

An Independent Licensee of the Blue Cross and Blue Shield Association

March 11, 2008

## LATE TESTIMONY

The Honorable Robert Herkes, Chair The Honorable Angus McKelvey, Vice Chair

House Committee on Consumer Protection and Commerce

Re: HCR 62 –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

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

Thank you for the opportunity to testify on HCR 62, which would request the Auditor to conduct a study of mandatory health care coverage for the diagnosis and treatment of autism spectrum disorders.

While we are pleased that the Legislature is requesting an Auditor's study as required under Hawaii Revised Statutes 23-51 and 23-52, we have concerns that the language in the accompanying measure (HB 2727 HD2) may be too broad to allow for a truly comprehensive study to be completed. This could potentially cause problems as the Auditor begins work on a study of this type.

We believe that due to the complexity in how children with autism currently receive services, the Auditor will need to examine how this system functions. We would like to add language to HCR 62 asking that the Auditor perform an impact assessment report to review the historical background on Hawaii's current system of providing services to individuals diagnosed with autism. We would ask that this review examine the current responsibilities of the private and public sectors in relation to providing services. We believe that this will provide valuable information to understand the current system.

We would also ask that the Auditor obtain data from the Departments of Education and Health on the incidence of autism within their systems at this time and the cost of providing these services. We believe the Auditor should also examine the role of coordination of care which currently exists between entities, agencies, and providers.

We have also added language asking the Auditor to examine other states where mandates of this type have been implemented. We would also ask that any incidence of cost-shifting to the private sector in these states be reviewed.

Lastly, we believe that any treatment should always be medically sound with proven outcomes and would therefore also add language to ask the Auditor to examine a specific set of services, many of which have been discussed by advocates in prior hearings. We believe this review will assist the Auditor in performing a valuable study that can be used by all stakeholders as we move forward in this process.

We also made one minor deletion to the resolution by removing language on Line 5 which references "pervasive developmental disorder not otherwise specified." We believe that this language could be very broadly interpreted to apply to a wide range of conditions. Some of these conditions could include: Mental Retardation, Borderline Intellectual Functioning, Academic Problems, Conduct Disorder and Oppositional Defiant Disorder. We have removed this language to ensure that the bill is focused on autism spectrum disorders.

Thank you for the opportunity to testify on HCR 62.

Sincerely,

Jennifer Diesman

Assistant Vice President

Government Relations

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## HOUSE CONCURRENT RESOLUTION

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.

WHEREAS, "autism spectrum disorders" means any of the pervasive developmental disorders as defined by the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders, including autistic disorder, Asperger's disorder, Rett's disorder, and childhood disintegrative disorder; and

WHEREAS, autism spectrum disorders are characterized by varying degrees of impairment in communication skills, social interactions, and restricted, repetitive, and stereotyped patterns of behavior that affect an estimated 3.4 out of every one thousand children three to ten years of age and that cause major disruptions in families and unfulfilled lives for many children; and

WHEREAS, section 23-51, Hawaii Revised Statutes, requires that "[b]efore any legislative measure that mandates health insurance coverage for specific health services, specific diseases, or certain providers of health care services as part of individual or group health insurance policies, can be considered, there shall be concurrent resolutions passed requesting the auditor to prepare and submit to the legislature a report that assesses both the social and financial effects of the proposed mandated coverage"; and

WHEREAS, section 23-51 further provides that "[t]he concurrent resolutions shall designate a specific legislative bill that:

- (1) Has been introduced in the legislature; and
- (2) Includes, at a minimum, information identifying the:

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- (A) Specific health service, disease, or provider that would be covered;
- (B) Extent of the coverage;
- (C) Target groups that would be covered;
- (D) Limits on utilization, if any; and
- (E) Standards of care.

For purposes of this part, mandated health insurance coverage shall not include mandated optionals"; and

WHEREAS, section 23-52, Hawaii Revised Statutes, further specifies the minimum information required for assessing the social and financial impact of the proposed health coverage mandate in the Auditor's report; and

WHEREAS, H.B. No. (2008) mandates coverage of diagnosis and treatment of autism spectrum disorders for individuals under twenty-one years of age for all policies and contracts, hospital and medical service plan contracts, medical service corporation contracts, and health maintenance organization plans and contracts issued after December 31, 2008; and

 WHEREAS, the Legislature believes that mandatory health insurance coverage of diagnosis and treatment of autism spectrum disorders, as provided in H.B. No. 2727 HD2 (2008), will substantially reduce illness and assist in the maintenance of good health for the people of this State; now, therefore,

BE IT RESOLVED by the House of Representatives of the Twenty-fourth Legislature of the State of Hawaii, Regular Session of 2008, the Senate concurring, that the Auditor is requested to conduct an impact assessment report, pursuant to sections 23-51 and 23-52, Hawaii Revised Statutes, of the social and financial impacts of mandating coverage of diagnosis and treatment of autism spectrum disorders for all policies and contracts, hospital and medical service plan contracts, medical service corporation contracts, and health maintenance

organization plans and contracts issued after December 31, 2008, as provided in H.B. No. 2727 HD2 (2008); and

BE IT FURTHER RESOLVED the Auditor is requested to submit findings and recommendations to the Legislature, including any necessary implementing legislation, twenty days prior to the convening of the Regular Session of 2009; and

BE IT FURTHER RESOLVED that the Auditor is requested to include in the impact assessment report a review of the historical background on Hawaii's current system of providing services to individuals diagnosed with autism. This review should examine the current responsibilities of the private and public sectors in relation to providing services to include input from the Department of Education, Department of Health, Department of Human Services, Hawaii Medical Association, Hawaii Medical Service Association and Kaiser Permanente; and

BE IT FURTHER RESOLVED that the Auditor is further requested to examine current data from the Department of Education and the Department of Health on the incidence rate of autism within their respective systems and a cost estimate for the provision of autism related services. The review should examine the role of coordination of care under the current system between entities, agencies, and providers. The review should also determine the number of potential individuals who would qualify to receive autism related services through their employer-sponsored health plan and the potential cost shift to private health plans; and

BE IT FURTHER RESOLVED that the Auditor is further requested to include in the impact assessment report a survey of other states in the U.S. which have implemented a mandate for autism services to examine what the experience has been in these states. The assessment shall include a review of the cost impact associated with the mandate of autism diagnoses; the effect on utilization of autism related services and how outcomes for children diagnosed with autism have improved as a result of the mandate. A review should also be included on the availability and utilization of autism services prior to the autism mandate (public v. private) and if there has been cost shifting to the private sector as a result; and

BE IT FURTHER RESOLVED that the Auditor is further requested to include in the impact assessment report a review of the medical effectiveness of current programs that address the symptoms of autism. A review of the scope of services to be provided by licensed medical providers shall include:

- comprehensive diagnostic assessments in all developmental areas (e.g. cognitive, speech and language, occupational skills, recreational skills, self-help, social, emotional, behavioral)
- 2. medication evaluation and intervention
- 3. speech and language therapy
  - 4. occupational therapy
  - 5. recreation therapy
  - 6. self-help skills training
    - 7. applied behavior analysis; and

BE IT FURTHER RESOLVED that certified copies of this Concurrent Resolution be transmitted to the Auditor and to the Insurance Commissioner, who in turn is requested to transmit copies to each insurer in the State that issues health insurance policies.

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

12 March 2008

Representative Robert Herkes
Chair, House Committee of Consumer Protection and Commerce
Hawaii State Capitol, Room 320
415 South Beretania Street
Honolulu, Hawaii 96813

## LATE TESTIMONY

Representative Angus McKelvey Vice-Chair, House Committee of Consumer Protection and Commerce Hawaii State Capitol, Room 315 415 South Beretania Street Honolulu, Hawaii 96813

Re.

Support of House Concurrent Resolution 62, 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

House Committee of Consumer Protection and Commerce, March 12, 2008, 2:15 p.m., Room 325

Dear Chair Herkes, Vice-Chair McKelvey, and members of the House Committee of Consumer Protection and Commerce.

I am writing as a concerned parent and citizen to express support of House Concurrent Resolution 62, related to House Bill 2727. This resolution will require the state auditor to determine the impact of HB2727 on consumers. HB 2727, otherwise known as Dylan's Law, 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. We 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 HCR62, which would enable House Bill 2727 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 Bu

Via Fax 586-6161

## LATE TESTIMONY

March 12, 2008

Chair Robert Herkes, Chair, Consumer Protection and Commerce Committee

Angus McKelveyVice Chair, Consumer Protection and Commerce Committee

Re: Testimony in SUPPORT for HCR62, Relating to Health Insurance Coverage for Autism Spectrum Disorders Consumer Protection and Commerce Committee, March 12, 2008, Room 325, 2:15 p.m

Dear Chair Herkes and Vice-Chair McKelvey, and the members of the Consumer Protection and Commerce Committee:

I am writing to express my support of HCR62 for health insurance coverage for autism spectrum disorders.

1 in every 150 children in the USA is being diagnosed with autism according to the CDC in Atlanta. 1 in every 94 boys are now diagnosed. There is no cure for autism but there is treatment.

With early intervention involving applied behavioral analysis therapy (ABA) there has been a 48 percent success rate in mainstreaming autistic kids back to their original grade levels with their peers. These kids become indistinguishable from other typical kids and continue without the need of further therapy. It should be noted that in the cases where autistic kids can't be placed back in the same class, the progress that they make with ABA therapy is remarkable. This is the only recommended therapy for autism by the US Surgeon General. Currently there is no health insurance coverage offered for treatment of any autism spectrum disorders in Hawaii.

Out of pocket expenses for ABA treatments can range from \$50,000 to \$100,000 depending on the city. Many families go into debt and bankrupt to provide these proven therapies. Providing ABA therapies for these children now will create cost savings to the state by giving these children a chance to become functioning tax paying members of society instead of wards of the state at a cost of over \$4 million per person over their lifetime.

Timing of treatment is critical. Currently, the CDC states "Research shows that early intervention can greatly improve a child's development"

If nothing is done now, our children will not outgrow this disorder. They could become unmanageable, and any intervention at this point will be in the form of managed care. This will put a great burden on the economic welfare of our state systems, because we will have to pay for managed care services over the entire lifetime of autistic adults.

Can you imagine if someone you loved dearly had a stroke, but they could not go to rehab, because the treatment was to expensive. How could you face them every day. This is one of the reasons why families with a child of Autism break-down. It is heartbreaking to watch your child be consumed by autism. This is one reason divorce rates among families with a child of autism are 80%.

We are all in this together as taxpayers. Let's be a part of the solution, and invest in our children now, and help them. It will be a win/win. Or, we can do nothing now, and invest later in a lifetime of managed care. Either way; we are all going to pay. Please pass Dylan's Law House Bill 2727 / HCR 62 and make insurance coverage for autism a reality.

Sincerely, Deborah Tasato-Kodama W