

SCR 51

Measure Title: REQUESTING THE AUDITOR TO ASSESS THE SOCIAL AND FINANCIAL EFFECTS OF REQUIRING HEALTH INSURERS TO PROVIDE COVERAGE FOR AUTISM SPECTRUM DISORDERS.

Report Title: Auditor Report; Mandatory Coverage of Autism Spectrum Disorders

Description:

Companion:

Package: None

Current Referral: CPN, WAM



HAWAII DISABILITY RIGHTS CENTER

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THE SENATE THE TWENTY-SIXTH LEGISLATURE REGULAR SESSION OF 2011

Committee on Commerce and Consumer Protection Testimony in Support of SCR 51

Tuesday, March 29, 2011 9:00 A.M.
Conference Room 229

Chair Baker and Members of the Committee:

I am Louis Erteschik, Staff Attorney at the Hawaii Disability Rights Center, and am testifying in support of this Concurrent Resolution.

The purpose of the measure is to request the Legislative Auditor to perform an impact study to determine whether health insurance plans should be required to provide coverage for autism spectrum disorders. This is a very important issue and this coverage is very appropriate for insurance policies. The whole point of insurance is to spread risk and cost among an entire population, so that disproportionate, catastrophic expenses are not heaped upon specific individuals or groups.

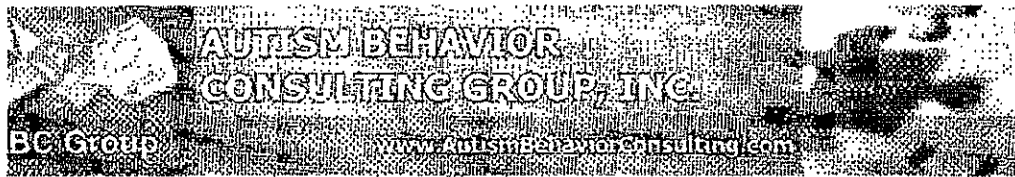
With that in mind, we need to realize that autism is occurring among children in epidemic proportions. According to current statistics, **one out of 110 children (1 out of 85 boys) are born with autism**. That is a staggering, alarming figure, as is the cost to those families and to society to care for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

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

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

Since the legislative proposal to mandate the coverage did not pass this session, we believe that it would be appropriate to update the study done a few years ago by the Legislative Auditor. In particular, we would suggest that the alarming incidence of autism be factored into the impact assessment and that the auditor look at the information which has come to light since the last study was undertaken.

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



TESTIMONY IN SUPPORT OF HOUSE BILL 821 INSURANCE COVERAGE FOR AUTISM SPECTRUM DISORDERS

March 28, 2011

Dear Senator Baker—I am writing to urge a “yes” vote on SCR 51, to request the auditor assess the social and financial effects of requiring health insurers to provide coverage for autism spectrum disorders. I am a provider of service and a special education teacher. The cost of care is prohibitive, and Department of Education resources are insufficient to be fully effective.

Autism is a medical condition. With proper treatment, children can go on to become independent, productive members of society. Without treatment, the Harvard School of Public Health estimates the cost of caring for an autistic person to be \$3.2 million. These costs are passed on to the taxpayers.

Please support SCR 51.

Dear Senator Baker,

I am a Board Certified Behavior Analyst (BCBA) and possess Master's and Bachelor's Degrees in Special Education, as well as being a PhD student at University of Hawaii in Exceptionalities. I have worked with children with Autism for over 17 years. We have a service provision agency, and a on Oahu, where we employ staff to provide intensive interventions based on Applied Behavior Analysis (ABA) to children and adolescents with Autism, and other developmental disabilities of Hawaii. We are a group of talented individuals who provide evidence based teaching and behavioral interventions to children/adolescents with Autism/ Aspergers, Mental Retardation (MR), Developmental Delays (DD), ADD/ ADHD and other related disabilities and behavioral challenges. We have 6 Board Certified Behavior Analysts/Assistants, and a Team of well trained Skills Trainers and Tutors.

Services for autism that families receive from the Department of Education (DOE) schools are very limited in the scope that they provide, and many children are not even receiving ABA treatment in school. The DOE is not equipped to handle the proportion of kids with Autism in Hawaii!

If Hawaii were to have this bill pass, this would give motivated families the option to seek additional funding for ABA via their health insurer to have the ability to access scientifically supported ABA services in order to make socially significant changes in their child's behavior, communication and functional skills. **This is the reason that I chose this profession-to be an integral part of these significant changes in behavior, communication and functional skills. The progress given a quality ABA program are astounding and life changing!**

The research states that educational programs specifically for children with Autism should be comprised of 30-40 hours per week of individualized instruction using ONLY evidence-based teaching procedures. Schools are not providing this. **The only available evidence-based teaching procedures are derived from the ABA literature (National Standards Report, 2009).** We at ABC Group pride ourselves on using the evidence-based interventions we are describing.

Applied behavior analysis (ABA) is the process of systematically applying interventions based upon the

principles of learning theory to improve socially significant behaviors to a meaningful degree, and to demonstrate that the interventions employed are responsible for the improvement in behavior
(Baer, Wolf & Risley, 1968)

The intensive and naturalistic teaching formats required for some children involve a high number of teaching trials (thousands) with carefully arranged contingencies (i.e. prompting, fading, careful shaping, transfer of stimulus control, use of the motivating operation, differential reinforcement, etc.), and careful measurement of progress. We collect data and graph each session, so that we know that our intervention is working, and making the changes that we targeted for change.
The science of ABA is very effective in creating desired outcomes.



Autism Behavior Consulting Group, Inc / ABC Group

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www.AutismBehaviorConsulting.com

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vs: 03/01107



ABA has several objectives when used to target a variety of skills or problem behaviors:

- o to increase behaviors (eg reinforcement procedures increase on-task behavior, or social interactions);
- o to teach new skills (eg, systematic instruction and reinforcement procedures teach functional life skills, communication skills, or social skills);
- o to maintain behaviors (eg, teaching self control and self-monitoring procedures to maintain 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 (eg, self injury or stereotypy).

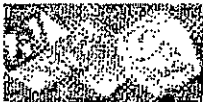
ABA can be used to teach speech articulation, vocabulary, language, gross and fine motor skills, eating and food preparation, toileting, dressing, personal self-care, domestic skills, time and punctuality, money and value, home and community orientation, functional work skills and many others! ABA is not only effective with individuals with Autism, but with individuals with other developmental disabilities, and typically functioning individuals such as you and I as well! Please consider passing this important bill. I strongly recommend that you also support House Bill 821 to mandate health insurance coverage for autism spectrum disorders in Hawaii. Autism is a developmental disability that results in impaired communication and social interaction. Rates of autism are estimated to be 1:100 kids.

There is an effective treatment for Autism and it is Applied Behavior Analysis (ABA) which is the only intervention 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 cost of intensive early intervention 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 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. They are limited in the activities they can participate in as a family, 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 in public.

Autism can be treated. All that matters right now is that we get the insurance companies involved the way 23 other states all ready have. Virginia was the most recent state to pass this legislation.

There is currently no cure for autism, however disruptive behaviors and symptoms, are treatable, much like any chronic disease or disorder is treated, and is routinely covered by insurance. Without treatment, there is little chance for leading a normal life. With treatment, some autistic individuals have actually lost their diagnosis.

Many insurers will cover gastric bypass (cost \$100, 000) for their patients who are overweight. And they will do this every year if needed. But they will not cover effective treatment for children who have **SO MUCH POTENTIAL TO LEARN!**



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Twenty-three states have already enacted legislation mandating insurance coverage for autism treatment. Indiana has no cap on cost, and most other states have \$50, 000 caps per year. **Let's end health insurance discrimination against children with autism in Hawaii and make Hawaii #24 of the 50 States providing mandated insurance coverage for children with Autism.**

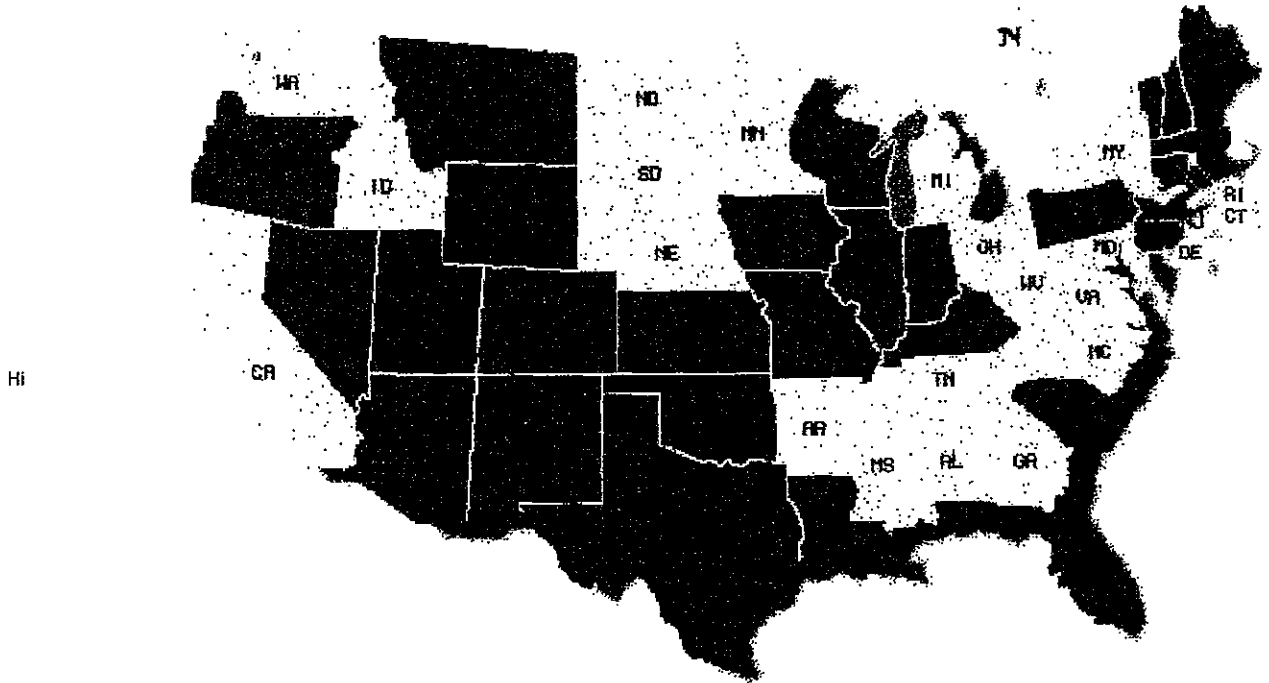
Sincerely,

A handwritten signature in black ink, appearing to read 'Amy Wiech', with a long, sweeping horizontal stroke extending to the right.

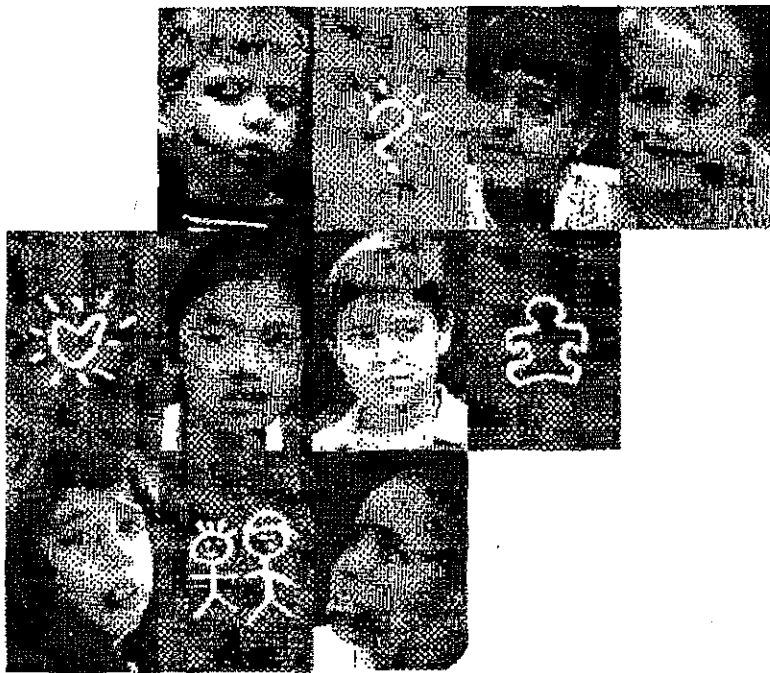
Amy Wiech, M.Ed., BCBA
Board Certified Behavior Analyst
CEO/Founder/Director of Operations



2011 State Initiative Agenda: Current Status of State Autism Insurance Reform Bills



Arizona	Missouri	Oregon	Alabama	Nebraska	Oklahoma
Colorado	Montana		Alaska	New York	Utah
Connecticut	Nevada		Arkansas	North Carolina	Wyoming
Florida	New Hampshire		California	North Dakota	
Iowa	New Jersey		Delaware	Ohio	
Illinois	New Mexico		Hawaii	Rhode Island	
Indiana	Pennsylvania		Georgia	South Dakota	
Kansas	South Carolina		Idaho	Tennessee	
Kentucky	Texas		Maryland	Virginia	
Louisiana	Vermont		Michigan	Washington	
Maine	Wisconsin		Minnesota	Washington, DC	
Massachusetts			Mississippi	West Virginia	



Self-Funded Health Plans:

Establishing an Autism Benefit

**Lorri Unumb, Esq.
Autism Speaks**

lorri.unumbaautismspeaks.org

What is Autism?

- **Autism is a medical condition, brought on through no fault of the family.**
- **Autism affects a person's communication abilities and social skills, and often causes repetitive patterns of behavior.**
- **Autism is diagnosed by a medical doctor (usually a developmental pediatrician).**
- **Treatment is prescribed by a medical doctor.**

"Autism"

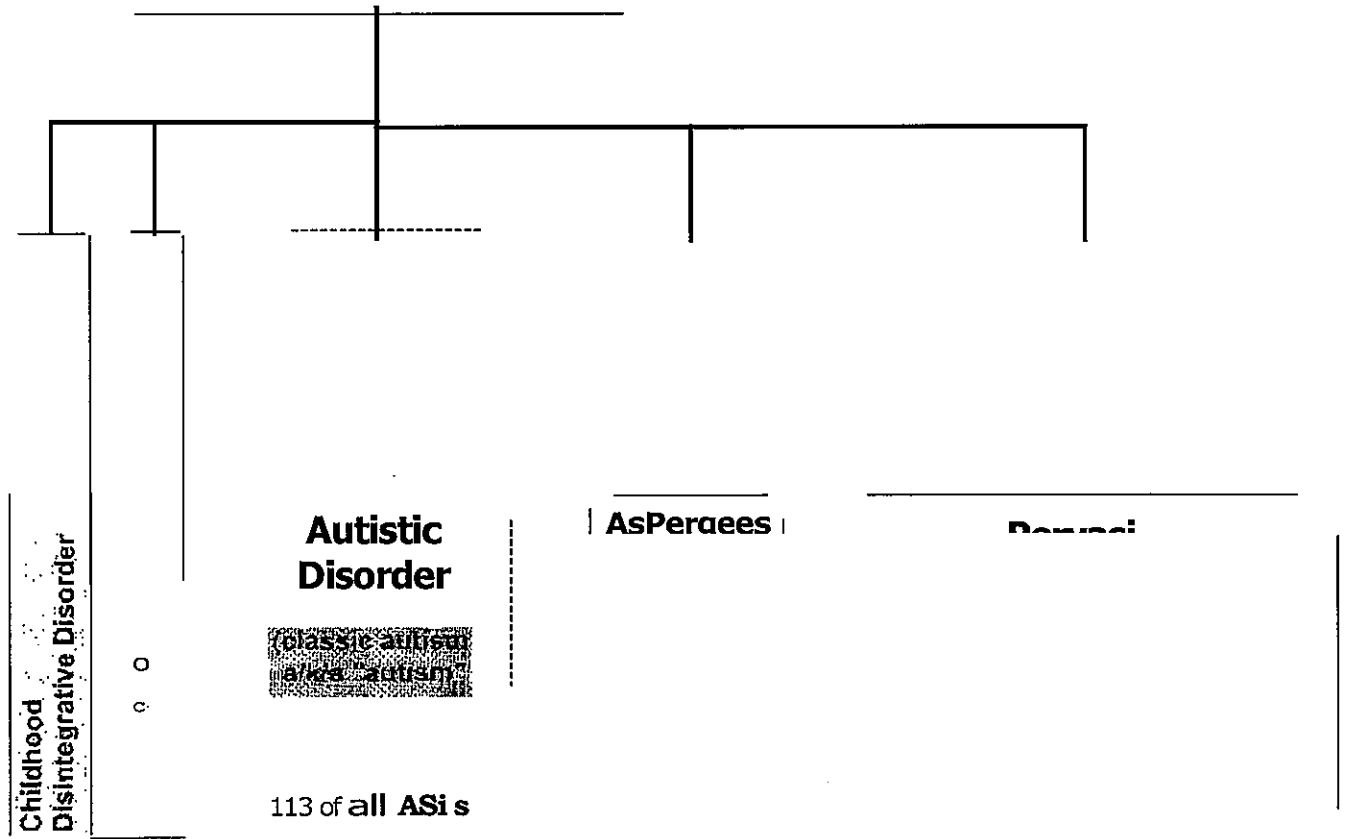
- The term "autism" is often used imprecisely:
 - some people use it interchangeably with "autism spectrum disorder"
 - others use it to mean one of the autism spectrum disorders.
- In fact, there are 3 distinct diagnoses within the family of autism spectrum disorders. (See chart on next slide.)
- Across the spectrum, people vary greatly in terms of type and severity of deficits.

Pervasive Developmental Disorders

the umbrella category in the DSM-111)

There are 5 Pervasive Developmental Disorders (PDDs).

Within the 5 PDDs, there are 3 **Autism Spectrum Disorders** (ASDs), shown in purple below,



Syndrome

**Developmental
Disorder — Not
Otherwise Specified**

PDD-N OS)

less than 110:
of all Mos

iApprx:::1/4.

Curable? Treatable?

- **Although there is no known cure for autism, it can be treated so that the symptoms are not disabling.**
 - **A non-verbal child can gain the ability to communicate**
 - **A non-social child can gain interaction skills.**
- **With treatment, children with autism are not cured but can overcome the disabling aspects of the condition.**

Autism Treatment:

- The most commonly-prescribed treatment protocol involves a therapy called "**Applied Behavior Analysis,**" or ABA therapy.
- ABA therapy has been used for many decades to treat autism, but many insurers deny coverage on the basis that ABA therapy is "experimental."
- That conclusion is simply not supported by the science, and the **Surgeon General, the National Research Council, and the American Academy of Pediatrics** endorse the use of ABA therapy for kids with autism.

American Academy of Pediatrics, 2007:

"The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups."

United States Surgeon General, 1999:

"Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."

Treatment Outcomes:

- Studies show that, if ABA therapy is administered intensively and by properly-trained therapists, approximately half of the treated kids will "overcome" their autistic characteristics to such an extent that they can enter 1st grade **indistinguishable from their peers**. And the other half make significant gains, too, such that they need less support for the rest of their lives. (Lovaas, UCLA 1987)
- Because ABA therapy must be administered intensively — sometimes 40 hours per week — it is quite expensive. (See next slides)

Wealthy parents pay out-of-pocket to provide their children ABA therapy, which typically lasts 3-4 years.

- Less fortunate children go without therapy, end up in costly special education programs, and eventually become wards of the state.

Applied Behavior Analysis: *Three Tiers of a Typical Program*

1. Consultant

- Highly educated and trained
- Board Certified
- Evaluates, designs, trains
- 3-6 hours per month



2. Mid-level supervisor (lead therapist)

- Highly educated and trained
- May be Board Certified
- Updates programming; trains; oversees
- 6 hours per week

3. Line therapists

- Often recent graduates or college students, trained by above
- Provide 25-40 hours per week of direct therapy, usually in 3-hour shifts

Applied Behavior Analysis: *Cost of a Sample Program*



1. Consultant

- 3-6 hours per month
\$100-\$150/ hour
- 6 hours x \$150 = \$900/month
- \$900 x 12 months = **\$10,800/year**

2. Mid-level Supervisor (lead therapist)

6 hours per week

- \$30-\$60/hour
- 6 hours x \$60 = \$360/week
\$360/week x 52 weeks = **\$18,720/year**

3. Line Therapists

40 hours per week

- \$10-\$20/hour
- 40 hours x \$20 = \$800/week
\$800/week x 52 weeks = **\$41,600/year**

\$10,800 + \$18,720 + \$41,600 = \$71,120

Taxpayer Burden

- **A 2006 Harvard study found that if a child with autism is not properly treated, the societal cost for that one child over their lifetime is \$3.2 million. (Ganz 2006).**
- **A Pennsylvania study projected an actual cost savings to the state of over a million dollars per child. (Jacobson, Green 1998).**

Increased Prevalence = Higher Burden

- In 1985, the prevalence rate of autism was 1 case per 2500. Today, it is 1 in 110. (CDC, 2009)
- Do the math: 1 in 110 kids diagnosed; only the wealthy few get treatment; and multiply each remaining child by over a million dollars. That's how much taxpayers will shell out if these kids don't get treatment.

Increased Prevalence = Higher Burden

- **Scientists don't know the reason for the increase in prevalence, but we all understand the ramifications. There's a huge autism tsunami coming, and it is going to cost taxpayers an extraordinary amount in special education and adult care if the current generation of kids does not get treatment.**
- **Without private insurance coverage, the treatment is simply not going to happen.**

States Taking Action

- **Faced with this reality, states are moving to mandate insurance coverage for autism treatment.**
- **Indiana passed the first meaningful bill in 2001, the same year the Attorney General in Minnesota settled litigation with that state's major insurer (BCBS) to require coverage for autism, including coverage of Applied Behavior Analysis therapy.**
- **21 states have passed autism mandates; 12 states & Congress are now considering them.**

Comparison of State Autism Benefits

	SC	MN (BCBS Covera ge)	AZ	MT	IN	PA
Annual Cap	\$50K (only on ABA)	Unlimited	\$50K thru 8; \$25K 9-16	\$50K thru 9; \$20K 9-18	Unlimite d	\$3 6 K
Diagnosed by age	8	n/a	n/a	n/a	n/a	n/a
Benefits until age	16	No age cap	17	18	No age cap	21

Treatment must be prescribed by licensed physician or psychologist.

In The States With Autism Insurance Reform.

- **Children who have never before been able to receive treatment are making remarkable progress.**
- **Providers have joined adequate networks of participating providers and negotiated satisfactory reimbursement rates.**
- **The impact on premiums has been negligible.**
- **The insurance industry's own association — the Council for Affordable Health insurance — estimates that mandated autism benefits have increased premium costs by LESS than 1%. (See chart)**

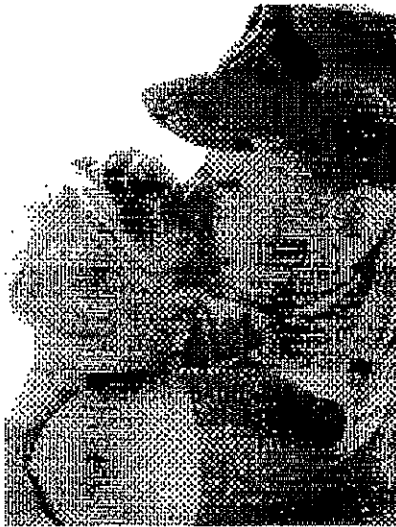
Excerpt from 2008 Report of the Council For Affordable Health Insurance:
"Health Insurance Mandates in the States"

BENEFITS:	Est. Cost	#
Alcoholism	1-3%	45
Autism	<1%	11
Contraceptives	1-3%	31
In Vitro Fertil.	3-5%	13
Prescriptions	5-10%	2

Available at www.CAHL.org.

The Council for Affordable Health Insurance is a research and advocacy association of insurance carriers active in the small group, individual, HSA, and senior markets. CAHI is an active advocate for market-oriented solutions to the problems in America's health care system.

United States Department of Defense



- Also, military insurance (TriCare) covers autism and specifically includes a benefit for Applied Behavior Analysis therapy.



Unfortunately . .

- **Even in the states that have passed autism insurance mandates, many children are still unable to receive treatment because they are insured through self-funded plans that are not regulated by the state.**

What is a Self-Insured Employer?

- If you work for a large company or government, there is a chance your health plan is self-insured.
 - These self funded plans are not really insurance. The employer pays employee benefits from the employer's own pocket and assumes the risks.
 - Self-funded employers often hire third-party administrators (TPAs) to keep track of premiums, claims, and related paperwork.
 - If the employee is in a self-insured plan, preempts most state insurance regulation, including benefit mandates.
-

ERISA: *The Employee Retirement Income Security Act*

- The Employee Retirement Income Security Act of 1974 (ERISA) is a federal law that sets minimum standards for most voluntarily established pension and health plans in private industry to provide protection for individuals in these plans.
- ERISA allows companies to set up self-funded plans that are governed by federal law and exempt from state insurance regulations.
- There have been a number of amendments to ERISA, including COBRA and HIPAA, expanding the protections available to health benefit plan participants and beneficiaries.
- The Autism Treatment Acceleration Act (ATAA) of 2009 seeks to amend ERISA law by requiring coverage of autism treatments.
- For more information about ERISA, visit the U.S. Department of Labor's website at

Companies With Self-Funded Plans that Cover Autism

Many self-funded companies have elected to implement autism benefits, even though ERISA law does not yet require them to do so.

- Mayo Clinic
- Home Depot
- Porter
- Symantec
- Microsoft
- H
- Lexington Medical Center
- Intel
- University of Minnesota
- Arnold & Progressive Group
- S
- Greenville Hospital System
- Halliburton
- Time Warner
- Eli Lilly

Why Implement an Autism Benefit?

- **Greater employee productivity.**
- **Employee retention is maximized - employees will not feel the need to leave in search of a job with state-regulated insurance.**
- **Children who achieve higher levels of functioning**
 - **have lower overall health care costs**
 - **do better in school**
 - **need less assistance from their families, from whom autism often exacts a terrible financial and psychological toll**
- **A child is given the opportunity for a functional, happy life and is saved from a lifetime of institutionalization.**

“[N]o
disability
claims
more
parental
time and
energy
than
..



New York
12120/01

What Should the Autism Benefit Look Like?

- Coverage should include
 - Applied Behavior Analysis (ABA) Therapy
 - Speech Therapy, Occupational Therapy, and Physical Therapy
 - Psychological, Psychiatric, and Pharmaceutical Care
 - Diagnosis and Assessments
- No visit limits (other than restrictions prescribed by treating physician)

What Should the Autism Benefit Look Like?

- **No denials on the basis that treatment is**
 - **Habilitative in nature**
 - **Educational in nature**
 - **Experimental in nature**
- **For Applied Behavior Analysis coverage, treatment must be provided or supervised by a behavior analyst who is certified by the Behavior Analyst Certification Board.**

For more assistance in crafting an autism benefit for your company, please contact Autism Speaks

Autism Speaks, the world's largest autism advocacy organization, is dedicated to increasing awareness of autism spectrum disorders, to funding research into autism, and to advocating for the needs of affected families.

_____ Please visit
www.AutismSpeaks.org for more information

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lorri.unumb@autismspeaks.org

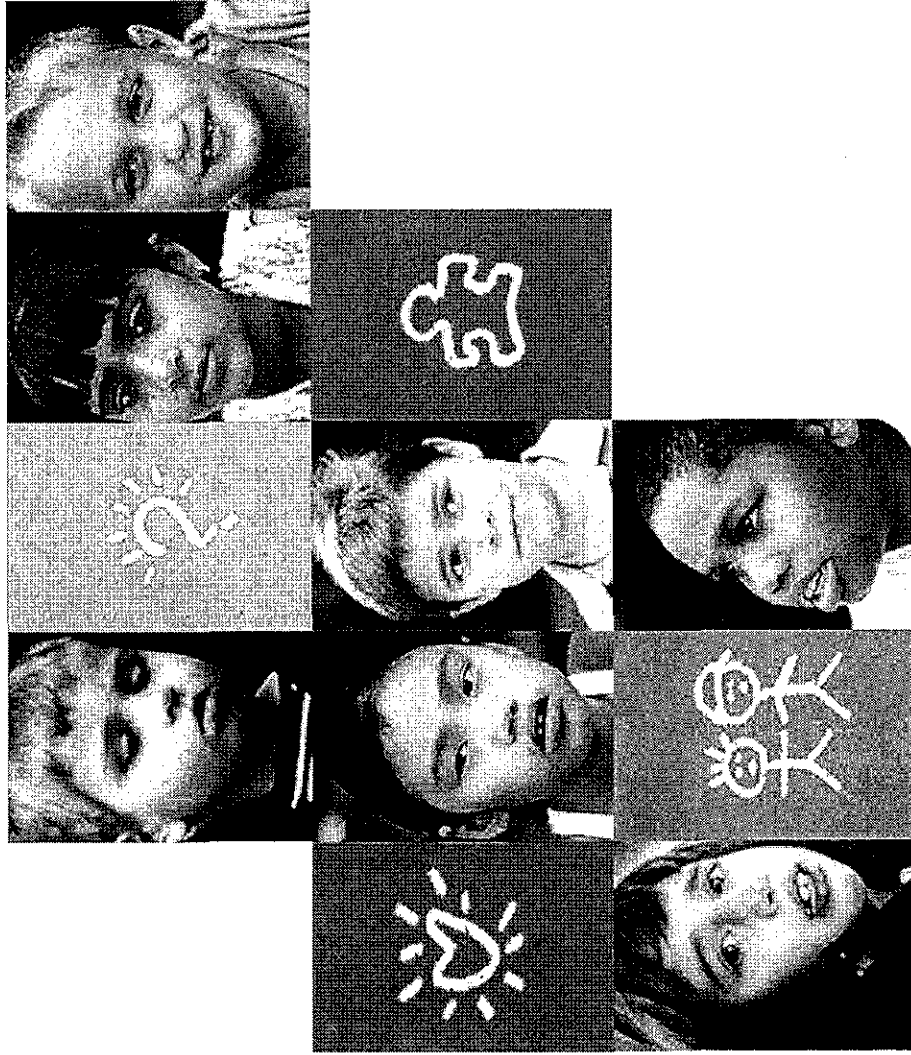
HOW PRIVATE HEALTH
COVERAGE WORKS:

A PRIMER
2008 UPDATE

APRIL 2008

THE HENRY J.
KAISER
FAMILY
FOUNDATION

Insurance Coverage for Autism in Hawaii



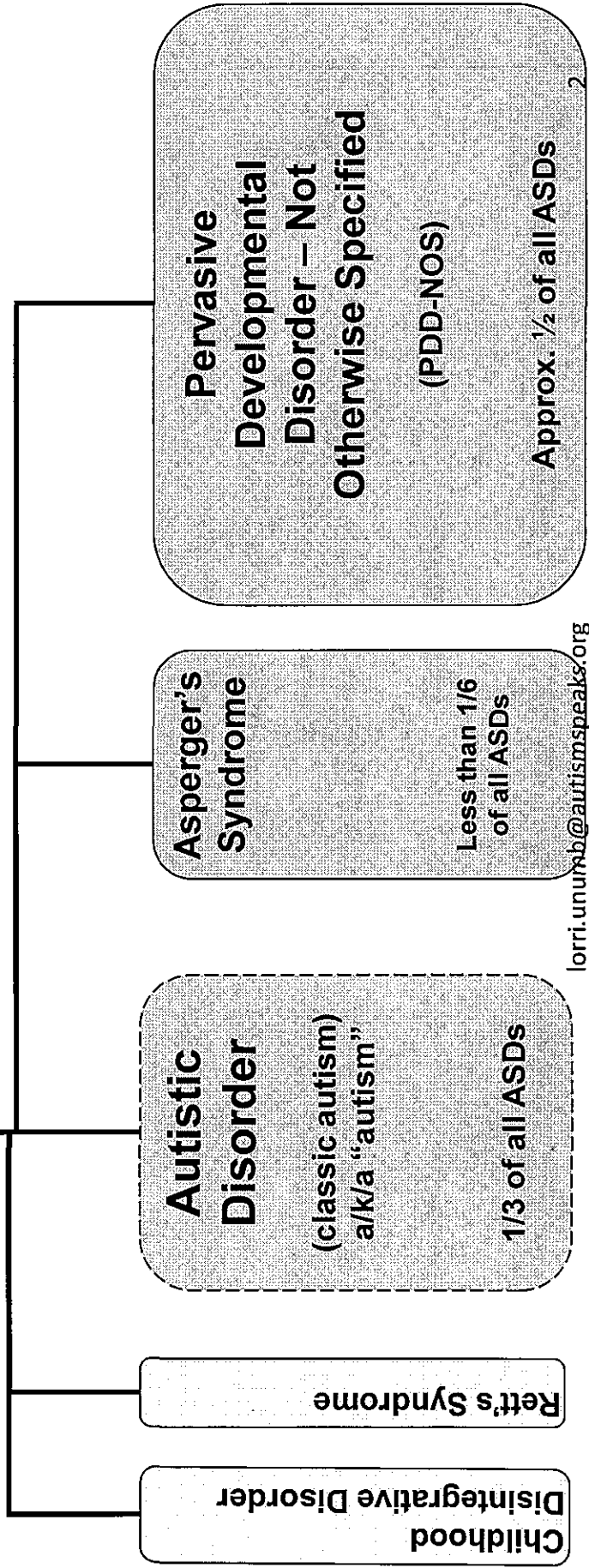
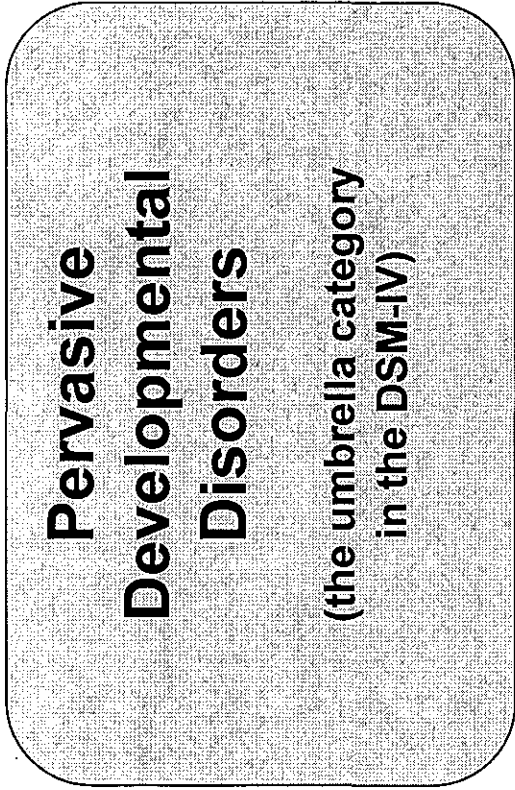
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1

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Autism Spectrum Disorder

- Curable? No
- Treatable? Yes

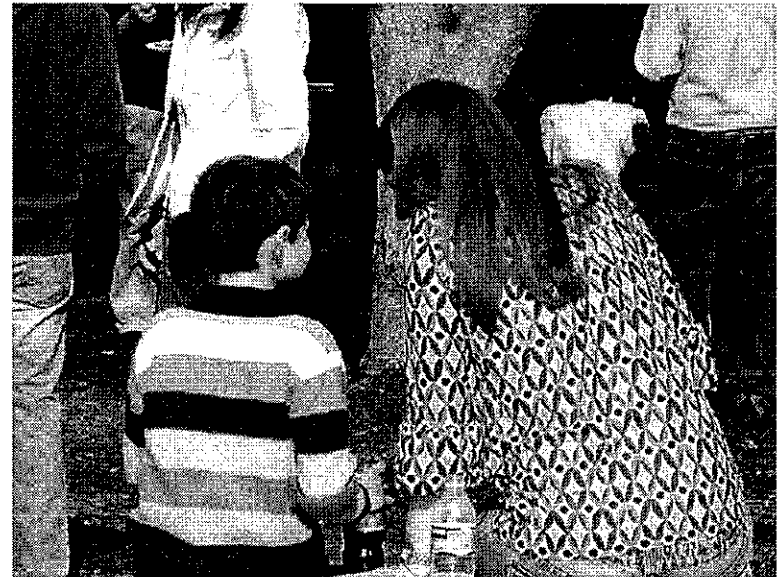
- Impaired Communication
- Impaired Social Interaction
- Repetitive or Stereotyped Patterns of Behavior
- Narrow Range of Interests

- Four times more common in boys than girls
- Average age of diagnosis: 5-1/2



Applied Behavior Analysis (ABA Therapy)

- One-on-one therapy based on principles of repetition, reinforcement, and extinction.
- When an environment supports a set of behaviors, they increase. When an environment does not support behaviors, they tend to extinguish and fade away.



ABA Therapy Is Not Experimental

- “Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior.”

Report of the Surgeon General of the United States, 1999

- “ABA therapy is not experimental or investigational in nature.”

McHenry v. PacificSource Health Plans (D. Oregon, Jan. 5, 2010)

- “The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research Children who receive early intensive behavioral treatment have been shown to make substantial, sustained gains in IQ, language, academic performance, and adaptive behavior as well as some measures of social behavior, and their outcomes have been significantly better than those of children in control groups.”

American Academy of Pediatrics

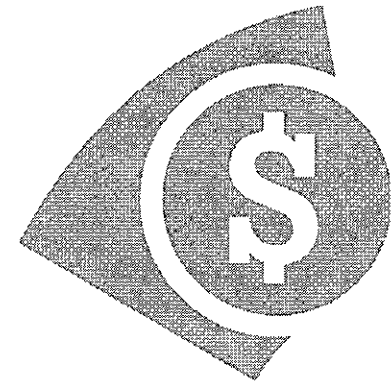
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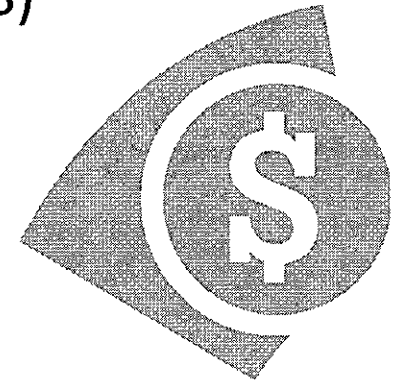
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- **\$10,800 + \$18,720 + \$41,600 = \$71,120**



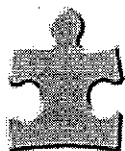
Societal Costs of Autism

- Harvard School of Public Health (Ganz, 2006)
- \$3.2 million per person over lifetime
 - Includes direct and indirect costs, such as lost productivity
- Pennsylvania (Green, Jacobson & Mulick, 1998)
- Over \$1 million per person



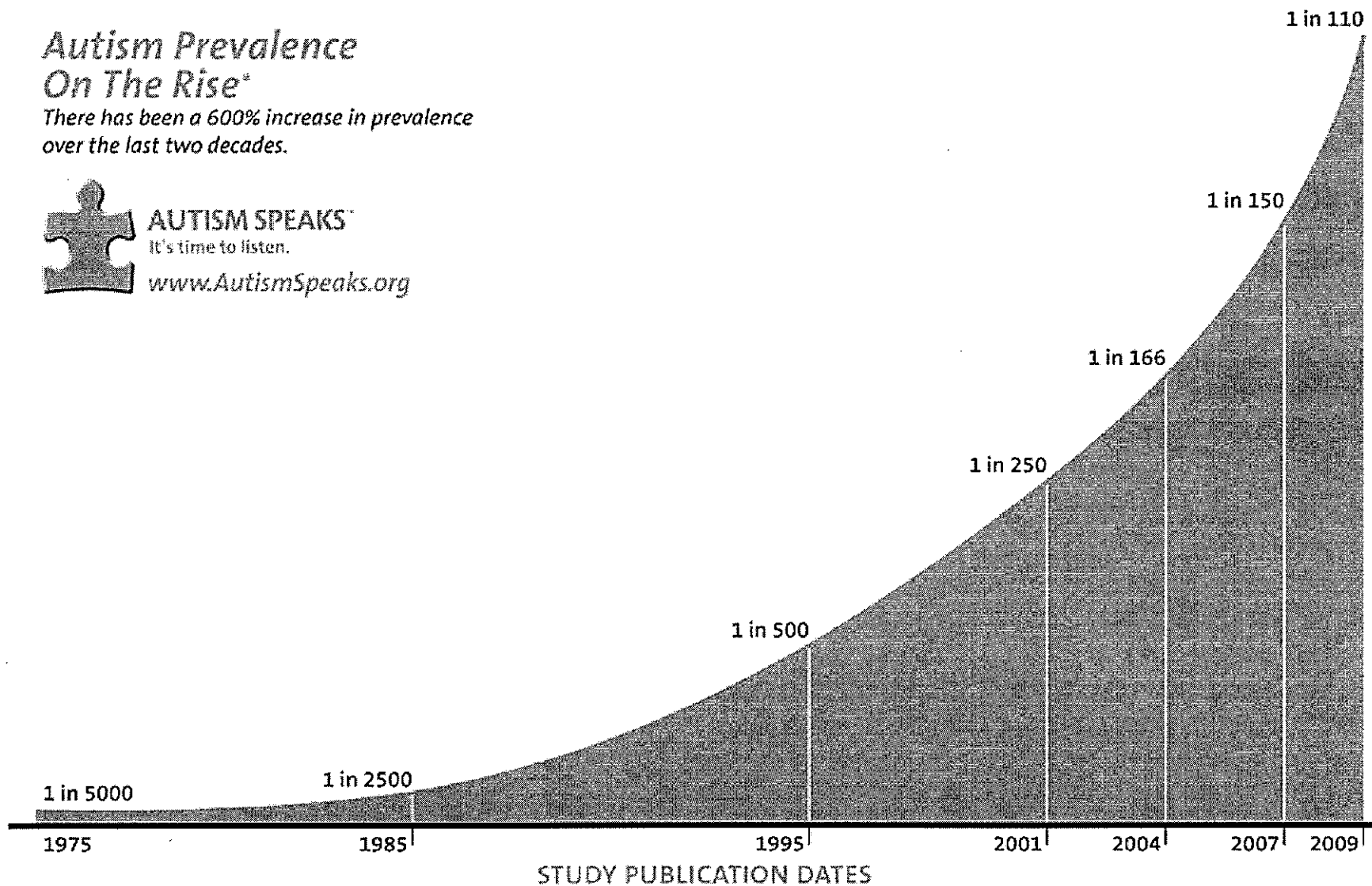
Autism Prevalence On The Rise*

There has been a 600% increase in prevalence
over the last two decades.



AUTISM SPEAKS™
It's time to listen.

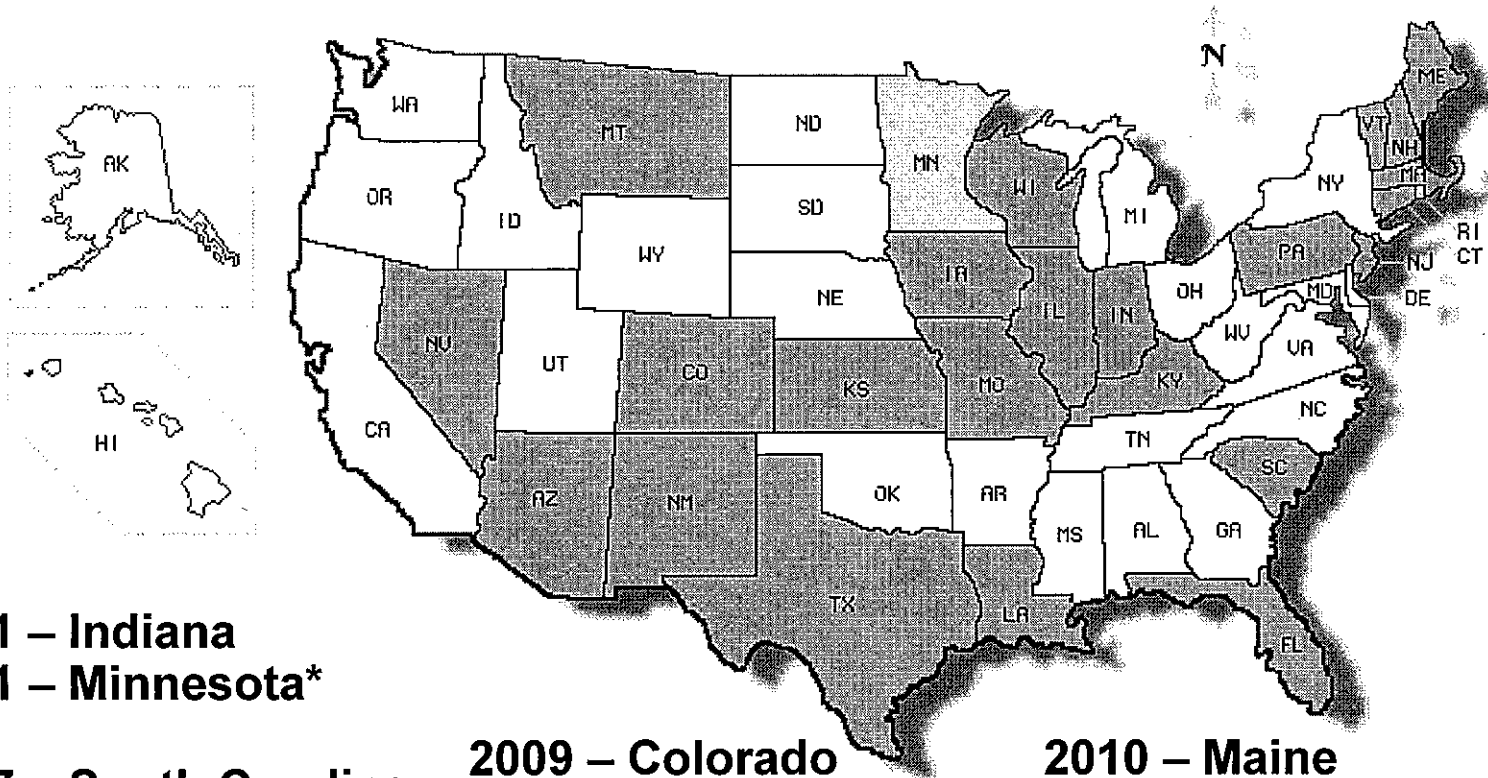
www.AutismSpeaks.org



*Recent research has indicated that changes in diagnostic practices may account for at least 25% of the increase in prevalence over time. However, much of the increase is still unaccounted for and may be influenced by other factors.

lorri@autismspeaks.org

States with Autism Insurance Reform



2001 – Indiana
2001 – Minnesota*

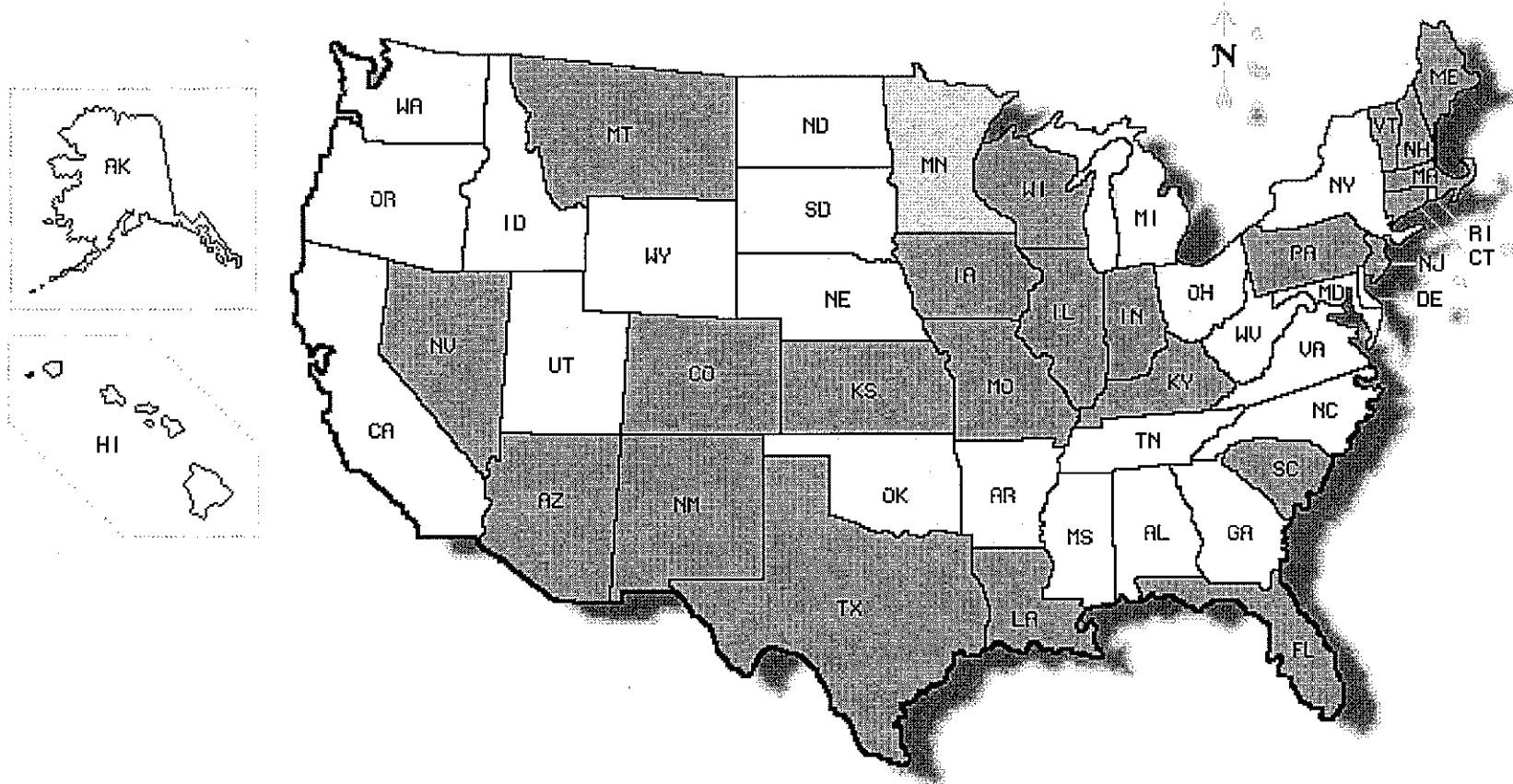
2007 – South Carolina
2007 – Texas

2008 – Arizona
2008 – Florida
2008 – Louisiana
2008 – Pennsylvania
2008 -- Illinois

2009 – Colorado
2009 – Nevada
2009 – Connecticut¹⁹⁻¹¹
2009 – Wisconsin
2009 – Montana
2009 – New Jersey
2009 – New Mexico

2010 – Maine
2010 – Kentucky
2010 -- Kansas
2010 -- Iowa
2010 -- Vermont
2010 – Missouri
2010 – New Hampshire
2010 -- Massachusetts

+ States with Bills Pending



1-19-11

Comparison of Autism Benefits

State	Annual Cap	Age Cap
Indiana	None	None
Minnesota**	None	None
South Carolina	\$50,000 - ABA	16
Texas	None	11
Pennsylvania	\$36,000	21
Montana	\$50,000/\$20,000 at 10	18
Arizona	\$50,000/\$25,000 at 9	17
Missouri	\$40,000	18
New Hampshire	\$36,000/\$27,000 at 13	21
Kansas*	\$36,000/\$27,000 at 7	19
Massachusetts	None	None
Vermont	None	6, or 1 st grade***
Iowa*	\$36,000 <small>lorri.unumb@autismspeaks.org</small>	21

Behavioral Therapy Benefits for Autism

Major Group



Student Guide



State of South Carolina State Health Plan Autism Spectrum Disorder Benefit

Effective with the 2009 Plan Year, the State Health Plan began covering Applied Behavior Analysis (ABA) for children diagnosed with an Autism Spectrum Disorder. The Employee Insurance Program (EIP) asked APS Healthcare to develop guidelines for administering the new benefit. Just like other services covered by APS for behavioral health diagnoses, the new Autism Spectrum Disorder (ASD) benefit services must be pre-authorized as medically necessary by APS, and providers must be contracted with APS as in-network providers. Only ABA providers fully certified by the Behavior Analyst Certification Board will be part of the network and be able to file claims for ABA services. All reimbursements for ABA services will be made by APS directly to ABA providers.

Board Certified Behavior Analysts (BCBA's) contracted with APS must provide direct supervision to their staff, including Board Certified Associate Behavior Analysts and/or any non-certified ABA therapists. Direct supervision includes the observation and oversight of the delivery of "hands on" ABA therapy by behavioral therapy staff.

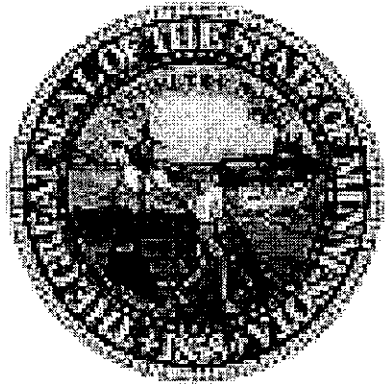
The new benefit became effective on January 1, 2009. Following is a summary of requirements for coverage under the new benefit.

Eligibility Requirements:

- 1) Member must be covered by the State Health Plan and under sixteen (16) years of age with no pre-existing condition exclusions.
- 2) Member must be diagnosed by age eight (8) with Autism Disorder, Asperger's Disorder or Pervasive Developmental Disorder Not Otherwise Specified by a Physician or Certified Registered Nurse Practitioner.
- 3) Diagnosis by age 8 must be confirmed by the following diagnosis-specific rescreening tools:
 - a. Autism Disorder using one of the following:
 1. Checklist for Autism in Toddlers (CHAT); or
 2. Modified Checklist for Autism in Toddlers (M-CHAT); or
 3. Screening Tool for Autism in Two-Year Olds (STAT); or
 4. Social Communication Questionnaire (SCQ) (recommended for children four-years of age or older)
 - b. Asperger's Syndrome using one of the following (recommended for school-age children):
 1. Autism Spectrum Screening Questionnaire (ASSQ); or
 2. Childhood Asperger Syndrome Test (CAST), or
 3. Krug Asperger's Disorder Index (KADI)
 - c. Pervasive Developmental Disorder, NOS using the following:
 1. One of the previously mentioned tools to rule out Autism and Asperger's; and
 2. DSM-IV Diagnostic Criteria/Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS)
- 4) Member must be evaluated by an appropriate diagnostician to rule out the following as a sole explanation for symptoms of Autism Spectrum Disorder:
 - a. Neurological Disorder (must be by an MD),
 - b. Lead Poisoning (must be by an MD),
 - c. Primary Speech Disorder, and
 - d. Primary Hearing Disorder.
- 5) Member must be evaluated by a licensed Psychologist within the last 6 months for current validation of the ASD diagnosis, using:
 - a. Autism Diagnostic Observation Schedule (ADOS); or
 - b. Autism Diagnostic Interview (ADI-R); or
 - c. Childhood Autism Rating Scale (CARS); or
 - d. A DSM-IV Diagnostic Criteria which validates one of the three ASD diagnoses.

Excerpt from 2009 Report of Council of Affordable Health Insurance: “Health Insurance Mandates in the States”

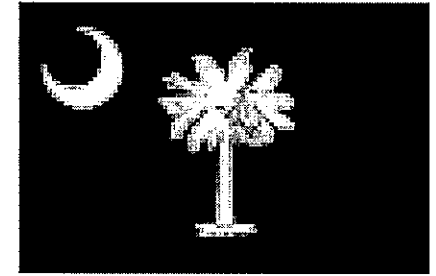
BENEFITS:	Est. Cost	#
Alcoholism	1-3%	45
Autism	<1%	23
Contraceptives	1-3%	29
In Vitro Fert.	3-5%	15
Prescriptions	5-10%	3



Actual Claims Data BCBS of Minnesota (2007)

- Dates
 - In effect 2001
- Population
 - State has population of 5.3M
 - BCBS has 2100 members with ASD
- Terms
 - No dollar cap
 - No age cap
- Cost
 - Total claims = \$12M
 - 315 of the 2100 members accounted for \$9.7M of the \$12M cost
- Premium impact PMPM (per member per month)
 - \$0.83 commercial mrkt
 - \$0.79 public programs
- Average annual cost for behavioral health treatment = \$30,000

South Carolina State Employee Plan



- Dates
 - Statute passed in 2007
 - Applicable to state health plan as of 1-1-09
 - Population
 - State has 4.5 M
 - State health plan has 350-390,000 members
 - Terms
 - \$50,000 cap on ABA
 - To age 16
 - Projected Cost
 - Original: \$18.9 million
 - Revised: \$9 million
 - Actual cost
 - 2009: \$856,371
PMPM - 20 cents
 - 2010: \$2,042,392
PMPM - 44 cents
PEPM – 75 cents
- (228,048 employees/subscribers;
79 kids accessing coverage)

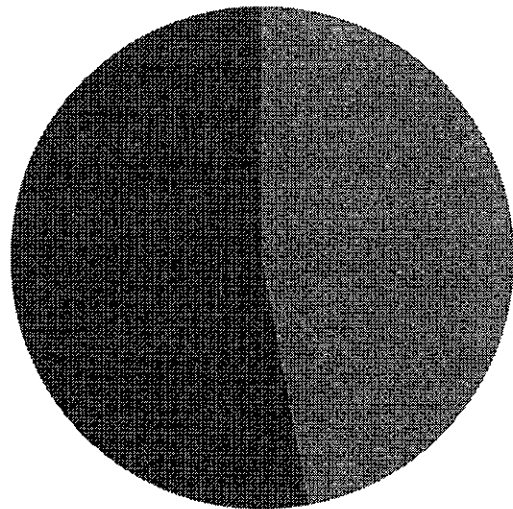
Hawaii Fiscal Impact Worksheet

- Number of *employees* in state plan _____
- X
- Per *employee* per month (PEPM) cost 75 cents
(using 2010 South Carolina actual claims data; SC has age 16 & \$50,000 cap on ABA)
- = _____
- X
- Number of months in year 12 months
- =
- Total annual cost _____
- (To determine total cost to state's general fund, discount the above total by percent of health insurance premium that a state employee pays, if any.)

Savings to the State: Special Education

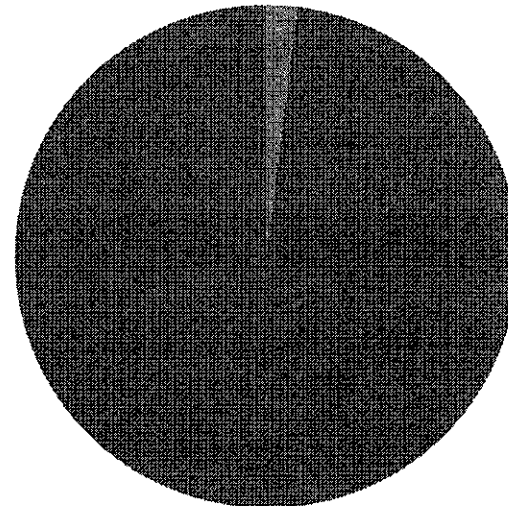
Outcome of 1987 UCLA Study on Efficacy of ABA

ABA Group



- 47% Achieved Normal IQ
- 53% Did Not Achieve Normal IQ

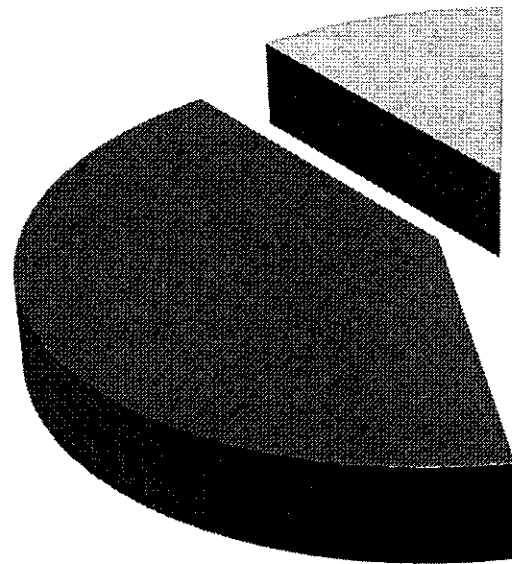
Other Intervention (Control) Group



- 2% Achieved Normal IQ
- 98% Did Not Achieve Normal IQ

Outcome of 1987 UCLA Study

Educational Placements for Group That Received ABA



■ 47% = Mainstreamed with No Support

■ 42% = Low-Intensity Special Education Placement (for language delay)

■ 11% = High-Intensity Special Education Placement (for autism or intellectual disability)

Savings to the State: Special Education

“A study published in a national journal found that Pennsylvania could save an average of \$187,000 to \$203,000 on each child who received three years of EIBI relative to one who received special education services until age 22. The Pennsylvania study also suggested that cost savings would likely continue to accrue after children exit the school system. The study found that the state could save from \$656,000 to \$1.1 million per child if expenditures up to age 55 are included.

Another study published in a national journal found that Texas could save an average of \$208,500 in education costs for each student who received three years of EIBI relative to a student who received 18 years of special education from ages four to 22. Applied to the estimated 10,000 children with ASDs in Texas, it was estimated that the state could save almost \$2.1 billion by implementing intensive treatment programs.”

Source: 2009 Report of the Joint Legislative Audit and Review Commission to the Governor and General Assembly of Virginia
(JLARC Report)



“Educational in Nature”?



- False choice
- What does “educational in nature” mean?
- *Schools provide?*
- *Schools would provide if adequate resources?*
 - No obligation under IDEA or state law to treat medical condition
 - Schools are required to accommodate the disabling condition, not remedy it.
- Is speech therapy “educational in nature”?
- AAP report.
- *Provided by school personnel?*
- Academic goals
- ASD is diagnosed by a doctor, not a principal
- Argument du jour
 - Rejected in 23 states
 - Rejected in federal court



“Educational in Nature”?

- *McHenry v. PacificSource Health Plans* (D. Oregon, Jan. 5, 2010)
- “While ABA therapy may have beneficial effects on an autistic child’s social and academic skills, its defining characteristic is application of techniques to modify behavior in every area of an autistic child’s life. In this regard, a sports analogy is instructive. While participation in sports can benefit a student’s academic and social skills, no one would classify sports as academic or social skills training.
- Similarly, the incidental benefits in these areas resulting from ABA therapy, while real, do not dictate that it be classified as either academic or social skills training.
- . . . While aimed at improving social and academic functioning, it does this by specifically addressing behavioral deficits possessed by autistic children that interfere with every area of their life, not by educating kids on social norms or teaching study skills or other tools specific to academic success.”

Impact of Federal Health Care Reform

- 2009 Amendments by Rep. Doyle (Pa.) & Sen. Menendez (NJ)
- Changed "**Mental health and substance use disorder services**", one of ten required benefits, to "**Mental health and substance use disorder services, including behavioral health treatments**".
- Applies to plans issued through Exchanges as well as small group and individual plans.
- N/A to existing coverage, large groups, self-funded
- Starts in 2014.
- <http://www.autismvotes.org/site/apps/nlnet/content2.aspx?c=frKNI3PCImE&b=3930723&ct=7522291>

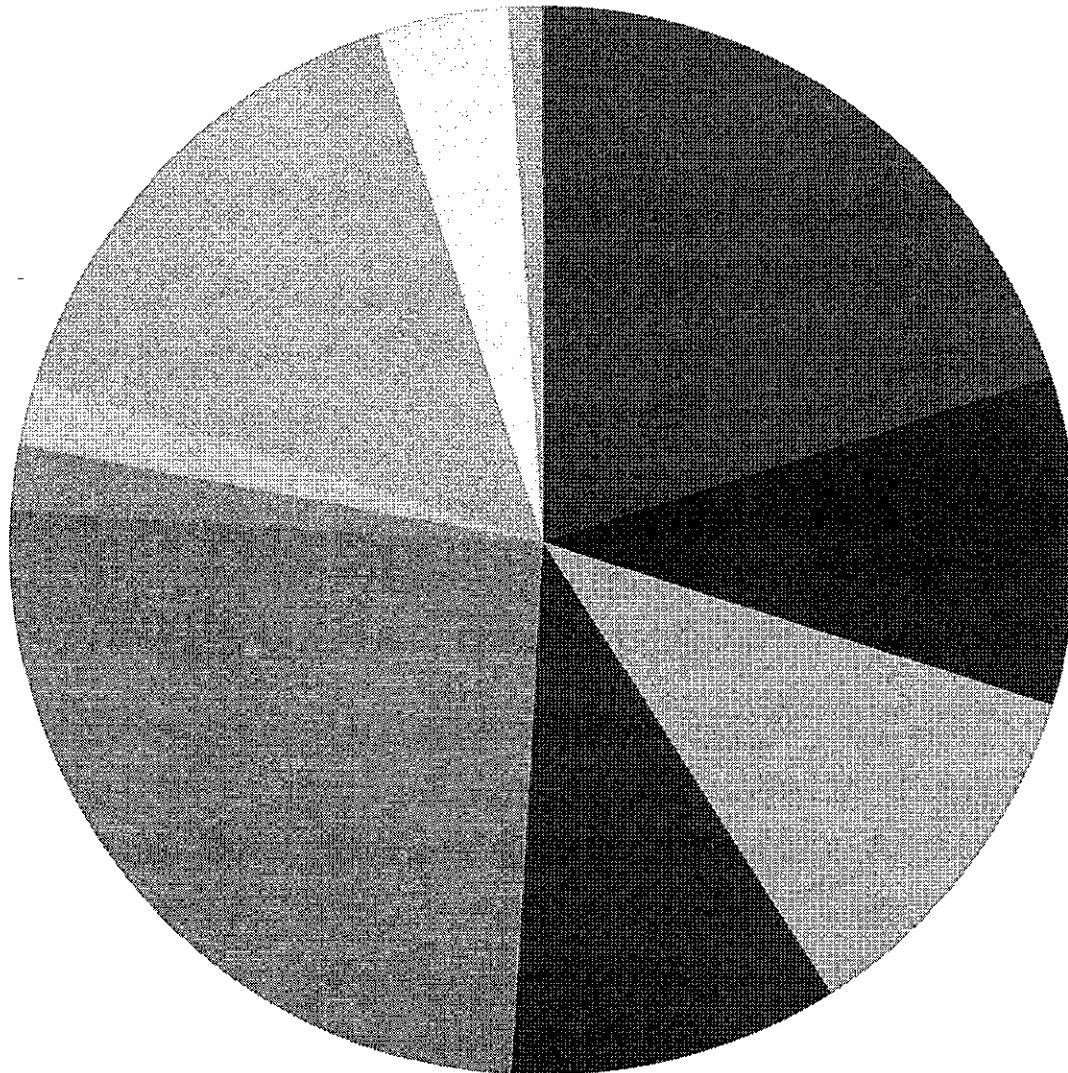
The Essential Benefits Package

- Ambulatory patient services
- Emergency services
- Hospitalization
- Maternity and newborn care
- Mental health and substance use disorder services, including behavioral health treatment
- Prescription drugs
- Rehabilitative and habilitative services and devices
- Laboratory services
- Preventive and wellness services and chronic disease management
- Pediatric services, including oral and vision care

Impact of 2008 Federal Mental Health Parity Law

- 2008 Wellstone-Domenici Act prohibits **treatment limitations** and **financial requirements** on “mental health benefits” if not on physical health benefits.
- Wellstone MHP law applies only to large group fully-funded and self-funded policies.
- Illinois, Iowa, Maine, Montana, New Hampshire, New Jersey explicitly and Connecticut, Florida, Kansas, Kentucky, Missouri implicitly include autism within their state definition of mental illness.
- All of these states except Florida have passed capped autism mandates since the passage of the Wellstone federal MHP law.

Sources of Health Care Coverage



- Medicaid - 20%
- Medicare - 10%
- Uninsured - 11%
- State Health Plan - 10%
- ERISA - ASO - 25%
- Federal Tricare - 2%
- Federal Civilian - 2%
- Other Insured - Large Group - 15%
- Other Insured - Small Group - 4%
- Other Insured - Individual - 1%



Self-Funded ERISA Plans

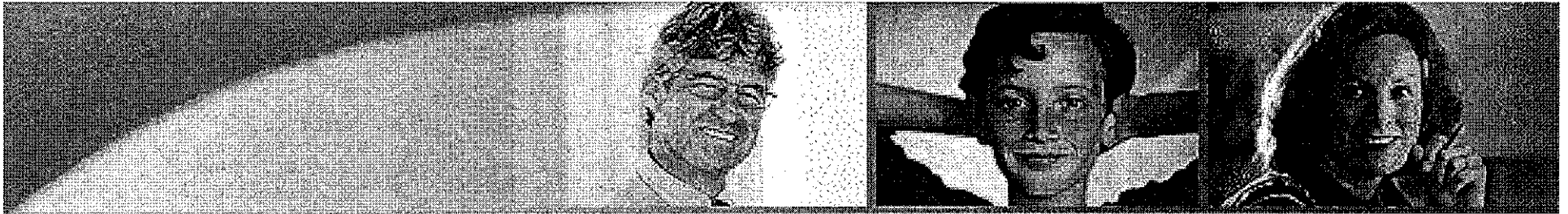
- “Overall, self-funded plans voluntarily cover 86% of the cost of mandated services.”
- 2008 Report of Maryland Health Care Commission

Self-Funded ERISA Plans That Cover Autism Treatments

- Microsoft
- Home Depot
- Intel
- Arnold & Porter
- Halliburton
- Eli Lilly
- Deloitte
- Ohio State University
- Time Warner
- Blackbaud
- Lahey Clinic
- Partners Healthcare
- Wells Fargo
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Greenville Hospital System
- Symantec
- DTE Energy
- Cerner
- State Street Financial
- Children's Mercy
- EMC
- Yahoo
- Sisters of Mercy
- Princeton University
- And many more . . .

Provider Credentials

www.BACB.com

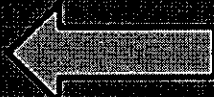


The Behavior Analyst Certification Board, Inc.* (BACB*) is a nonprofit corporation established as a result of credentialing needs identified by behavior analysts, state governments, and consumers of behavior analysis services.



The BACB's mission is to develop, promote, and implement a voluntary international certification program for behavior analyst practitioners.

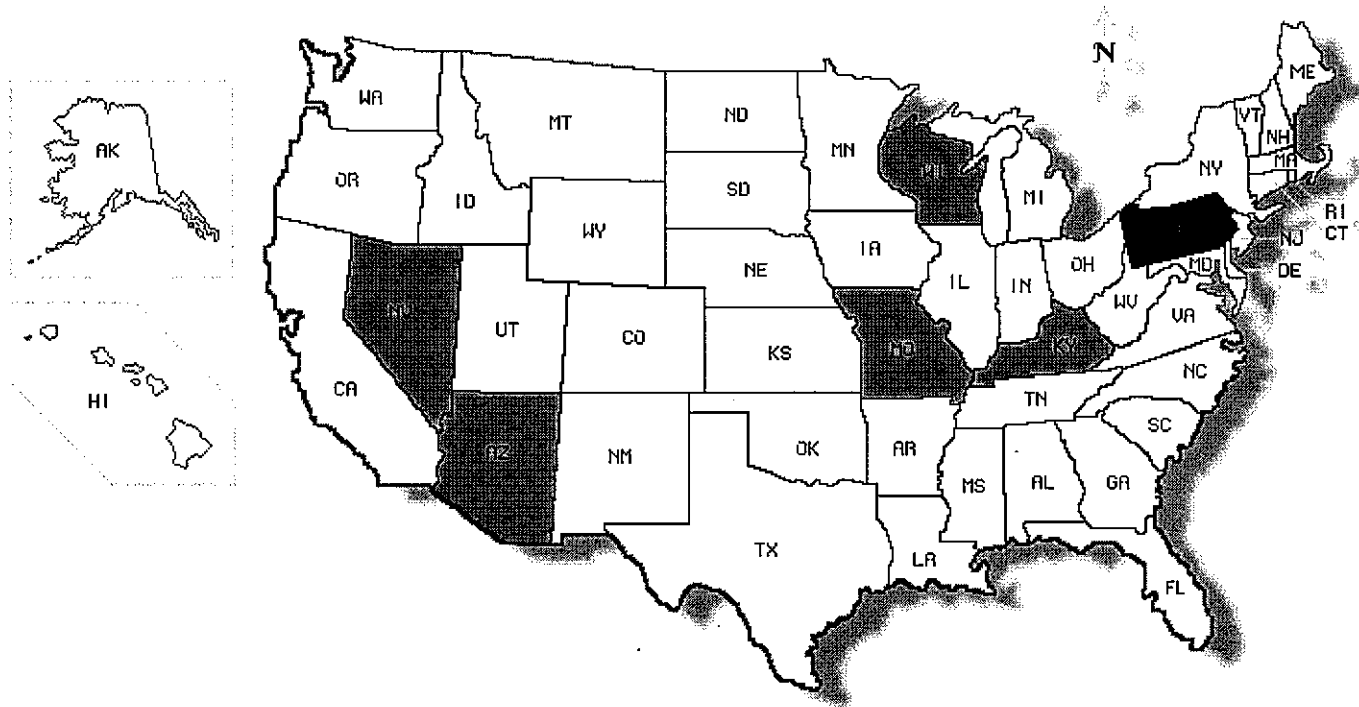
The BACB credentials Board Certified Behavior Analyst* (BCBA*) and Board Certified Assistant Behavior Analyst* (BCaBA*).



info@nccanet.org

Insurance States that License Behavior Analysts

- - License
- - "Behavior specialist"
- License/no insurance



5-29-10

lorri.unumb@autismspeaks.org

Neurology

January 2007 Issue

Table 3 Summary of evidence: Incidence and prevalence of 12 neurologic disorders

Disorder	Class of evidence	Range of ages included (y)	Median estimates				Rate ratio, M/F†	Age(s), y, of peak incidence
			Annual incidence		Prevalence			
			Rate/100,000	No.*	Rate/1,000	No.*		
Autism spectrum disorders	I, II	2-15	—	—	5.8	500,000‡	4.2	—
Cerebral palsy	I, II	3-13	—	—	2.4	207,000‡	1.3	—
Tourette syndrome	II	7-17	—	—	3.5§	301,000	4.8	—
Migraine	I, II	12-65	—	—	121	35,461,000	0.4	—
Epilepsy	I, II	All	48	142,000	7.1	2,098,000	1	<1, ≥80
Multiple sclerosis	I	All	4.2	12,000	0.9	266,000	0.5	30
Traumatic brain injury	I	All	101	298,000	—	—	2.1	20, ≥80
Spinal cord injury	I,II	All	4.5	13,000	—	—	4.2	20
ALS	I, II	All	1.6	5,000	0.04	12,000	1.3	≥60
Stroke	I, II	All	183	541,000	10	2,956,000	1.1	≥80
		≥65	1,093	401,000	—	—	—	
Alzheimer disease	I,II	≥65	1,275	468,000	67	2,459,000	0.5	≥80
Parkinson disease	I,II	≥65	160	59,000	9.5	349,000	1.8	≥70

* Estimated number of cases in United States in 2005, rounded to nearest 1,000.

† Ratio of rates among males to rates among females.

‡ Estimated number of cases among children younger than 21 years of age only.

§ Data inadequate for firm estimate.

Why Our Job Is Not Done

- May 27, 2010 at 5:08pm
- Subject: thanks
- I just wanted to say thank you for accomplishing what many people would not have attempted. I live in Charleston, SC. My husbands insurance is self funded so we are having to give up custody of our autistic 2 year old to my parents because their insurance is better. ABA is really helping and there is nothing I wouldn't do for him. You are inspirational to me and a hero. God bless you.



“[N]o
disability
claims more
parental
time and
energy than
autism.”

New York Times,
12/20/04

Michael and Lisa Davies
115 Alohi Place
Pukalani, HI 96768
davieslisaa@aol.com
Phone: 808-264-4016

March 27, 2011

RE: Health Insurance coverage for autism services

Dear Senators Tsutsui, Baker and English and Representatives Yamashita, Fontaine and Souki:

Our family currently resides on Maui and has been Upcountry residents for over 16 years. I was born and raised in Hawaii and my husband has lived here for nearly 30 years.

We have 3 children – 7 year old twins and a 5 year old. Noah, one of our 7 year olds, was diagnosed with mild to moderate autism when he was 3 years old by a private doctor specializing in the field of Autism. We sought a private evaluation due to the misdiagnosis by a DOE psychologist.

Noah continues to make progress, however since the DOE is unable to provide the “additional” specialized services he requires, we pay privately for Occupational Therapy, a Linda Mood Bell reading instructor and a home and community program supervised by a Behaviorist who specializes in Autism therapy and a skills trainer.

When Noah was first diagnosed with Autism, we contacted our insurance carrier. We filed claims for over a year, got all the “required” paper work from the providers and never heard back from the claims department. We jumped through all the hoops as requested by our insurance carrier. However, after numerous emails and phone calls over the course of about 15 months, we gave up. We’re sure this is exactly what the insurance company wanted us to do since Autism has no known cure and therapy is highly specialized and will be life long.

Last year alone, we spent over \$22,000 in private services. Each year as we see the gap between neurologically typical peers and our son widen, we have seen the need to increase private services accordingly. Even though the DOE has a Federal obligation to provide a free, “appropriate” public education under IDEA, it is unfair that private insurance companies in Hawaii do not cover any Autism services.

Autism is a medical condition, just like leukemia or diabetes or cancer and should be covered as such. Autism currently affects 1 in 90 children.

Nearly half of all states in America support mandatory coverage of autism service by health insurance providers. We strongly urge you to follow their lead.

Sincerely,



Lisa and Mike Davies

Testimony for CPN 3/29/2011 9:00:00 AM SCR51

Conference room: 229
Testifier position: support
Testifier will be present: No
Submitted by: Tera Deal
Organization: Individual
Address:
Phone:
E-mail: teradeal@gmail.com
Submitted on: 3/28/2011

Comments:

Dear Senator Baker—I am writing to urge a “yes” vote on SCR 51, to request the auditor assess the social and financial effects of requiring health insurers to provide coverage for autism spectrum disorders.

I am the parent of an 8 year old son with autism. The cost of care is prohibitive, and Department of Education resources are insufficient to be fully effective. It is also not fair to expect the Department of Education to provide all the support these children need.

Autism is a medical condition. With proper treatment, children can go on to become independent, productive members of society.

I have seen first hand the results of proper and effective treatment can do. In Arizona (the state I previously lived) there was a 3 year study that showed with appropriate treatment children with autism can become a part of a typical classroom with little to none supports. Appropriate treatment will save the tax payers thousands if not millions of dollars in the long term. Without treatment, the Harvard School of Public Health estimates the cost of caring for an autistic person to be \$3.2 million. These costs are passed on to society.

When appropriate treatment is given the child with autism is not the only one effected. The whole family benefits and is no longer trapped in the world of autism.

Please support SCR 51. Mahalo.

Sincerely,
Tera Deal

Dear Senator Baker—I am writing to urge a “yes” vote on SCR 51, to request the auditor assess the social and financial effects of requiring health insurers to provide coverage for autism spectrum disorders. I am the parent of a 19 year old son with asperger. The cost of care is prohibitive, and to have to pay out of pocket for most of his medical expense is a financial burden on me. By passing this bill my son will be able to get more medical service. He is presently attending Community College and will hopefully get a college degree. By allowing this bill to pass this will allow him to get more medical help and will help him succeed in school.

Autism is a medical condition. With proper treatment, children can go on to become independent, productive members of society. Without treatment, the Harvard School of Public Health estimates the cost of caring for an autistic person to be \$3.2 million. These costs are passed on to society.

Please support SCR 51. Mahalo

Sincerely,

Vera Marie Asato

March 27, 2011

Dear Senator Baker—I am writing to urge a “yes” vote on SCR 51, to request the auditor assess the social and financial effects of requiring health insurers to provide coverage for autism spectrum disorders. I am the parent of a 3 year old son with autism. He needs much more therapy than can be provided through the Department of Education, but the cost is prohibitive.

Autism is a medical condition. With proper treatment, children can go on to become independent, productive members of society. Without treatment, the Harvard School of Public Health estimates the cost of caring for an autistic person to be \$3.2 million. These costs are passed to society. Families, educators, and tax payers bear the burden of their care. Only the insurance industry is let off the hook. This type of discrimination is not fair.

Please support SCR 51. Mahalo.

Sincerely,

Tom Pearson

Dear Senator Baker—I am writing to urge a “yes” vote on SCR 51, to request the auditor assess the social and financial effects of requiring health insurers to provide coverage for autism spectrum disorders. I am the parent of a 3year old son with autism. He currently receives services through the Department of Education, but he really needs more intensive therapy. It is so hard knowing there are proven therapies that would help him, but I simply cannot afford it, and insurance will not cover them. A leading autism center here on Oahu charges \$16,000 per month for full-time treatment. Most of their students are “just cause” cases, which means the State of Hawaii picks up the cost of their care.

Autism is a medical condition. With proper treatment, children can go on to become independent, productive members of society. Without treatment, the Harvard School of Public Health estimates the cost of caring for an autistic person to be \$3.2 million. These costs are passed on to society.

Please support SCR 51. Mahalo.

Sincerely,

Janet Edghill

Aloha.

I am a single mother with a 9 year old daughter with autism, living on Oahu.

My daughter's treatment includes weekly private speech therapy (paid for by me at \$104 a visit for the past 5 years), ABA therapy 40 hours a week (paid for by the DOE now in full - for the first three years I paid for the Board Certified Behavior Analyst's time at about \$10,000 a year) and speech therapy in school.

I am a pediatrician and am fortunate to have resources, but I have spent down my savings providing for my daughter's needs now as her therapy is NOT covered by medical insurance. This is very concerning as I need to be saving for her future needs as she will likely always need support.

Autism is very expensive in many ways. The therapy is labor-intensive and thus expensive. Even simple babysitting is not easy - I cannot have a young adult without training watch my daughter, so babysitting/daycare is expensive. She cannot attend camps/school programs/etc. without an aide. All of these expenses are a drain on a family and many families go into debt.

Autism is a neurodevelopmental issue. It IS a medical problem. Evidence-based, effective treatment is available (ABA therapy, Occupational Therapy, Speech Therapy) and should be covered by Health Insurance. The more time/money/effort spent on these children in their childhood, the more self-sufficient they can become - which is cost effective for the future.

Hawaii needs to join the ranks of responsible states and require Health Insurance to cover the proven therapies. We need to support our families as they endeavor to give their children their best hope for the future.

Linda P. Smith M.D.
1781 Ho'okupa Street
Pearl City, HI 96744
808 781 8420

March 27, 2011

Dear Senator Baker:

My son has autism. I strongly feel that medical insurance should cover all autism related services. It would make all the difference in my son's life.

Jessica Crowe

Lihue, Hawaii.

To whom it may concern:

I am the mother of a child diagnosed with PDDNOS which falls under the autism umbrella. He has been attending a public school although this is not an ideal learning environment for him, only because this was the only way he could receive services. As of 2 weeks ago he is no longer attending as he has been too affected by his allergies and other problems that I decided to homeschool him. Now we get no services. I was so surprised to find that there are no services provided for children with autism when homeschooled. Homeschooling is an option that should be considered for a child with special needs as it may prove to be the most appropriate for some children. There should be support and services provided for homeschooled children through insurance companies.

Sincerely,

Danitza Galvan
Kauai

333 Aina Loli Place
Kapaa, HI 96746

March 27, 2011

RE: health insurance coverage for autism services

Dear Honorable Representatives:

We live on Kauai and have done so for the past 30 years. We were both born and raised in Hawaii. We have two children - ages 12 and 7. Our youngest child was diagnosed four years ago with high functioning autism. By all accounts, our son has progressed significantly with the services he has received, but still there is a lot of work to be done with him. We, and the DOE, have worked really hard with him for the past 4 years. We are grateful for the services the DOE has provided, but have often felt our son needed very specialized services, which the DOE providers sometimes lacked the crucial training needed to effectively provide. So, we have sought our own services from reputable consultants.

Last year AT OUR OWN EXPENSE, we flew in an autism consultant from Seattle, for five work days (she worked with our son and trained his DOE providers on her methods). We spent \$7,000 - for her fees, airfare, rental car, etc. Last week, HMSA completely denied our claim - they will not reimburse us even one dollar! In two months, we are taking our son to the UC-Santa Barbara Koegel Autism Clinic - a 5-day training for parents to more effectively teach their children language and social skills. The fees, airfare, rental car, hotel, for the week will cost us about \$6,000. There is a one-week clinic in LA with a similar program; their fees are \$10,000 for one week - just for tuition - not including airfare, hotel, etc. I anticipate HMSA will also completely deny this claim for reimbursement. (We will not get any tax deduction for these expenses, as we barely make too much money to deduct them.)

I am in contact with a lot of families on Kauai with children with autism. Almost NONE are doing any kind of supplemental services, I suspect in large part because they are cost-prohibitive. While the DOE is obligated to provide a free and appropriate education to children with autism under federal IDEA law, I think it is unfair that private insurance companies thus far have not paid any of the cost of raising a child with autism. Autism is a medical-neurological condition - certain areas of our son's brain are over-developed and certain areas are under-developed. If our son had brain cancer, our medical insurance would cover the very expensive treatments. It is unfair that his autism is unilaterally not covered by medical insurance.

The US Department of Defense for years now has been covering autism services, via their health insurance, for active military and other employees. If you google "autism tri-care" you can read about their very common sense coverage - so many hours per week, with care supervised by appropriately trained personnel, etc. Do not believe the insurance companies if they say a workable autism coverage policy is not possible.

We urge you to please follow the lead of about half the states across the country and support mandatory coverage for autism services by health insurance providers. You may contact us at tracymurakami@gmail.com.

Thank you,

Tracy Murakami

Peter Morimoto

TO: Hawaii State Legislature

RE: SCR51 - Auditor Report; Mandatory Coverage of Autism Spectrum Disorders

My name is Les Daijo and I have a 5 year old son that has an Autism Spectrum Disorder, specifically, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). The state has been a huge help with Early Intervention before he was 3 years old, and afterwards, with the support and services of the Department of Education, The Windward School District and Enchanted Lake Elementary School.

However, the medical & speech therapy coverage offered by HMSA, and all other Hawaii medical insurance companies is the complete opposite. First, let me address the coverages. We have visited numerous doctors and completed many blood tests, which are not out of the ordinary, but as soon as the insurance companies hear that it is for Autism Spectrum Disorders they do not cover any of the fees. 100% of it is needed to come out of our pockets. Doctor visits range from \$100-several hundred dollars, and the tests range from \$75-\$800 or \$900. This may sound high to you, but a simple blood test to check for allergies runs \$300-500. Most people do not see bills of this size, because their medical coverage will pay for most of these. Imagine if you were having issues with your body and the doctor thought you had high levels of mercury, or lead and recommended that tests be run for this. But instead of your insurance company paying for it, they now asked you to pay for a \$500 bill or 100% of the cost of it. That is what my family lives through every day to watch over and care for our son. I have a flexible reimbursement plan through my employer and my family takes advantage of the maximum \$5000 per year to cover medical expenses that are not covered by insurance company. Year in and year out we easily surpass that amount, just for my son alone. On top of that, we also utilize speech therapy for one hour per week at \$100 / hour. Of this amount, ZERO is covered by medical insurance. We will continue this therapy, because prior to him beginning the speech therapy, he was more than 3 years behind his peers in speech, but has improved dramatically and is now only 2 years behind.

I work for a world-wide company, which is known for having excellent benefits, especially medical coverage. Nationally, they have an excellent medical plan that covers 70-100% of autism medical and speech therapy expenses. There is an exception to this, due to insurance laws for the State of Hawaii. They discovered that this national plan did not meet Hawaii State standards for short term and long term disability, and therefore, needed to put me on a Hawaii medical plan. This plan(HMSA), and all others that they researched for the state of Hawaii, did not cover Autism Spectrum Disorder expenses. How is this right? Everyone else in my company, 10,000 employees, has Autism benefits, except myself, because I live in Hawaii. This definitely is not paradise.

Our family income puts us in the higher levels of income for residents of Hawaii. Due to these high medical bills that are completely out of pocket and not covered by Hawaii insurance, we are forced to take out home equity loans to live day to day. We are not wasteful at all, and previous to our son's diagnosis, we were fortunate to live very comfortably and maximize our 401k and other retirement contributions. After the diagnosis, we have only been able to contribute up to the amount that our employers would match, which is only 6% of our pay. How is it that we are considered "high income" here in Hawaii, but have to take out loans to survive and to get medical help for our child? Is it right where he is discriminated against, because he has a particular disorder? A disorder that 1 in 100 kids in this country has. Should we wait until 1 in 50 has it? 1 in 25? Maybe wait until more Hawaii State Legislators' children have it? We are not asking for something extraordinary - we are merely asking for medical coverage for our son, for the kids in Hawaii to have comparable medical care that all of the

other kids in Hawaii have. Kids have different needs and different medical conditions. Shouldn't they be able to get medical care for this that would be covered by the Hawaii medical plan providers?

I am in support of this measure and ask you to also be in support of it. ASD kids can be treated and make vast improvements to function normally in society, just as their peers. One last thought – as a higher income family, again, we struggle to pay these medical bills. My thoughts and hopes go to the lower and mid-level income families that have kids with ASD – how much medical attention are they turning down due to out-of-pocket costs? Are they doing the absolute thing that no parent ever wants to do, but may be forced to do...give up on their kids? For many, what else can they do, but give up on their kids, since medical coverage does not pay for ASD types of medical care?

Thank you for your time, and again, please support this measure to help Hawaii's keiki.

Sincerely,

Les Daijo

3068 Kahako Place

Kailua, HI. 96734

808.255.6625

Father to a 5 year old son with ASD

TO: Hawaii State Legislature

RE: **SCR51 - Auditor Report; Mandatory Coverage of Autism Spectrum Disorders**

My name is Lisa Daijo and I have a 5 year old son that has an Autism Spectrum Disorder, specifically, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). He regressed tremendously from the age of 2 until he was 3 1/2 years of age. He was unable to speak until we invested a tremendous amount of money to see doctors who specialize in autism. They gave us specific diets and vitamins as well as providing him speech therapy. Our child would be a burden on his school and his teachers if we did not look to other sources to increase his ability to speak and function in a classroom.

I currently own an employment agency were our laws mandate we cover each and every employee that works over 20 hours a week for 4 consecutive weeks. Hawaii is the only state that requires this type of coverage for their employees. We really need to take this thought process to help provide for our children. It is sad to know how many children are going untreated. This cost is going to be an even greater burden on our state when this children grow up and are not able to function in society.

I am in support of this measure and ask you to also be in support of it. ASD kids can be treated and make vast improvements to function normally in society, just as their peers.

Mahalo,

Lisa Daijo (Mother of a 5 year old ASD child)

3068 Kahako Place

Kailua, HI. 96734

808.255.6625

My name is Heather Mason. Here is my testimony. I side only with the children of this truly disabling medical issue, Autism, and the families that suffer at times even greater than the children with the disability. The system fails them both.

Oh the experience we have had trying to get services for my son... :(
I'll try to make this as short as possible.

I am going to leave my son's name out for privacy reasons, mahalo for your understanding.

To quote my father, "***The needs of the Institution will always be met first; maybe in this process the needs of an individual might be addressed.***"

The IEP failure is in three parts: the school's inability and unwillingness to implement the IEP they helped create, the IEP procedures seemingly every student starts from scratch and has to forge a way for him/herself (mediation, court, etc.), and the hindrance of the schools from allowing ABA therapists paid by insurance companies onto campuses and into classrooms.

I noticed my son was really quiet, the staff doctor at my son's 12 month appointment disregarded my concerns. Right before Christmas in 2006 finally, at 18 months he was Diagnosed with speech delay, not speaking at all. Several hearing tests were completed. No hearing issues. We took advantage of the speech therapy opportunity, began in January of 2007, twice a week one hour sessions. My son did not make any progress even after 6 months. I had asked everyone about Autism or other medical issues that could be the root of my son's non-speaking. Every professional or doctor brushed off these theories and I was very confident it was a hearing issue.

In June of 2007, I was forced to put my son into a private childcare center, much like the Helemano CDC for 3 weeks. I spoke with the director of the facility and let her know about my son's speech delay, but the teacher in the classroom was not to know. And my son was perceived as shy. However, he made more progress in those 3 weeks than the entire time he had been in speech therapy in 6 months. There was a gap in speech services of 3 1/2 months. We switched from private-insurance speech therapy to Early Intervention. October 2007, he began speech with Erica through Early Intervention Kapiolani Women's & Children's. The next six months were speech therapy, and preparing to transfer to services under DOE.

The local school was Mililani Uka Elementary, which we were excited about. However, our experiences have opened my eyes. My son entered the school year in April of 2008, and his teacher Ms. Farry was GREAT. My son was doing the BEST he'd ever done and I was hopeful and truly joyous for the first time since June of 2007.

The beginning of the 2008-2009 school year was rough and then things got worse. My son behaviors became impossible to get him to school on time, the school was nasty and even harassed me if I needed help getting my son to school. This should have been a warning sign, but I kept taking him in hopes that he would be getting his speech therapy. I had no education regarding IEP's, inclusion settings, etc. I have gained much knowledge, but I wish I knew what I do now, then. The non-inclusion setting of the classroom caused my son much distress. I not understand that my dropping my son off and picking him up to be able to speak to the teacher matter ---not at all--- and whatever I said was not even listened to, and the teacher had no intentions to keep an eye on my son for his own health. To keep his hands and feet out of his mouth & keep him from getting sick, infections, needing medication and antibiotics, etc. What a horrible year! Every moment of everyday difficult, my son was becoming impossible.

March 2009, my friend who had known my son as a toddler stressed to me that I needed to get my son checked for Autism, I disregarded this. Over a month of her hounding me I broke down and took him to Dr. Gallegher, April 2009. The doctor's reputation was very highly rated and he was recommended by many. I was shocked when my son was diagnosed with Autism. ALL THIS TIME... wow. I didn't know where to begin. I was half way through shock and clinging a little to denial.

I had spoken to my son's teacher, Ms. Baker, that my son had an appointment and would miss school. When I dropped my son off the next day and showed the teacher the diagnosis and gave her a copy, I asked when we could have a meeting to update my son's IEP. My son's teacher, Ms. Baker, said stuff like, "He doesn't have Autism," and all sorts of stuff. Then Ms. Baker said that the IEP would not get updated, it was already the end of April and the school year ended beginning of June.

I was appalled. I contacted the school's office to get an appointment. I could not get an appointment to update the IEP in a timely manner. The principle Ms. Wilhelm recommended that I pull my son and he'd be better in a "private setting," What??? The school was forcing me into a corner.

What were my options? What should I do? Could they force us out? Doesn't my son have a Right to an education? Was it worth a legal battle? Could I actually accomplish anything? Where would my son be in the mean time?

I was at a complete loss. I tried to work with the school to get my son the services he needed in accordance with what they told me. I know now this was a HUGE mistake. The only person at my son's school who seemed to be helping me was Ms. Parks. Ms. Parks was unable to make any real changes for us, for lack of power.

I worked really hard to get things together for the new IEP meeting. I got in touch with an advocate, got a quick IEP education.

I felt the IEP meet was a huge success. Everything started making sense with the Autism diagnosis. We gladly & eagerly waited the upcoming fall semester.

The 2009-2010 school year began, the first day of school I found out my son was once again in Ms. Baker's classroom, I knew now that my son needed an inclusion setting and that he had been having suffering through my stages and processes of regression. We as a family could not endure this War, and my son could not endure the classroom either. Could they force us out? They just did.

My son's needs were never going to be met and or fully addressed by the school. I had to try. That first week of school I sat in the main office almost the entire week, calling, leaving messages and notes trying to get a hold of the principal to get my son into another class. After a long week, Ms. Wilhelm's answer was, "No changing classes. Your son seems happy." He doesn't speak much how could she know if he was happy when she glanced by the classroom, my son's record of tardiness and absences to school is a better indicator. If at all from a business stand point the school was losing a huge chunks of money everyday my son was absent. Ms. Wilhelm told me her final word on the matter late Friday during a Baseball Game; she had no regard for the situation at all. I had given Mililani Uka Elementary an entire week to place my son in a classroom like Ms. Farry's (one which he had benefited from tremendously, even though only 2 months long). For the emotional and physical well-being and health of my son, I was forced to pull him from the school.

From this point we approached new possibilities for an education differently.

We found through a friend, who warned me against the company, an ABA company who had inclusion setting classroom and a tutor for my son.

To address the warning, my friend warned me that the 'businesses' side of the ABA company was a disaster and impossible to deal with. I looked elsewhere first, and avoided the ABC ABA Group completely. I found several good companies. No tutors were allowed on DOE campuses, unless you lived in Waianae. And my son needed the most help with non-family members. *I could not find a program like*

they had gotten at the Helemano CDC. After a huge deliberation of the pros and cons of the situation I ventured on the sole sake of my son's hope for improvement to go through the program at Helemano CDC. My son's doctor said with the right ABA and therapies my son could mainstream into a regular classroom within 1-2 years. We took a leap of faith.

The intake began as soon as possible, August 2009. My son had to wait for a spot at Helemano CDC, but immediate up arriving there he was doing AMAZING. This was the milestones we were hoping for and the real improvements we had only been able to dream of. It should have been a red flag, but we were so excited with my son's progress we endured the changing of tutors, 3 tutors in one month. The tutor quitting after the first week should have been a key factor too, but naively I brushed it off. The first several months were WONDERFUL. My son was thriving at Helemano and making huge progress. His tutor was great.

Enduring, counting the painful interactions between ABC ABA Group as all for the sake of my son's improvements. Everything seemed fine, and then the lies began. I am a trusting person; there was no need to lie to me. However, our tutor with the guidance of the owner Amy W. of ABC ABA Group came up with a story, and put me on the spot. Either we keep the tutor or keep the spot at Helemano. I did NOT at ALL know the Importance of the classroom setting at Helemano, and Amy W. lied to me completely about the setting at the Ft. Shafter CDC. The Ft. Shafter 'classroom' was not a classroom at all; it was a 2-3 year old 5am-6pm daycare. The classroom my son was 'supposed' to be in was full. Hanging on daily promises that the situation would change, my son began the worst regression I'd ever seen. I had never even heard that regression could get this bad. Over two months were spent trying to get out of Ft. Shafter.

From a completely scientific aspect it was a 'good' experiment. We know Never to do that again, Never! The classroom setting wasn't changing at Ft. Shafter; we needed to get back to Helemano. I didn't care if we needed to start over with another tutor we just needed to get back to Helemano CDC. My son just needed to get back to where he started from at least, we were waiting on our tutor. She gave me her word she'd be on the mainland for Christmas and be back. Lie. Mid January 2010, more than a week after the 'winter break,' I got a call from Amy W. to say our tutor would not be able to work with my son any longer. At this point my son was worse off than he'd ever been. Now we had no tutor and no spot at any CDC. The horrible holidays weren't the worst of it.

Finally, my son got a spot at Helemano CDC and tutor #5. Things were looking up. My son began to recover from the Ft. Shafter CDC experience, and make new head-way. By March 1st, 2010, we had had enough of the ABC ABA Group's business methods and decided to leave the company while my son was doing well.

The Owner of the business, Amy W., had no sense of business, lied to parents, lied to tutors, no trail of paperwork, never gave parents complete files of documents, made false promises, unable to schedule, time management skills, impossible to get a hold of or get paper work, just for starters.

I have petitioned to the Governor, Linda Lingle, at the time and my insurance company that the CDC program is a great-program, but to open it up to other and better ABA companies.

The end of ABA with ABC ABA Group was a relief. We began with Ana King ABA to get a good introduction for my son, a base line. Ana King ABA was really great. We were simply exhausted as a family. We chose to limit the therapies, doctors, doctor appointments, etc. to an essential care only. My son with Autism isn't our only child with a disability. We decided to focus on another child's real physical medical issues. We did not have the ability to fight on all sides, and we wanted to create positive things and a positive way of living. An antithesis to everything I had imagined our lives would be at this time. Starting home schooling is something I had never regarded for us, yet here we are.

We have not gone to court, or spent years in mediation, or nights awake with physical illness over the out-come of all the deliberation. The IEP failure is in three parts: the school's inability and unwillingness to implement the IEP they helped create, the IEP procedures seemingly every student starts from scratch and has to forge a way for him/herself (mediation, court, etc.), and the hindrance of the schools from allowing ABA therapists paid by insurance companies onto campuses and into classrooms.

What about parents who are: single, working, with other children that have disabilities, deployed, not understanding of the legal repercussions of the IEP, not involved, financially limited, worn out & worn down that are not able to fight the battle with the school to get appointments, advocates, legal advice, and go through the long non-productive hurdles of mediation, formal complaint, court, supreme court, etc? What about all of the Children who have an IEP, whose needs as an individual are not being met. This failure is a deliberate failure! This failure is unacceptable.

Kalma K. Wong
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March 28, 2011

Senator Rosalyn Baker
Chair, Committee on Commerce and Consumer Protection
Hawaii State Capitol, Room 230

Senator Brian Taniguchi
Vice Chair, Committee on Commerce and Consumer Protection
Hawaii State Capitol, Room 219

Re: Testimony in SUPPORT of SCR51, Requesting the Auditor to Assess the Social and Financial Effects of Requiring Health Insurers to Provide Coverage for Autism Spectrum Disorders, Senate Committee on Commerce and Consumer Protection, March 29, 2011, Room 229, 9:00 a.m.

Dear Chair Baker, Vice Chair Taniguchi, and Members of the Senate Committee on Commerce and Consumer Protection:

I am writing to express my support of Senate Concurrent Resolution 51, which would request that the State Auditor assess the social and financial effects of requiring health insurers to provide coverage for autism spectrum disorders.

Autism is a complex neurobiological disorder that currently affects 1 in 110 children, according to the Centers for Disease Control. This disorder is four times more likely to affect boys 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, muscle or joint problems, ear infections, allergies, vision and hearing problems, and gut issues. The wide range of co-occurring problems leads to the need for services from trained medical professionals and for a full-range of therapies, including but not limited to speech therapy, occupational therapy, behavioral therapy, and biomedical interventions.

As the mother of two children affected by autism, one of whom has been successfully mainstreamed without support, I can personally attest to the effectiveness of these interventions, as well as to the financial hardship faced by families who often have to pay for these therapies and interventions out of pocket. Medical insurance companies will tell you that these interventions are already covered in their plans; however, closer examination of the insurance plans will tell you that this is stretching the truth. Speech therapy, for example, is often denied in cases that are habilitative, when the patient requires the therapy to learn how to speak (versus

rehabilitative, when the patient needs the therapy to re-learn how to speak). Psychological evaluations are often not covered as well, with the insurance companies claiming that the necessary assessments are “educational” and not “medical.” This same reason is given for the lack of coverage for crucial behavioral consultation and one to one behavioral therapies.

The medical insurance companies will erroneously tell you that these therapies and interventions, such as speech and behavioral therapies, are already provided by the Department of Education and Department of Health, and therefore it is not necessary for the medical insurance companies to provide coverage. A similar inaccurate conclusion was made by the Hawaii State Auditor in the July 2009 Report, “Study of the Social and Financial Impacts of Mandatory Health Insurance Coverage for the Diagnosis and Treatment of Autism Spectrum Disorders.” Adding insult to injury, the report made the highly erroneous observation that, “...social impacts appear minimal.”

While some children are lucky enough to receive therapies through the Department of Education and Department of Health, many children do not receive enough necessary treatments, and many others simply do not receive any at all. Passing the responsibility off to others in order to save money seems to be the standard operating procedure of government and non-government agencies alike. However, if these children do not get the treatments they require when they are young, they will most certainly grow up into adults who will need even more services and will cost the community millions of dollars more. Insurance coverage for autism treatments will help to prevent this tragedy from happening.

Please pass SCR51, as it is a necessary step in getting insurance coverage for autism in Hawaii. However, I ask that this committee request that the State Auditor’s office review their report for accuracy.

Sincerely,

Kalma K. Wong

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

Children with autism often have co-occurring conditions, such as behavioral problems, speech disorders, anxiety, muscle or joint problems, ear infections, gastro-intestinal problems, 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.

Unfortunately, children with autism are often denied coverage for necessary therapies by private health insurance companies. The therapies frequently denied include speech therapy, occupational therapy, and intensive behavioral therapy, such as Applied Behavior Analysis (ABA). Applied Behavior Analysis (ABA) is a data-based intervention for autism that has a decades-long record of efficacy. ABA therapy has shown to increase educational placements and increased IQ levels of those with autism. This therapy is recognized by the U.S. Surgeon General's 2001 Report on Mental Health as being widely accepted as the effective treatment for autism. But insurers frequently deny ABA as a benefit, and families are often forced to pay for these costly services out of pocket.

Thank you very much for your time.

Sincerely,

Deborah Tasato-Kodama