013. <http://www.cms.gov/CCIIO/Resources/Letters/Downloads/commissioner-letter-11-14-2013.pdf>

the following amendment to this provision which further clarifies that certain non-QHPs must also be excluded from coverage:

HB 2174 HB 1; page 4, lines 15-19 and page 11, lines 10-14

“(i) Nothing in this section shall apply to accident-only, specified disease, hospital indemnity, ~~qualified health plans as defined in section 1301 of non-grandfathered plans in the individual and small group markets that are required to include essential health benefits under the Patient Protection and Affordable Care Act, Medicare supplement, disability income, long-term care, or other limited benefit hospital insurance policies.~~”

Can Luke’s Law include coverage for ABA as an Essential Health Benefit in Hawaii?

The U.S. Department of Health and Human Services intends to reevaluate essential health benefits and the benchmark selection process in late 2015 for calendar year 2016. Advocates are hopeful that HHS may require coverage for ABA in all State EHBs at that time. However, until further guidance is issued there is no clear way to add coverage for ABA to Hawaii’s essential health benefits package without triggering an obligation to defray the cost of the benefit.

In addition to Hawaii, nine other states are debating autism insurance legislation this year. Several are considering the following provision that declares their intent to add ABA to their EHB in 2016:

“By December 31, 2014, the Department of Insurance shall request that the United States Department of Health and Human Services include the coverage of applied behavior analysis in [State’s] essential health benefits package when the next benefit set is selected in 2016. These services will be included as essential health benefits so long as they are not considered an additional required benefit for which the state must defray the cost.”

It is important to note that even if HHS declares that coverage for ABA is required in all State EHBs, legislation such as Luke’s Law is still necessary to extend the benefit to the large group market and grandfathered plans in the small group and individual markets.

Is Applied Behavior Analysis (ABA) Educational in Nature?

Opponents of legislation that requires insurance coverage for ABA frequently assert that ABA is “educational” or “academic” in nature and therefore should not be a covered benefit. This assertion has been refuted in court (McHenry v PacificSource Health Plans, Crum v Anthem) and rejected by the United States Office of Personnel Management and 34 State legislatures.

Applied behavior analysis is a behavioral therapy based upon principles of behavioral psychology. Its efficacy in the treatment of autism has been documented in hundreds of

peer-reviewed studies over the past 50 years. ABA uses positive reinforcement to encourage desired behavior and eliminate harmful or undesired behaviors. As new skills are acquired, they are generalized into other settings.

“Comprehensive” ABA therapy for individuals with autism addresses multiple areas (e.g. language and communication, social skills, coping and tolerance skills) to bring the child’s functioning to levels typical of that chronological age. The prescription for comprehensive ABA therapy is commonly 30-40 hours per week. When treatment is provided early and with the prescribed intensity, the number of treatment goals decreases with age. As a result, older individuals generally require less intense or “focused” ABA therapy to address maladaptive behaviors.

Key findings in the McHenry and Crum cases were that ABA is *medically necessary* and *not educational or academic in nature*. Opponents often assert that ABA is educational because it may have positive effects on an individual’s academic performance. From McHenry vs Pacificsource Health Plans:

While ABA therapy may have beneficial effects on an autistic child's social and academic skills, its defining characteristic is application of techniques to modify behavior in every area of an autistic child's life. In this regard, a sports analogy is instructive. While participation in sports can benefit a student's academic and social skills, no one would classify sports as academic or social skills training. Similarly, the incidental benefits in these areas resulting from ABA therapy, while real, do not dictate that it be classified as either as academic or social skills training. Rather, it is more properly classified as behavioral modification.

PacificSource's contrary interpretation would sweep many other covered benefits into this exception to which it clearly does not apply. Nearly all types of psychological treatment (counseling, psychotherapy, etc.) could be classified as academic or social skills training. These types of treatments, like ABA therapy, undoubtedly have benefits on a person's ability to succeed in education and help to teach proper skills and behaviors for social interactions. However, they would presumably not fall within those exclusions.

With further regard to ABA, the McHenry decision also states:

While aimed at improving social and academic functioning, it does this by specifically addressing behavioral deficits possessed by autistic children that interfere with every area of their life, not by educating kids on social norms or teaching study skills or other tools specific to academic success.

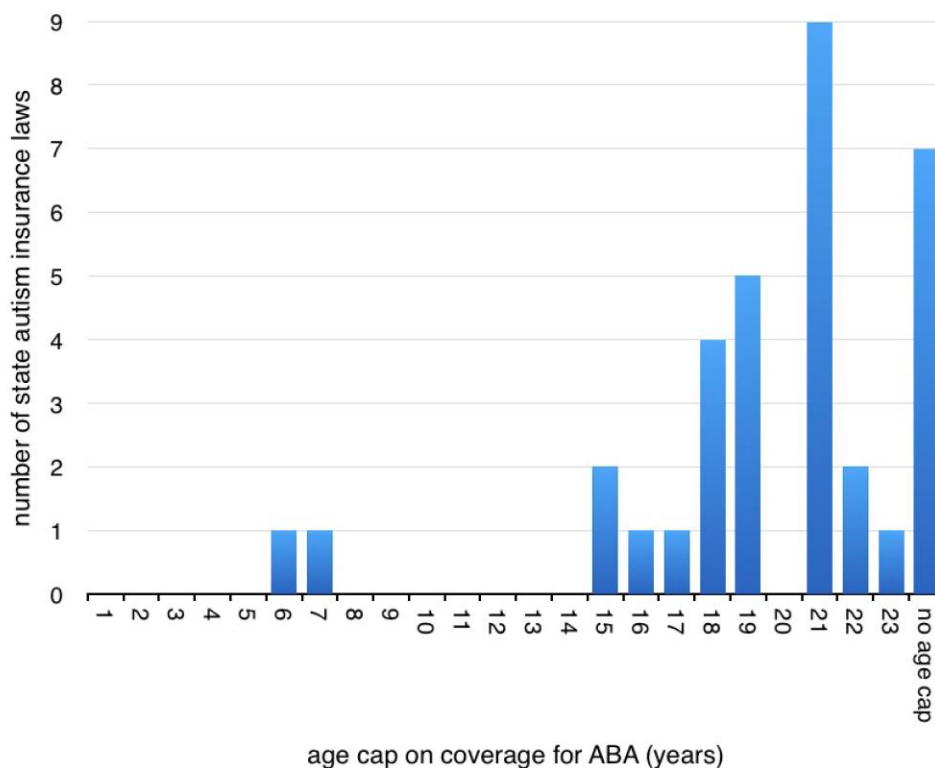
The United States Office of Personnel Management (OPM) administers the health benefit plans for over 8 million Federal civilian employees and families. In its finding that ABA was not “educational” the Crum v Anthem case cited a recent decision by OPM that there is sufficient evidence to categorize ABA as a medical therapy:

The Director of Healthcare and Insurance for OPM testified to a Senate Subcommittee that: “OPM made a decision to reclassify ABA as a medical therapy rather than an educational service based on the evolving body of clinical research and the maturing provider infrastructure to deliver this modality under a medical model.”

The issue of whether ABA is educational or medical has also been debated in State legislatures across the country. Thirty four (34) States have acknowledged the medical necessity of ABA for autism and require coverage for ABA in state regulated health insurance plans.

A Discussion of Age Caps on Coverage of ABA for Autism

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



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

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

While Autism Speaks is opposed to age caps on coverage for ABA, the proposed cap of 21 years in Luke's Law is consistent with median age cap in existing autism insurance laws across the country.

Thank you for your consideration of my comments,



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United States Senate

WASHINGTON, DC 20510-3005

January 31, 2012

The Honorable Kathleen Sebelius
Secretary of Health and Human Services
200 Independence Avenue, S.W.
Washington, DC 20201

Dear Secretary Sebelius,

I want to thank you for all your work on implementing the Patient Protection and Affordable Care Act (PPACA). Thanks to your leadership, the provisions of the law are being implemented in a timely manner, and families and businesses across our nation are starting to realize the benefits. As you continue your work, I wanted to bring to your attention a concern I have with the Essential Health Benefits (EHB) Bulletin released on December 16, 2011. I am particularly concerned with how this bulletin addresses the coverage of behavioral health services generally, and autism services specifically.

Autism spectrum disorders (ASDs) are pervasive, chronic and life-long developmental disorders with no cure. The Centers for Disease Control and Prevention estimate that roughly 1 in 110 children in the United States are affected by autism. While there is no cure for autism, early interventions – such as specialized education and behavioral programs – significantly improve outcomes and diminish symptoms. However, in spite of the empirical evidence demonstrating the medical utility and effectiveness of behavioral therapies, people with autism confront underinsurance, a monumental barrier to accessing early intervention treatments for autism. Historically, many health insurance plans have denied coverage of proven treatments for autism, particularly those involving behavioral treatments such as speech therapy and applied behavioral analysis, based on claims that these treatments are medically unnecessary or experimental. Families in New Jersey and throughout our nation deserve access to these vital services, so all children coping with ASD are able to live up to their full potential and can grow to lead healthy, happy and productive lives.


In the December bulletin, HHS provides individual states with the ability to choose from select plans to use as a “benchmark” upon which their state’s EHBs will be based. As you know, section 1302(b) of the ACA outlines the ten benefit categories that all qualified health plans must provide, with section 1302(b)(E) explicitly stating that “mental health and substance use disorder services, including behavioral health treatment” be included. This language originates with an amendment I included during the Senate Finance Committee’s markup of the legislation. During the Committee’s discussion of this amendment, it was made explicitly clear that it was intended to cover the behavioral health services associated with autism treatments and therapies.

Currently, 29 states mandate some form of autism coverage. However, even those states with mandates in place often exclude large group plans and plans offered through the Federal

Employees Health Benefits Plan. In addressing the issue of behavioral health and autism services, the December bulletin states that “[t]he extent to which plans and products cover behavioral health treatment, a component of the mental health and substance use disorder EHB category, is unclear. In general, plans do not mention behavioral health treatment as a category of services in summary plan documents. The exception is behavioral treatment for autism, which small group issuers in the [Institute of Medicine] survey indicated is usually covered only when mandated by States.” While the bulletin takes the approach that this means behavioral health falls outside the scope of a “typical employer plan,” I believe it actually underscores the need for uniform, national standards. My amendment’s language is specifically targeted to provide uniformity in available benefits and security to families coping with ASD, regardless of their health insurance plan or state’s mandate.

As you continue to finalize the rules surrounding the EHB package, I strongly urge you to consider the effects the current benchmarking approach would have on meeting the statutory requirement that all plans include behavioral health services. I ask that you exercise strong federal oversight of qualified health plans to ensure their benefit packages recognize this requirement and adhere to both the letter and the intent of the law.

Sincerely,



ROBERT MENENDEZ
United States Senate

Table 1

Plan Type	Grandfathered status	QHP status	Sold on or off the Exchange?	Grandmothered status	Must this type of plan include EHB?	Must the State pay for a mandated benefit that exceeds EHB in this type of plan?	Coverage required under proposed amendment to Luke's Law
Large Group	grandfathered	N/A	/OFF	N/A	NO	NO	YES
	non-grandfathered	N/A	/OFF	N/A	NO	NO	YES
Small Group and Individual Markets	grandfathered	N/A	/OFF	N/A	NO	NO	YES
	non-grandfathered	QHP	ON/	N/A	YES	YES	NO
			/OFF	N/A	YES	YES	NO
	non-grandfathered	non-QHP	/OFF	grandmothered ¹	NO	NO	YES
/OFF			non-grandmothered	YES	NO	NO ²	

- (1) A “grandmothered” plan refers to a non-QHP that does not comply with certain market reforms required in this market by the ACA (e.g., inclusion of EHB). Grandmothered plans (or transitional renewal plans) are allowed under a transitional HHS policy if the plans were in effect on October 1, 2013.
- (2) Except for grandmothered plans, HHS has clarified that they would not allow differences in benefits offered between QHPs and non-QHPs. Therefore, even though the State would not be required to defray the cost of benefits offered in non-QHPs that exceed EHB, “Luke’s Law” cannot require coverage for ABA in this market.



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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

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

- Baer, D. M., Peterson, R.F., & Sherman, J.A. (1967). The development of imitation by reinforcing behavioral similarity to a model. *Journal of the Experimental Analysis of Behavior*, 10, 405-416.
- Baer, D.M. & Guess, D. (1971). Receptive training of adjectival inflections in mental retardates. *Journal of Applied Behavior Analysis*, 4, 129-139.
- Baer, D.M. & Guess, D. (1973). Teaching productive noun suffixes to severely retarded children. *American Journal of Mental Deficiency*, 77 (5), 498-505.
- Barbetta, P.M., Heron, T.E., & Heward, W.L., (1993). Effects of active student response during error correction on the acquisition, maintenance, and generalization of sight words by students with developmental disabilities. *Journal of Applied Behavior Analysis*, 26, 111-120.
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- Belchic, J.K., & Harris, S.L. (1994). The use of multiple peer exemplars to enhance the generalization of play skills to the siblings of children with autism. *Child and Family Behavior Therapy*, 16,1-25.
- Bellini, S., & Akullian, J. (2007). A Meta-Analysis of Video Modeling and Video Self-Modeling Interventions for Children and Adolescents with Autism spectrum disorders. *Exceptional Children*, 73, 261-284.
- Bellini, S., Peters, J.K., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skills interventions for children with autism spectrum disorders. *Remedial and Special Education*, 28, 153-162.
- Bernard-Opitz, V., Sriram, N., & Nakhoda-Sapuan, S. (2001). Enhancing social problem solving in children with autism and normal children through computer-assisted instruction. *Journal of Autism & Developmental Disorders*, 31, 377-384.
- Bibby, P., Eikeseth, S., Martin, N.T., Mudford, O.C., & Reeves, D. (2001). Progress and outcomes for children with autism receiving parent-managed intensive interventions. *Research in Developmental Disabilities*. 22, 425-447.
- Billingsly, F.F., & Neel, R.S. (1985). Competing behaviors and their effects on skill generalization and maintenance. *Analysis and Intervention in Developmental Disabilities*, 5, 357-372.

- Blew, P.A., Schwartz, I.S., & Luce, S.C. (1985). Teaching functional community skills to autistic children using nonhandicapped peer tutors. *Journal of Applied Behavior Analysis*, 18, 337-342.
- Brown, F., Holvoet, J., Guess, D., & Mulligan, M. (1980). Individualized curriculum sequencing model (III): Small group instruction. *Journal of the Association for the Severely Handicapped*, 5, 352-367.
- Buggey, T., Toombs, K., Gardener, P., Cervetti, M. (2000). Training responding behaviors in students with autism: Using videotaped self-modeling. *Journal of Positive Behavior Interventions*, 1, 205-214.
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February 10, 2014

**Special Education
Advisory Council**

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

RE: HB 2174, HD1 - RELATING TO HEALTH

Dear Chair McKelvey and Members of the Committee,

The Special Education Advisory Council (SEAC), Hawaii's State Advisory Panel under the Individuals with Disabilities Education Act (IDEA), **strongly supports** HB 2174, HD 1, that proposes to mandate health insurance coverage for the diagnosis and treatment of autism spectrum disorders (ASD).

SEAC has been active over the last number of years in advising the Department of Education on appropriate educational supports for students who are on the autism spectrum. 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 in dialogue over the last three years with a variety of key stakeholders who have collectively acknowledged the critical need for mandated insurance coverage in Hawaii to identify children with ASD and provide timely and evidence-based interventions to improve their health, academic and life outcomes. We therefore urge passage of HB 2174, HD1 and offer our availability for further discussion on this legislation.

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

Respectfully,

Ivalee Sinclair, Chair

kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 09, 2014 3:16 PM
To: CPCtestimony
Cc: luluperucci@yahoo.com
Subject: Submitted testimony for HB2174 on Feb 10, 2014 17:00PM

HB2174

Submitted on: 2/9/2014

Testimony for CPC on Feb 10, 2014 17:00PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
taffy perucci	Malama Pono Autism Center	Support	No

Comments: We strongly support HB2174 with amendments to the start date of the Act to NOT be July 1,2050. Families have waited long enough. The date should be considered for July 1, 2014 or 2015.

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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Experiad Solutions

3025 Diamond Head Road, Honolulu, HI 96815 • (808) 445-1633

Dear Legislators,

I strongly support passage of Bill HB2174, which will provide insurance coverage for services for children on the autism spectrum which are not currently covered.

I am the owner of a Hawaii small business that performs research funded by the National Institutes of Health. We recently brought in a \$700K federal grant to Hawaii. We are working with researchers at the University of Hawaii and the University of Washington Autism Center to develop and evaluate autism behavioral therapy tools. In this capacity, I have evaluated the scientific research on the effectiveness of ABA therapy for autism. Large scale research studies funded by NIH show that children with autism who receive intensive ABA treatment show profound lifelong results in terms of increased IQ and improved verbal ability, and increased capacity for normal social interaction. These children are far more likely to live an independent life when they become adults, to maintain employment and contribute to society. Children who do not receive the treatment are far more likely to be on welfare for their entire lifetime. Each child treated with ABA represents millions of dollars of saved taxpayer money over their lifetime. But without insurance coverage, ABA therapy is out of reach for most families.

Washington State and many other states have recently passed legislation similar to HB2174, based on the clear research evidence that ABA is effective in treating autism. Please help Hawaii join the rest of these forward-looking states in supporting this legislation. The investment is a no-brainer.

Sincerely,

A handwritten signature in black ink, appearing to read "Rex Jakobovits". The signature is fluid and cursive, with a large loop at the end.

Rex Jakobovits, PhD
President, Experiad Solutions

kawakami3-Benigno

From: Emaley McCulloch <emaley@advancedtrainingsolutions.com>
Sent: Sunday, February 09, 2014 4:30 PM
To: CPCtestimony
Subject: testimony for HB2174

Dear Representatives McKelvey and Kawakami,

My name is Emaley McCulloch. My life has been deeply impacted by autism. I have many family members and friends who have children on the autism spectrum. I am also a Board Certified Behavior Analyst (BCBA) that has been working in the field of autism and ABA since 1996. I am writing to show my support for HB2174 / **Luke's Law**. I am looking forward to seeing Hawaii join the other 33 states in providing insurance coverage for families impacted by autism.

I have lived in Hawaii for 11 years and have met and worked with over 100 of individuals with autism in Hawaii. During my experience working in the schools, homes and clinics I have experienced first hand the positive outcomes of Applied Behavior Analysis. People can tell you over and over again that ABA is effective, it's evidence-based, it's the only treatment recommended by the Surgeon General etc. but until you actually see a child start maintaining eye-contact or start speaking for the first time, you will not fully understand the impact this bill will make for Hawaii. The impact will not only effect families but also the community.

Studies show that if children can get a dosage of 25-40 hours of ABA, that nearly 50% of them will improve enough to mainstream into general education. Imagine how much that will mean for families and how much money the state will save if these children become contributors to the community, rather than requiring state services.

If you would like to actually see a story of a child with autism's progress with ABA, here is a short 5 min video about a boy with autism who lives in Hawaii that received ABA. He ran for class president in his 4th grade class last year. This video shows what he was like when he was diagnosed at age 3. It shows what his ABA program looked like and how he aquired language and social skills over the span of 3-4 years.

Kainoa's Story

<http://www.youtube.com/watch?v=DjiVB6v2Q9Y&feature=c4-overview&list=UUty6dSboq16COoTPJomVHCw>

Pictures speak a thousand words so I will end my letter by respectfully asking for your support. Thank you for your time and for hearing my point of view of why you should vote to pass HB2174 / **Luke's Law**.

Mahalo palena 'ole,

Emaley McCulloch M.Ed. BCBA
President, Advanced Training Solutions
2800 Woodlawn Drive, #175
Honolulu HI 96822
mobile: 808 349-0645
office: 808 237-5124

*"Teach as though the future depends on it.. It does!"
~unknown*

kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 08, 2014 7:58 PM
To: CPCtestimony
Cc: tstanich@hawaii.rr.com
Subject: Submitted testimony for HB2174 on Feb 10, 2014 17:00PM

HB2174

Submitted on: 2/8/2014

Testimony for CPC on Feb 10, 2014 17:00PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Toni Stanich	Individual	Support	No

Comments: I wish to support this bill!

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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kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Saturday, February 08, 2014 7:59 PM
To: CPCtestimony
Cc: starsister2000@yahoo.com
Subject: Submitted testimony for HB2174 on Feb 10, 2014 17:00PM

HB2174

Submitted on: 2/8/2014

Testimony for CPC on Feb 10, 2014 17:00PM in Conference Room 325

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

Comments: I strongly support HB2174 and ask that you pass this bill. Children and families of those affected by autism so greatly need ABA. In my own experiences, I have seen the amazing, positive changes ABA can have. Thank you for your consideration.

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

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Dear Representatives,

This letter is in strong support of HB 2174.

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

Please pass HB 2174 in this legislative session.

Sincerely,

Brian J. Burdt

COMMITTEE ON CONSUMER PROTECTION & COMMERCE

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

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

February 9, 2014

In regards to HB2174 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.

There are some Key points:

1. ABA interventions work, the data is strong and it's a necessary component of a child's treatment program.
2. The financial burden placed on families is extensive. ABA treatment is one intervention that is necessary for children on the spectrum. They have to pay for many interventions services, special modifications that are substantially more than the demands placed upon a typical family. Assisting them with this particular treatment, which is highly efficacious is best practice, stress reducing and the future outcomes and benefits tremendous. Even by providing this, the financial burden is certainly not completely alleviated for these families.
3. One argument is that this is a schools responsibility. Yes they do have a responsibility and they should and do in some instances provide a small degree of these services. However, having working as a contract provider for the school and worked in families homes, community and a private clinic, it is fact that treatment for these children MUST occur in ALL settings and by all caretakers. This to me justifies that entities outside of the DOE (i.e. 3rd party reimbursement) must become part of the treatment options available for these children and their families.
4. My only concern with this legislation is the lack of a licensing requirement for Board Certified Behavior Analysts. Though they are highly trained and very skilled in the area of Applied Behavior Analysis, they are do not necessarily have the extensive training, practicums or education in treating the comprehensive overall needs of children and adults with mental health conditions compared to other professionals that are granted access to 3rd party reimbursement from insurers. One suggestion is that BCBA need to attain a license to practice consistent with other professions and/or be supervised by a Licensed Professional with commensurate training, experience and education.

HB2174 emphasizes the need for these services for these children and their families. There is ample research based evidence that supports the use of intensive behaviorally based treatment programs as an 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. The needs of children and young adults on the spectrum persist through their lifespan, and 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.

My only concern with this legislation is the lack of a licensing requirement for Board Certified Behavior Analysts. Though they are highly trained and very skilled in the area of Applied Behavior Analysis, they do not necessarily have the extensive training, practicums or education in treating the comprehensive needs of children with mental health conditions compared to other professionals that are granted access to 3rd party reimbursement from insurers, such as Licensed Psychologists, Licensed Mental Health Counselors, Licensed Clinical Social Workers or Licensed Marriage and Family therapists. One suggestion is that BCBA need to attain a license to practice consistent with other professions and/or be supervised by a Licensed Professional with commensurate training, experience and education.

Thank you for the opportunity to share my perspective

Sincerely

Gabrielle Toloza, Psy.D.

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kawakami3-Benigno

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 09, 2014 3:16 PM
To: CPCtestimony
Cc: luluperucci@yahoo.com
Subject: Submitted testimony for HB2174 on Feb 10, 2014 17:00PM

HB2174

Submitted on: 2/9/2014

Testimony for CPC on Feb 10, 2014 17:00PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
taffy perucci	Individual	Support	No

Comments: We strongly support HB2174 with amendments to the start date of the Act to NOT be July 1, 2050. Families have waited long enough. The date should be considered for July 1, 2014 or 2015.

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

Friday, January 31, 2014 / 8:30 AM
Conference Room 329, Hawai'i State Capitol
415 South Beretania Street, Honolulu, HI

Dear Rep. Della Au Belatti & Rep. Dee Morikawa,

My name is Dana Simmons and I am the aunt of an amazing nine year old boy with autism as well as a Board Certified assistant Behavior Analyst (BCaBA) currently working with children diagnosed with autism and developmental disabilities. I am writing to you because I want to talk about SB2054 / Luke's Law and how it will benefit children and families with autism.

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

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

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

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

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

I am more than willing to share a thousand more stories if you would like to contact me but I hope that you have also taken a moment to meet some of these beautiful children and see the difference ABA has made in their lives. I honestly thank you for your time and for hearing my point of view of why you should vote to pass HB2174.

Respectfully,

Dana Simmons, BCaBA
dana@autismbehaviorconsulting.com
(228) 357-0840

kawakami3-Benigno

From: Suzanne Egan <segan808@gmail.com>
Sent: Sunday, February 09, 2014 4:31 PM
To: CPCtestimony
Cc: susan_okano@notes.k12.hi.us
Subject: testimony_Luke's_Law

re: Luke's Law

Aloha,

We are writing today as a family who has been devastated by Autism.

Without access to Evidence Based Practices such as ABA Intensive Early Intervention, our child's outcome has been severely compromised. With the wealth of information available Nationally, this state's neglect is nothing short of sinful. The culture of service avoidance by the DOE/ the State's lack of accountability to it's own service model (DOE), and the lax interpretation of Medicaid law are breeches of Legal Rights. The failure of Hawaii's Private Health Insurance companies to recognize the glaring evidence base is unjust.

Health Care reform, would, without question, begin a process of rectification, without which, families like my own, communities, the State and Health Insurance Companies themselves suffer exacerbated socio-economic costs. Already, my insurance co. has been paying for regular psychotherapy which I've needed to mitigate mental health issues related to lack of support for my child. My son has broken his arm twice, due to lack of attention to his sensory regulation needs and lack of supervision at school related to ignorance/resistance to knowledge, lack of awareness which is chronic across fields; there will likely be an injury claim against the state.

My son, who is non-verbal, has had clear communicative intent since age 2 , and has been ripe for ABA therapy for a long time. He has regressed due to lack of application of appropriate methodology and service intensity. The formative window is almost closed. My son has just qualified for DOH/DD services; Without appropriate early intervention, he may be with them for his lifetime. Without appropriate early intervention, he may be a recipient of SSI benefits for his lifetime.

Children with Autism need appropriate services, particularly early Identification and Intensive Early Interventions. My son needs Behavioral/ABA and Developmental Interventions, OTSI and Speech Therapies particular to praxis. At almost 5 years of age, without access to these therapies, he may never speak. He may never be independent. It is an appalling Deliberate Indifference, for which many will pay a price.

We are grieving and angry; to know what your child needs and not be able to secure it, is like watching your child starve to death.

Please accept our testimony in support of:

Luke's Law

Thank You,
Suzanne Egan and Family

LATE



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
February 10, 2014

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

Dear Representative McKelvey and Members of the Committee:

SUBJECT: HB 2174 HD1 – Relating to Health

The State Council on Developmental Disabilities (DD) **SUPPORTS THE INTENT of HB 2174 HD1**. The bill requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder (ASD) treatment.

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.

There are three bills (HB 2174 HD1, SB 2054 and SB 668 SD2 HD1) before this Legislature. It is our understanding from the joint Senate Health and Commerce and Consumer Protection Committees' hearing regarding SB 2054 on January 28, 2014 that the Insurance Commissioner will be working with the Committees' Chairs on establishing coverage for ASD treatment (Applied Behavior Analysis) as a separate insurance code. SB 668 SD2 HD1 was addressed during the 2013 Regular Session, deferred in Conference Committee on April 26, 2013, and carried over to this session. This bill mirrors SB 2054 and reflects the work and consensus of a large stakeholder group.

The Council acknowledges that the above bills are a work in progress and appreciate the opportunity for continued discussions between the Legislature and stakeholders to flesh out the specific provisions of each bill to develop a final measure.

The Honorable Angus L.K. McKelvey, Chair
February 10, 2014
Page 2

Thank you for the opportunity to provide testimony supporting the intent of HB
2174 HD1.

Sincerely,


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


J. Curtis Tyler III
Chair

kawakami3-Benigno

From: Louis Erteschik <Louis@hawaii Disability Rights.org>
Sent: Sunday, February 09, 2014 8:42 PM
To: CPCtestimony
Subject: FW: HB 2174 Autism Insurance



Follow Up Flag: Follow up
Flag Status: Flagged

Categories: Might Be Important for Later

The Hawaii Disability Rights Center is in support of this measure. We will submit more detailed testimony tomorrow morning.
Mahalo

Louis Erteschik
Executive Director

The House of Representatives, Committee on Consumer Protection and Commerce, has scheduled a hearing on Monday, February 10, 2014 at 5:00pm in Conference Room 325.

The following measure may be of interest to you;

HB 2174, HD1 RELATING TO HEALTH. Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism spectrum disorder treatments. Effective July 1, 2050.

For information on the hearing, please refer to the notice below or posted on the Hawaii State Legislature website at:

http://www.capitol.hawaii.gov/session2014/hearingnotices/HEARING_CPC_02-10-14_3_.HTM

Testimony may be submitted up to 24 hours prior to the start of the hearing. For instructions on submitting testimony, please refer to the notice.

LATE

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

Monday, February 10, 2014, 5:00 PM
Conference Room 325, State Capitol
415 South Beretania Street

Dear Representatives McKelvey and Kawakami,

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

I was first introduced to applied behavior analysis in 2010 by accepting a position as behavior interventionist (therapist/tutor) who works with children with autism ranging in ages from 2 to 13 years old in Colorado. One of the first clients I worked with demonstrated deficits in communication and social skills as well as engaged in aggressive behaviors that further impacted him from learning. Being new to the field, I honestly was not sure how ABA would decrease those behaviors (fecal smearing, biting and hitting others) of this child. Over a short period of time, this client made significant process and there was apparent reduction in those behaviors. That was only one of many experiences that helped me understand how ABA helped and how it can shape behaviors, whether it is a behavior to increase or a behavior to decrease. Aside from the research stating the effectiveness of behavior analysis, it was just plain obvious based on my interactions with each child I work with. In that same year, I decided to pursue further education in behavior analysis and received my certification in 2013 as a Board Certified Behavior Analyst. Prior to behavior analysis, I have 10 years experience working with the mental health population, particularly adolescent girls ranging from 13 to 18 years old and adults in transition from psychiatric hospital to residential health care facility ranging from 18 to 75 years old. I hear myself saying, "if I only knew then, what I know now..." because behavior analysis would have been extremely beneficial to that population as well. The only prevalent issue is that behavior analysis is not widespread or accessible. Unfortunately, this is not an isolated situation. In 2014, families in 17 of the 50 United States are still without the support they need from their communities, state legislators and insurance companies. Part of my position now is not only to help the individual with Autism but also train the parents and caregivers the techniques and strategies to improve their quality of life in the home and community. I know that I am doing my job when I hear parents, family members, educators, and professionals say, "he/she is doing so well!" "I cannot believe how much he has learned!" "he talks now!" "he can use the bathroom all on his own!" "he's eating more AND can sit at the table without any problems!" "he's talking to his classmates!"

I moved to Hawaii last year and, in my short time here, see the lack of services that are available to individuals with Autism. Previous states have endured the struggles that Hawaii is now experiencing, though support from the community, families, and professionals have made remarkable impact on enacting autism insurance reform. I am employed as a Clinical Supervisor at Malama Pono Autism Center (MPAC) in Mililani where I am responsible in providing supervision and consultation to behavior clinicians (therapist/tutor), lead clinicians, and parents across several settings (in-home, center, and school). At this time, we are able to provide services to families in the military (Tricare) and to families with the ability to pay for treatment (private pay). We met many families who were looking for ABA services, though their insurance does not cover that service or the out-of-pocket expense was too high.

I would like to also mention that ABA is not solely an educational treatment, but medically necessary, evidence-based treatment approach for children diagnosed with autism. Schools are not fully equipped to meet the needs of children with autism. This is clearly indicated in the recent ruling by Administrative Law Judge Haunani Alm, regarding the abuse at Kipapa Elementary in Mililani. (<http://www.Hawai'inewsnow.com/story/24391699/charges-of-cover-up-in-mililani-abuse-case>). ABA is not just another trend because of the prevalence of autism; it is a science of evidence-based interventions and is supported by organizations such as the US Surgeon General, American Academy of Pediatrics, American Psychological Association, and Autism Society of America, to name a few. (<http://appliedbehaviorcenter.com/ABAEndorsements.htm>). ABA is effective for individuals from birth to death.

I would like to state my support for HB 2174. I appreciate your time and thank you and the committee for hearing my point of view of why you, and all of Hawaii's legislators should vote to pass Luke's Law.

Respectfully,

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

February 9, 2014



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

Dear Legislators,

My wife Emily and I strongly support passage of HB 2174 "Luke's Law" which will provide insurance coverage for services for children on the autism spectrum which are not currently covered.

We also urge you to make the Act effective on 7/1/14.

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

In August 2013 we started her at an autism clinic where her primary services are in Applied Behavioral Analysis. Since then she has shown slow but steady progress. We have never seen that before and for the first time are genuinely encouraged. We understand that Applied Behavior Analysis can result in improved behavior which should transfer into adulthood.

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

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

We urge you to pass HB 2174 so that children on the autism spectrum can get what they need the most – a chance in life. Thank you.

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



February 10th, 2014

House Committee on Commerce and Consumer Protection

Representative Angus L.K. McKelvey, Chair

Representative Derek S.K. Kawakami, Vice Chair

Re: In Support of HB 2174 HD 1; Relating to Health

Aloha Representatives McKelvey, Kawakami and Committee,

Luke continues to brave the effects of his Autism. Just recently he had his first cavity. He needed to go to Kapiolani and go under anesthesia to have the dental work done. What an emotional toll on all of the family. Now this week we received the hospital bill statement, \$13,000, just for the hospital. If Luke was to get therapy at say 60 dollars an hour for 100 hours he could be conditioned to sit with his mouth open in a dentist chair like other children and it would be less than half the 13,000. So please don't put a lower age cap on this bill. Luke deserves to have the medical coverage that other children receive right through college. We can then hopefully have the means and way to get therapy for him in the future. Speaking of the future, Luke recently wrote a journal entry in his school about wanting to go to U.H.. I will let him read it to you. We just had his IEP on February 4th and they did say he probably will get a certificate of completion rather than a diploma. So no U.H. for him when he graduates in 4 years. I know deep in my heart that if Luke was afforded the services starting when he was younger he would be able to graduate with a diploma! Why is it that we can support people who need drug rehabilitation, for whatever the circumstance, and yet we can not help Luke who did **NOT CHOOSE** Autism?

Respectfully Submitted,

Gerilyn Pinnow

Luke's Mom

kawakami3-Benigno

LATE

From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 09, 2014 6:45 PM
To: CPCtestimony
Cc: kbartell808@gmail.com
Subject: *Submitted testimony for HB2174 on Feb 10, 2014 17:00PM*

HB2174

Submitted on: 2/9/2014

Testimony for CPC on Feb 10, 2014 17:00PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Kristina Bartell	Individual	Support	No

Comments:

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

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From: mailinglist@capitol.hawaii.gov
Sent: Sunday, February 09, 2014 6:49 PM
To: CPCtestimony
Cc: adam.g.bartell@gmail.com
Subject: *Submitted testimony for HB2174 on Feb 10, 2014 17:00PM*

HB2174

Submitted on: 2/9/2014

Testimony for CPC on Feb 10, 2014 17:00PM in Conference Room 325

Submitted By	Organization	Testifier Position	Present at Hearing
Adam Bartell	Individual	Support	No

Comments:

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

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5.14-22-14

Five years from now
I will be 18 years
old. I'll be in college
named University of
Hawaii. I will

join Band and History
Class. I will might

drive a car to

Ala Moana mall. I

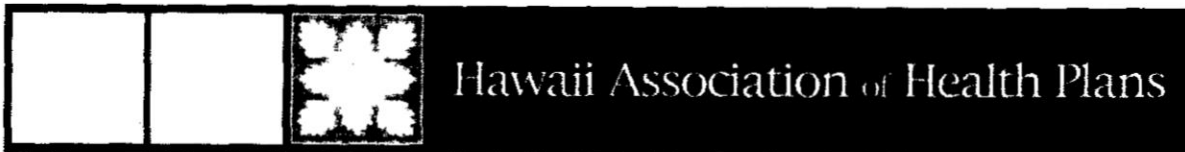
will go to Hilo

to see grandpa.

I will come back

to Ewa Beach.

I will graduate
when I'm 21.



February 10, 2014

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

Committee on Consumer Protection and Commerce

Re: HB 2174 – Relating to Health

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

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

AlohaCare
Hawaii Medical Assurance Association
HMSA
Hawaii-Western Management Group, Inc.
Kaiser Permanente

MDX Hawai’i
‘Ohana Health Plan
University Health Alliance
UnitedHealthcare

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

HAHP appreciates the opportunity to provide testimony on HB 2174 which requires health plans to provide coverage for autism and related services. We would like to call your attention to the language in the Affordable Care Act (ACA), which includes a provision that would require the State to bear costs associated with this mandate. We have attached the relevant ACA provisions for your review.

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

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

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

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

(A) In general

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

(B) States may require additional benefits

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

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

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

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

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

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

a) Essential health benefits package

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

- (1) provides for the essential health benefits defined by the Secretary under subsection (b);
- (2) limits cost-sharing for such coverage in accordance with subsection (c); and
- (3) subject to subsection (e), provides either the bronze, silver, gold, or platinum level of coverage described in subsection (d).

(b) Essential health benefits

(1) In general

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

- (A) Ambulatory patient services.
- (B) Emergency services.
- (C) Hospitalization.
- (D) Maternity and newborn care.
- (E) Mental health and substance use disorder services, including behavioral health treatment.
- (F) Prescription drugs.
- (G) Rehabilitative and habilitative services and devices.
- (H) Laboratory services.
- (I) Preventive and wellness services and chronic disease management.
- (J) Pediatric services, including oral and vision care.

(2) Limitation

(A) In general

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

Dr. Kathryn Taketa-Wong, N.D., L.Ac.
Naturopathic Physician
Licensed Acupuncturist

LATE

February 10, 2014

Dear Honorable Representatives of the Committee on Consumer Protection & Commerce:

Re: IN SUPPORT OF HB2174

I am a naturopathic physician practicing here in Hawaii specializing in the treatment of medical conditions co-morbid with autism, having been trained through the Medical Academy of Pediatric Special Needs and the Autism Research Institute. I work closely with many autism support and advocacy groups here in Hawaii including Talk About Curing Autism Hawaii, Autism Society of Hawaii, and the Hawaii Autism Foundation. Approximately 75% of my patients have been diagnosed with an autism spectrum disorder. I am also personally involved in the autism community as my brother is an adult with high-functioning autism.

While I am not a provider for Applied Behavior Analysis (ABA) therapy, I refer many of my patients for ABA services as I have seen its clinical efficacy in helping autistic children and adults to decrease problem behavior and increase functional living skills. Especially when used along with other early intervention services such as occupational therapy and speech therapy, ABA can sometimes make the difference between a child who becomes dependent for life on the state and federal government, or a child who can function in the world and potentially become an employable taxpayer. Please see the attached study on how early intervention services provide significant economic savings in the long run, and essentially pay for themselves within 8 years.

Because the only insurance carrier in Hawaii which regularly covers ABA services is Tricare, most of my patients with other insurance companies need to pay out of pocket for these services. I know families who have literally depleted all their savings and retirement funds and taken out loans to fund the cost of these services. Families should not be asked to go to such measures to secure evidenced-based and effective therapies for their child. I have seen some of my patients make remarkable strides when in ABA therapy from a BCBA, then regress significantly when families run out of funds to continue the therapy.

Imagine if your child was diagnosed with a condition for which there was evidenced based, effective treatment but you were told it would not be covered by insurance. That is what many of my patients' parents hear when their child receives a diagnosis of autism. While not all families with autism choose to pursue ABA therapy, I do not think that should limit the choices of those families who want these services for their children. **Please SUPPORT HB2174.**

Sincerely,

Kathryn Taketa-Wong, N.D., L.Ac.
Medical Academy of Pediatric Special Needs Fellowship Candidate



AUTISM SPEAKS
It's time to listen.



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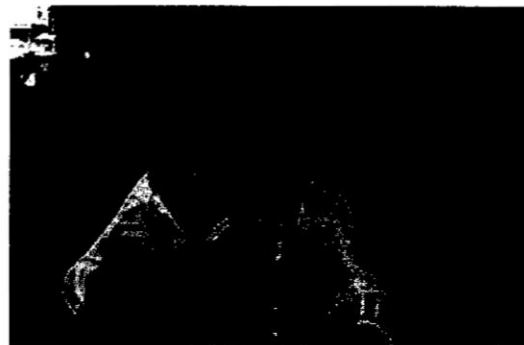
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Science » Science News

High-Quality Early Intervention for Autism More Than Pays for Itself

Date: May 01, 2013

Early Start Denver Model program for toddlers produces cost savings by reducing subsequent need for therapy and support services



Early intervention with high-quality autism therapy leads to long-term cost savings as it increases children's abilities.

Last year, University of Pennsylvania health-policy researcher David Mandell, Sc.D., reported that autism's costs the nation around \$137 billion per year. Now Dr. Mandell has calculated the cost-savings produced by a high-quality and intensive early behavioral intervention program.

The analysis focused on the Early Start Denver Model (ESDM). ESDM uses techniques from Applied Behavioral Analysis (ABA) for early intervention with toddlers. It emphasizes relationship-building and interactive play. Previous studies have found that ESDM significantly boosts IQ and social-communication skills and improves underlying brain responses to social cues.

"While early intensive behavioral intervention costs more to deliver in the early years, it more than pays for itself in terms of reduced needs for therapy and educational support by the time a child reaches high school," Dr. Mandell said.

Dr. Mandell reported his preliminary results today at a meeting of Autism Speaks Toddler Treatment Network, being held in conjunction with the International Meeting for Autism Research (IMFAR), in San Sebastian, Spain.

His cost-benefit analysis was supported by a research grant from Autism Speaks.

Dr. Mandell and his research team tracked the autism-related services used by 39 children who had participated in a two-year ESDM study led by Jeff Munson, Ph.D., and Annette Estes, Ph.D., at the University of Washington. At the time, the children were 18 to 30 months old. Twenty-one received two years of ESDM. For comparison, 18 children received a comparable amount of services through the early intervention programs in their community (Seattle). After the trial ended, parents were referred to their community's early intervention and special education programs for further services. The researchers tracked their use of these services over the following four years.

Higher up-front costs

During the two years of the ESDM study, autism-related services totaled \$9,619 per child per month for those receiving ESDM therapy. Of this, the cost of ESDM was \$5,560 per month. (As the children were part of a research study, the families did not bear this cost.) By comparison, the cost of services received by the children in the outside

SEARCH



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Harvard researchers find substantial costs in healthcare and education; more in-depth findings to come from Autism Speaks



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Researchers urge more attention to signs of pain; flag need to address underlying medical issues to improve sleep in those with autism



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LATE



HAWAII DISABILITY RIGHTS CENTER

1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813

Phone/TTY: (808) 949-2922 Toll Free: 1-800-882-1057 Fax: (808) 949-2928

E-mail: info@hawaiidisabilityrights.org Website: www.hawaiidisabilityrights.org

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

Committee on Consumer Protection and Commerce Testimony in Support of H.B. 2174, HD1 Relating to Health

Monday, February 10, 2014, 5:00 P.M.
Conference Room 325

Chair McKelvey, and Members of the Committee:

The Hawaii Disability Rights Center testifies in support of this bill.

The purpose of the bill is to require health insurance plans to provide coverage for autism spectrum disorders. This is a very important bill and this coverage is very appropriate for insurance policies. The whole point of insurance is to spread risk and cost among an entire population, so that disproportionate, catastrophic expenses are not heaped upon specific individuals or groups.

With that in mind, we need to realize that autism is occurring among children in epidemic proportions. According to current statistics, **one out of 110 children (1 out of 85 boys) are born with autism.** That is a staggering, alarming figure, as is the cost to those families and to society to care for these individuals over the course of their lives. **It is estimated that the cost of caring for a single individual with autism for a lifetime is \$3 million.** Evidence suggests that techniques such as applied behavioral analysis have been effective in mitigating or reducing or eliminating the effects of autism if used at an early age. While the treatments may seem costly in the short run, hundreds of thousands of dollars, if not millions, are saved over the course of a lifetime by the early utilization of treatments.

Further, while some services are supposed to be provided via the DOE under the Individuals With Disabilities Education Act, in reality, the DOE has done a very poor job of either educating or providing needed services to children with autism. Therefore, other means of providing coverage and services need to be addressed.

Inasmuch as autism is unfortunately becoming common and the costs are so high, insurance coverage is appropriate as a mechanism to spread the risk and cost amongst all of us. We note that **approximately half the states in the country currently mandate some insurance coverage for autism**. Therefore, this would seem to be an approach to addressing this problem which has received broad support.

Thank you for the opportunity to testify in support of this measure.

Testimony of Phyllis Dendle

Before:

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

February 10, 2014
5:00 pm
Conference Room 325

HB 2174 HD1 RELATING TO HEALTH

Chair McKelvey, and committee members, thank you for this opportunity to provide testimony on HB2174 HD1 which would mandate expanded insurance coverage for people with autism spectrum disorders.

Kaiser Permanente Hawaii supports this bill with our amendments.

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

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

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

Date—the date of July 1, 2014 on page one line 14 and page 8 line 11 are normally too early for the health plans to comply with. It is necessary with all additional benefits that health

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 updated criteria 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.

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

This amended bill specifically seeks to provide coverage for applied behavioral analysis. The research that is available including the March 2, 2012 actuarial cost estimate done by Oliver Wyman at the request of Autism Speaks shows that the ABA utilization and therefore costs peak at age 5. From there utilization falls off dramatically through age 8 when it drops to almost no usage. This bill proposes to have health insurance pay for coverage up to age 6 when individuals become eligible for services through the Department of Education.

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

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

Thank you for your consideration.

the treatment of autism have not been covered as habilitative services. The purpose of this Act is to require health insurance to provide coverage for behavioral health treatment of autism spectrum disorders when it is prescribed by an individual's physician and provided by trained professionals, at the time it will most benefit the individual. This treatment shall be covered by health insurance up to the age of six when the individual with autism may receive services as required by federal law from the department of education.

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

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

"§431:10A- Autism spectrum disorders benefits and coverage; notice; definitions. (a) Each individual or group accident and health or sickness insurance policy, contract, plan, or agreement issued or renewed in this State on or after July 1, 2014, shall provide to the policyholder and individuals under twenty-one years of age covered under the policy, contract, plan, or agreement coverage for the screening, including well-baby and well-child screening, diagnosis, and evidence based treatment of autism spectrum disorders.

~~calendar year to health insurance policies subject to this section.~~

~~Payments made by an insurer on behalf of a covered individual for any care, treatment, intervention, or service other than behavioral health treatment shall not be applied toward any maximum benefit established under this subsection.~~

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

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

~~(f) Coverage for treatment under this section shall not be denied on the basis that the treatment is habilitative or non-restorative in nature.~~

~~(g) Except for inpatient services, if an individual is receiving treatment for autism spectrum disorders, an insurer may request a review of that treatment not more than once every twelve months unless the insurer and the individual's licensed physician, psychiatrist, psychologist, clinical social worker, or nurse practitioner agree that a more frequent review is necessary. Any such agreement regarding the right to review a treatment plan more frequently shall apply only to a~~

Manual of Mental Disorders to remain eligible for coverage under this section.

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

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

~~"Autism service provider" means any person, entity, or group that provides treatment for autism spectrum disorders.~~

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

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

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

~~"Treatment for autism spectrum disorders" includes the following care—behavioral health treatment; and habilitative services as defined by the state for the benchmark benefit package in the health insurance exchange; that are prescribed or ordered for an individual with an autism spectrum disorder by a licensed physician, psychiatrist, psychologist, licensed clinical social worker, or nurse practitioner if the care is determined to be medically necessary:~~

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

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

"§432:1 Autism spectrum disorders benefits and coverage; notice; definitions. (a) Each individual or group accident and health or sickness insurance policy, contract, plan, or agreement issued or renewed in this State on or after July 1, 2014, shall provide to the policyholder and individuals under twenty-one years of

~~chapter 92 before adjusting the maximum benefit. The commissioner shall publish the adjusted maximum benefit annually no later than April 1 of each calendar year, which shall apply during the following calendar year to health insurance policies subject to this section.~~

~~Payments made by an insurer on behalf of a covered individual for any care, treatment, intervention, or service other than behavioral health treatment shall not be applied toward any maximum benefit established under this subsection.~~

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

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

~~(f) Coverage for treatment under this section shall not be denied on the basis that the treatment is habilitative or non-restorative in nature.~~

~~(g) Except for inpatient services, if an individual is receiving treatment for autism spectrum disorders, an insurer may request a review of that treatment not more than once every twelve months unless the insurer and the individual's licensed physician, psychiatrist,~~

~~(1) If an individual has been diagnosed as having a pervasive developmental disorder or autism spectrum disorder, then that individual shall not be required to undergo repeat evaluation upon publication of a subsequent edition of the Diagnostic and Statistical Manual of Mental Disorders to remain eligible for coverage under this section.~~

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

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

~~"Autism service provider" means any person, entity, or group that provides treatment for autism spectrum disorders.~~

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

~~"Psychological care" means direct or consultative services provided by a licensed psychologist.~~

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

~~"Treatment for autism spectrum disorders" includes the following care—behavioral health treatment; and habilitative services as defined by the state for the benchmark benefit package in the health insurance exchange; that are prescribed or ordered for an individual with an autism spectrum disorder by a licensed physician, psychiatrist, psychologist, licensed clinical social worker, or nurse practitioner if the care is determined to be medically necessary:~~

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

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

"§432D-23 Required provisions and benefits. Notwithstanding any provision of law to the contrary, each policy, contract, plan, or agreement issued in the State after January 1, 1995, by health maintenance organizations pursuant to this chapter, shall include

LATE

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:

House Committee on Consumer Protection and Commerce

HB 2174, HD 1, Relating to Health

Testimony of Gary L. Gill Acting Director of Health

February 10, 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.