LATE TESTIMONY



DISABILITY AND COMMUNICATION ACCESS BOARD

919 Ala Moana Boulevard, Room 101 • Honolulu, Hawaii 96814 Ph. (808) 586-8121 (V/TDD) • Fax (808) 586-8129

February 20, 2008

TESTIMONY TO THE HOUSE COMMITTEE ON HEALTH

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.

The Disability and Communication Access Board (DCAB) supports House Concurrent Resolution 62 which requests the Auditor to conduct an impact assessment report of the social and financial impacts of mandating health insurers to provide coverage for the diagnosis and treatment of autism spectrum disorders.

Hopefully, this study related to the social and financial effects of mandating health insurers to offer coverage for the diagnosis and treatment of autism spectrum disorders will result in recommendations that will assist the Legislature, health insurers, and parents of children with autism spectrum disorder in crafting a law that will address the needs of those concerned with this issue. We look forward to seeing the results of this study.

Thank you for the opportunity to testify.

Respectfully submitted,

PATRICIA M. NIELSEN

Chairperson

Legislative Committee

FRANCINE WAI Executive Director

Via Fax 586-6051

February 19, 2008

COMMITTEE ON HEALTH Rep. Josh Green, M.D., Chair Rep. John Mizuno, Vice Chair

LATE TESTIMONY

Rep. Karen Leinani AwanaRep. Karl Rhoads

Rep. Della Au BelattiRep. Maile S. L. Shimabukuro

Rep. Joe Bertram, IIIRep. James Kunane Tokioka

Rep. Rida T.R. CabanillaRep. Genc Ward, Ph.D.

Re: HCR 62 Status 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 members of the House Health Committee:

I am writing to express my support of HB 2727, HCR 62 also known as Dylan's Law. This bill mandates health insurance coverage for autism spectrum disorders.

I in every 150 children in the USA is being diagnosed with autism according to the CDC in Atlanta. I in every 94 boys are now diagnosed. There is no cure for autism but there is treatment. That treatment is called Applied Behavioral Analysis Therapy. Autism impairs a person's ability to communicate and relate to others. Autism is also associated with rigid routines and repetitive behaviors, such as obsessively arranging objects or following very specific routines. Symptoms can range from very mild to quite severe.

The good news is that Autism is treatable. 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. Without intervention now, this practice will put a great burden on the economic welfare of our state systems. 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 reliab, because the treatment was to expensive, and out of reach? How could you face them every day knowing that treatment available, but they cannot have access to it, because of the cost. I would not be able to live in peace. This is one of the reasons why families with a child of Autism break-down. It is difficult to watch your child disappear, and be consumed by autism. This is one reason divorce rates among families with a child of autism are 80%.

Currently the following states already have insurance laws for coverage of Antism: California, Georgia, Illinois, Indiana, Iowa, Kansas, Kentucky, Louisiana, Maine, Maryland, Montana, New Hampshire, New Jersey, New York, Tennessee, Virginia, Oregon.

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. 50% have the potential to recover, and the rest progress to becoming independent, productive adults. 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. I want my daughter to be able to give back to this community that is giving to her now. I do not want her to become a burden to the state; especially when it does not have to happen.

Thank you for your consideration.

Deborah Tasato-Kodama

Attachments

Letter - American Academy of Pediatrics - Colorado Chapter Insurance coverages - list of states



AUTISM SOCIETY OF HAWAI'I P.O. BOX 2995 HONOLULU, HAWAI'I 96802 808 228-0122

February 20, 2008

Representative Dr. Josh Green Chair, House Committee on Health Hawaii State Capitol, Room 327 415 South Beretania Street Honolulu, HI 96813

Representative John Mizuno Vice Chair, House Committee on Health Hawaii State Capitol, Room 436 415 South Beretania Street Honolulu, HI 96813

Representative Maile Shimabukuro Chair, House Committee on Human Services & Housing Hawaii State Capitol, Room 406 414 South Beretania Street Honolulu, HI 96813

Representative Karl Rhoads Vice Chair, House Committee on Human Services & Housing Hawaii State Capitol, Room 326 414 South Beretania Street Honolulu, HI 96813

Subject: In strong 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 Committees on Health and Human Services & Housing, February 20, 2008, 9 a.m., Room 329

Dear Chair Green, Vice-Chair Mizuno, and members of the House Health Committee and Chair Shimabukuro, Vice-Chair Rhoads, and members of the Human Service and Housing Committee:

The Autism Society of Hawai'i offers its strong support for House Concurrent Resolution 62. The Autism Society of Hawai'i is an affiliate chapter of the Autism Society of America. It members are composed of families who deal with living with the effects of autism spectrum disorders and the professionals and paraprofessionals who serve them.

The Autism Society of Hawai'i will provide leadership in the field of autism spectrum disorders dedicated to supporting families who advocate on behalf of their children and are committed to reducing the consequences of autism through education, research, and advocacy.

First of all, thank you for considering this important need for the autism community. Autism continues to grow at an epidemic pace and proportion and requires specific health services, such as, an array of early intervention and intensive services. Currently, there is a great need in Hawai'i to provide options and alternatives from the Individuals with Disabilities Education Act (I.D.E.A.) in order for children and students to access these important service programs to meet the unique health and education needs once established under the Felix consent decree.

Parents are being told that the Department of Education (DOE) no longer provides a medical, but an educational service model. All child-serving agencies promised to sustain these services even when federal oversight of the Felix consent decree was removed. As the DOE shifted procurement of these services away, other child-serving agencies did not sustain the level of services that was once provided. For example, the DOH Child and Adolescent Mental Health Division (CAMHD) private contract providers diminished its thirty (30) private contract provider agencies gradually to less than seven (7) when it shifted procurement of services from CAMHD to DOE School-based Behavioral Health (SBBH) model and philosophy.

Specific to autism spectrum disorders, methodologies such as applied behavior analysis (ABA) services are not provided by Hawai'i insurance companies except for Tri-Care insurance for Hawaii-based military families. However, commercial insurance coverage, such as those served under HMSA, is very specific to not approve Felix-related health services to children even when this may be contraindicated.

Parents have a rightful concern to seek out solutions when a promised seamless system of care in both health and education is not sustained nor being responsive.

We need to ensure that children access appropriate medical services in order to restore functionality and the skill-building capacity to grow and become contributing, caring and competent members of their community and the community-at-large. It will be more cost effective to intervene now than to wait and pay later when the costs are greater.

Autism is a complex neurobiological disorder that currently affects 1 in 150 children, according to the Center for Disease Control. This disorder affects boys four times more likely than girls. Autism impairs a person's ability to communicate and relate to others, and is often associated with repetitive behaviors, poor eye contact, and rigidity in routines. Children with autism often have co-occurring conditions, such as behavioral problems, speech disorders, depression, anxiety, muscle or joint problems, ear infections, vision and hearing problems, and allergies. The wide range of co-occurring problems leads to their need for services from trained medical professionals and for 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.

Unfortunately, children with autism are often denied coverage for necessary therapies by private health insurance companies. One important therapy denied by insurers is Applied Behavior Analysis (ABA). ABA has a decades-long record of efficacy. It is a data-based intervention for autism that has over forty years of research behind it. In a 1987 study by Ivar Lovaas, the children who underwent early intensive ABA therapy achieved higher educational placement and increased IQ levels than those who did not. ABA is recognized by The U.S. Surgeon General's 2001 Report on Mental Health as the treatment that is widely accepted as being effective for autism, and the National Institute of Child Health and Human Development acknowledges that Applied Behavior Analysis is an effective treatment for autism. Although ABA is the single intervention most often sought by parents of children with autism, insurers frequently deny it as a benefit. As a result, families are often forced to pay for these costly services out of pocket.

Too many families of children with autism are deeply in debt as a result of the lack of insurance coverage for these necessary therapies. However, the cost of paying for the therapies out of pocket not only causes financial strain for the families, but it also causes heavy emotional distress. For many of these families, the stress is more than they can bear and many of the marriages end in divorce. But in spite of the burdens of autism on the insurance companies, the government, the families, and even on society as a whole, the most important point in this issue is the CHILD.

The Autism Society of Hawai'i is in strong support of and appreciates the opportunity to submit this letter for 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 and make insurance coverage for autism a reality. We look forward to hearing that this house concurrent resolution is passed in the House today. The children with autism spectrum disorders in Hawai'i deserve to have the opportunity to thrive.

Naomi Grossman

Sincerely,

Autism Society of Hawai'i, president