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Testimony COMMENTING on SB 791RELATING TO AUTISM SPECTRUM DISORDERS

SENATORS JOSH GREEN & ROSALYN H. BAKER, CHAIRS SENATE COMMITTEES ON HEALTH & COMMERCE & CONSUMER PROTECTION Hearing Date: 2-6-15 Room Number: 414

1 **Fiscal Implications:** Deferred to legislative audit, DHS and others

2 Department Testimony:

- 3 The Department of Health appreciates the intent of S.B. 791 to improve the access of individuals
- 4 with autism spectrum disorders (ASD) to appropriate services.
- 5 S.B. 791 amends Chapter 431, Hawaii Revised Statutes to provide coverage for the
- 6 treatment of ASD in children, and with maximum benefits stipulated in the bill. One of the most
- 7 important sections on the bill is (h) "This section shall not be construed as reducing any
- 8 obligation to provide services to an individual under any publicly funded program, an
- 9 individualized family service plan, an individualized education program, or an individualized
- service plan." This is essential as many families receive access treatment through the
- 11 Department of Health Early Intervention Section and school programs. These programs should
- not stop and actually should be bolstered in many cases. This insurance benefit could help
- families obtain enhanced services in school settings or in homes, which are important placed to
- 14 provide these services for many children.
- This bill will also allow best practice, evidence-based treatments such as Applied
- 16 Behavioral Analysis (ABA) that have been shown to improve socialization and language of
- individuals especially children with ASD. Treatment of ASD at an early age using ABA and/or
- other treatments will increase the opportunity for children to develop the skills and functioning
- 19 needed for adult life. Improved outcomes may lessen the need for long-term supports when
- 20 children with autism become adults.

The Developmental Disabilities Division serves many adults with autism spectrum disorders who have significant socialization, and language problems as well as significant service needs. Most of these individuals did not have the opportunity to receive intensive treatments as children. Addressing insurance coverage for children at the earliest possible age will make a large impact on programs, and more importantly on the well-being of families.



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TO THE SENATE COMMITTEES ON HEALTH AND COMMERCE AND CONSUMER PROTECTION

TWENTY-EIGHTH LEGISLATURE Regular Session of 2015

Friday, February 6, 2015 1:15 p.m.

TESTIMONY ON SENATE NO. 791 – RELATING TO AUTISM SPECTRUM DISORDERS.

TO THE HONORABLE JOSH GREEN, M.D. AND ROSALYN H. BAKER, CHAIRS, AND MEMBERS OF THE COMMITTEES:

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

This bill adds a new mandated health insurance benefit requiring 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 federal Patient Protection and Affordable Care Act 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.



February 5, 2015

Senate Committee on Health Senator Josh Green, Chair Senator Glenn Wakai, Vice Chair

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

State Capitol 415 South Beretania St Honolulu, HI 96813

Re: In Support of SB791

Relating to Health. Requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism diagnosis and treatment.

Dear Chair Green, Chair Baker, Vice Chair Wakai, Vice Chair Taniguchi, and Members of the Committees:

I am Lorri Unumb, Vice President for State Government Affairs at Autism Speaks and the parent of a child with autism. Autism Speaks is the world's leading autism science and advocacy organization, dedicated to funding research into the causes, prevention, treatments and a cure for autism; increasing awareness of autism spectrum disorders; and advocating for the needs of individuals with autism and their families. Our state government affairs team has played a role in most of the now 38 states that have enacted autism insurance reform laws. Autism Speaks is pleased to submit testimony in strong support of SB791.

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 first to enact autism insurance reform laws; and the long-term cost savings and fiscal imperative of autism insurance reform.

Autism Speaks strongly supports SB 791 and makes note of the following items for consideration during the committees' deliberations:

Page 1, line 9: "issued or renewed in this State after January 1"

According to the National Association of Insurance Commissioners, Hawaii applies mandated coverage for the benefit of its residents if the residents work for (and receive insurance from) an employer who has a branch office or principal place of business in Hawaii, regardless of whether the policy was written in Hawaii, so long as the language of the mandate supports such application. To prevent Hawaii residents whose policies happen to be written elsewhere from losing the benefit of this mandate, Autism Speaks recommends striking "in this State" from line 9.

Page 1, line 11: "under eleven years of age"

Autism Speaks opposes artificially-drawn age caps and believes such caps violate federal mental health parity law. (See Interim Final Rules Under Paul Wellstone and Pete Domenici Mental Health Parity and Addiction Equity Act of 2008, 75 Fed. Reg. 5410, 5413.) Should the legislature decide to nevertheless include an age cap, it is imperative that the cap be applied only to "behavioral health treatment" and not to all autism —related treatment, such as medications, psychiatric care, etc. Given that "behavioral health treatment is already limited by age in paragraph (d), Autism Speaks recommends striking "under eleven years of age" from paragraph (a).

Page 2, line 9: "coverage for treatment provided under this section"
Autism Speaks recommends changing this language to "coverage for behavioral health treatment under this section" in order clarify that only behavioral health treatment is subject to paragraph d's age and dollar restrictions and to be consistent with the final sentence of paragraph (d), which states that payments made for treatment other than behavioral health treatment shall not be applied to any maximum benefit established under this subsection.

Page 2, paragraph (d):

Autism Speaks opposes artificially-drawn dollar limits on treatment and believes such limits violate federal mental health parity law.

Such limits also ensure that children whose parents pay for private health insurance receive inferior coverage to children on Medicaid, since Medicaid coverage under the Early and Periodic Screening Diagnostic and Treatment program is limited only by medical necessity and not by random dollar limits.

With regard to the age restrictions, note that autism is a lifelong condition. While more intense "comprehensive" ABA therapy to address multiple treatment goals is most commonly prescribed at a younger age, "focused" ABA therapy to address isolated maladaptive behaviors

may be required at times throughout the lifespan. Recognizing this fact, the median age cap on ABA in the 38 other states that require autism coverage is 21 years. Seven states impose no age cap on coverage for ABA. Due to the fact that treatment intensity decreases with age, a higher age cap would have a negligible impact on cost of the benefits. In the legislature decides to include an age cap, Autism Speaks recommends that the cap be set either at age 21, to be consistent with Medicaid coverage for ABA, or age 26, the age at which children are no longer dependents under the Affordable Care Act.

Page 3, line 7: "provisions for other medical services covered by the policy" In this paragraph ensuring financial parity for autism treatments, Autism Speaks recommends that the language be amended to read "provisions for substantially all medical services covered by the policy." Pursuant to federal mental health parity law, the "substantially all" standard is the appropriate measure by which to gauge whether a mental health benefit is being treated on par with non-mental health benefits. See attached explanation from United Healthcare.

Page 3, paragraphs (f) and (g): "Except for inpatient services"

Autism Speaks questions whether the sentences permitting insurers to review medical necessity and continued authorization are meant to exclude inpatient services. Autism Speaks also questions whether the sentences in paragraphs (f) and (g) are duplicative, as it is our understanding that reviewing a treatment plan for continued authorization of coverage is the same as reviewing for medical necessity.

Page 4, lines 7-8: "Services and supplies that are not clinically appropriate" Autism Speaks recommends changing this language to "Services and supplies that are not medically necessary," since medical necessity is the governing standard.

Page 4, line 11: "Services provided outside of the State"

Autism Speaks recommends striking this line. Should an individual with autism require, for example, intensive, inpatient treatment at a specialized autism center such as the Kennedy Krieger Institute in Baltimore, which has a program especially for severely aggressive or self-injurious children, there is no reason why the child's health insurance should not cover an otherwise coverable service simply because the treatment occurs outside the State. Such a limitation likely violates federal mental health parity law, unless substantially all medical services are likewise restricted to in-state treatment. So, if, for example, a resident of Hawaii with private health insurance would be able to seek treatment at the Mayo Clinic for a rare heart condition and receive coverage for such treatment, then a resident of Hawaii with autism must be able to likewise receive coverage for medically necessary, out-of-state treatment.

Page 4, paragraph (j):

Autism Speaks is in favor of this paragraph but simply wishes to alert the committee that including behavioral health treatment benefits in Affordable Care Act plans <u>may</u> trigger a cost to the state. Under the ABA, states must defray the cost of a mandate that exceeds the essential health benefits. It is unclear at this point whether the state will incur a cost, because the U.S. Department of Health and Human Services has not yet announced what the essential

health benefits package will be after the 2014-15 transition period during which essential health benefits were defined for each state by reference to the state's chosen benchmark plan.

Page 5, paragraph (I):

Autism Speaks recommends that this paragraph be stricken. There is no scientific justification for requiring all individuals with well-established ASD diagnoses using valid instruments under the DSM in effect at the time of diagnosis to undergo re-evaluation upon publication of a new edition of the manual. Such re-evaluation might be called for on a case-by-case basis where the presentation of symptoms suggests it, but a bright-line rule that simply requires all individuals to be re-diagnosed is not sound, would serve to prevent timely access to care, and would further exacerbate waiting lists for diagnoses that currently exist.

Page 5, paragraph (m):

Although there is currently no license in Hawaii for behavior analysts (the professionals who provide and supervise ABA programs), Autism Speaks can support this approach so long as the legislature understands that a license will need to be created for behavior analysts within one year of the implementation of this benefit, per subparagraph (1). Autism Speaks does not support any requirement that requires or permits any other type of licensed professional to oversee Board Certified Behavior Analysts.

Page 6, line 9: "Autism has the same meaning as defined by the most recent" DSM. The term "Autism" is not defined in the DSM; only "Autism Spectrum Disorder" is defined. As such, the term being defined in the bill should be "Autism Spectrum Disorder."

Thank you for considering my comments. We encourage the committee to pass SB791 and look forward to working with you and the health plans to reach consensus on acceptable terms of coverage.

Respectfully submitted,

Koni Study Unb

Lorri Shealy Unumb

Vice President, State Government Affairs

Autism Speaks

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- Regulations published as the Interim Final Rule are effective on the first day of the plan year beginning or renewing on or after July 1 and must be complied with even though it is not the Final Rule.
- The U.S. Department of Labor (DOL), Department of The Treasury and Centers for Medicare and Medicaid Services (CMS) are seeking feedback on the interim final regulations via an open comment period which ends May 3.
- Regulations are not applicable to Medicaid Managed Care Plans. Separate regulations will be provided from CMS for those plans, but they are still subject to the law.

Benefit Requirements

Establish six classifications of benefits: Parity for treatment limits and financial requirements defined by the regulations, is to be applied classification by classification:

- 1. Inpatient In-Network
- 2. Inpatient Out-of-Network
- 3. Outpatient In-Network
- 4. Outpatient Out-of-Network
- 5. Emergency
- 6. Prescription Drugs
- The definitions of what constitutes Inpatient, Outpatient and Emergency are not defined by the regulations but instead defined by the plan or applicable state law. However, the terms cannot be defined differently for mental health/substance use disorder than for medical/surgical.
- Benefits for mental health and substance use disorder are not mandated, but to
 the extent benefits are provided in one of the six classifications, they must be in
 parity with that classification's medical benefits. Plans are not required to cover
 all mental health conditions or all substance use disorders but may define which
 they will or will not cover. Fully-insured plans are still subject to state mandates
 which may require certain mental health or substance use disorder benefits.
- Financial requirements and quantitative treatment limitations must be in parity
 with the requirements and limitations applied to substantially all benefits for the
 applicable classification on medical benefits. "Substantially all" means the
 requirement/limitations apply to at least two-thirds of the benefits in that
 classification.
- Regulations do not allow recognition of distinction between primary and specialty financial requirements/treatment limitations for parity purposes.
- Regulations prohibit separate cost sharing, e.g., no separate but equal deductibles or out-of-pocket maximums.
- Parity applies to non-quantitative limits and specifically lists the following

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classifications and specifies these **must** be in parity:

- Medical management standards, such as medical necessity
- Formulary design for prescription drugs
- Standards for provider admission to network, including reimbursement rates
- Plan methods for determining usual and customary rates Fail-first or step therapy requirements (e.g., must try certain treatment before obtaining approval for another treatment
- Exclusions for failure to complete a course of treatment These limits must be comparable to and applied no more stringently for mental health/substance use disorder benefits than they are for medical benefits.

Product Requirements

- Employee Assistance Program (EAP) gatekeeper models are prohibited.
- A plan sponsor cannot avoid parity requirements by establishing a separate group health plan for mental health/substance use disorder benefits.
- Plan sponsors with multiple medical benefit plans but a single mental health/substance use disorder plan must ensure compliance for parity purposes between the mental health/substance use disorder benefit plan and each medical plan.
- No guidance is available yet on cost exemption. (This remains under development)

Parity Relevance

Federal Mental Health Parity is relevant to all group health plans (fully insured and self-funded) with few exceptions, such as self-funded non-ERISA government (non-federal) plans that have expressly opted out under existing law and groups with 50 or fewer total employees.

Reference Materials

The Federal Mental Health Parity – A Summary of the Interim Final Rules: What You Need to Know brochure provides an overview of the new Federal Mental Health Parity regulations. The document highlights the key provisions, including implementing parity regulations for financial requirements and treatment limitations.

For more information please contact your UnitedHealthcare representative.

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2/6/15

The Honorable Senator Josh Green, Chair and Senator Glenn Wakai, Vice Chair Committee on Health

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

SB791 Relating to Autism Spectrum Disorders

I am a Board Certified Behavior Analyst (BCBA) since 2004 and possess Master's and Bachelor's Degrees in Special Education, and hold a PhD from University of Hawaii in Exceptionalities/Special Education with an emphasis in Applied Behavior Analysis (ABA).

ABA is defined as the process of systematically applying interventions based upon the principles of learning theory to improve socially significant behaviors to a meaningful degree, and todemonstrate that the interventions employed are responsible for the improvements in behavior (Baer, Wolf & Risley, 1968).

There is an effective and medically necessary treatment for Autism and it is ABA, which is the only intervention for ASD recommended by the Surgeon General. When Autism is identified early and with early ABA treatment the symptoms and deficits of autism can be ameliorated and in many cases reversed. The research states that behavioral programs specifically for children with Autism should be comprised of 25-40 hours per week of individualized instruction using ONLY evidence-based teaching procedures and behavior reduction procedures. The only available evidence-based teaching procedures are derived from the ABA literature (National Standards Report, 2009).

In 2009, the National Autism Center (NAC) recommended that behavioral treatment services begin as soon as a child is suspected of having an autistic spectrum disorder. Such services should include a minimum of 25 hours a week, 12 months a year, in which the child is engaged in systematically planned, and developmentally appropriate activity toward identified objectives. What specifically constitutes these hours, however, will vary according to a child's chronological age, developmental level, specific strengths and weaknesses, and family needs. The priorities of focus should include increasing functional spontaneous communication, social instruction delivered throughout the day in various settings, cognitive development and play skills, and proactive approaches to reducing behavior problems.

ABA can be used to target teaching a variety of skills or reduction of socially significant problem behaviors:

oto increase behaviors (eg reinforcement procedures increase on-task behavior, or socialinteractions);



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- to teach new skills (eg, systematic instruction and reinforcement procedures teachfunctional life skills, communication skills, or social skills);
- oto maintain behaviors (eg, teaching self control and self-monitoring procedures tomaintain and generalize job-related social skills);
- o to generalize or to transfer well in the mainstream classroom);
- o to restrict or narrow conditions under which interfering behaviors occur (eg, modifying the learning environment); and
- o to reduce interfering behaviors and barriers to learning (eg, self injury or stereotypy).
- o Can be used with young children as well as adolescents, and young adults, as well as adult populations.

If Hawaii were to have an insurance mandate pass, this would give families the option to obtain ABA treatment for their child via their health insurer. These families would have the ability to access scientifically supported ABA services in order to make socially significant changes in their child'sbehavior, communication and functional skills. The progress given an intensive and well designed ABA program are astounding and life changing! And surprisingly, many children here in Hawaii have never received ABA treatment before. Especially our keiki of Hawaiian ancestry!

The cost of ABA is minimal compared to the estimated \$3.2 million over the cost of a lifetime, which is ultimately passed on to society and the tax payers who flip the bill to place these adults in residential settings that cost a fortune. That puts a dollar figure on it, but there is no way to measure the lost contributions to society of afflicted individuals if untreated.

Many families who have children with autism are not able to live a "normal" life, because of their child's significant behavior problems. The activities they can participate in as a family are limited, which is so unfortunate to hear when families tell us they can't go to church, or to the beach, or the movies as a family, for fear that their child will have a huge tantrum or engage in life threatening self injurious behaviors in public.

There is currently no cure for autism, however disruptive behaviors and symptoms, aretreatable, much like any chronic disease or disorder are treatable. Without treatment, there is little chance for leading a "normal" life. With intensive ABA treatment, some individuals with ASD actually are able to lose their diagnosis, as they may learn skills, and reduce behaviors to the extent of not meeting the criteria for ASD any longer.

Numerous scientists have reviewed the complete corpus of scientific research and have concluded that competently delivered ABA interventions are evidence-based, effective, and safe for improving functioning, preventing deterioration, and ameliorating symptoms in people with ASD. Therefore, ABA is a medically necessary behavioral health treatment for those spectrum of disorders. Although I am recommending that a bill be passed, I believe it needs to be amended. Behavior analysis is a distinct discipline. The practice of ABA is a distinct profession. It is not the same as psychiatry, clinical psychology, psychiatric nursing, or social work. The competencies and training required to practice ABA have been identified by the profession of behavior analysis through extensive job analyses spanning more than a decade. Those requirements are contained in the standards for obtaining the professional credentials in ABA that are issued by the Behavior Analyst



Certification Board (BACB), a nonprofit organization that is accredited by the National Commission on Certifying Agencies of the Institute for Credentialing Excellence. Part of the rationale for establishing the BACB credentialing programs in 1999 was to provide consumers, funding agencies (such as insurers), and governments a means to identify practitioners who have demonstrated that they meet the standards which were established by the profession for practicing ABA. To illustrate the value of this credential, the Department of Defense and Tricare recognized the value of the BACB credentials in its 2007 report on ASD, and adopted them as the principal requirements for ABA supervisors in the provider standards ABA services. Many other health insurers recognize the value of the BACB credentialing for the provision of ABA for their members, such as Cigna, Aetna, and United Behavioral Health.

Please <u>strongly consider</u> passing this bill for the sake of our keiki in Hawaii.

Respectfully submitted,
Mahalo palena 'ole (for life's blessings),
Amy Smith Wiech, PhD., BCBA
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COMMENTS ON S.B. 791, RELATING TO AUTISM SPECTRUM DISORDERS Friday, February 6, 2015, 1:15 p.m., Conference Room 414

February 5, 2015

The Honorable Josh Green, Chair The Honorable Glenn Wakai, Vice Chair Committee on Health

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

Dear Chairs, Vice Chairs, and Members of the Committees:

This bill would enact cost-sharing legislation similar to laws enacted in more than thirty States to require health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism diagnosis and treatment.

I. Actuarial Report - Cost of Autism Insurance Coverage

The actuarial report required by Act 185, Hawaii Session Laws 2014, estimates that the cost to policyholders of providing for treatment of autism spectrum disorder through applied behavior analysis would be \$24.00 per year in 2015, or \$2 per month. The total cost for 362,000 policyholders (specified in Appendix D, page 2, of Wakely's actuarial report) would be, therefore, \$8,688,000 per year.

II. Need for Additional Funding of Autism Treatment

1. In the past 20 years, the prevalence of autism has increased dramatically from 1 or 2 in 10,000 to a current estimate from the Centers for Disease Control of 1 in 68 (Autism and Developmental Disabilities Monitoring Network (2010)). The reasons for the increase are unknown, since the underlying causes are mostly unknown and appear to be multiple in nature. We know that increased awareness accounts for about one-third of the increase, but the remaining two-thirds is genuine. One of the problems in determining the actual increase is we have tended to rely on routine data from physicians and educators which will give us an underestimate of the issue.

- 2. In addition to the dramatic increase in cases, combined with our ignorance of the causes and the degree of impairment autism causes, we are looking at a dramatic rise in the costs of life-long care for those affected by autism. The best estimate of the lifetime costs of autism (done by the Harvard School of Public Health) is \$3.2 million per person, or \$320 million for every 100 young people who are likely to meet this cost due to the inadequacy of treatment. These costs are shared by parents and state agencies, but the majority of the costs are state based, as they arise between the years after the completion of schooling at age 22 and 50+ years of dependent care.
- 3. This worrisome increase in autism is mostly a new social condition what we know about the symptoms and causes show that society has not faced this condition before, which is why we are so unprepared. Because of this there has been a dramatic increase in research by the federal government and many private groups such as Autism Speaks. However promising this sounds, we are still stuck with an unknown number of years of an extremely expensive condition.
- 4. What we do know about causes and treatment is that autism is a neurologic condition in which the inner connections in the brain are mis-wired. This is a physical fact, so it does not respond to the usual medical treatments like medications and surgery. The reason for this is that the brain is a different organ than the heart, lungs, kidneys, etc. Brain function is based on our experience with the environment. Thus, correction of mis-wiring requires corrective changes in the child's life experience. These changes require intensive exposure to positive, corrective social behavior and language experience. This is why medical insurance has previously not covered these social and language treatments, seeing them as 'habilitative'. However, current neuroscience, genetics and brain imaging all point to the benefits of the kind of behavioral and social-language treatments that this Bill is proposing. There is also abundant evidence-based data showing that these treatments are effective and do reduce long-term impairment. What's important is that the earlier autism is diagnosed and given effective treatment, the better is the outcome and the less the financial impact on families and the state.
- 5. The reason that universal insurance coverage for autism treatments is so important is the fact that it involves all social and ethnic groups. Thus, insurance needs to be broad-based. Fortunately, the experience of 30+ other states shows that autism insurance causes a very small increase in insurance costs given the broad base of the condition.

III. No Appropriation of State Funds Required

In a message transmitting the actuarial analysis by Wakely Consulting Group, the Insurance Commissioner stated that Section 1311(d)(3) of the Patient Protection and Affordable Care Act of 2010 ("PPACA"), 42 U.S.C. § 18031(d)(3), would require the

State to fund the cost of any autism treatment mandate if it is in addition to the ten "essential health benefits" specified in PPACA Section 1302(b), 42 U.S.C. § 18022(b). That is not the case with the insurance coverage mandated by this Bill.

This bill would mandate insurance coverage for (1) behavioral health treatment; (2) pharmacy care; (3) psychiatric care; (4) psychological care; and (5) therapeutic care. Section 2(n) ("treatment for autism").

- Items (1), (3), and (4) are not in addition to the PPACA's "essential health benefits" because they are included in "Mental health ... services, including behavioral health treatment." 42 U.S.C. § 18022(b)(1)(E).
- Item (2) is included in "Prescription drugs," also an essential health benefit. 42 U.S.C. § 18022(b)(1)(F).
- Item (5) includes speech pathology, occupational therapy, physical therapy, and social worker care. Those are "Rehabilitative and habilitative services," also essential health benefits required by the PPACA. 42 U.S.C. § 18022(b)(1)(G).

The Insurance Division says that the State may be responsible for the cost of mandated services exceeding the cost of the benchmark plan, but the PPACA requires the State to pay for mandates that exceed the ten "essential health benefits" specified in the statute, not mandates that exceed the benchmark plan. The State should not be required, therefore, to defray the cost of services mandated by this bill.

IV. Additional Concerns

- 1. Section 2 of the Bill (adding HRS §431:10A-__(a)) and Section 3 (adding HRS §432:1-__(a)) would limit benefits to children under eleven years of age. S.B. 2054 (2014) included individuals to age 21. A higher age limit (to age 26, the age limit for dependent coverage under the PPACA) should be enacted because the lack of treatment services in the past has increased the need for treatment of older individuals. In the future, a reduction of age eligibility might be reasonable.
- 2. Benefit limits in HRS §431:10A-__(d) and HRS §432:1-__(c) are substantially lower than last year's bill -- \$25,000 per year instead of \$50,000 for a much shorter period. ABA therapy, to be successful, would require higher benefits in many cases. Wakely's actuarial report is based on the previous benefit levels, and there is no basis for believing that the lower benefits would result in appreciable cost savings. In fact, they may result in waste if treatment ends prematurely so that benefits are not attained.

3. Subsection (f) provides that an insurer may request a review of treatment plans, but it does not specify any procedures or standards for such review or who would bear the cost.

Thank you for the opportunity to testify.

Respectfully submitted,

Ryan Lee, M.D. President, Autism Society of Hawaii

John P. Dellera, J.D. Legislative Committee



COMMUNITY CHILDREN'S COUNCIL OF HAWAII

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February 4, 2015

Senator Josh Green Chair Senate Committee on Health – Hawaii State Capitol

Representative Rosalyn Baker Chair House Committee on Commerce and Consumer Protection – Hawaii State Capitol

RE: SB791 - RELATING TO AUTISM SPECTRUM DISORDERS.

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

The 17 Community Children's Councils (CCCs) of Hawaii **strongly supports the intent of SB791** which requires health insurers, mutual benefit societies, and health maintenance organizations to provide coverage for autism diagnosis and treatment.

Current statistics show that about 1 in 68 children have been identified with autism spectrum disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. ASD is reported to occur in all racial, ethnic, and socioeconomic groups and is almost 5 times more common among boys (1 in 42) than among girls (1 in 189). Harvard did a study in 2006 that shows it cost \$3.2 million dollars to take care of one autistic individual over their lifetime, estimating costs at least \$17,000 more per year to care for a child with ASD compared to a child without ASD. Costs include health care, education, ASD-related therapy, family-coordinated services, and caregiver time. For a child with more severe ASD, costs per year increase to over \$21,000, these costs put a tremendous burden on the families with children who have ASD. The actuarial report required by Act 185, Hawaii Sessions Law 2014, estimates the cost to policy holders of providing for treatment of autism spectrum disorder through applied behavior analysis would be \$24.00 per year in 2015, or \$2 per month. This cost can be significantly lowered with early identification and treatment which allows the child to reach their maximum potential in college or in their career path and hopefully independent or assisted living.

The CCCs respectfully suggests the following recommendations:

- Increasing the age of intensive behavioral therapy treatment to individuals up to age 26. Young adults, including those with autism, may remain on their parents' insurance up to age 26. (42 U.S.C. § 300gg-14). However, we support the comments issued by Department of Human Services (DHS) on January 2015 that recognizes intensive behavioral therapy be provided to individuals younger than 21 years when determined to be medically necessary.
- 2) Removal of the Annual Dollar Caps. Plans may not place lifetime or annual limits for essential benefits you receive. (42 U.S.C. § 300gg-11)
- 3) Clarifying the term "autism service provider" to section (m) by adding the following:
 - a. A person licensed as a physician and surgeon, physical therapist, occupational therapist, psychologist, marriage and family therapist, educational psychologist, clinical social worker, professional clinical counselor, speech-language pathologist, or audiologist, who designs, supervises, or provides treatment for pervasive developmental disorder or autism, provided the services are within the experience and competence of the licensee. (California Health and Safety Code Section 1796.14-1796.17)
- 4) Clarifying the term "autism service provider" to the definition section (n) by adding the following:

- a. A person, entity, or group that is certified by a national entity, such as the Behavior Analyst Certification Board, that is accredited by the National Commission for Certifying Agencies, and who designs, supervises, or provides treatment for pervasive developmental disorder or autism, provided the services are within the experience and competence of the person, entity, or group that is nationally certified. (California Health and Safety Code Section 1796.14-1796.17)
- 5) Adding in an "unlicensed level similar" to the following in California. Section 'iii' is particularly important because it allows the department to adopt emergency regulations for the immediate implementation of practice so services will not be delayed and 24 months for a certification of completion:
 - a. "Qualified autism service paraprofessional" means an unlicensed and uncertified individual who
 meets all of the following criteria:
 - i. Is employed and supervised by a qualified autism service provider.
 - ii. Provides treatment and implements services pursuant to a treatment plan developed and approved by the qualified autism service provider.
 - iii. Meets the criteria set forth in the regulations adopted pursuant to Section 4686.3 of the Welfare and Institutions Code.
 - 1. The department shall adopt emergency regulations to address the use of paraprofessionals in group practice provider behavioral intervention services and establish a rate. The regulations shall also establish a rate and the educational or experiential qualifications and professional supervision requirements necessary for the paraprofessional to provide behavioral intervention services. The adoption, amendment, repeal, or re-adoption of a regulation authorized by this section is deemed to be necessary for the immediate preservation of the public peace, health and safety, or general welfare, for purposes of Sections 11346.1 and 11349.6 of the Government Code, and the department is hereby exempted from the requirement that it describe specific facts showing the need for immediate action. A certificate of compliance for these implementing regulations shall be filed within 24 months following the adoption of the first emergency regulations filed pursuant to this section.
 - iv. Has adequate education, training, and experience, as certified by a qualified autism service provider. (California Health and Safety Code Section 1796.14-1796.17)

 This further definition is necessary because otherwise it will limit who can provide services to children with Autism. Many of the direct service providers do not have reimbursable licenses and are not "autism service providers" under the definition. The Behavior Analyst Certification Board has created a certification for this level this year in 2015.
- 6) A timeframe for the establishment of a certification program, which includes the above recommendations, should be completed with input from pertinent community stakeholders by the next session. This should to be done in collaboration with the multiple state agencies impacted by this bill i.e. DHS, DOE, DOH etc. in order to meet the needs of this population in the most effective and seamless way possible.

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

We respectfully request your consideration of SB791. Should you have any questions or need additional information, please contact the Community Children's Council Office (CCCO) at 586-5363. Thank you for considering our testimony,

Tom Smith, Co-Chair

Jessica Wong-Sumida, Co-Chair

(Original signatures are on file with the CCCO)



1132 Bishop Street, Suite 2102, Honolulu, Hawaii 96813

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

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

THE SENATE THE TWENTY-SEVENTH LEGISLATURE REGULAR SESSION OF 2015

Committee on Health
Committee on Commerce and Consumer Protection
Testimony on S.B. 791
Relating to Autism Spectrum Disorders

Friday, February 6, 2015, 1:15 P.M. Conference Room 414

Chair Green, Chair Baker and Members of the Committees:

The purpose of the bill is to require health insurance plans to provide coverage for autism spectrum disorders. This is a very significant problem and this coverage seems 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 an increasing number of states in the country currently mandate some insurance coverage for autism. Hawaii in fact is now in a smaller minority. Therefore, this would seem to be an approach to addressing this problem which has received broad support.

Moreover, we recently filed a class action lawsuit in Federal Court against the Department of Human Services to require them to cover applied behavioral analysis under the Medicaid EPSDT program. It now appears that in response to the Court case the Department has announced that it will begin to cover applied behavioral analysis services. In light of that it would seem anomalous to provide these services to our children on Medicaid and not require their provision to the children of families who are working and paying into their system of private health plan coverage.

Thank you for the opportunity to testify on this measure.

SB791: Relating to Autism Spectrum Disorders

Chairs Green and Baker, Vice Chairs and Members of the Health and Health and Consumer Protection Committees

I support this bill. This bill may benefit by including Licensed Marriage and Family Therapists for therapeutic care and treatment of autism. By doing this, the bill would become more comprehensive in the therapeutic care and treatment of Autism Spectrum Disorders. Many Licensed Marriage and Family Therapists statewide are members of multidisciplinary teams that work effectively with Autism. Amending lines 15, 16 and 20 to include Licensed Marriage and Family Therapists would align with the multidisciplinary approach for the care and treatment of Autism Spectrum Disorders. Thank you for the opportunity to provide this for your information.

Abby Halston, Ed.D, NCC, LMFT #189

The Honorable Senator Josh Green, Chair and Senator Glenn Wakai, Vice Chair Committee on Health

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

SB791 Relating to Autism Spectrum Disorders

Committee Chair, Vice Chair, and Committee Members,

I support the intent of SB791, with revisions.

My name is Amanda N. Kelly. I am a Board Certified Behavior Analyst at the Doctoral (BCBA-D™) level. I have been certified as a behavior analyst from the Behavior Analyst Certification Board (BACB™) for the past 10 years, and have been working with keiki with autism for the past 15.

Currently, I serve as:

- Executive Director, Keiki Educational Consultants, Inc. (Haleiwa, Hawai'i)
- K8 Counselor at Assets Elementary (Honolulu, Hawai'i)
- Adjunct Professor, University of West Florida's ABA online program
- Exam Prep Instructor, Global Autism Project (GAP)
- President, Hawai'i Association for Behavior Analysis (HABA)

First, a few facts:

- 1) Autism spectrum disorder (ASD) affects 1 in 68 children in the US, 1 in 42 boys
- 2) The only evidenced-based effective treatment is applied behavior analysis (ABA)
 - a. ABA is endorsed by the US Surgeon General, the American Academy of Pediatrics, the Center for Disease Control (CDC) and many other reputable agencies and experts.
 - b. ABA is recognized by the American Medical Association (AMA)
- 3) 38 States in the United States have passed meaningful Autism Insurance Mandates.
 - a. 12 States remain.
 - b. Hawai'i is the last democratic state remaining.
- 4) Behavior analysts are being reimbursed for their services as CERTIFIED professionals
 - a. Request or "requirements" for licensure have been used as stall tactics in other states
 - b. The process for developing state licensure will require several years
 - c. 18 states license behavior analysts and 1 state. Ohio, credentials behavior analysts at the state level.
 - d. All states that require licensure, accept the BACB credentials (BCBA-D™, BCBA™, BCaBA™)
- 5) Imposing age caps conflict with the mental health-parity law
 - a. Imposing dollar caps may conflict with intention of the affordable care act (ACA)
 - b. Medicaid (the state of Hawai'i) has released a memo extending services through age 21.

The question no longer remains "will Hawai'i pass an autism insurance mandate" but "when will Hawai'i pass a autism insurance". We know it's the right thing to do, from a humanistic as well as a financial perspective. Waiting does damage to individuals affected with autism, their families, schools, and communities. Waiting misses valuable teaching opportunities. Waiting is something our keiki simply can't afford to do. I'm asking you to do what's right and #MalamaOurKeiki.

Many mahalos for the discussion on autism insurance reform in Hawai'i.

Sincerely,

Amanda N. Kelly, PhD, BCBA-D

President, Hawai'i Association for Behavior Analysis

2/5/2015

For the Senate Committee on Health and Committee on Commerce and Consumer Protection,

My name is Anne Lau and I am the Clinical Director of the Autism Behavior Consulting Group clinic. I am writing to show my **SUPPORT** for **SB 791 with amendments**.

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

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

This particular bill has several problems. First, this bill would not require treatment after age 11. This will cause gaps in service for children as they would be required to switch coverage to Medicaid, which is federally obligated to cover services until age 21.

The second problem is the annual maximum benefit cap at \$25,000 and \$30,000. This would effectively provide less than 10 hours of therapy per week. Treatment should be based on medical necessity, and for many children this would be inappropriate.

Thank you for your time and for hearing my point of view of why you should amend SB 791

Respectfully,

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



Derrick K. Abe, O.D.

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

2/6/15

The Honorable Senator Josh Green, Chair and Senator Glenn Wakai, Vice Chair Committee on Health

The Honorable Senator Rosalyn H. Baker, Chair and Senator Brian T. Taniguchi, Vice Chair

Committee on Commerce and Consumer Protection

SB791 Relating to Autism Spectrum Disorders

I am a small business owner in Hawaii, and I am writing to ask you to support autism insurance coverage, specifically the language of HB1108. As you know, children with autism in Hawaii currently aren't covered under most medical insurances.

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

Please support HB1108. Not only does it make good fiscal sense for our state, it is morally and ethically the right thing to do.

Mahalo,

Derrick K. Abe, O.D.

SB791: Relating to Autism Spectrum Disorders

Chairs Green and Baker, Vice Chairs and Members of the Health and Health and Consumer Protection Committees

I support this bill. This bill may benefit by including Licensed Marriage and Family Therapists for therapeutic care and treatment of autism. By doing this, the bill would become more comprehensive in the therapeutic care and treatment of Autism Spectrum Disorders. Many Licensed Marriage and Family Therapists statewide are members of multidisciplinary teams that work effectively with Autism. Amending lines 15, 16 and 20 to include Licensed Marriage and Family Therapists would align with the multidisciplinary approach for the care and treatment of Autism Spectrum Disorders. Thank you for the opportunity to provide this for your information.

Douglas Kainoa Dang, LMFT

From: <u>mailinglist@capitol.hawaii.gov</u>

To: <u>HTHTestimony</u>

Cc: <u>gpinnow@rocketmail.com</u>

Subject: Submitted testimony for SB791 on Feb 6, 2015 13:15PM

Date: Wednesday, February 04, 2015 10:42:53 PM

SB791

Submitted on: 2/4/2015

Testimony for HTH/CPN on Feb 6, 2015 13:15PM in Conference Room 414

Submitted By	Organization	Testifier Position	Present at Hearing
Gerilyn Pinnow	Individual	Comments Only	Yes

Comments: I will be bringing my testimony with copies to the Hearing on Friday. Please include me to orally testify at the Hearing. Thanks for your consideration, Geri Pinnow (Luke's Mom)

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

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

The Honorable Senator Josh Green, Chair and Senator Glenn Wakai, Vice Chair Committee on Health

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

SB791 Relating to Autism Spectrum Disorders

Friday, February 06, 2015, 1:15 PM Conference Room 414, State Capitol 415 South Beretania Street

Dear Chair Green, Chair Baker, Vice Chair Wakai, Vice Chair Tanguchi and members of the Committee,

My name is Johanna Taylor and I am a Board Certified Behavior Analyst (BCBA) with a PhD in early intervention and a specialization in autism spectrum disorder (ASD). I reside on the Big Island of Hawaii. I am writing to encourage you to <u>support SB791</u> with the following changes:

- The age cap should be 21 to match the state obligation related to Medicaid.
- The dollar cap should be removed as it violates the mental health parity law.
- I would like to ensure that BACB credentials are acceptable and frontline staff (RBT, Skills trainers) are also covered as providers, if they are overseen by BCaBA, BCBA, BCBA-D or Psychologists with ABA with-in their scope of practice.

I support SB791 for several reasons. First, as a researcher and clinician I have observed the monumental impact services based in applied behavior analysis (ABA) have had on individuals with ASD and their ohanas. A wealth of research exists supporting ABA clearly demonstrating that it is the most effective intervention approach for individuals with ASD to improve IQ, language, academic performance, adaptive behaviors, challenging behaviors, and social behaviors (Myers and Johnson, 2007, p. 1164). Research has demonstrated that children with ASD can reach typical skill development if provided with services early in life because this is when the brain is the most malleable (Dawson et al., 2010). It is imperative that all children with ASD receive individualized ABA-based services from a young age so they can succeed later in life.

My second reason for supporting this bill is that I have observed the current climate for support for families of children with autism. Unfortunately, in the state of Hawaii, the supports for families of children with autism are extremely limited. Some children receive services through the Department of Education; however, it is clear that the programs for children are not individualized for children with autism, developed by a behavior analyst or grounded in ABA. Therefore, in the cases I have observed, challenging behaviors increased as the child grew older, the level of service needed intensified, and the educational cost for the children grew exponentially over time. There

is often little-to-no parent involvement or parent training; therefore, caregivers are unsure of how to deal with challenging behaviors in their child's natural environment. I have witnessed firsthand parents on the Big Island that are struggling to understand how to deal with challenging behaviors and how to appropriate teach their children; if this bill were to pass, parents would have options and no longer feel confused it would empower families to help their child with autism using effective and evidence-based strategies.

My final reason for supporting SB791 is that currently on the Big Island there are very few individuals trained in behavior analysis. It is my belief that because there is no funding stream to cover services based in ABA, providers are unlikely to move to the island. The Big Island is a beautiful place to live and has a population larger than any other island outside of Oahu. The families here deserve to have appropriate supports so that their children can succeed and live a meaningful lives. If this bill were to pass, it is likely that more BCBAs would choose to move to the Big Island and make it their home as I have done.

Insurance reform is a necessary step towards providing effective services for individuals with ASD. I hope that you consider supporting **SB791** in this legislative session.

Respectfully,

Johanna P. Taylor, PhD, BCBA johannapatriciataylor@gmail.com

Hawaii Association for Behavior Analysis Neighbor Island Representative

References

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., . . . Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*, *125*(1), e17-e23.

Johnson, C. P., & Myers, S. M. (2007). Identification and evaluation of children with autism spectrum disorders. *Pediatrics*, *120*(5), 1183-1215.



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

2/6/15

The Honorable Senator Josh Green, Chair and Senator Glenn Wakai, Vice Chair Committee on Health

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

SB791 Relating to Autism Spectrum Disorders

I support the discussion of Autism insurance coverage in Hawai'i, specifically the language of HB1108. 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 HB1108.**



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

Sincerely,

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

2/5/2015

For the Senate Committee on Health and Committee on Commerce and Consumer Protection,

Children with Autism have been a part of my life for the past 15 years. I worked as a Skills Trainer for a little boy with Autism and never looked back. I have worked in several disciples as a Special Education Teaching Assistant to Developmental Specialist to a Behavior Analyst. I have always been passionate about improving the lives of children, particularly those with disabilities but it wasn't until I studied Behavior Analysis that I had the skills to help make significant and long lasting changes in children's lives. Applied Behavior Analysis (ABA) has given me the skills to teach children to become part of the world around them, to find the joy and happiness they deserve, and allow them to be live a life with as much independence as they can.

Now that myself, and a lot of other talented Behavior Analysts, have the skills and knowledge to teach children who are difficult to teach, not having the resources to do so is devastating. Insurance companies not covering effective treatment is detrimental to children's quality of life but also drastically affects the amount of resources that will be required to care for these children in the future without independent skills. Bills HB 1108 and SB 791 will give my children the chance to get evidence based treatment that is effective. Children with Autism deserve the chance to succeed and in my experience they need Applied Behavior Analysis to do so.

Thank you for your time and for hearing my point of view of why you should amend SB 791

Respectfully,

Kelly Deacon



1

The Honorable Senator Josh Green, Chair and Senator Glenn Wakai, Vice Chair Committee on Health

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

SB791 Relating to Autism Spectrum Disorders

February 6, 2015

Dear Chairs Green and Baker, and Vice Chairs Wakai and Taniguchi,

Thank you for the opportunity to submit testimony on SB791 for **support with revisions**. My name is Kristen Koba-Burdt and I am Board Certified Behavior Analyst (BCBA). For several years, I have worked with individuals with autism on Maui, Oahu, and the Big Island. Similarly, I have submitted testimony and supported efforts to pass meaningful autism insurance reform in Hawaii, for several years. Each year, I've watched as more and more children receive insufficient or no early intervention services and enter the DOE far behind their peers. Sadly, this trend continues and children with autism slip farther and farther away from their neurotyipcal peers. As of today, 38 states, the District of Colombia, and the US Virgin Islands have all passed autism insurance reform and have helped the children of their area gain access to medically necessary treatment. **It's time to do the right Hawai'i.**

While I appreciate the intent of SB791, **limiting services to age 11 does not meet the needs of our state**. As evidenced in the actuarial study commissioned from last year's bill, SB2054, children in Hawai'i are diagnosed on average after their 4th birthday. In my experiences, neighbor island children receive even later diagnosing and a significant delay or no access to services. I have worked with numerous children in intermediate and high school that have not yet acquired a functional way to communicate, are not able to perform activities of daily living independently, and need assistance round the clock for safety. These 13, 15, 17 and even 21 year old individuals with autism can, and do, benefit from Applied Behavior Analysis (ABA) services. I have seen first-hand clients make significant progress in their adolescent years. This progress not only improves the quality of life for the child, but also for their ohana. **Without appropriate services, beyond age 11, individuals with autism will exit the DOE and be reliant on the state for the rest of their lives.** Hawai'i's DOH DDD-Medicaid Waiver system is already stretched thin and the state does not have the capacity to handle the sheer volume of individuals that will need support and services. This number becomes exasperated by the fact

that many of the individuals will enter the DOH-DDD system without having developed basic skills, requiring higher levels of staff support and training. As a former DOH-DDD Training and Consultation provider, I can attest that the current system is not equipped to deal with this higher level of need.

There are numerous service providers in this state that are ready and willing to provide medically necessary ABA services. It is important that the language of SB791 reflect the model of ABA services used around the world. Frontline staff, Registered Behavior Technician's (RBT) or skills trainers, need to also be listed as covered providers, if they are overseen by a BCaBA, BCBA, BCBA-D, or Psychologists with ABA in the scope of their practice. Additionally, it is crucial that credentials from the Behavior Analyst Certification Board (BACB) are accepted for a five year window following implementation and any additional requirements for providers be clearly detailed.

Autism rates have continued to soar. Currently 1 in 68 children are diagnosed with autism. The need for treatment has never been greater and it's important that this bill support an appropriate frequency and duration of treatment, which is why the dollar caps need to be removed. Children with autism can make significant gains, when allowed access to the appropriate level of treatment. Please allow Hawai'i children their right to effective treatment by removing the age and dollar caps.

Malama our keiki,

Kristen Koba-Burdt, M.S., BCBA

Vice-President, Hawaii Association for Behavior Analysis (HABA)

Behavioral Services Manager, BAYADA Habilitation—Maui

I spent two years as a special educator in the DOE working with students with a range of special needs. For my students with autism, there seemed to always be a lack of support for them and their families. I had one student in particular whose mother was very vocal. She was a single mother, an immigrant who spoke English quite well, who worried constantly about her child. Although the DOE provided what they could and we, as a school, provided as much support as we could, it was still a struggle. We need to offer more support to families such as these. Students with autism come from a variety of backgrounds. Some families are unable to afford the care and training they need to raise and aid their child. As a community and as a state, we need to step in with the resources we have to help these families. Please require health insurers, mutual benefit societies, and health maintenance organizations provide coverage for autism diagnosis and treatment. It is not just a benefit to those with autism and their families, but their communities as a whole. Thank you.



February 4, 2015

Honorable Senator Green, Cair Honorable Senator Wakai, Vice Chair Honorable Senator Baker, Chair Honorable Senator Taniguchi, Vice Chair

RE: SB 791: Mandatory Health Coverage for Autism Spectrum Disorders - SUPPORT

Chairman Green, Vice Chair Wakai and Members of the Committee on Health, Chairwoman Baker, Vice Chair Taniguchi and Members of the Committee on Commerce and Consumer Protection:

I fully support SB 791. Mandated insurance coverage for autism treatment in Hawai'i is crucial. Passing this legislation is the right thing to do for individuals with autism and their families- and the right thing to do for our community as a whole.

As a provider with over ten years of experience treating individuals with autism I have seen families loose precious time searching and on waiting lists for a professional with expertise to provide treatment for their child or worse skip treatment completely due to lack of funding.

Each individual with autism and their family is unique; their treatment needs just as unique. *I* am especially supportive of the language of the bill that recognizes state licensed professionals as providers as many, including Licensed Clinical Social Workers (LCSWs) and psychologists are already credentialed with Hawai'i based insurance companies and ready to provide services.

As many children in Hawai'i are diagnosed later than national averages, and even more so on neighbor islands, *I respectfully submit that the age limits be raised to at least 21*.

I look forward to championing this bill and am hopeful that this will be the year we can celebrate its passage and signing. Keiki are waiting and loosing precious time.

Sincerely, Lauren Wilson, MSW Autism Service Provider From: mailinglist@capitol.hawaii.gov

To: <u>HTHTestimony</u>

Cc: <u>gpinnow@rocketmail.com</u>

Subject: Submitted testimony for SB791 on Feb 6, 2015 13:15PM

Date: Thursday, February 05, 2015 7:10:18 AM

SB791

Submitted on: 2/5/2015

Testimony for HTH/CPN on Feb 6, 2015 13:15PM in Conference Room 414

Submitted By	Organization	Testifier Position	Present at Hearing
Luke Pinnow	Individual	Comments Only	Yes

Comments: Luke will have his testimony and copies at the hearing. He would like to give oral testimony. Thanks for understanding.

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

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I am a concerned citizen in Hawai'i and I support Autism insurance. Hawai'i is 1 of 12 states that does not provide meaningful Autism insurance coverage. This needs to change! I support Autism insurance campaigns in Hawai'i, specifically House Bill 1108.

Name	Signature	Date
Sandi Takayama	Saidethoon	2/2/15
Patricia Kido	Patricia Kido	2/2/15
Jan Ohta	Santotita	2/2/15
Patricia Ssupinura	Patricia Jukimena	2/2/15
Jenna Ham	tema sochall	1/4
CANDI PONELL		2/3/15
Chrohne Vunchano	Manghin	2/3/15
Deburah Carter	Dibaah & Cante	2/3/15
Verna Ling-Roche	Gen Sing	2/3/15
Mandakini Boode	Ill	2/3/15
Jodi Stein	July-	2/3/15
Michelle Mmerda	Mich	2/3/15
Corinne K. Thompson	Conneck. They	2/3/15
Tatiana Masuda	Tation masure	2/3/15
Melany Savard	Thelen Sel	2/3/15
Kimberry Nakahashi		2-3-15
Jag Pawloudi	Day Pawloushi	2-4-15
Tara Sesepasaa-Williams	J 5	2-3-15
MINER GARELA	mik Sames	2-3-15



I am a concerned citizen in Hawai'i and I support Autism insurance. Hawai'i is 1 of 12 states that does not provide meaningful Autism insurance coverage. This needs to change! I support Autism insurance campaigns in Hawai'i, specifically House Bill 1108.

Name	Signature	Date
Tiffany Masato	Tifusprects	2/3/15
Kapiolani Kaawalog.	Kapiolini Kaansla	2/3/15
Alison Hoza	allem Hoza	02/03/15
Paula Reachia	- Buspachia	2/3/15
Bridget Reynolds	modest fails	403/15
Adva Matsumuse	adjus	2-3-15
Paul Wasada	Should	2-3-15
Sheri Fujii	Chip of	2-3-15
JOSNICA-THOMAIL	TAXXIAN (MODAL (243/15
Ronnunier	I Rome hope	2/3/15
Ryan Gonzales	Penn y	2/3/15
Jeanne Fukuoka	Jame Lukuoka	2/3/15
Laurice Sogama	Muni P. Myn.	210/15
VIVA, WIA D'AMATO	Ulifai Demeto	2/3/15
Karen Yamamoto	Xauepea	2/3/15
Carolyn Taguchi	Colembia	2/3/15
GERRIE NAKAMURA	Shreet John	2/3/2015
Albert Grandle	alled Thoch	2/3/2015
Gina Antonic	griph	2/3/2017



I am a concerned citizen in Hawai'i and I support Autism insurance. Hawai'i is 1 of 12 states that does not provide meaningful Autism insurance coverage. This needs to change! I support Autism insurance campaigns in Hawai'i, specifically House Bill 1108.

Name	Signature	Date
Sharon Quitevis	Tharm Well	2/3/15
Lois Soto	Por Act	2/3/15
Arlene Sato	aleneSato	2/3/15
Creoffrey Sorto	the	2/3/15
Sara Sofo	Sara Salo	2/3/15
Stephanie DeVrice	Spill	5 Feb 2015
JEREMIAH DEVRIES	Dill	5 FEB 2015
Shannon China	Col-	0/6/16
Lindsay Jones	Literal	2/5/15
Voni Wong	How Mong	2/5/15
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I am a concerned citizen in Hawai'i and I support Autism insurance. Hawai'i is 1 of 12 states that does not provide meaningful Autism insurance coverage. This needs to change! I support Autism insurance campaigns in Hawai'i, specifically House Bill 1108.

Name	Signature	Date
Sandi Takayama	Saidethoon	2/2/15
Patricia Kido	Patricia Kido	2/2/15
Jan Ohta	Santotita	2/2/15
Patricia Ssupinura	Patricia Jukimena	2/2/15
Jenna Ham	tema sochall	1/4
CANDI PONELL		2/3/15
Chrohne Vunchano	Manghin	2/3/15
Deburah Carter	Dibaah & Cante	2/3/15
Verna Ling-Roche	Gen Sing	2/3/15
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Jodi Stein	July-	2/3/15
Michelle Mmerda	Mich	2/3/15
Corinne K. Thompson	Conneck. They	2/3/15
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Kimberry Nakahashi		2-3-15
Jag Pawloudi	Day Pawloushi	2-4-15
Tara Sesepasaa-Williams	J 5	2-3-15
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Tiffany Masato	Tifusprects	2/3/15
Kapiolani Kaawalog.	Kapiolini Kaansla	2/3/15
Alison Hoza	allem Hoza	02/03/15
Paula Reachia	- Buspachia	2/3/15
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Paul Wasada	Should	2-3-15
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Ryan Gonzales	Penn y	2/3/15
Jeanne Fukuoka	Jame Lukuoka	2/3/15
Laurice Sogama	Muni P. Myn.	210/15
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Karen Yamamoto	Xauepea	2/3/15
Carolyn Taguchi	Colembia	2/3/15
GERRIE NAKAMURA	Shreet John	2/3/2015
Albert Grandle	alled Thoch	2/3/2015
Gina Antonic	griph	2/3/2017



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Name	Signature	Date
Sharon Quitevis	Tharm Well	2/3/15
Lois Soto	Por Act	2/3/15
Arlene Sato	aleneSato	2/3/15
Creoffrey Sorto	the	2/3/15
Sara Sofo	Sara Salo	2/3/15
Stephanie DeVrice	Spill	5 Feb 2015
JEREMIAH DEVRIES	Dill	5 FEB 2015
Shannon China	Col-	0/6/16
Lindsay Jones	Literal	2/5/15
Voni Wong	How Mong	2/5/15
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Committee on Health

The Honorable Senator Rosalyn H. Baker, Chair and Senator Brian T. Taniguchi, Vice Chair

Committee on Commerce and Consumer Protection

SB791 Relating to Autism Spectrum Disorders

First Name : jesica Last Name : LA rue

and Street Address: hc2 box 5726

City/Town : keaau Island : Hawaii

Email: divineewon@gmail.com

Message to legislators: Aloha. Mahalo for your support

Committee on Health

The Honorable Senator Rosalyn H. Baker, Chair and Senator Brian T. Taniguchi, Vice Chair

Committee on Commerce and Consumer Protection

SB791 Relating to Autism Spectrum Disorders

First Name : Willy Grace Last Name : Bunghanoy Diama Affiliation (optional) : BAYADA

and Street Address: 95-178 Kipapa Drive #61

City/Town : Mililani Island : Hawaii

Email: gbunghanoy-diama@bayada.com

Message to legislators: My name is Grace Bunghanoy-Diama and I am a Board Certified Behavior Analyst. I am also a Licensed Social Worker (LSW). I have worked with children and families affected with autism for the past 15 years in Hawaii. I am writing to you because I want to talk about SB791 how it will benefit children and families with autism.

I have seen the positive outcomes in utilizing Applied Behavior Analysis. When I first started off as a skills trainer 14 years ago, I had training on behavior modification but not on Applied Behavior Analysis. It wasn¿t until I attended a training on ABA and working with mentors with ABA experience that I witnessed firsthand how systematic, objective, and effective ABA has on children with autism. I remember working with a child with no vocal language and primarily communicating by gesturing or grabbing his mother to indicate what he wanted. If his mother did not know what he wanted, he would flop to the ground and engage in a tantrum. Within in a week of working with him, he was saying a few words and on his way to more functional communication. Of course, his parents were so happy to see his progress and gave them hope that their child could achieve so much more and reach his fullest potential.

I have also seen the struggles families go through with trying to obtain services for their child. Only a few families that I worked with were able to pay for services on their own but not with a lot of financial sacrifices. Most of my families cannot afford to pay for services and must rely on state assisted programs, if they are fortunate enough to be eligible. There is an abundance of literature that illustrates the effectiveness of utilizing ABA in reducing problem behaviors and increasing appropriate skills in communication skills, social skills, and ultimately a better learner. I have witnessed the effectiveness of running an ABA program across the lifespan from infants in the Early Intervention program and after they graduate from high school. The key to an effective ABA program is that it is created by a well-qualified BCBA.

Respectfully,

Grace Bunghanoy-Diama, LSW, BCBA

Committee on Health

The Honorable Senator Rosalyn H. Baker, Chair and Senator Brian T. Taniguchi, Vice Chair

Committee on Commerce and Consumer Protection

SB791 Relating to Autism Spectrum Disorders

First Name : Caroline Last Name : Kong

and Street Address: 3711 Mahina Ave.

City/Town: Honolulu

Island: O'ahu

Email: haha@hawaii.rr.com

Message to legislators: I am writing here in STRONG SUPPORT for SB791:

As the mother of a special needs child I know the struggles within a system that so often blocks not only the fundamentals for a child with complex needs but more so the medically necessary specialized services required for safety and long term successes. The strain on an entire family in this situation is an immense and heartbreaking experience from the gravity and ramifications of a serious disorder carried by a sibling or child. To add more of a burden on families and children in this situation by denying much needed support services, such as ABA (Applied Behavioral Analysis) and related evidence based treatments is cruel and painful for everyone effected. These services are overseen and implemented by what is currently known as a BISS (Behavioral Instructional Support Services) in the Hawai'i DOE systems.

Behavior analysis is a scientifically validated approach to understanding behavior and how it is affected by the environment. In this context, "behavior" refers to actions and skills. "Environment" includes any influence, physical or social, that might change or be changed by one's behavior.

On a practical level, the principles and methods of behavior analysis have helped many different kinds of learners acquire many different skills, from healthier lifestyles to the mastery of a new language. Since the 1960s, therapists have been applying behavior analysis to help children with autism and related developmental disorders.

I implore the Senate and specifically the Senate Committee on Health at the Legislature to vote IN FAVOR of SB791. Please listen to the voices of parents and medical professionals as well as highly regarded academies and associations (CDC, AAP and the U.S. Surgeon General). Understand that the cost benefits to the State will be huge in the approval and implementation of SB791. By the early mediation services of ABA, community based interventions, and the improvement of access to measures direly needed, SB791 will ensure the safety and well being of our students. Hawai'i can only then be on par with 38 other states in preparing children on the Autism Spectrum to become active and secure members of society as they grow into adulthood. Mahalo for your time and consideration in this urgent matter.

The Honorable Senator Josh Green, Chair and Senator Glenn Wakai, Vice Chair

Committee on Health

The Honorable Senator Rosalyn H. Baker, Chair and Senator Brian T. Taniguchi, Vice Chair

Committee on Commerce and Consumer Protection

SB791 Relating to Autism Spectrum Disorders

First Name : Elena Last Name : Vieu

and Street Address: 14-3385 Paradise

City/Town: Pahoa Island: Big island

Email: kozmovieu@gmail.com

Message to legislators: Please pass this bill, it's life saving for our children. ABA is proven to

be one of the best therapies for autism and every child deserve a chance !!

TESTIMONY OF THE AMERICAN COUNCIL OF LIFE INSURERS COMMENTING ON SENATE BILL 791, RELATING TO AUTISM SPECTRUM DISORDERS

February 6, 2015

Via e mail: hthtestimony@capitol.hawaii.gov

Honorable Senator Josh Green, Chair Committee on Health Honorable Senator Rosalyn H. Baker Committee on Commerce and Consumer Protection State Senate Hawaii State Capitol, Conference Room 414 415 South Beretania Street Honolulu, Hawaii 96813

Dear Chair Green, Chair Baker and Committee Members:

Thank you for the opportunity to comment on SB 791, relating to Autism Spectrum Disorders.

Our firm represents the American Council of Life Insurers ("ACLI"), a Washington, D.C., based trade association with more than 284 member companies operating in the United States and abroad. ACLI advocates in federal, state, and international forums for public policy that supports the industry marketplace and the 75 million American families that rely on life insurers' products for financial and retirement security. ACLI members offer life insurance, annuities, retirement plans, long-term care and disability income insurance, and reinsurance, representing more than 90 percent of industry assets and premiums. Two hundred nineteen (219) ACLI member companies currently do business in the State of Hawaii; and they represent 92% of the life insurance premiums and 89% of the annuity considerations in this State.

As drafted, SB 791 would amend Article 10A of Hawaii's Insurance Code to require all individual and group accident and health or sickness issued after a stated date to provide coverage for autism spectrum disorders for individuals under 7 years of age.

By its terms, Article 10A of the Code (by reference to HRS §431:1-205) defines "accident and health or sickness insurance" to include disability insurance.

In 2010, Hawaii enacted HRS §431:10A-102.5, relating to limited benefit health insurance which states in relevant part:

Except as provided . . . elsewhere in this article, when use in this article, the terms "accident insurance", "health insurance", or sickness insurance" shall not include an accident-only, specified disease, hospital indemnity, long-term care, disability, dental, vision, Medicare supplement, or other limited benefit health insurance contract that pays benefits directly to the insured or the insured's assigns and in

which the amount of the benefit paid is not based upon the actual costs incurred by the insure.

However, SB 791, as drafted, mandates autism spectrum disorders coverage for "each individual or group accident and health or sickness insurance policy issued or renewed in this State . . .". ACLI submits that the intent and purpose of this bill is to require only health insurers to provide coverage for autism spectrum disorders – not insurers issuing disability insurance and other limited benefit health insurance policies or contracts.

In order to dispel any confusion as to what this bill is intended to cover, ACLI suggests that paragraph (b) of the new section proposed to be added to §431: 10A (beginning at line 13, page 1, be amended as follows:

§431: 10A- Autisim spectrum disorders; benefits and coverage; notice; definitions. (a) ...

(b) This section shall not apply to accident-only, medicare, medicare supplement, student accident and health or sickness insurance, dental-only, and vision-only policies or policies or renewals of six months or less, or other limited benefit health insurance as defined in HRS §431:10-A-102.5.

Again, thank you for the opportunity to comment on SB 791.

LAW OFFICES OF OREN T. CHIKAMOTO

A Limited Liability Law Company

Oren T. Chikamoto

1001 Bishop Street, Suite 1750

Honolulu, Hawaii 96813 Telephone: (808) 531-1500

E mail: otc@chikamotolaw.com

Please don't write my daughter off.

She is four years old and has her entire life ahead of her. Yet, if she is written off as unable to learn, it would be doing an injustice to society, on a monetary level and an ethical one. She may seem intellectually disabled due to her non-verbal, severe autism, however, she has proven to me on multiple occasions that there is more to her than that.

In addition to my anecdote, data has been collected on her as an individual, demonstrating her ability to learn. Without proper ABA instruction, however, she might never be able to live up to her potential. Doing so allows her to grow up nurtured, with an edge of uniqueness, and challenges leading to higher motivation because, with proper therapy and support, these first challenges in life are solvable. She will have the confidence to succeed with a basic, deserved foundation, as part of her natural rights. From there, she can learn more, catch up to her peers, and once again, be a contributor to society.

It is well documented people with autism sometimes are able to convey their amazing gifts. This may happen spontaneously, or because of learned communication skills. Once my daughter learns to speak, by way of therapies she is not yet covered under by insurance, and develop the associated skills for self care and independence, I have no doubt that her contribution will not only save on Medicaid costs in the long run, but that she will contribute to society in more profound ways than the average.

With a mother who is also diagnosed autistic, with a verbal IQ of 145, I do not doubt that my daughter has the intelligence. It's the severe autism that is in the way, something I never suffered from to this extent. The only way to help her navigate through this world is to learn skills that cannot be taught in a traditional way. The research all points to ABA having significant CAUSATION effects towards improving the outcome for children like my daughter, to the point of complete rehabilitation where it is undetectable by average teachers that these children ever were diagnosed with autism. These are lifelong changes

Amaya, my daughter, has limited use of her hands for fine motor. It will take a lot of fine tuning by people more qualified than myself to assist her in developing those skills. The same is true for her gross motor skills. She is also, sadly, physically disabled. If some sort of intense intervention doesn't take place, she will likely remain in this state, disabled and non-communicative (non-verbal). That means, she will, for her entire life, need public assistance. This can be avoided by covering ABA therapy to improve her functioning level, so she can prove to the world what she has to offer. Every human life deserves that chance.

Committee on Health

The Honorable Senator Rosalyn H. Baker, Chair and Senator Brian T. Taniguchi, Vice Chair

Committee on Commerce and Consumer Protection

SB791 Relating to Autism Spectrum Disorders

My name is Sara Sato and I am Board Certified Behavior Analyst (BCBA). I have a Master's Degree in Special Education, Severe Disabilities/Autism Specialization from the University of Hawai'i at Manoa and have been working with individuals with disabilities for 15 years. I have worked in Hawai'i and San Francisco as an Educational Assistant, Skills Trainer, Behavioral Therapist, Special Education Teacher, and Behavior Analyst practicing Applied Behavior Analysis (ABA). I am writing this testimony to voice my support for encouraging a discussion on autism insurance coverage in Hawai'i. While I appreciate the intent of SB791, I would encourage the committees to consider a few points for revision:

- The age cap should be 21 to match the state obligation related to Medicaid.
- -The dollar cap should be removed as it violates the mental health parity law.
- -I would like to ensure that BACB credentials are acceptable and frontline staff (RBT, Skills trainers) are also covered as providers, if they are overseen by BCaBA, BCBA, BCBA-D or Psychologists with ABA with-in their scope of practice.

Today, about 1 in 68 children has been identified with Autism Spectrum Disorder (ASD) according to estimates from CDC's Autism and Developmental Disabilities Monitoring (ADDM) Network. There are numerous studies which show that Early Detection and Early Intervention are key in addressing the symptoms of ASD (Moore & Goodson, 2003; Peters-Scheffer, N., et. al, 2011, etc.). However, for individuals diagnosed with ASD and their families in Hawai'i, there are very limited state-funded options available for treatment. Families are left to accept the minimal amount of assistance provided by the State (sometimes only 1 therapy session per week); wait until their child reaches school age to seek Special Education Services; or are forced to pay out of pocket for intensive behavioral therapy which can cost between \$40,000 to \$60,000 per year and which only a very small percentage of residents can afford. Additionally, it is estimated to cost at least \$17,000 more per year to care for a child with ASD compared to a child without ASD. Costs include health care, education, ASD-related therapy, family-coordinated services, and caregiver time. For a child with more severe ASD, costs per year increase to over \$21,000. Taken together, it is estimated that total societal costs of caring for children with ASD were over \$9 billion in 2011 (Lavelle, et. al, 2014). It is unreasonable for the citizens of Hawai'i to believe that families affected by ASD can bear the financial and emotional burden on their own.

If this bill is passed there will certainly be an increase in insurance premiums, however, there are studies to support cost savings of Early Intensive Behavioral Intervention compared to Special Education Services (Chasson, G. S., 2007) and Early Intensive Behavioral Intervention and cost-savings over the

lifespan of individuals with ASD (Peters-Scheffer, N., 2012). When we consider this research, it only makes logical and fiscal sense to mandate Hawai'i health insurers to cover the cost of treatment for ASD.

Nationwide there are 38 states which currently require private health insurers to cover the cost of ABA therapy. Let's make Hawai'i the 39th and show our local Ohana affected by Autism that there is hope. There is a way.

Sincerely,

Sara Sato, M.Ed., BCBA

Sara Sato

References:

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Peters-Scheffer, N., Didden, R., Korzilius, H., & Sturmey, P. (2011). A meta-analytic study on the effectiveness of comprehensive ABA-based early intervention programs for children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, *5*(1), 60-69.

Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., & Prosser, L. A. (2014). Economic burden of childhood autism spectrum disorders. *Pediatrics*, *133*(3), e520-e529.

Chasson, G. S., Harris, G. E., & Neely, W. J. (2007). Cost comparison of early intensive behavioral intervention and special education for children with autism. *Journal of Child and Family Studies*, 16(3), 401-413.

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Good Morning Senator Green,

I am Sunshine Carter. I live here on the Big Island. I am writing to you in SUPPORT of S.B. No. 791.

I am writing to you on behalf of my son and all of the children that are falling through the cracks here on the Big Island and the outer islands.

I am a mother of a son with autism. He is bright, beautiful, loving and can light up a room. However, being diagnosed with autism has been our family's biggest hurdle.

In his first year of pre-school, Evan has been released 4 times for his disability due to his autistic behavior and anxiety issues. As stated by his teachers, "Evan needs more than we can provide." He will be attending kindergarten in the fall at the DOE; however, being that he is "high functioning" and extremely bright on the Autism Broad Spectrum, they may not have a way to help him.

You see, services are only offered for children on the low end of the Spectrum. This leaves many children and teachers without help or opportunity. Children with autism clearly need to be taught to learn in a very different way than the mainstream majority.

I am currently trying to get him a Board Certified Behavior Analyst (BCBA); however, there are none on this island. That is hugely due to the fact that insurance coverage does not support autism services offered by these trained BCBA autism specialists.

There are currently no services here on the Big Island that can help my son and his disability because medical insurance will not pay for it.

The unintended consequence that arises when there is no autism coverage to support Board Certified Behavior Analysts (BCBA) or any other autism support services, is that families give up because there are no other alternatives. Teachers suffer because they are not educated in autism and the children suffer when ultimately, they could have thrived.

I have heard this statement many times over from the many doctors and outreach services that I have been in contact with here on the Big Island.

This is not fair at all. As a mother, this is heartbreaking. My husband and I live with this every day.

Both my husband and I are in demanding positions. I work with the County Council and my husband works as a homicide detective with the Hawai'i Police Department. To be able to have a autism aide for my son on a daily basis would be a breath of fresh air for all of us. It would heal our family to know everything that can be done to help Evan, is available to him. Especially parental support, which is often overlooked. This bill will advocate for everyone affected by autism. I commend all efforts that have been put forth to bring attention to this disability.

I am pulled away almost weekly to come to his school to help the teachers settle him. This is extremely hard on the teachers because they do not understand the 'triggers of an autistic child' and how to transition an outburst or anxiety episode, as does a BCBA, autism specialist. Not to mention, how hard it is on his father and I to have to be 'on call' when needed.

TriCare, the United States Military's health insurance, and United Behavioral Healthcare pay for services for children with autism.

TriCare, exists on O'ahu and in several states in the U.S. The children with autism and their families are able to flourish. I have heard there are at least 80 BCBA's on O'ahu that service autistic children under TriCare. Specialists go where they are paid.

All families should have this option, not just military families. All children deserve a chance.

Children and adults with autism and related disorders have the right to effective education and treatment based on the best available scientific evidence. Research has clearly documented the effectiveness of applied behavior analysis (ABA) methods in the education and treatment of people with autism.

Senator Green, don't we all just want the best for our kids? We need to make them the best they can be before the world takes them.

I just want to be heard and my son to have a chance. I am my son's advocate. I am his voice. I am speaking for every parent that is struggling with this.

Thank you for all you do. I hope this testimony touches you.

"Making the decision to have a child is momentous. It is to decide forever to have your heart go walking around outside your body. \sim Elizabeth Stone



Warmest Mahalo,

Sunshine Carter 808 443-3186 sunshinemcarter@gmail.com