

**testimony**

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**From:** JORDON & LAURALEI TANAKA [jnltnaka@hawaiiantel.net]  
**Sent:** Thursday, April 03, 2008 10:45 PM  
**To:** testimony  
**Subject:** SCR196

LATE

Chair Senator Rosalyn Baker and Vice Chair Shan Tsutsui:

I am sending this email in support of SCR196. Please help u sparents help our children.

My son was diagnosed with autism last March and is currently in the Early intervention administered by the Dept of Health. This program is terrific, he is receiving great services, but as soon as he turns 3 he will transition out of this program and into the Dept of Education. The Dept of Education for the most part will only provide him services when he is at school even though we are willing to have therapy sessions after school and on the weekends. An intensive treatment plan has been shown most effective but when I inquired with my HMSA and Kaiser insurances for coverage the answer I received was that they do not provide services to treat developmental disorders. How is a parent in Hawaii supposed to be able to afford additional speech therapy at \$120/hour? The doctor at Kaiser told me that if you were in an accident and you lost your speech that Kaiser would treat you but if you never developed speech they wouldn't. My child is not verbal yet and I am struggling trying to figure out how to get my son all the services I can so that we can hopefully put him in mainstream education classes and one day hear him say 'Mommy'.

Thank you for helping us get the treatment for our children that they need and deserve. Autism is treatable if we get to these children quickly and early; otherwise they will never be able to be a contributing member of our society.

Aloha,

Jordon and Lauralei Tanaka  
3276 Uilani Place  
Honolulu, HI 96816

Kerri Wong  
46-312C Haiku Rd.  
Kaneohe, HI 96744  
247-5956

LATE

4 April 2008

Senator Rosalyn Baker,  
Chair, Senate Ways and Means Committee  
Hawaii State Capitol, Room 210  
415 South Beretania Street  
Honolulu, Hawaii 96813

Senator Shan Tsutsui  
Vice-Chair, Senate Ways and Means Committee  
Hawaii State Capitol, Room 206  
415 South Beretania Street  
Honolulu, Hawaii 96813

Re: Support of Senate Concurrent Resolution 196, Requesting the Auditor to Assess the Social and Financial Effects of Requiring Health Insurers to Provide Coverage for Diagnosis and Treatment of Autism Spectrum Disorders  
Senate Committee of Ways and Means, April 4, 2008, 10:05 a.m., Room 211

Dear Chair Baker, Vice-Chair Tsutsui, and Members of the Senate Committee of Ways and Means,

I am writing as a concerned parent and citizen to express support of Senate Concurrent Resolution 196, related to Senate Bill 2532, otherwise known as Dylan's Law. This resolution will require the state auditor to determine the impact of SB2532 on consumers. SB2532 mandates health insurance coverage for autism spectrum disorders.

I am a parent of a 4 year old son on the autism spectrum named Billy. Billy was diagnosed with autism by a Department of Health psychologist days before his third birthday. He had been receiving services for developmental delay from the Department of Health. On his 3<sup>rd</sup> birthday, the Department of Education assumed responsibility of his services and he attended a DOE Special Education Preschool for 5 months. Unfortunately, together with our team of experts in the fields of psychology and autism, we felt that the "Free Appropriate Public Education" (FAPE) guaranteed to my son by federal IDEA law, was not appropriate for my son's unique learning needs. We therefore were forced to remove Billy from the DOE school, place him in a private preschool, provide the Applied Behavior Analysis (ABA) therapy that we felt was appropriate for his disabling condition out of pocket, and file for due process in an attempt to help pay for these services.

With the changes we have made to Billy's education and therapy, he has made amazing improvement in one year. Here are some examples: Whereas before he could barely answer a simple question and spoke in terse, awkward 3-4 word phrases, now he is having conversations with us, speaking in sentences with over 10 words, and is able to express increasingly complex ideas. Whereas before the extent of his playing with toys was spinning the wheels of cars, now he plays appropriately, makes the "zoom zoom" sounds, and sometimes even narrates what he is doing. What I am most excited and thrilled about is that he is now talking to and interacting with not only his 2 year old sister, but also his peers in preschool.

**My husband and I are optimistic that with continued intensive therapy in his formative years, Billy will eventually shed his diagnosis and become a fully independent, contributing member of society.** It is most important to begin intensive therapy in the years between 2 and 6 yrs old so that he will have the best chances of recovery. Without such therapy, children with autism become lifelong dependents of their families and the State. For each child affected by autism, the potential socioeconomic drain on public resources is immense.

The improvements I see in Billy are a direct result of his intense Applied Behavior Analysis (ABA) program. However, because this type of therapy is time consuming, highly individualized, and must be implemented by trained therapists and consultants, we truly pay through the nose. **Our costs range from \$7,000 to over \$10,000 per month.** Although we have recently been informed that we have won our Due Process Hearing and the DOE will have to reimburse us for part of what we have spent for Billy's therapy, the reimbursement is limited and delayed. **Therefore we still currently bear these costs directly without assistance from the DOE or other governmental agencies.** Despite the exorbitant cost, it is all worthwhile to see our son understand and tell jokes, play appropriately with his toys, converse with us, and for us to see so many other skills emerging. We feel truly blessed that due to our present circumstances we are currently able to afford the therapy. However, it is still an enormous burden on our family. Any amount of financial help from insurance companies would help us immensely and would truly be appreciated.

Autism is a complex neurobiological disorder that currently affects 1 in 150 children, according to the Center for Disease Control. It is a medical diagnosis as defined in the DSM IV - Diagnostic and Statistical Manual of Mental Disorders Fourth Edition (ICD-9 code 299.0) which requires treatment services from trained medical professionals and a full-range of therapies. The therapies include speech therapy, occupational therapy, and intensive behavioral therapy, such as Applied Behavior Analysis (ABA), among others. With proper medical intervention and intensive therapies children with autism can improve to such an extent that they can enter mainstream classrooms unassisted. In our personal experience, such therapies are successful but expensive. Children with autism have been routinely denied coverage for necessary therapies by private health insurance companies. **It is incredulous that such a serious medical disorder has been universally denied coverage by medical insurance carriers. Medical insurance carriers must be required to provide coverage for Autism therapy. Currently these costs are borne by the State Departments of Education and Health and the families themselves.** Virtually all families of children with autism are deeply in debt as a result of the lack of insurance coverage for these necessary therapies. With the epidemic increase in prevalence of this disease, and because needed therapies are prohibitive due to cost, and as these children grow older without improvement, they will eventually become burdens of the State. It is no doubt that the State will be facing a crisis with already strained finances and resources. In the end, the victims will be our children.

In spite of the burdens of autism on the insurance companies, the government, the families, and society as a whole, the most important issue is the child. Dylan's Law is about all children with autism who deserve to have a better quality of life.

I respectfully urge you to pass SCR196, which would enable SB2532 to pass and make insurance coverage for autism a reality. Children with autism in Hawaii deserve to have the opportunity to thrive.

Sincerely,

Kerri Wong, Mother of Billy

LATE

William K. Wong Jr.  
46-312C Haiku Rd.  
Kaneohe, HI 96744  
247-5956

4 April 2008

Senator Rosalyn Baker,  
Chair, Senate Ways and Means Committee  
Hawaii State Capitol, Room 210  
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Sincerely,

William K. Wong Jr., Father of Billy

LATE

Teresa Chao Ocampo  
215 N. King Street, Apt 207  
Honolulu, HI 96817

April 3, 2008

Senator Rosalyn Baker, Chair  
Senator Shan Tsutsui, Vice Chair  
Senate Ways and Means Committee  
Hawaii State Capitol  
415 South Beretania Street  
Honolulu, HI 96813

RE: Testimony for SCR 196, Friday, April 4, 2008, Room 211 at 10:05 a.m.

Dear Senators Baker, Tsutsui and Committee:

I am writing to STRONGLY SUPPORT SCR 196. This resolution is an extremely important for children with Autism since it is related to their health and well being AND the future of our State. Consider the following facts.

In 2005, the CDC found that 8.9% of children from 0 to 17 years of age have asthma, up from 7.5% in 1995. According to estimates from Hawaii's DOH, there were over 28,600 children with childhood asthma in 2006. Although children may outgrow asthma, there are many who will not. Here in Hawaii, vog and other environmental pollutants can exacerbate this condition in children as well as adults requiring a lifetime of treatment throughout adulthood. This medical condition and the various complications related to asthma including respiratory failure, hospitalization, cardiac arrest, and emergency room visits ARE COVERED by Hawaii's health insurers.

According to the CDC's 2005 report, 1 in every 400 to 600 children less than 20 years of age has Type 1 Diabetes. Unlike childhood asthma, Type 1 diabetes cannot be out grown. Like asthma, this too can require a lifetime of treatment throughout adulthood. The treatment of diabetes and its complications such as renal failure, heart and blood vessel diseases, peripheral neuropathies, and blindness currently ARE COVERED by health insurance.

In a February 2007 CDC report, 1 out of 150 children have Autism compared to a 2004 report that found 1 in 166 children with Autism. In 2005, the CDC found that as many as 24,000 children are diagnosed with Autism in the US every year. In 2006, the CDC found that 5.5 out of every 1000 SCHOOL-AGED children are diagnosed with Autism. It has been proven that children diagnosed with Autism who receive intensive treatment early in life including those such as Applied Behavioral Analysis, Speech Therapy, Physical Therapy, Occupational Therapy in addition to Psychological services can learn to function independently in society as adults.

Unlike childhood asthma and diabetes, Autism DOES NOT REQUIRE A LIFETIME OF TREATMENT and therefore, in comparison, could not possibly "cost" as much to Hawaii's health insurers as they claim. To make this even more inequitable for our children, Hawaii's health insurers DO NOT RECOGNIZE AUTISM AS A MEDICAL CONDITION and therefore, the treatment for Autism IS NOT A BENEFIT from Hawaii's health insurers.

Statistics from Hawaii's Department of Education show that Hawaii's School-Aged Autism population EXCEEDS that of the national norm of 5.5 out of 1000. The following statistics come from the DOE's Performance Reports for the quarters October 2007-December 2007, 2006, 2005 and 2004.

Count as of 12/30/Year	# Children under Autism Category (DOE)
2002	646
2003	788
2004	897
2005	975
2006	1025
2007	1133

The official DOE enrollment for School Year 2007-2008 is 171,712 children. **However, with 1133 children under the Autism category currently in the DOE, 0.66% (1133 out of 171,712) compared to the CDC's estimate of 0.55% (5.5 in 1000 School Aged children) with Autism, Hawaii's children are being diagnosed at a rate HIGHER than the national average.**

**In the 5 year time period from 2002 to 2007, the Autism population of School-Aged students in Hawaii's DOE INCREASED BY 75.4%.** This statistic does not even include those children who are not of school-age. What will it be in another 5 years, 10 years? Our children need help now.

Health insurers need to recognize Autism as a condition that is medically treatable with medically necessary therapies. The DOE currently provides minimal services including speech, occupational therapy and physical therapy; however, these services are NOT medically based. They are educationally based. Since they are educationally based, these services are too narrowly focused to truly help the child to acquire practical and functional skills needed to freely participate in a community or society where the child can survive independently.

This is why SCR 196 is so important to our children. Our children deserve a chance to become independent, contributing individuals in our society. The time frame upon which to apply these medical interventions is very narrow. If left untreated, these children may have no choice but to rely on the State as adults beginning at age 21 for support including room and board at a day foster care facility, a living stipend, medical and dental insurance, transportation and other daily living expenses. This could easily add up to an additional 60 years until 80 years of age, the average life expectancy of Hawaii residents. The financial consequences of providing MILLIONS of State dollars every year PER individual PER lifetime will be much less if a resolution such as SCR 196 leads to comprehensive health insurance coverage for all Autistic children in this state.

Doesn't it make more financial sense to have health insurers cover in the relative short term, a treatable MEDICAL condition that SHOULD be a health insurance benefit to Autistic children in the first place? Or is it more financially practical to have the State take on the burden of providing social services to these untreated adults so that they can merely coexist in society and remain totally dependent on these services for up to perhaps 60 years or more throughout their entire adulthood? Given the current economic conditions, Hawaii cannot afford NOT to have SCR 196 passed. The financial implications to this state are much too great to ignore.

Insurance companies will argue that there will be a shift in the cost of Autism related services to those private members who currently pay premiums. This is the usual argument from the insurance companies whenever they face this type of situation, however, the findings almost always show that there is little to no impact on the private members. We will never know the answer unless the proposed assessment is conducted. We owe it to these children to find out before it's too late for them.

Based on statistics from the US Department of Education and other governmental agencies, Autism is growing at a rate of 10 to 17 percent per year. At these rates, it is estimated that the prevalence of Autism could reach 4 million Americans in the next decade.

At 2, 3, 4, 5 years old, the time of diagnosis, it is highly unlikely that a child developed Autism as a form of mental illness from 0 to 5 years of life. They CAN develop a Neurological disorder at

this age or any age involving the brain which is a medical disorder. Autism is a neurological disorder that develops at an early age. Once a child is diagnosed with Autism, it will be a long journey from beginning to end, if there IS an end.

This is why it is so important that this Committee pass SCR 196. Our children need your help in passing this resolution.

**Autism DOES NOT require a lifetime of treatment but the benefits of early treatment WILL LAST A LIFETIME.**

Thank you for your consideration on this very important matter.

Sincerely,

Teresa Chao Ocampo  
Parent