Approved: March 25, 2009
Date

MINUTES OF THE HOUSE INSURANCE COMMITTEE

The meeting was called to order by Chairman Clark Shultz at 3:30 p.m. on March 19, 2009, in Room 784 of the Docking State Office Building.

All members were present.

Committee staff present:
Bruce Kinzie, Office of the Revisor of Statutes
Sean Ostrow, Office of the Revisor of Statutes
Melissa Calderwood, Kansas Legislative Research Department
Cindy Lash, Kansas Legislative Research Department
Sue Fowler, Committee Assistant

Conferees appearing before the Committee:
Louis Ruiz, District 32
Michael Wasmer, Kansas Coalition for Autism Legislation
Lorri Unumb, Council for Autism Speaks
Dr. Bill Craig, Chair, Autism Task Force
Dr. Kathy Ellerbeck, Center for Child Health & Development, KU Medical Center
Joe Fiorella, Past Chief Operating Officer of Health Insurance Company in Kansas
Stuart Jackson, Kansas small business owner, Helzberg Entrepreneurial
Carrie Wright, Parent of a child with autism
Melissa Cooper, Parent of a child with autism
Sky Westerlund, Kansas Chapter National Association of Social Workers
Tom Laing, Interhab
Rachelle Columbo, Kansas Chamber
Jim Leiker, Kansas Autism Task Force Member
Marlee Carpenter, KS Association of Health Plans
Brad Smoot, Kansas BC/BS and KC BC/BS
Dan Murray, National Federation of Independent Businesses
Bill Sneed, America's Health Insurance Plans

Others attending:
See attached list.

Discussion and action on:

HB 2075 - Providing insurance coverage for colorectal cancer screening.

Representative Neighbor moved to propose a substitute bill for **HB 2075** by removing the current language from **HB 2075** and amend the language with the impact study language. Seconded by Representative Grant. Motion passes. Representative Neighbor moved to pass **HB 2075** out as amended. Seconded by Representative Hermanson. Motion passes.

SB 105 - Enacting the public adjusters licensing act.

Representative Dillmore made a motion to amend **SB 105** by striking lines 13-17, subsection f, in Section 9 on page 6. Seconded by Representative Burroughs. Division was called with five in favor and seven against. Motion failed. Representative Dillmore moved to amend **HB 2160** into **SB 105.** Seconded by Representative Burroughs. Division was called with five in favor and seven against. Motion failed.Representative Olson made a motion to pass **SB 105** out favorably. Seconded by Representative Hermanson. Motion passes.

SB 126 - Controlled insurance program act.

Representative Peck made a motion to adopt subcommittee report on **SB 126**. Seconded by Representive Olson. Motion Passes. Representative Peck moved to put new language from subcommittee report into **SB 126** and create **House Substitute for SB 126**. Seconded by Representative Olson. Motion passes. Representative Peck moved to pass **House Substitute for SB 126** out favorably. Seconded by Representative Grant. Motion passes.

Minutes of the House Insurance Committee at 3:30 p.m. on March 19, 2009, in Room 784 of the Docking State Office Building.

SB 174 - Removal of mandatory participation requirements for group life insurance.

Representative Peck made a motion to table **SB 174**. Seconded by Representative Brown. All in favor motion passes.

Hearing on:
HB 2367 - Insurance coverage; autism.

Melissa Calderwood, Kansas Legislative Research Department, gave a brief overview on **HB 2367.**

The Chairman opened the hearing on **HB 2367**.

Proponents:
Louis Ruiz, District 32, (Attachment 1), appeared before the committee in support of **HB 2367**.
Michael Wasmer, Kansas Coalition for Autism Legislation, (Attachment 2), gave testimony before the committee in support of **HB 2367**.
Lorri Unumb, Council for Autism Speaks, (Attachment 3), presented testimony before the committee in support of **HB 2367**.
Dr. Bill Craig, Chair, Autism Task Force, (Attachment 4), appeared before the committee in support of **HB 2367**.
Dr. Kathy Ellerbeck, Center for Child Health & Development, KU Medical Center, (Attachment 5), gave testimony before the committee in support of **HB 2367**.
Joe Fiorella, Past Chief Operating Officer of Health Insurance Company in Kansas, (Attachment 6), presented testimony before the committee in support of **HB 2367**.
Stuart Jackson, Helzberg Entrepreneurial Mentoring Program, (Attachment 7), appeared before the committee in support of **HB 2367**.
Carrie Wright, Parent of a child with autism, (Attachment 8), gave testimony before the committee in support of **HB 2367**.
Melissa Cooper, Parent of a child with autism, (Attachment 9), presented testimony before the committee in support of **HB 2367**.
Sky Westerlund, KS Chapter National Association of Social Workers, (Attachment 10), presented written testimony in support of **HB 2367**.
Tom Laing, Interhab, (Attachment 11), presented written testimony in support of **HB 2367**.
Rachelle Columbo, Kansas Chamber, (Attachment 12), presented written testimony in support of **HB 2367**.
Jim Leiker, Kansas Autism Task Force Member, (Attachment 17), presented written testimony in support of **HB 2367**.

Opponents:
Marlee Carpenter, KS Association of Health Plans, (Attachment 13), appeared before the committee in opposition to **HB 2367**.
Brad Smoot, Kansas BC/BS and KC BC/BS, (Attachment 14), presented testimony in opposition to **HB 2367**.
Dan Murray, National Federation of Independent Businesses, (Attachment 15), presented written testimony in opposition to **HB 2367.**
Bill Sneed, America's Health Insurance Plans, (Attachment 16), presented testimony in opposition to **HB 2367**.

Hearing closed on **SB 2367**.

Representative Grant moved without objection to pass the March 12 and March 17, 2009 committee minutes, with one minor change, as written.

The meeting was adjourned at 6:00 p.m.

House Insurance Committee
Guest Sign In Sheet
Thursday, March 19, 2009

Name	**Representing**
Ken Keller	ASA
Bill Miller	ASA
Sue Collins	AS.
Lorri Unumb	Autism Speaks
Mike Wasmer	Autism Task Force
Bill Robinson	ASA and Autism Society of America-Heartland
Joe Fiorella	KCAL
Bill Craig	Autism Task Force
Carrie Wright	KCAL
Steve Anderson	Parent / KCAL
Courtney Anderson	Parent / KCAL
Jo Hartman	KCAL
RICK BENNETT	KCAL
Jennifer Smith Currier	KCAL / Parent
Debra Kisinger	Autism Speaks
Dorothy McCafferty	Autism Speaks
Judy Borchers	Parent
Erin Borchers	Observer
Arun Ramasamy	Parent
Bob Alderson	NAPIA
Bill Sneed	AHIP
Carolyn Wilson	KDHE
Nan Perrin	ECAP
Alex Kotoyantz	P.I.A.
Marlee Carpenter	KAHP
John Campbell	KID
DAN MORGAN	Builders' Assn.
Dannielle Finan	WU MSN
Katie Hicks	WU MSN
[illegible]	UHG

House Insurance Committee
Guest Sign In Sheet
Thursday, March 19, 2009

Name	Representing
[illegible]	KS Chamber
John Beetz	KID
Barbara Torkelson	KID
Linda Sheppard	KID
Amy Campbell	KmctC
Jackie Bart	Parent of Jacob Bart
Renee Frias	Parent of Lucas Frias
Randy Seiner	AIU Holdings
Dan Murray	NFIB
Bruce Witt	PHS
KEVIN & SHARON McCARTER	PARENTS OF AUSTIN McCARTER
Elizabeth Boresow	Elizabeth Boresow
Sunee Mickle	BCBSKS
Kristin Sneid	KCAL
Barry Fike	Parent of Caleb Fike

STATE OF KANSAS

LOUIS E. RUIZ
REPRESENTATIVE, 32ND DISTRICT
2914 W. 46TH AVE.
KANSAS CITY, KS 66103
(913) 262-1634

OFFICE:
STATE CAPITOL
TOPEKA, KS 66612
(785) 296-7122

TOPEKA

HOUSE OF
REPRESENTATIVES

COMMITTEE ASSIGNMENTS
COMMERCE AND LABOR–RANKING DEMOCRAT
FEDERAL AND STATE AFFAIRS
GOVERNMENT EFFICIENCY AND TECHNOLOGY
JOINT COMMITTEE ON HEALTH POLICY
OVERSIGHT
DISASTER RECOVERY COMMITTEE—RANKING
DEMOCRAT

March 18, 2009

Chairman Schultz, Members of the Committee,

Thank you for the opportunity to appear before your committee today to express remarks about insuring persons diagnosed with autism.

HB 2367 will give families of Kansas the much needed relief from the stress of the financial burden due to the diagnosis and treatment of the medical condition known as autism. I believe it is our duty as elected officials to ensure benefits to those that are in dire need of lifetime medical assistance.

Imagine the fear when your strong vibrant child becomes a virtual stranger. With no financial assistance available you find yourself caught in a web of bureaucracy and red tape that leads to a path of denial of benefits from insurance companies. For the families and caretakers of these children the fear and frustration are very real and never ending.

For this reason I urge you as legislators and citizens of the great state of Kansas, as parents and grandparents to give HB 2367 every consideration and pass it favorably.

Sincerely,

Louis Ruiz
State House Representative District 32

House Insurance
Date: 3-19-09
Attachment # 1

Testimony in Support of Kansas House Bill 2367 (Kate's Law)

Michael Wasmer, DVM, Dipl ACVIM
March 19, 2009

Thank you for the opportunity to offer testimony in strong support of HB 2367, known as "Kate's Law". If enacted Kate's Law would require that private health insurance cover the diagnosis and appropriate treatment for autism spectrum disorders.

I am the parent of a child with autism and an appointed member of the Kansas Autism Task Force. The Kansas Legislature unanimously passed legislation that created the Autism Task Force in 2007, directing us to study and conduct hearings on the issues relating to the needs of, and the services available for persons with autism spectrum disorders. The Autism Task Force has concluded that inequities in health insurance coverage create one of the most significant barriers to appropriate early intervention for children with autism in Kansas. The Kansas Autism Task Force strongly endorses House Bill 2367.

In fulfillment of KSA 40-2248 and 40-2249, we have submitted a social and financial impact report for HB 2367. In addition, a detailed third party actuarial analysis of the estimated impact on health insurance premiums related to the provisions of HB 2367 has been performed and submitted for your review.

The Financial Benefit of Providing Appropriate Treatment for Autism

Although there is no proven "cure" for autism, over 30 years of scientific research support the effectiveness of early intensive intervention in reducing the effects of this disorder. Approximately 50% of children that receive appropriate early intervention for autism will mainstream in a public school setting and become productive tax paying Kansans. When access to appropriate treatment is denied, only 2% of affected children will achieve this level of success. The net loss incurred by the State of Kansas per child with autism who does <u>not</u> receive appropriate treatment has been estimated to be $4.4 million through age 55 (see attachment 1).

The existing fiscal note for HB 2367, which estimates the cost of providing appropriate coverage for the estimated 173 children with autism in the State Employees Health Plan, is reported to be $3.8 million for FY 2010. We are currently reviewing some of the assumptions that were made when calculating this estimate and expect that a more accurate figure may be as much as 66% lower. However, even if it were to cost $3.8 million to treat these 173 children, this is less than the $4.4 million dollars lost as a result of denying appropriate treatment to just <u>one</u> of them.

House Insurance
Date: 3-19-09
Attachment # 2

The cost savings to the State of Kansas by investing in appropriate and timely treatment for autism offer strong support for enacting HB 2367.

Estimation of the Effect of HB 2367 on Health Insurance Premiums

Opponents of HB 2367 (SB 12) have offered a variety of estimates of its impact on health insurance premiums with little or no documentation of how their estimates were derived. The most outrageous of these estimates was a 19.8% increase based upon analysis of a similar bill that was introduced this year in Oklahoma. A formal complaint has been filed in Oklahoma against Mr. Thomas Cummins, who is the actuary that performed this analysis. The complaint alleges that Mr. Cummins committed several violations of the American Academy of Actuaries' Code of Professional Conduct in preparation of his report and demonstrated bias in a purposeful effort to defeat the Oklahoma autism insurance bill.

The Cummins report was submitted by opponents of Kate's Law in the Senate hearing in January, along with a recommendation to the Committee Chair not to take action on Kate's Law. That is exactly what has happened. If submitted again today, I would ask that the Cummins report not be considered pending the outcome of the complaint against Mr. Cummins.

Proponents of Kate's Law have submitted two detailed analyses of the estimated impact of enacting the provisions of HB 2367 (SB 12) for your review. The report from Oliver Wyman is an independent third party actuarial analysis. Both analyses demonstrate <u>a 1% increase or less, which equates to approximately $25 per covered person per year</u>. Our estimates are well documented and are very consistent with estimates prepared for similar legislation in other states by members of the American Academy of Actuaries.

Rationale for exempting HB 2367 from KSA 40-2249a; the "pilot project statute"

You may hear testimony from opposition today that questions why Kate's Law was written to be exempt from the Kansas statute that requires a state employer group pilot project for newly mandated health benefits. The intent of this 1-year test track is to determine the impact of such benefits on the State Employees Health Plan including the cost of coverage.

Kansas is not unique in seeking legislation to require that private health insurance cover the diagnosis and appropriate treatment of autism. Eight states

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have existing autism mandates similar to Kate's Law. Of these, Indiana's has been in effect the longest - over 8 years. In contrast to the limitations on coverage imposed by HB 2367, the Indiana Autism Mandate has no age limits or financial caps, and applies to both large and small businesses.

During the October 25, 2007 meeting of the Kansas Autism Task Force, we cited this precedent set in Indiana. At this meeting, we specifically asked the representative of the health insurance industry who was appointed to the Task Force as well as the lobbyist for Blue Cross Blue Shield of Kansas who was also present, to investigate the impact of the Indiana mandate and report their findings back to the Task Force. They have provided no information on this issue.

To date, there has been no data presented by any government body or insurer to show that the Indiana Autism Mandate has had negative effects upon health insurance premiums, the number of uninsured in the State, the viability of small businesses or the ability of the state to attract large and small businesses to the State.

Indiana has already completed an 8-year test track for us. Considering the number of children with autism in Kansas and the importance of appropriate early intervention, delaying implementation of HB 2367 to private health insurance carriers for an additional year is an unnecessary and costly delay.

No private health insurance carrier in Kansas <u>consistently</u> provides coverage for the diagnosis and <u>appropriate</u> treatment of autism spectrum disorders

Opponents of Kate's Law have questioned the need to mandate health insurance coverage for autism because of their assertion that they "already cover it." The fact of the matter is that no private health insurance carrier in Kansas <u>consistently</u> covers the <u>appropriate</u> treatment for autism as recommended by the American Academy of Pediatrics and the U.S. Surgeon General. "Consistent" and "appropriate" are key words in this discussion. Your constituents have testified through the Kansas Autism Task Force and will testify this afternoon that health insurance coverage for their children with autism is neither consistent nor appropriate.

At the October 25, 2007 meeting of the Autism Task Force, representatives from Blue Cross Blue Shield of Kansas presented claims data from August 2006 through July 2007 that, according to their interpretation demonstrated that they "already cover autism". Their data show that 2,577 claims were submitted related to services for their 421 members with an autism spectrum disorder (see attachment 2). Of these claims, 197 were for speech therapy (Procedural Code

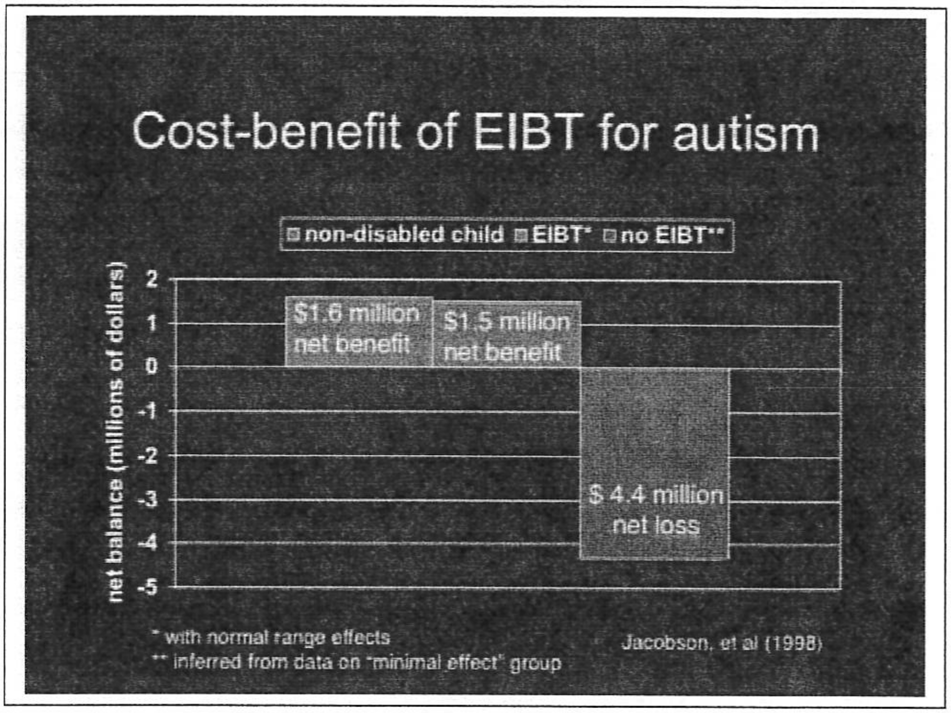
92507). This equates to less than one speech therapy session per patient with autism per year (i.e. 197 speech therapy sessions/421 patients with autism /year = 0.5 speech therapy sessions/patient/year). This company covers speech therapy for autism but is the coverage medically appropriate for each child?

An analogous situation would be a child with a form of cancer for which the standard of care was to administer a combination of three different chemotherapy drugs. Appropriate coverage for this child's treatment means that he receives the correct dose of each drug at the appropriate interval. An insurance company may correctly state that they cover treatment for this form of cancer even if they were covering only one of the three drugs, and at a fraction of the recommended dose. However that coverage is not medically appropriate.

No private health insurance carrier in Kansas is consistently covering the diagnosis and appropriate treatment of autism. If there were then individuals could simply switch carriers to obtain this medically necessary coverage. However, in this case, the free market has failed and the Kansas legislature must intervene.

Consistent coverage for the appropriate treatment of children with autism in Kansas can only be accomplished with a legislative mandate. I appreciate your putting aside any philosophical opposition to mandates and considering the many benefits to children with autism, their families and the State of Kansas that would come from enactment of Kate's Law. Parents, state supported programs (e.g. the Autism and DD Waivers) and our public schools are stretched beyond capacity to do more. It is time for the health insurance industry to come to the table as equal partners in the solution to this medical crisis.

Attachment #1


Cost-benefit of EIBT for autism

* with normal range effects
** inferred from data on "minimal effect" group

Jacobson, et al (1998)

Using representative costs from the state of Pennsylvania, a 1998 study performed a cost-benefit analysis of providing early intensive behavioral therapy (EIBT) such as ABA to children with autism. Factors considered through age 55 included the costs associated with 3 years of EIBT, special education, and adult disability services; as well as the median income of a non-disabled adult, versus supported wages.

The area in red represents the cost-benefit of providing regular education for a non-disabled child, and demonstrates a net benefit of $1.6 million.

The area in blue represents the cost-benefit scenario of a child with autism who receives EIBT and achieves successful placement in regular education classes, and demonstrates a net benefit of $1.5 million. Approximately 50% of children with autism who receive appropriate early intensive behavioral therapy will achieve this level of success.

The area in purple represents the cost associated with NOT providing EIBT to a child with autism. This demonstrates a net LOSS of $4.4 million per child.

Considering the skyrocketing prevalence of autism, and the cost savings of providing access to appropriate treatment for autism, enactment of Kate's Law is critical to the fiscal health of Kansas.

Reference:
Jacobson, John W, Mulick, James A., Green Gina. "Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism," Behavioral Interventions, 13, 201-226 (1998)

February 19, 2009

Actuarial Cost Estimate: Kansas Senate Bill 12 – An Act Concerning Insurance; Providing Coverage for Autism Spectrum Disorder

OLIVER WYMAN

Prepared By:

Marc Lambright, FSA, MAAA

MMC MARSH MERCER KROLL
GUY CARPENTER OLIVER WYMAN

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1

Background

Oliver Wyman Actuarial Consulting, Inc. (Oliver Wyman or We) has been engaged by Autism Speaks to develop a cost model in order to analyze and estimate the impact of mandated insurance benefits for Autism Spectrum Disorders (ASD) on insurance premiums. As part of this work, Oliver Wyman has developed a range of independent estimates of the impact on insurance premiums for the benefits mandated by Kansas Senate Bill 12 (SB 12) which provides coverage for the diagnosis and treatment of autism spectrum disorder in individuals under the age of 21.

Oliver Wyman is a part of the Marsh & McLennan (MMC) family of companies. With over 60 members of the American Academy of Actuaries, Oliver Wyman is one of the largest actuarial practices in North America. Oliver Wyman's health practice, which has twelve credentialed actuaries, advises insurers, regulators, governments, interest groups, and others.

This report, along with its supporting analysis, was developed by Marc Lambright, a Principal and consulting health actuary in Oliver Wyman's Philadelphia office. Marc is a Fellow of the Society of Actuaries and a member of the American Academy of Actuaries and is professionally qualified to analyze the cost impact of SB 12 and provide the estimates shown in this report. As part of Oliver Wyman's quality assurance process, the underlying analysis and this report were independently peer reviewed by another credentialed Oliver Wyman actuary.

2

Scope and Limitations

The intent of this analysis is to provide a reasonable range of estimates for the insured costs of the mandated ASD benefits provided for in SB 12 and the associated premium impact on the markets affected by SB 12. This analysis makes no attempt to quantify potential offsetting cost savings associated with successful ASD treatment, nor does it include any estimate of the potential reduction in other government expenditures associated with providing ASD services that might overlap with the benefits provided by this mandate. Therefore, the reader is cautioned that this report should only be considered a cost analysis, and not be misconstrued as a cost-benefit analysis when assessing the merit of SB 12.

We note that cost estimates for autism mandates have varied widely state to state, based on differences in the state specific mandates and the methods and assumptions used in the estimating costs, though typically independent estimates show premium increases due to mandated autism benefits of less than 1%. The reason for this variability is that the largest component of the increase in costs under the SB 12 mandated ASD benefits is for Applied Behavior Analysis ("ABA"), which is almost universally excluded from health coverage, and therefore essentially no insured data exists for use in developing credible utilization and unit cost estimates for ABA.

The reader is cautioned that the ultimate cost of covering ABA benefits is uncertain; however, this analysis attempts to reflect the likely behavior of consumers, providers and insurers of ABA services in developing the assumptions underlying the cost estimates. Likewise, the additional costs for mandated medical services other than ABA are difficult to quantify. Insurance policies often cover some services for children diagnosed with an ASD, although the mandate could cause the costs for certain services to increase because ASD exclusions are common, and certain services that may have been denied or terminated following utilization review might be covered due to the mandate.

3

Description of Key SB 12 Provisions and their Impact on Covered Benefits

Insurance Markets Covered by Mandate

New Section 1. (a) (1) states: *Any individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides coverage for accident and health services and which is delivered, issued for delivery, amended or renewed on or after July 1, 2009, shall provide coverage for the diagnosis and treatment of autism spectrum disorders in any covered individual.*

New Section 1 goes on to state in (e) (1) *Any employer that has 50 or fewer employees shall have the option to exclude the coverage required by this section from any health benefit plan, as such term is defined in K.S.A. 40-2209d, and amendments thereto, offered to such employees.*, and in (e) (2) *Any individual with an individually underwritten health insurance policy shall have the option to exclude the coverage required by this section from such policy.*

The bill, as written, mandates coverage of ASD services for the large group (51+ employees) market, as well as requires insurers to offer coverage of ASD services as a benefit option in the small group (2-50 employees) and Individual markets. Autism Speaks has asked us to model the following scenarios:

1. Mandated coverage applies to large group market, only.
2. Mandated coverage applies to large and small group markets.
3. Mandated coverage applies to the large group, small group, and individual markets.
4. Mandated coverage applies to the large group market, and a mandate to offer coverage applies to the small group market.

Covered Benefits

Treatment includes: *(A) Habilitative or rehabilitative care; (B) pharmacy care; (C) psychiatric care; (D) psychological care; and (E) therapeutic care.*

The inclusion of applied behavioral analysis (ABA) in the definition of *Habilitative or rehabilitative care* is especially important. The coverage of ABA has the most significant impact on cost of any mandated service. ABA programs are marked by intensive therapy that may include 30-40 hours of therapy a week under the most intensive programs, though many programs would not utilize that level of resources. Key assumptions underlying our ABA cost estimates are outlined in Section 5.

Annual ABA Maximum Benefit of $75,000 through Age 21

The annual coverage maximum is important as it has the effect of capping costs for the heaviest users of ASD services. From a practical standpoint, this would generally apply to young children whose therapy includes an intensive ABA program.

Medical Necessity and Treatment Review

The bill does allow for utilization review by specifically stating: *an insurer will have the right to request a review of that treatment not more than once every 12 months unless the insurer and the individual's licensed physician or licensed psychologist agrees that a more frequent review is necessary.* This is important as insurers will develop protocols to review treatments and manage care which will limit unnecessary treatments if reviews are done appropriately.

4

Modeling Methodology

The following outlines the general modeling methodology used to develop the cost estimates. Estimates were developed both on a per member per month (PMPM) basis, and as a percentage of average annual premiums as shown in Section 6. Details of key assumptions are discussed in Section 5 and illustrated graphically in the exhibits shown in Appendix 1.

Modeling Perspective

In general, the model was developed to produce costs under the assumption that sufficient providers would be available to meet the demand for autism services, especially with regard to ABA services. It also assumes that there would be sufficient awareness of autism and motivation (primarily by parents) to seek treatment so that the diagnosis and treatment of ASDs would be more in line with CDC prevalence estimates. We would expect that it would take at a minimum several years for both the supply of providers to meet the demand for mandated ASD services and for parents of autistic children to aggressively seek diagnosis and treatment of their childrens' disorders.

In spite of these real limitations that will likely limit short-term costs associated with mandated autism benefits, we feel that it is appropriate from a public policy perspective to look at the costs from a longer term perspective and assume that both awareness of ASDs will increase and that supply and demand for ASD services would eventually be in balance. We have developed our estimates with this in mind.

In the near term we would note that the supply of ABA service providers, specifically credentialed Board Certified Behavior Analysts (BCBAs) and Board Certified Associated Behavior Analysts (BCaBAs) would not be sufficient to meet the demand for ABA programs if ABA benefits are mandated. There are currently about 35[1] certified BCBAs and BCaBAs in Kansas, which translates to approximately one therapist per 117 children

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[1] BACB Certificant Registry: http://www.bacb.com/cues/frame_about.html, accessed January 2009.

2-12

treated for ASD in Kansas based on the prevalence and age at diagnosis assumptions outlined in this report. While it is true that not all autistic children will have an ABA program, it is also true that behavioral analysts provide services to individuals other than autistic children. It is reasonable to conclude that demand for ABA services, at least initially, would far exceed supply should health care coverage similar to that mandated by SB 12 become typical. Therefore, the long-term estimates shown in this report should not be used as a basis for trying to determine the near-term cost impact of the mandated benefits.

In trying to ascertain the near-term impact of SB 12, it is also instructive to look at some of the limited evidence available related to actual costs of ABA mandated benefits in other states. Aetna noted in December 2008 that it had tracked the cost of the autism mandate in Texas for its first year of existence and found that it increased costs for policyholders who filed autism-related claims by $379 a month. A total of 235 policy holders had filed autism claims in the state as of the time the data was released. At that time, the company had not decided whether to pass those costs on to the policyholders because the cost of the mandate might change after the first year.[2] While this is only first year experience for a single insurer, it illustrates that initial mandate costs are likely low. Aetna's Texas block of business is quite large (approximately $1.5 - 2.0 billion in premium[3]), so the statistics provided indicate a mandate cost of less than 0.1% of premium. This experience is likely not atypical of experiences in other states.

General Modeling Process

The modeling process employed to develop our cost estimates was as follows:

1. Assumed treated prevalence for the United States is 1 in 150 based on the CDC's estimate of ASD prevalence in the United States. For Kansas, we decreased this prevalence rate by 15% based the fact that the percentage of children reported with autism in Individuals with Disabilities Education Act (IDEA) Part B child count[4] data is approximately 30-40% (depending upon ages considered) lower in Kansas than in the United States. These child counts should be a reasonable indicator of the relative likelihood of children receiving medical treatment for ASD in different states.
2. Prevalence rates by diagnostic subtype (autistic disorder, PDD-NOS, Asperger's Syndrome) were estimated separately as diagnosis patterns and service utilization could reasonably be expected to vary by diagnostic subtype.

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[2] Lawmaker: Oklahoma autism bill has momentum. Associated Press. December 4, 2008. http://newsok.com/article/3327594 accessed January 2009.

[3] NAIC Annual Statements for 2007.

[4] IDEA Part B database. http://www.ideadata.org/PartBChildCount.asp. Accessed January 2009.

3. The percentage of children diagnosed by age for each diagnostic subtype was estimated so that the average age of diagnosis implicit in the modeling is consistent with publicly available age at diagnosis statistics[5].
4. The percentage of diagnosed children who could be expected to have an ABA program was estimated for each age based on assumptions regarding how many children would start a program and typical program continuance.
5. A distribution of the number of annual hours for an ABA program was developed based on ABA provider input and an assumption that utilization review by insurers would impact utilization to some degree.
6. Based on the assumed treatment prevalence, likelihood of having an ABA program, assumed distribution of ABA program hours, and estimated ABA program cost per hour of therapy, ABA cost estimates by age were developed and adjusted to reflect the impact of the annual $75,000 cap.
7. Non-ABA costs were estimated based upon studies of medical costs for ASD children and judgment regarding the increase in costs that could be expected due to the mandated benefits.
8. Based on Census demographic data and the cost estimates for mandated ASD services by age as outlined in 1-7 above, an annual cost per covered individual was developed.
9. The cost of services was increased to reflect administrative and other insurer costs or profit charges.
10. The estimated size of the covered market was developed based on Census, Medical Expenditure Panel Survey (MEPS) enrollment and premium information for Kansas, and Kaiser Family Foundation coverage data. These assumptions are further documented in the following section.
11. In order to understand how regulations for rating affect the rates that can be charged to individuals in Kansas, we reviewed the rating requirements in the Kansas Insurance Department Administrative Regulations (Agency 40, Article 4- Accident and Health Insurers).[6] This review is discussed further in section 6 of this report.
12. The cost of the mandated services per covered person and as a percentage of premiums were calculated based on the model cost estimates and market data.

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[5] IAN database. http://dashboard.ianexchange.org/StateStatsAdvanced.aspx?A1=VA&ADU=T. Accessed January 2009.

[6] Kansas Administrative Regulations. http://www.ksinsurance.org/legal/regs_list.htm. Accessed February 2009.

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5

Summary of Key Assumptions

Key assumptions underlying the cost estimates for the mandated benefits are summarized in this section. Appendix 1 further illustrates these assumptions.

Treated Prevalence and Age at Diagnosis

Overall treated prevalence is based on the 2007 CDC[7] study estimating United States' ASD prevalence of 1 in 150 adjusted downward by 15% due to reported autism rates per IDEA Part B child count data being significantly lower in Kansas than for the country as a whole. Prevalence by diagnostic subtype estimated based on an academic study published in the American Journal of Psychiatry[8].

As noted in the previous section, the percentage of children diagnosed by age for each diagnostic subtype was estimated so that the average age of diagnosis implicit in the modeling is consistent with publicly available age at diagnosis statistics.

The base model treated prevalence and age at diagnosis assumptions for Kansas are shown below:

Kansas Prevalence

Diagnostic Subtype	Ultimate Prevalence	Average Age of Diagnosis
Autistic Disorder	1 in 529	3
PDD-NOS	1 in 353	3
Asperger's	1 in 1059	6
All ASD	**1 in 176**	

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[7] Centers for Disease Control. Morbidity and Mortality Weekly Report. February 9, 2007.

[8] Fombonne, E. and S. Chakrabarti. American Journal of Psychiatry. June 2005.

ABA Program Utilization and Cost

ABA Program Utilization by Age

ABA programs require a significant commitment from affected children, as well as their families. It is likely that a significant number of ASD children will not have an ABA program regardless of the availability of a provider. For this reason, we have assumed that two-thirds of diagnosed children will begin an ABA program. Based on discussions with ABA providers and researchers, actual utilization of ABA programs has been significantly lower. In Minnesota, a state that is widely regarded as having some of the most extensive ABA coverage and services in the nation, provider data indicates ABA utilization of approximately 20% of diagnosed three to six year olds[9], which is considerably lower than the 66.7% assumption employed in cost modeling shown in this report. While this (66.7% of diagnosed children under age six will have ABA program) higher assumption is likely conservative at least in the near-term, it is probably reasonable since insurers will likely have some conservatism in their cost estimates and premium rates, private insurance utilization will likely be higher than under the public/private programs in Minnesota, and utilization will likely increase over time due to increased awareness of ASD and potentially increased supply in ABA providers.

ABA programs are generally geared towards addressing deficits in younger children and are generally not intended to be continued indefinitely. For this reason, we have assumed that no programs would terminate prior to school age, that a large percentage of ABA programs would terminate at ages six and seven when an autistic child could be expected to enter elementary school, and thereafter a large percentage of programs would terminate annually until only a very small percentage of children have ABA programs in their teenage years. Programs would be expected to terminate if a child has experienced sufficient progress so that a program is no longer necessary or if the insurer or family sees no progress, as well as for other reasons.

The assumed percentage of children diagnosed with ASD that have an ABA program is shown in the table below:

% of Diagnosed Children w/ ABA	
Under 6	66.7%
6	50.0%
7	33.3%
8	22.2%
9	14.8%
10	9.9%
11	6.6%
12	4.4%
13 to 21	3.3%

---

[9] Discussion with Dr. Eric Larsson Executive Director, Clinical Services, The Lovaas Institute for Early Intervention Midwest Headquarters regarding ABA utilization research in Minnesota. February 2009.

ABA Program Annual Number of Hours

In developing the assumed annual ABA program hours, we discussed typical ABA programming with ABA providers, and reviewed some benefit materials from one of the few large self-insured employers who offer ABA benefits[10]. For three age bands, we developed a distribution of expected hours that resulted in the annual averages shown in the table below.

Average ABA Program Hours	
Ages Under 8	1,500
Ages 8 to 12	671
Ages 13 to 21	401

The general assumption is that pre-school aged children will have programs for 20 to 40 hours a week, averaging about 30 hours a week. This time will be reduced by over half by age eight when children would be expected to be in school and the school system would be required to provide services during the school day, and then again would be reduced significantly at age 13 as the child ages and ABA programs would be expected to be less time consuming and address a smaller number of behavioral deficits.

Cost per Hour of ABA Service

In developing the costs per hour, we reviewed ABA program staffing information and ABA provider wage and overhead cost assumptions. We developed an average cost for the entire United States and then adjusted this for Kansas, based on Bureau of Labor Statistics[11] health care wage data. The resulting average cost per hour of ABA therapy in Kansas is $41.34.

Other (than ABA) Medical Costs

Based on several studies[12], we estimated that children with ASDs had costs approximately three times the average for non-inpatient medical services under current benefit programs. It is also likely that the mandate would mean that some services that an insurer could currently deny or exclude would now be covered. In our base estimate, we assumed that the mandate would result in additional insured medical costs equal to the current level of covered non-inpatient costs for services to children diagnosed with an ASD.

Administrative Costs

Typically, group medical claims costs could be expected to be 80 to 90% of premiums, meaning 10 to 20% of premiums are available for administration, profit, or other costs,

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[10] Autism Therapy Reference- Microsoft Corporation (administered by Premera Blue Cross).

[11] BLS wage data. http://www.bls.gov/guide/geography/wages.htm accessed January 2009.

[12] Mandell, Cao, Ittenbach, & Pinto-Martin, 2006. Croen, Najjar, Ray, Lotspeich, & Bernal, 2006. Liptak, Stuart, & Auinger, 2006.

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often collectively referred to as "retention." We have estimated the incremental retention charge to be 15% of premium under our base assumptions.

Kansas Market Data

The MEPS survey provides average premiums, enrollees, offer rates, take-up rates, and self-insured percentages by employer size for healthcare coverage sponsored by privately insured employers. From this data we can estimate the size of the privately insured small group, insured large group, and self-insured markets. State specific premium data for Kansas was available for 2006[13], so we trended this based on average recent employer premium increases provided from the Kaiser Family Foundation HRET[14] survey to estimate the 2009 average annual premium per member necessary to compute the cost of mandated benefits as a percentage of annual premiums.

To estimate average premiums for the individual market, we reviewed survey results developed by America's Health Insurance Plans[15] that showed premiums and average members by contract type and state.

As part of our development of premiums and membership estimates, we completed reasonableness tests by reviewing insurer annual statement filings to ensure that the individual and group premium estimates were not unreasonable.

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[13] MEPS state survey data. http://www.meps.ahrq.gov/mepsweb/data_stats/state_tables.jsp?regionid=-1&year=-1. Accessed January 2009.

[14] Kaiser Family Foundation and Health Research Educational Trust. Employer Health Benefits- 2008 Annual Survey.

[15] AHIP Individual Health Insurance 2006 - 2007: A Comprehensive Survey of Premiums, Availability, and Benefits. http://www.ahipresearch.org/pdfs/Individual_Market_Survey_December_2007.pdf. Accessed January 2009.

6

Cost Estimates

Base Cost Estimates

As we noted in Section 3, we developed cost estimates assuming various markets would be affected by the mandate, as follows:

1. Mandated coverage applies to large group market, only.
2. Mandated coverage applies to large and small group markets.
3. Mandated coverage applies to the large group, small group, and individual markets.
4. Mandated coverage applies to the large group market, and a mandate to offer coverage applies to the small group market.

Large and Small Group Mandated ASD Coverage

The table below summarizes the mandate costs and impact on small and large group premiums under the base assumptions outlined in Section 5. The base estimate is that the long-term cost of the mandated benefits provided by SB 12 would be about 0.73% of insured premiums, though this cost would likely initially be much lower in the years immediately following the passage of the mandate due to the limited supply of ABA therapy providers. If only the large group market were to be covered, our base estimate indicates a 0.76% of premium increase.

	Market		
	Small Group	Large Group	All
Covered Persons	230,000	272,000	502,000
Average Premium per Person	$3,800	$3,500	$3,637
Annual Mandate Claim Cost per Covered Person	$22.60	$22.60	$22.60
Claim Cost as a Percentage of Premium	0.59%	0.65%	0.62%
Estimated Premium Increase with Admin @ 15%	$26.60	$26.60	$26.60
Premium Increase as a Percentage of Premium	0.70%	0.76%	0.73%

Large Group, Small Group, and Individual Mandated Benefits

The large and small group estimates are the same as those shown on the previous page.

Individual Market

In developing the individual market cost estimates we reviewed SB 12 and Kansas rating regulations, and noted the following:

- SB 12 includes the following language: *No individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides coverage for accident and health services and which provides coverage with respect to an autism spectrum disorder shall: …* (2) *deny or refuse to issue coverage on, refuse to contract with, or refuse to renew, refuse to reissue or otherwise terminate or restrict coverage on an individual solely because the individual is diagnosed with an autism spectrum disorder*;
- Kansas Insurance Department Administrative Regulations (Agency 40, Article 4- Accident and Health Insurers) do not include any rating restrictions based on health status.

Mandating coverage or allowing an individual the option of covering ASD services could potentially have similar impacts on premium rates in the individual market. In either case the coverage would be expensive since insurers would likely price individual coverage assuming that the insured would have a much higher likelihood of utilizing ASD services when purchasing optional ASD coverage, or having a dependent with ASD. Carrier pricing strategies and the manner in which the insurance department would regulate rates for ASD coverage is difficult to ascertain at this time, however, it is reasonable to assume that insurers would price it conservatively to mitigate the financial risk associated with covering individuals with high expected medical costs.

We have assumed that the average amounts would be based on the same cost assumptions outlined in the prior sections of this report. We estimate an average increase of 1.07% assuming a 15% average retention percentage for all markets as shown in the table below:

	Market
	Individual
Covered Persons	175,000
Average Premium per Person	$2,200
Annual Mandate Claim Cost per Covered Person	$20.00
Claim Cost as a Percentage of Premium	0.91%
Estimated Premium Increase with Admin @ 15%	$23.50
Premium Increase as a Percentage of Premium	1.07%

We note that the premium increases in the individual market would be borne primarily by the purchasers of policies who have dependents with ASD. Policyholders that would not be at risk for ASD claims would likely see little or no premium increase, with actual premium increase amounts being dependent upon carrier pricing strategies which will vary.

If the mandate covers the large group, small group and individual markets, we estimate that the overall premium increase for affected policyholders will be approximately 0.79%.

Large Group Mandated and Small Group Optional ASD Coverage

The large group premium increase under the Base Scenario would still be the same, 0.76%. Pricing the optional small group coverage will be a little bit difficult in that the carrier will have to make some assumptions regarding the likelihood of groups electing coverage and the morbidity of the groups electing coverage. For optional ASD coverage, a carrier will likely charge some amount, perhaps 2-3 times the 0.70% premium increase estimated for mandated coverage since a carrier would likely assume that those groups electing coverage will have higher claims. The carrier also could potentially include a small contingency charge for all policyholders to account for the additional risk of offering a new benefit that is difficult to price. Overall, premiums for policyholders electing optional ASD coverage would likely see premium increase of 1-3%, and policyholders not electing coverage could potentially see a small risk charge. An upper bound on the average increase in premiums for optional small group coverage is the 0.70% estimate assuming mandated coverage for all small groups, though the average increase would likely be less than that amount as certain groups would not purchase optional coverage.

Scenario Estimates

As discussed in Section 1, very little insurance data exists that can be used to directly estimate the costs of ABA benefits mandated by SB 12. This causes uncertainty in developing actuarial assumptions and cost estimates. Due to this uncertainty, it is useful to develop cost estimates for additional scenarios using more optimistic and pessimistic assumptions. Ranges of the long-term premium increases associated with mandated benefits under SB 12 are that premiums would increase as follows assuming the mandate covers various markets:

1. Mandated coverage applies to large group market, only- premium increase of 0.57% to 0.95%.
2. Mandated coverage applies to large and small group markets- premium increase of 0.55% to 0.91%.
3. Mandated coverage applies to the large group, small group, and individual markets- premium increase of 0.59% to 0.99%.
4. Mandated coverage applies to the large group market, and a mandate to offer coverage applies to the small group market- Average increase will likely be similar to Estimate 2 above - 0.55% to 0.91%.

Appendix 1

Cost Assumptions – Illustrative Exhibits

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EXHIBIT I - SUMMARY OF SENATE BILL 12 ASSUMPTIONS AND COSTS

State	Kansas

Mandate Market	
Individual	No
Small Group	Yes
Large Group	Yes
Self-Insured (ERISA)	No
State and Local Govt	No

Age Limits for Autism Benefits	
Minimum	0
Maximum	21

Additional Annual Medical Costs for Non ABA Services

All Ages $ 3,700

Annual Limits by Covered Service

	Hours Limit	Max Hours	Dollar Limit	Max $s
ABA	No	-	Yes	$75,000

Key Assumptions:

United States Prevalence

Diagnostic Subtype	Ultimate Prevalence	Average Age of Diagnosis
Autistic Disorder	1 in 450	0
PDD-NOS	1 in 300	0
Asperger's	1 in 900	0
All ASD	**1 in 150**	

Kansas Prevalence Adjustment: 0.85

Kansas Prevalence

Diagnostic Subtype	Ultimate Prevalence	Average Age of Diagnosis
Autistic Disorder	1 in 529	3
PDD-NOS	1 in 353	3
Asperger's	1 in 1059	6
All ASD	**1 in 176**	

% of Diagnosed Children w/ ABA	
Under 6	66.7%
6	50.0%
7	33.3%
8	22.2%
9	14.8%
10	9.9%
11	6.6%
12	4.4%
13 to 21	3.3%

Average ABA Program Hours	
Ages Under 8	1,500
Ages 8 to 12	671
Ages 13 to 21	401

Cost per ABA Hour: $41.34

	Coverage Estimates			Costs Excluding Administrative Expense			Premium Increase including Admin @ 15%		
Market	Number of Persons Covered	Premium (Per Person)	Total Premium	Costs	Costs (% of Premium)	Cost (Per Covered Person)	Incremental Premium	Premium Increase %	Annual Increase per Covered Person
Individual									
Small Group	230,000	3,800	874,000,000	5,198,000	0.59%	22.60	6,115,000	0.70%	26.60
Large Group	272,000	3,500	952,000,000	6,147,200	0.65%	22.60	7,232,000	0.76%	26.60
Self-Insured (ERISA)									
State, Local and Federal									
Total	502,000	$ 3,637	$ 1,826,000,000	$ 11,345,200	0.62%	$ 22.60	$ 13,347,000	0.73%	$ 26.60

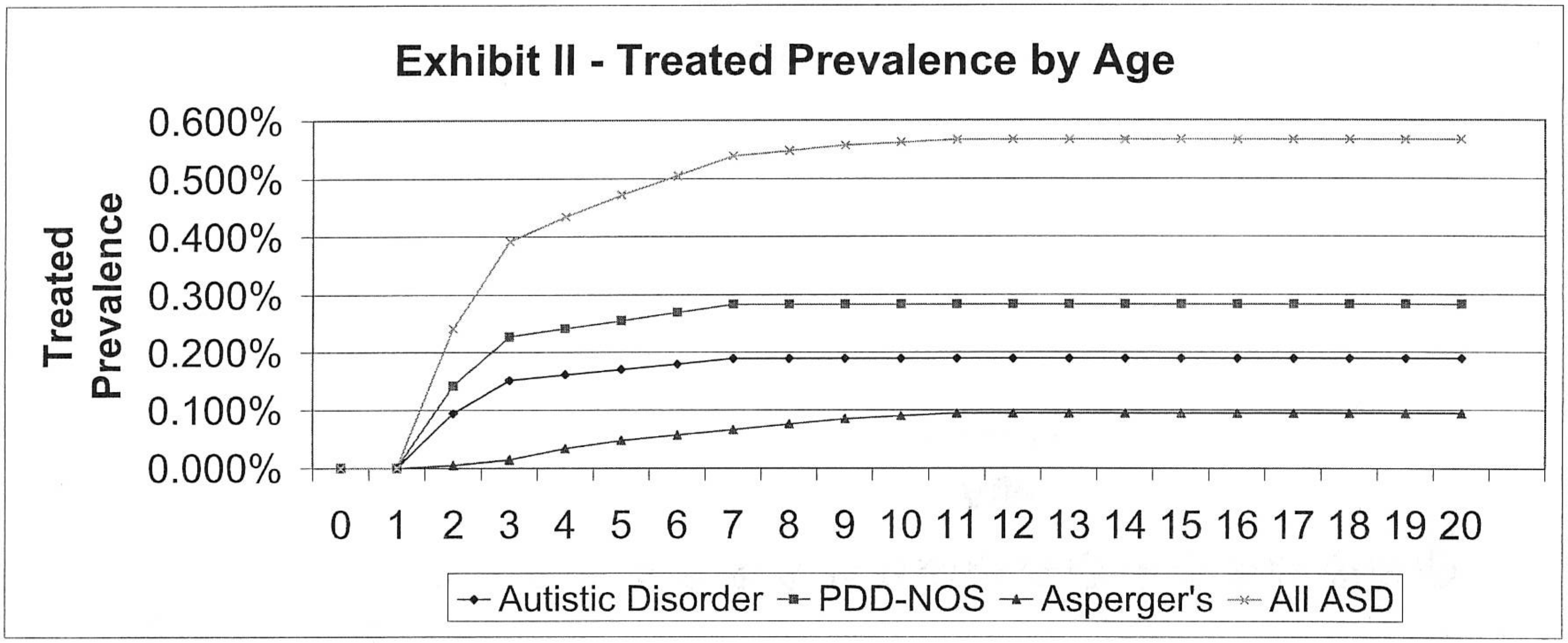

Exhibit II - Treated Prevalence by Age

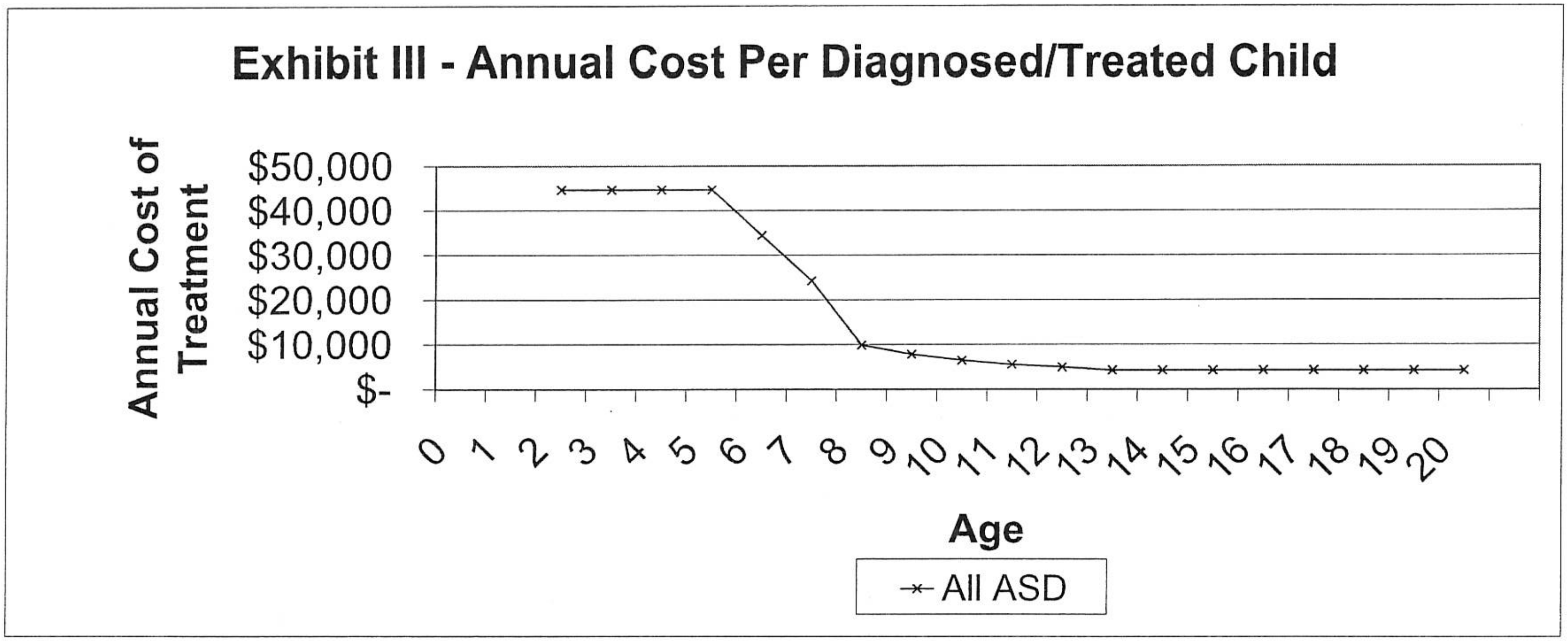

Exhibit III - Annual Cost Per Diagnosed/Treated Child

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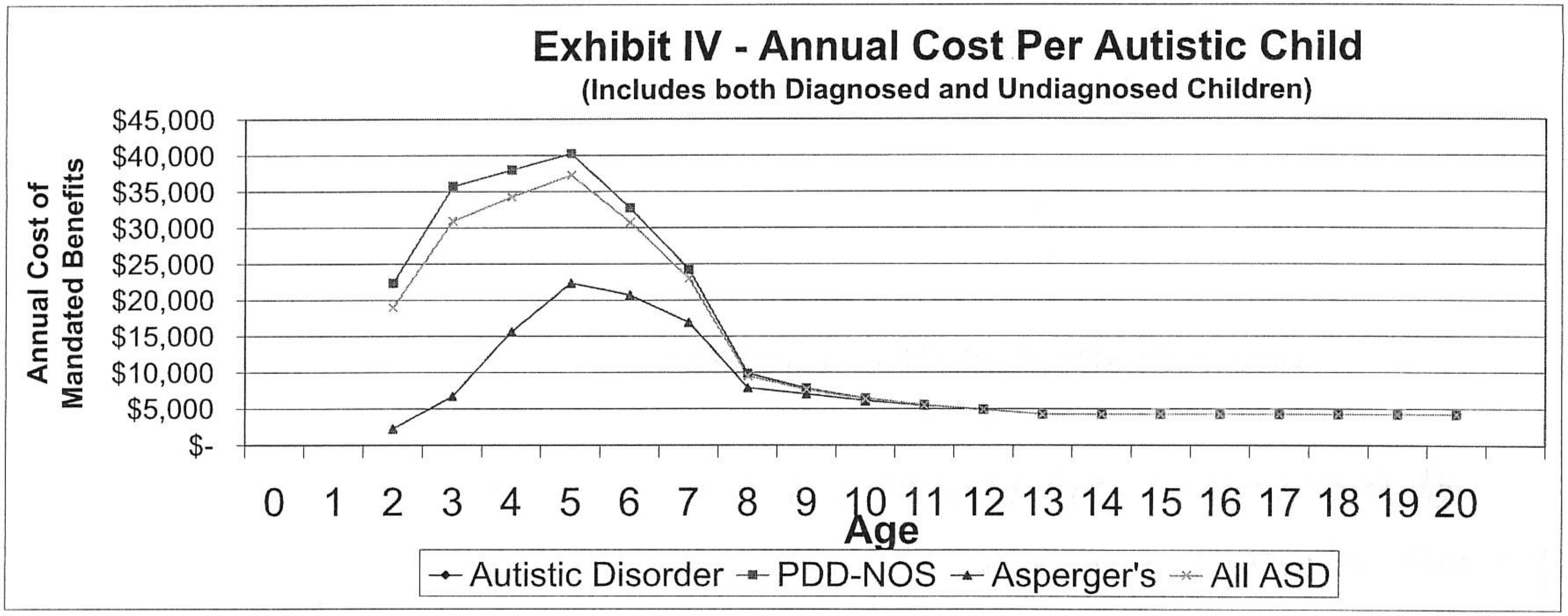
Exhibit IV - Annual Cost Per Autistic Child
(Includes both Diagnosed and Undiagnosed Children)
Annual Cost of Mandated Benefits
$45,000
$40,000
$35,000
$30,000
$25,000
$20,000
$15,000
$10,000
$5,000
$-
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20
Age
Autistic Disorder
PDD-NOS
Asperger's
All ASD

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Exhibit V - ABA Utilization vs. Treated Prevalence

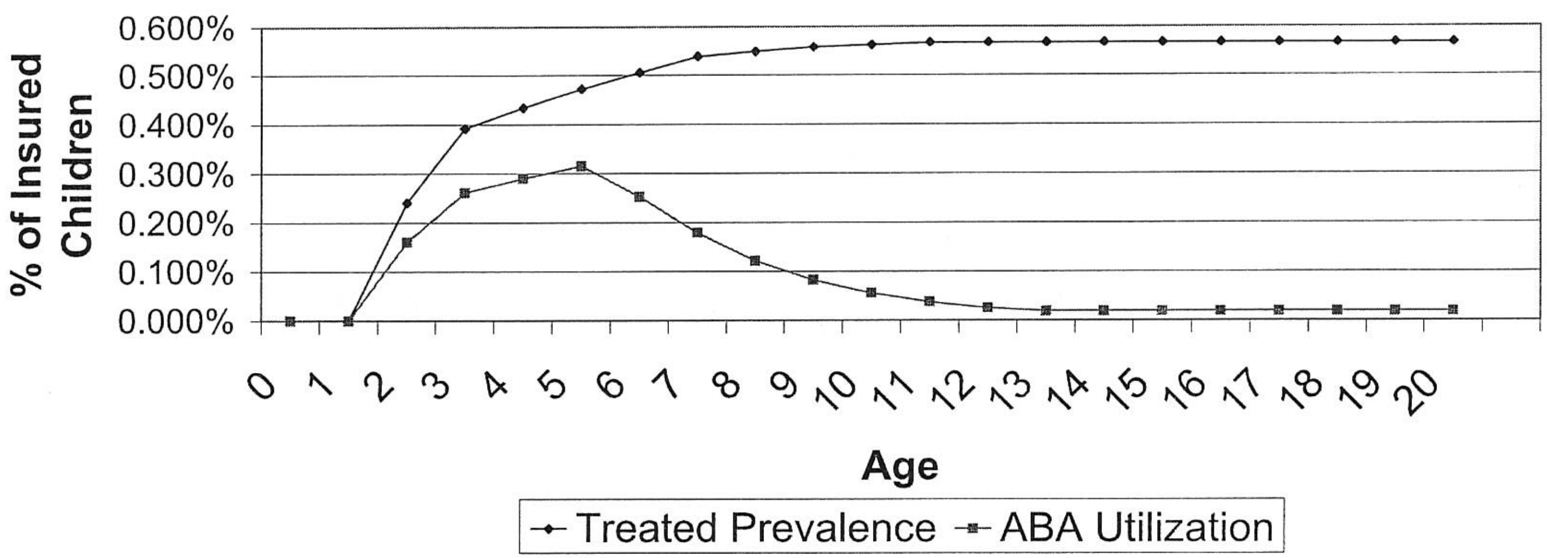
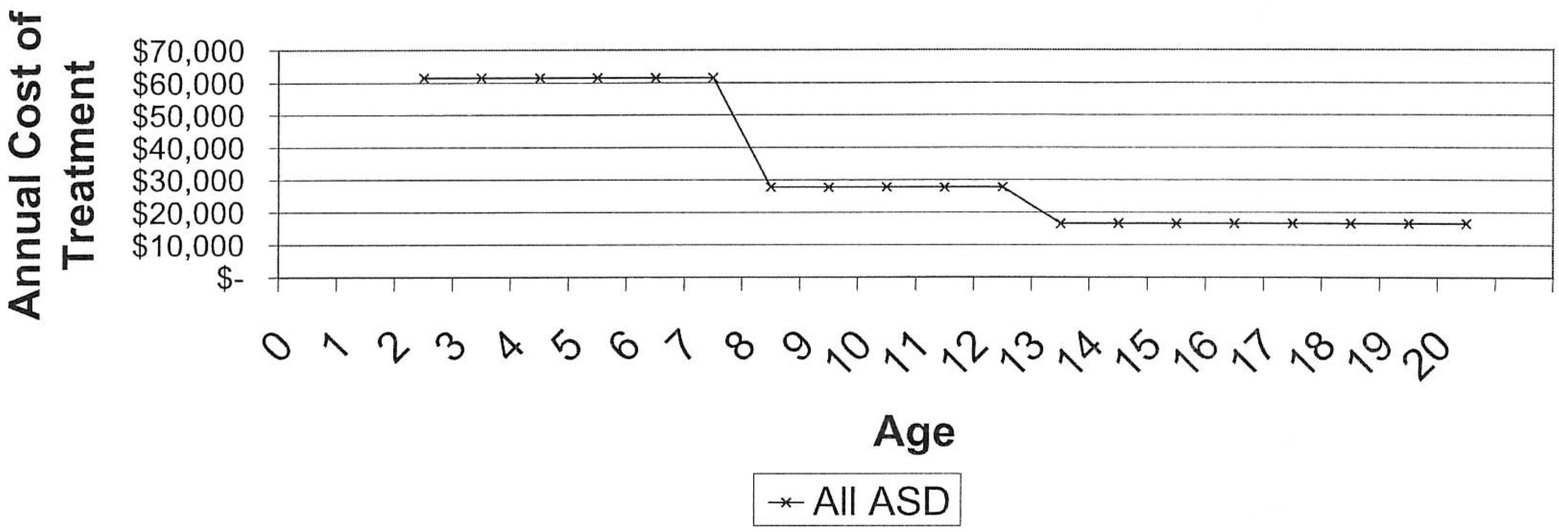


Exhibit VI - Annual Cost per Child With ABA Program



OLIVER WYMAN

Two Logan Square, 22nd Floor
Philadelphia, PA 19103-2797
1 215 246 1000

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March 18, 2009

Kansas SEHP Cost Estimate for Kansas House Bill 2367 & Kansas Senate Bill 12

Addendum to February 19, 2009 Oliver Wyman Report

Actuarial Cost Estimate: Kansas Senate Bill 12 – An Act Concerning Insurance; Providing Coverage for Autism Spectrum Disorder

OLIVER WYMAN

Prepared By:

Marc Lambright, FSA, MAAA

MMC MARSH MERCER KROLL
GUY CARPENTER OLIVER WYMAN

2-30

Addendum

Kansas SEHP Fiscal Note Cost Estimate

Oliver Wyman was engaged by Autism Speaks to develop a cost estimate to the Kansas State Employees Health Plan (SEHP) for the benefits mandated by Kansas House Bill 2367 and Senate Bill 12 which provide coverage for the diagnosis and treatment of autism spectrum disorders in individuals through age 21. In developing this cost estimate, we are utilizing our estimates developed for insured lives under the assumption that SEHP claims costs would be similar. These cost estimates and all of the assumptions underlying them were provided in our report "Actuarial Cost Estimate: Kansas Senate Bill 12 – An Act Concerning Insurance; Providing Coverage for Autism Spectrum Disorder" dated February 19, 2009. This fiscal note estimate is an addendum to that report.

	Market		
	Small Group	Large Group	All
Covered Persons	230,000	272,000	502,000
Average Premium per Person	$3,800	$3,500	$3,637
Annual Mandate Claim Cost per Covered Person	$22.60	$22.60	$22.60
Claim Cost as a Percentage of Premium	0.59%	0.65%	0.62%
Estimated Premium Increase with Admin @ 15%	$26.60	$26.60	$26.60
Premium Increase as a Percentage of Premium	0.70%	0.76%	0.73%

Page 12 our February 19, 2009 report includes the table above. We believe that the annual claims cost per covered person for the SEHP will be similar to the $22.60 estimated for the group insured market.

Based on this $22.60 per person per year cost estimate, we have developed a cost estimate for the SEHP for FY 2010 as shown in the table below.

KANSAS SEHP FY 2010 COST ESTIMATE FOR HB 2367			
Children under 22 in SEHP per fiscal note		26,666	(A)
Estimated under 22 population percentage of total SEHP total per Census*		35.9%	(B)
Estimated covered persons within SEHP		**74,333**	**(C) = (A)/(B)**
Cost Estimate per person from Oliver Wyman 2/19/2009 Report for CY 2009		$22.60	(D)
Cost Estimate in 2009 Dollars	**$**	**1,679,920**	**(E) = (C) x (D)**
Annual Trend (Same as underlying the KHPA Estimate)		6.5%	(F)
Trend Period (Middle of CY 2009 to middle of FY 2010)		0.5 Years	(G)
Trend Factor		**103.2%**	**(H)= (1 + F)^(G)**
SEHP Cost Estimate for FY2010	**$**	**1,733,658**	**(I) = (E) x (H)**

*Note this is the same demographic data underlying OW cost estimates

This claims cost estimate is approximately one-half of the FY2010 cost estimate for ASD therapies developed by KHPA of $3,753,000. As we do not have the detailed underlying assumptions for the KHPA estimate, we cannot determine why our estimate is considerably lower. However, we believe that the diligence underlying the assumptions used to develop our $1,733,658 FY2010 estimate, as documented in our February 19, 2009 report, makes our estimate credible.

We would also note that assuming some cost reduction for the first year the mandate is in place is warranted, which is important in estimating the fiscal impact of the mandated benefits on SEHP. We could reasonably expect limited utilization of ABA therapies in the first year due to the lack of ABA providers; this has been experienced elsewhere immediately following the introduction programs covering ABA. The expected first year cost reduction could be significant in FY 2010 for SEHP, and the lack of ABA providers likely will impact costs in the out years for the period covered by the fiscal note (FY2011 – FY2013), as well.

OLIVER WYMAN

Two Logan Square, 22nd Floor
Philadelphia, PA 19103-2797
1 215 246 1000

Oliver Wyman Actuarial Consulting, Inc.

Kansas Autism Insurance Coverage

Social and Financial Impact of House Bill 2367 (Kate's Law)

In Fulfillment of the Requirements of
K.S.A. 40-2248 & 40-2249

Provided to the Members of the
House Insurance Committee
March 19, 2009

**Accessing Autism
Services Bill**

Prepared and Offered by:

Michael L. Wasmer, DVM, Diplomate ACVIM (SAIM)
Member, Kansas Autism Task Force
Founder, Kansas Coalition for Autism Legislation

Elizabeth Emken
Vice President, Government Relations
Autism Speaks

Judith Ursitti, CPA
Regional Director State Advocacy Relations
Autism Speaks

March 19, 2009

The Honorable Representative Clark Shultz
Chair, House Insurance Committee
Kansas State Capitol
Room 141- W
300 SW 10th Street
Topeka, KS 66612

Dear Representative Shultz,

I sincerely appreciate your thoughtful consideration of **House Bill 2367** (Kate's Law), a bill that if enacted would require that private health insurance companies cover the diagnostic evaluation and treatment for autism spectrum disorders for fully funded policyholders in Kansas.

In fulfillment of K.S.A 40-2248 & 40-2249, I respectfully submit the required impact report that "assesses both the social and financial effects of the proposed mandated coverage". The financial impact portion of this report was prepared with generous assistance from Autism Speaks, the world's largest autism advocacy organization. A third party certified actuarial analysis of Senate Bill 12 (identical to HB 2367) has also been performed and has been submitted in conjunction with this report.[i]

The Kansas Coalition for Autism Legislation (KCAL) is an independent group of parents, professionals and service providers who advocate for legislation to benefit individuals with autism spectrum disorders in Kansas. On behalf of KCAL and the thousands of Kansas families whose lives have been impacted by autism, I thank you and the members of this committee for your attention to this critical issue and urge you to vote "Yes" for Kate's Law.

Please contact me if you would like additional information.

Sincerely,

Michael L. Wasmer, DVM, Diplomate ACVIM (SAIM)
Member, Kansas Autism Task Force
Founder, Kansas Coalition for Autism Legislation
Kate and Sam's Dad

14617 South Garnett St
Olathe, KS 66062
mike@kscoalitionforautism.org

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[i] Prepared by Marc Lambright, FSA, MAAA of Oliver Wyman; *Actuarial Cost Estimate: Kansas Senate Bill 12 – An Act Concerning Insurance; Providing Coverage for Autism Spectrum Disorder*, February 19, 2009

Impact Report for Kansas House Bill 2367

In fulfillment of K.S.A. 40-2248 & 40-2249

March 19, 2009

Introduction

Autism spectrum disorders (ASDs) are biologically based, neurodevelopmental disabilities that are characterized by impairments in communication, social interaction and sensory processing. Autism spectrum disorders are pervasive developmental disorders that include autistic disorder, Asperger syndrome and pervasive developmental disorder-not otherwise specified (*see Appendix #1*). With varying degrees of severity, ASDs interfere with an affected individual's ability to learn and establish meaningful relationships with others.

Recent evidence from multiple epidemiologic studies, points to a population prevalence of autism spectrum disorders of about 1 per 150 children. The incidence of ASDs in Kansas and nationwide is increasing at an alarming rate. Autism has become the fastest-growing serious developmental disability in the U.S. In Kansas, from 1999 to 2006, the number of children with autism as reported under Part B of IDEA increased by 236%.

Recognizing the importance of addressing the unmet needs of Kansans with autism spectrum disorders, the 2007 Kansas Legislature unanimously passed Senate Bill 138, which created the Kansas Autism Task Force. The Autism Task Force was directed to study and conduct hearings on the issues relating to the needs of, and the services available for persons with ASDs.

As directed by statute, the final report to the Legislative Educational Planning Committee (LEPC) was filed prior to November 15, 2008 and includes recommendations for legislative changes. The Kansas Autism Task Force found that inequities in health insurance coverage create one of the most significant barriers to appropriate early intervention for children with autism spectrum disorders in Kansas.[1] This conclusion led to draft legislation that was endorsed by the LEPC and introduced as Senate Bill 12.

Enactment of Senate Bill 12 would require that private health insurance companies cover the diagnostic evaluation and treatment for autism spectrum disorders for fully funded policyholders in Kansas (*See Appendix #2*). Senate Bill 12 states that health insurance companies cannot deny coverage on an individual solely because the individual is diagnosed with an autism spectrum disorder. Among the covered treatments, coverage for applied behavior analysis shall be subject to a maximum benefit of $75,000 per year through age 21.

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[1] The Kansas Autism Task Force, "Report of the Kansas Autism Task Force to the 2009 Kansas Legislature", December 2008

Small businesses, i.e. employers with 50 or fewer employees, may "opt out" of the provisions set forth in SB 12.

As demonstrated in the fiscal impact portion of this report, the expected increase on health insurance premiums related to enactment of Senate Bill 12 is 0.17% to 1.86%, with a likely mid-range impact of 0.44%.

In return for this negligible impact on premiums, enactment of Senate Bill 12 will have a widespread positive effect for the state of Kansas. Dr. Bill Craig, Chairperson of the Kansas Autism Task Force states:

> "This legislation will save children by giving them their potential back. It will save families by giving them their lives back. It will save schools by decreasing the catastrophic costs. And it will save Kansas by growing productive children and intact families." [2]

Social Impact of Senate Bill 12

40-2249 (a) (1): *The extent to which the treatment or service is generally utilized by a significant portion of the population.*

Recent evidence from multiple epidemiologic studies points to a population prevalence of autism spectrum disorders (ASDs) of about 1 per 150 children.[3] Based on this information and the most recent Kansas population estimates[4], the number of children aged 0-21 with an autism spectrum disorder in Kansas is estimated to be 5,738.

Senate Bill 12 states that private health insurance "shall provide coverage for the diagnosis and treatment of autism spectrum disorders in any covered individual." Treatments covered by SB 12 are those prescribed by a licensed physician or licensed psychologist and include medically necessary treatments such as speech and language therapy, occupational therapy and Applied Behavior Analysis. These services are among those specified by the American Academy of Pediatrics as "the primary treatments for children with autism spectrum

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[2] Bill Craig, *Video Testimony in Support of Kate's Law*, produced by the Kansas Coalition for Autism Legislation, November 2008.

[3] CDC Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, 2007. "Prevalence of Autism Spectrum Disorders–Autism and Developmental Disabilities Monitoring Network Surveillance, 14 sites", United States, 2002. Morbidity and Mortality Weekly Report 56/SS-1:12-28

[4] Kansas Department of Health and Environment, *Kansas Population Table by County*, http://kic.kdhe.state.ks.us/kic/popeth_table.html

disorders."[5]

The *demand* for diagnostic evaluation of children with developmental delays and treatment of autism spectrum disorders is directly related to the rising incidence of ASDs and will be addressed in detail in response to KSA 40-2249 (a) (5). However, access to and *utilization* of these services in Kansas is significantly hampered by several factors including discriminatory practices of health insurance companies relating to the implementation of health insurance policies to individuals with ASDs.[6]

Private health insurance commonly denies coverage for medically necessary services such as Applied Behavior Analysis, speech therapy and occupational therapy for individuals with ASDs in Kansas. Kansas has excellent university programs, many considered within the top ten in the nation. Many students are being trained in autism in these programs from disciplines such as Applied Behavior Analysis, speech and language pathology and occupational therapy. However, because of the challenges in reimbursement from private health insurance providers, Kansas is losing these highly qualified service providers to states that *facilitate* reimbursement for their services. Dr. Matt Reece from the University of Kansas discusses this negative impact on Kansas' knowledge economy:

> "...As students graduate, part of the problem is there's no job for them. There's no consistent reimbursement if you're in the field of autism. So we've got these experts that are being attracted all over the United States and they're not staying in Kansas. And part of this difficulty in reimbursement is the whole insurance struggle."[7]

Loss of autism service providers further compromises already struggling state funded programs such as the HCBS Autism Waiver and Developmental Disability Waiver programs. Currently, some Autism Waiver recipients (particularly those in more rural areas of Kansas) are going without services because there are no qualified local service providers.

Enactment of Senate Bill 12 is a critical step toward improving access to medically necessary services for individuals with autism spectrum disorders in Kansas. It would ease the burden on state funded programs and at the same time provide incentive for qualified service providers to remain in Kansas.

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[5] Scott M. Myers, Management of Children with Autism Spectrum Disorders, *Pediatrics*, Vol 120, No 5 (November 2007)

[6] Kansas Autism Task Force, supra note 1

[7] Matt Reece, *Video Testimony in Support of Kate's Law*, produced by The Kansas Coalition for Autism Legislation, November 2008

40-2249 (a) (2): ***The extent to which insurance coverage is already generally available.***

Easter Seals, in cooperation with the Autism Society of America, recently completed a survey of 1,652 parents of children with ASD and 917 parents of typically developing children about several topics including finances and health care. In this survey, parents of children with ASD reported that health insurance companies "always or often" pay for services only 39% of the time. Additionally, only 18% of parents of children with ASD reported that they have health insurance that adequately covers their child's needs versus 42% of parents of children with no special needs.[8]

Many insurance companies designate autism as a diagnostic exclusion, "meaning that any services rendered explicitly for the treatment of autism are not covered by the plan, even if those services would be covered if used to treat a different condition."[9] The Developmental Disability Center (DDC) at the University of Kansas Medical Center performed a survey of parents of children with ASD seen at their clinic between 2005 and 2006 regarding health insurance coverage for ASD. The following is a quote from a parent reporting the reason that was given for why their private health insurance denied claims for speech therapy for their child with ASD:

> "They will pay benefits for speech therapy only when the speech impediment or dysfunction results from injury, sickness, stroke, congenital anomaly or is needed following the placement of a cochlear implant".[10]

In some cases, a developmentally delayed child may be covered for certain therapies such as speech, but once actually diagnosed with ASD, is denied private reimbursement for the same therapies since insurers are not required to cover treatments once they are associated with an ASD diagnosis. Even where a diagnosis of autism is not an absolute bar to treatment, the nature of the care may result in a denial of service. Children with autism often require habilitative care – that is, they require care that imparts a new ability, rather than care that restores one that has been lost. This arbitrary distinction can result in a denial of service. The following is a parent quote from the DDC survey explaining the

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[8] Easter Seals, *Living with Autism Study*, http://www.easterseals.com/site/PageServer?pagename=ntlc8_living_with_autism_study_home (2009)

[9] Douglas L. Leslie, Andres Martin, "Health Care Expenditures Associated with Autism Spectrum Disorders", *Archives of Pediatric and Adolescent Medicine*, Vol. 161 (April 2007)

[10] Laura Lillich, "Autism and Health Insurance Coverage", The University of Kansas Medical Center – Developmental Disabilities Center (now the Center for Child Health and Development), presented to Insurance Subcommittee of the Kansas Autism Task Force, September 7, 2007

reason that was given for why claims for speech therapy were denied for their child with ASD:

> "Our speech was denied twice by both branches of BCBS ... it was stated that speech was denied since it was [habilitative], not rehabilitative. If he'd had a stroke – they would give speech benefits!"[11]

Very few private health insurance plans in Kansas cover Applied Behavior Analysis (ABA). ABA is often denied on the basis if it being "investigational" or "experimental", notwithstanding the scientific evidence of its efficacy and its endorsement by the nation's leading health authorities. The American Academy of Pediatrics clinical report on the medical management of children with ASD noted its decades-long record of efficacy.

> The effectiveness of ABA-based intervention in ASDs has been well documented through 5 decades of research by using single-subject methodology and in controlled studies of comprehensive early intensive behavioral intervention programs in university and community settings. 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.[12]

The Academy's findings mirrored conclusions of the Surgeon General of the United States: "Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."[13]

Tri-Care is the Department of Defense health insurance plan for military dependants. Federal Law prohibits Tri-Care from covering "unproven care or special education." Applied Behavior Analysis is covered under Tri-Care's Extended Care Health Option (ECHO).[14] Applied Behavior Analysis is also recognized and provided by the Kansas HCBS Autism Waiver program as an effective treatment for ASD.

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[11] Lillich, supra note 10

[12] Myers, supra note 5

[13] U.S. Department of Health and Human Services, "Mental Health: A Report of the Surgeon General" 163-64 (1999).

[14] Department of Defense Report and Plan for Services to Military Dependent Children with Autism (2007).

The Kansas Mental Health Parity Act

It is important to clarify terminology when discussing autism spectrum disorders. Pervasive Developmental Disorders (PDD) refers to a group of developmental disorders including autism spectrum disorders, childhood disintegrative disorder, and Rett's Syndrome. Autism spectrum disorders (ASDs) include the diagnostic categories autistic disorder, Asperger's Syndrome (or Asperger's Disorder), and pervasive developmental disorder-not otherwise specified (PDD-NOS).[15] Use of the term "autism" alone can lead to confusion because it may mean "pervasive developmental disorder", "autism spectrum disorder" or "autistic disorder" depending on the user.

Section 40-2,105a, paragraph 2(c) of the Kansas Mental Health Parity Act, lists "pervasive developmental disorder, including autism" among disorders defined as "mental illness". This section is both unclear and inaccurate, and has contributed to a great deal of confusion among both health insurance policyholders and those implementing the policy.

It is not clear whether the intent of the use of the word "autism" in this section is to mean "autism spectrum disorder" (so that autistic disorder, Asperger's Syndrome and PDD-NOS are included) or "autistic disorder" (which would exclude Asperger's Syndrome and PDD-NOS from coverage). The inaccuracy in this section of the Kansas Mental Health Parity Act is that ASD is <u>not</u> a mental illness. The American Academy of Pediatrics defines ASD as "a biologically based neurodevelopmental disability"[16], i.e. a biologically based condition that affects the developing brain. While individuals with autism spectrum disorders may have a comorbid diagnosis of mental illness, ASD is not a mental illness.

The confusion and inaccuracy propagated by this section is partly responsible for inconsistent health insurance coverage for individuals with ASD in Kansas. Both parents and service providers in Kansas frequently report that claims for services for children with ASD are frequently "bounced" between mental and medical health policies resulting in long delays and ultimate denials. The following quote is from a parent describing the difficulty with a claim for speech therapy for their child with ASD:

> "Most companies want to say it's a medical diagnosis, and then medical wants it to be under mental health, then mental health sends it back to medical ... It's so much work and the disappointment – and that's exactly what they (the insurance company) want! For you to give up." [17]

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[15] Myers, supra note 5

[16] Committee on Children with Disabilities, "The Pediatrician's Role in the Diagnosis and Management of Autistic Spectrum Disorder in Children", *Pediatrics*, Vol. 107 No 5 (May 2001)

[17] Lillich, supra note 10

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Furthermore, in both testimony to the Kansas Autism Task Force and other forums, the enforceability of the existing Kansas Mental Health Parity Act relative to coverage for services related to ASD has frequently been questioned. In 2006, through a contract with the Kansas Department of Social and Rehabilitative Services, Health Care Policy division, the University of Kansas School of Social Welfare undertook a study of service provision to children with ASD.[18] From this report:

> Parents with insurance reported that their insurance companies routinely denied claims for coverage if their child did not have a primary medical diagnosis (e.g. seizure disorder) in addition to an autism spectrum diagnosis. In one focus group, parents reported that after taking their insurance company to court and the state ruling in their favor, the insurance company in question still refused payment. Insurance denials shift the burden of treatment to the state; as such, they could be investigated to determine whether denials are inappropriate and a breach of the Kansas Mental Health Parity Act of 2001.

Senate Bill 12 specifies that private health insurance must cover the diagnosis and treatment of autism spectrum disorders and strikes the passage "pervasive developmental disorder, including autism" from Section 40-2,105a, paragraph 2(c) of the Kansas Mental Health Parity Act.

40-2249 (a) (3): *If coverage is not generally available, the extent to which the lack of coverage results in the persons being unable to obtain necessary health care treatment.*

Lack of coverage for diagnostic evaluation

Early diagnosis resulting in early, appropriate and consistent intervention is critical to improved long-term outcomes in individuals with autism spectrum disorders. In order to make the categorical diagnosis of an ASD and to determine the extent of the search for an associated etiology, the American Academy of Pediatrics recommends evaluation by an interdisciplinary team of child specialists with expertise in ASD.[19] Denials for coverage of the diagnostic evaluation of children suspected of having ASD (e.g. children who are referred from a primary care provider because of a positive screening test for ASD) are becoming more commonplace. The Center for Child Health and Development (CCHD) at the University of Kansas (KU) Medical Center reports a 34% rate of

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[18] Bryson, Corrigan and Holmes, "Service Challenges for Children with Autism Spectrum Disorders and Mental Health Needs", University of Kansas School of Social Welfare, presented to the Kansas Autism Task Force, September 20, 2007

[19] Johnson CP, Myers SM, "Identification and evaluation of children with autism spectrum disorders." *Pediatrics*. Vol. 120 No. 5 (2007)

denials from private health insurance for a comprehensive team assessment. The rate of denial reported by the KU Department Pediatrics, which sees largely typically developing children is 15%.[20]

Denials for coverage of the diagnostic evaluation of children suspected of having ASD further compound delays in diagnosis already imposed by long waiting lists for an appointment. The current waiting list for a child with a developmental delay to be evaluated by the CCHD at KU Medical Center is 6 months. The cost of a full team assessment at the CCHD is $2,057.00. If families cannot afford to pay for the diagnostic evaluation out of pocket, a definitive diagnosis is not obtained which will complicate access to appropriate treatment services. For example, the Kansas Home and Community Based Services (HCBS) Autism Waiver program requires confirmation of a diagnosis of ASD in order to be eligible for treatment services under the waiver.

Lack of coverage for treatment

When insurance fails to cover the treatment of ASD, the cost of treatment falls to state-funded programs such as tiny-k services, the HCBS Autism Waiver and Developmental Disability Waiver. All three of these programs were identified in the final report of the Kansas Autism Task Force as current *barriers* to individuals with autism and their families in Kansas:[21]

- The tiny-k network is not adequately funded and provides no allowance for the high cost of early intervention.
- Current funding for the newly created Autism Waiver is limited to fewer than 50 children. The current waiting list contains more than three times the current number served.
- Most Kansas families of individuals with autism eventually will need to look to the public Developmental Disability system for services. The current waiting list for needed service (2,233 individuals waiting for HCBS services and an additional 1,279 awaiting other services, for a total of 3,512) is growing each year as appropriations have failed to keep pace with the need. In addition, the inadequacy of reimbursement rates to cover the cost to recruit and retain direct support workers of acceptable quality has further rendered this system a broken resource.

Too often, as result of health insurance denials and limited resources of state funded treatment programs, the cost of providing appropriate treatment for children with ASD must be borne entirely out of pocket by the parents. As will be detailed in response to KSA 40-2249 (a)(4), the financial hardship this creates for families is immense. Many Kansas families simply cannot afford to provide the medically necessary treatments for their child with ASD.

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[20] KU, personal email, January 26, 2009

[21] Kansas Autism Task Force, supra note 1

When a child goes without appropriate early intervention for ASD, the direct and indirect cost fall to the public schools as a consequence of increased special educational needs, and ultimately to the State of Kansas. The cost of supporting an individual through age 55 (including special education, lost wages, adult disability services and lifelong supports) who does not receive an early diagnosis and appropriate treatment for ASD has been estimated to be $4,400,000.[22]

40-2249 (a) (4): ***If the coverage is not generally available, the extent to which the lack of coverage results in unreasonable financial hardship on those persons needing treatment.***

Multiple local and national studies have documented the financial strain associated with raising a child with an autism spectrum disorder as a result of large out of pocket medical expenses. A survey of 423 Midwest parents or primary care givers of children with ASD concluded that:

> Diagnosis of autism spectrum disorders places a large financial burden on families who often must pay for expensive treatments out-of-pocket. Documented efficacy of early intervention heightens the intense pressure to use whatever means possible – including placing the family's financial future at risk – to secure needed therapy NOW.[23]

In video testimony in support of Senate Bill 12 (Kate's Law), when describing her battles with her health insurance company over reimbursement for services for her child with ASD, a Kansas parent states:

> "The choice is to either say 'OK, my child can be institutionalized for the rest of his life or he can get this therapy and could actually may be able to go to first grade and be with his friends and learn and be a productive member of society'... The credit cards are long maxed out, we have no savings, my parents even took out a second mortgage to pay for this – Thank the Lord they did that... We are in debt immensely but to *not* do this for him – that would have been even worse."[24]

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[22] Jacobson, John W, Mulick, James A., Green Gina. "Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism," *Behavioral Interventions*, 13, 201-226 (1998)

[23] Deanna L. Sharpe & Dana Lee Baker, "Financial Issues Associated with Having a Child with Autism," 28 *J. Fam. Econ. Iss.* 247, 262 (2007).

[24] Carrie Wright, *Video Testimony in Support of Kate's Law*, produced by the Kansas Coalition for Autism Legislation, November 2008.

When describing the consequence to her family as a result of denial for coverage for services related to her child with ASD, a second parent in the video testimony states:

> "… so we took on the responsibility of paying for them out of pocket. So that meant my husband's 14 years of working in one company, we took out his retirement fund and then we decided to take out a second mortgage on our house."[25]

A national study of the family impact of autism spectrum disorders in the U.S. found that children with ASD were more likely to live in families that report financial problems, need additional income for the child's medical care, reduce or stop work because of the child's condition and spend more than 10 hours per week providing or coordinating care.[26] Raising a child with ASD has been reported to cause an average loss of 14% of reported annual income.[27]

Easter Seals, in cooperation with the Autism Society of America, recently completed a survey of 1,652 parents of children with ASDs and 917 parents of typically developing children about several topics including finances and health care. Statistics of note from this report include:[28]

- **74%** of parents of children with ASD **fear their children will not have enough financial support after they die**, while only 18% of parents of typical children share this fear.
- **52%** of parents of a child with ASD responded that the costs associated with caring for this child **drains <u>current</u> family financial resources**, versus 13% of parents of typically developing children
- **50%** of parents of a child with ASD responded that the costs associated with caring for this child **will drain <u>future</u> family finances**, versus 10% of parents of typically developing children.
- **54%** of parents of a child with ASD responded that the costs associated with caring for this child **will cause them to fall short of cash during retirement** versus 13% of parents of typically developing children

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[25] Melissa Cooper, *Video Testimony in Support of Kate's Law*, produced by the Kansas Coalition for Autism Legislation, November 2008.

[26] Michael D. Kogan, PhD, Bonnie B Strickland et al, "A National Profile of Health Care Experiences and Family Impact of Autism Spectrum Disorder Among Children in the United States, 2005-2006," *Pediatrics* Vol 122, No 6 (December 2008)

[27] Montes and Halterman, "Association of Childhood Autism Spectrum Disorders and Loss of Family Income" *Pediatrics* 2008; 121 (2008)

[28] Easter Seals, supra note 8

- **47%** of parents of a child with ASD responded that the costs associated with caring for this child **financially impacts raising typically developing siblings**

The following table lists the reported costs of several of the primary services for individuals with autism spectrum disorders in Kansas:[29]

		Cost per visit	**Cost per hour**	**Cost per year**
Interdisciplinary full team assessment		$2000 - 2200		
Applied Behavior Analysis	Paid for by Infant Toddler Services		$68	
	Paid by KS HCBS Autism Waiver		$70	
	Private pay		$80 - 90	
	Paid by Tri-Care		$125	
	Center-based autism treatment programs			$45,000 - 120,000**
Speech and Language Therapy	Paid by ITS		$68	
	Private pay		Information not available	
Occupational Therapy	Paid by ITS		$68	
	Private Pay		$100 - 432	

* Provided by a board certified behavior analyst (BCBA)
** Depending on the level of severity of the affected child

40-2249 (a) (5): *The level of public demand for treatment or service.*

The level of public demand for diagnostic evaluation and treatment for autism spectrum disorders has steadily increased as the incidence of ASD has increased. Autism has become the fastest-growing serious developmental disability in the United States.[30] From school years 1999/2000 to 2006/2007, the number of children with autism in Kansas as reported under Part B of IDEA increased by 236%.[31] Recent evidence from multiple epidemiologic studies,

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[29] Michael Wasmer, Information collected from random polling of service providers in the Kansas City and Wichita metropolitan areas, (January 2009)

[30] Autism Speaks, *Facts About Autism,* http://www.autismspeaks.org/whatisit/facts.php; accessed January 20, 2009.

[31] Reported by the State of Kansas in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs; from Easter Seals; http://www.easterseals.com/site/PageServer?pagename=ntlc8_autism_state_profiles_kansas; accessed January 20, 2009

points to a population prevalence of autism spectrum disorders (ASD) of about 1 per 150 children.[32]

The demand for diagnostic evaluation of children with developmental delays in Kansas is reflected by the current waiting times to be seen by the two primary diagnostic centers that serve Kansans, The Center for Child Health and Development (CCHD) at the University of Kansas Medical Center and Children's Mercy Hospital (CMH) Section of Developmental and Behavioral Sciences. If a parent were to call today to make an appointment for their child to be evaluated at CCHD, there is a 6-month wait.[33] The waiting time for evaluation at CMH has decreased from 6 months to 80 days in the last 2 years not because of decreased demand, but due to increased Missouri State funding which allowed the addition of 3 professional staff that work solely in the diagnostic area.[34]

The level of public demand for services related to treatment of individuals with ASD has increased with the growing body of evidence that demonstrates the effectiveness of intensive early intervention.

Behavioral Therapy

American Academy of Pediatrics: "There is a growing consensus that the important principles and components of effective early childhood intervention for children with ASDs include...intensive intervention...at least 25 hours per week, 12 months per year... Three studies that compared intensive ABA programs (25-40 hours/week) to equally intensive eclectic approaches have suggested that ABA programs were significantly more effective. In the same report, the AAP goes on to write that the "effectiveness of ABA –based intervention in ASDs has been well documented through 5 decades of research...."[35]

U.S. Surgeon General's Report on Mental Health (2001): "Among the many methods available for treatment and education of people with autism, applied behavior analysis (ABA) has become widely accepted as an effective treatment. Thirty years of research demonstrated the efficacy of applied behavioral methods

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[32] CDC Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators, 2007, supra note 3

[33] Dr. Kathy Ellerbeck, Center for Child Health and Development at the University of Kansas Medical Center, personal email, January 19, 2009

[34] Dr. Michele Kilo, Children's Mercy Hospital Section of Developmental and Behavioral Sciences, personal email, January 20, 2009

[35] Myers, supra note 5

in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."[36]

New York State Department of Health: Assessed interventions for children with autism, and recommended that "behavioral interventions for reducing maladaptive behaviors be used for young children with autism when such behaviors interfere with the child's learning or socialization or present a hazard to the child or others." [37]

Maine Administrators of Services for Children with Disabilities: Notes in their report that "There is a wealth of validated and peer-reviewed studies supporting the efficacy of ABA methods to improve and sustain socially significant behaviors in every domain, in individuals with autism. Importantly, results reported include 'meaningful' outcomes such as increased social skills, communication skills academic performance, and overall cognitive functioning. These reflect clinically significant quality of life improvements. While studies varied as to the magnitude of gains, all have demonstrated long term retention of gains made." [38]

The National Institute of Child Health and Human Development: Lists Applied Behavior Analysis among the recommended treatment methods for Autism Spectrum Disorders. [39]

National Research Council (NRC [2001]): Report on Educating Children with Autism acknowledged, "There is now a large body of empirical support for more contemporary behavioral approaches using naturalistic teaching methods that demonstrate efficacy for teaching not only speech and language, but also communication." [40]

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[36] U.S. Department of Health and Human Services, "Mental Health: A Report of the Surgeon General", 163- 64 (1999).

[37] New York Department of Health, "Clinical Practice Guideline: Report of the Recommendations, Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children (Age 0-3 Years)" (1999), Retrieved from http://www.health.state.ny.us/community/infants_children/early_intervention/autism/index.htm

[38] Maine Administrators of Services for Children with Disabilities, "Report of the MADSEC Autism Task Force", (2000). Retrieved from http://www.madsec.org/docs/ATFReport.pdf

[39] National Institute of Child Health and Human Development website: Questions and Answers (2006). Retrieved from http://www.nichd.nih.gov/publications/pubs/autism/QA/sub18.cfm

[40] National Research Council, Educating Children with Autism. (Catherine Lord & James P. McGee, Eds. 2001). Retrieved from http://www.nap.edu/openbook.php?isbn=0309072697.

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Association for Science in Autism Treatment: Recommends ABA-based therapies, stating, "ABA is an effective intervention for many individuals with autism spectrum disorders." [41]

Speech Therapy

The AAP states that "people with ASDs have deficits in social communication, and treatment by a speech-language pathologist usually is appropriate." [42]

Occupational Therapy

According to the American Occupational Therapy Association, for children with ASD, "occupational therapy can provide intervention that helps children to develop.... The therapist aids the child in achieving and maintaining normal daily tasks" through evaluation, interventions, and facilitation of tasks typical to the child's age. [43]

40-2249 (a) (6): *The level of public demand for individual or group insurance coverage of the treatment or service.*

Recognizing the importance of addressing the unmet needs of Kansans with autism spectrum disorders, the 2007 Kansas Legislature unanimously passed Senate Bill 138, which created the Kansas Autism Task Force. The Autism Task Force was directed to study and conduct hearings on the issues relating to the needs of, and the services available for persons with ASDs.

As directed by statute, the final report to the Legislative Educational Planning Committee (LEPC) was filed prior to November 15, 2008 and includes recommendations for legislative changes. The Kansas Autism Task Force found that inequities in health insurance coverage create one of the most significant barriers to appropriate early intervention for children with autism spectrum disorders in Kansas.[44] This conclusion led to draft legislation that was endorsed by the LEPC and introduced as Senate Bill 12.

Endorsement of Senate Bill 12 by the Kansas Autism Task Force represents endorsement of the entire autism community of Kansas. The Kansas Coalition

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[41] Association for Science in Autism Treatment, *Applied Behavioral Analysis (ABA)*, http://www.asatonline.org/resources/treatments/applied.htm accessed January 27, 2009

[42] Myers, supra note 5

[43] The American Occupational Therapy Association, *Understanding Autism*, http://www.aota.org/featured/area6/links/link02d.asp accessed January 27, 2009.

[44] Kansas Autism Task Force, supra note 1

for Autism Legislation (KCAL) is an independent group of parents, professionals and service providers who advocate for legislation to benefit individuals with ASD in Kansas. Since announcing its support for Senate Bill 12, the number of advocates in the KCAL database has more than doubled. Currently, these 1,132 advocates are distributed among 100% of the Kansas Senate districts and 94% of the Kansas House districts.[45]

Kansas is not unique in recognizing the necessity for health insurance reform to meet the needs of individuals with ASD. State governments across the country have begun to pressure the private insurance industry to come to the table as an equal partner with public entities to negotiate a fair and balanced approach for covering the costs of treatment associated with ASD. [46] To date, eight states have enacted legislation similar to Senate Bill 12: Indiana[47], South Carolina[48], Texas[49], Arizona[50], Florida[51], Louisiana[52], Pennsylvania[53] and Illinois[54]. Similar bills have been introduced in seven other states including Missouri and Oklahoma, and are in various stages of development in at least 22 other states.[55]

The Indiana Autism Mandate (IC 27-13-7-14.7) has been in effect for over 7 years. It has no age limits or financial caps on coverage, and applies to both large and small businesses. There has been no data presented by any government body or insurer to show that it has had negative effects upon the cost of private health insurance premiums, the number of uninsured in the state,

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[45] KCAL database, accessed January 27, 2009

[46] New Hampshire Commission On Autism Spectrum Disorders, Findings And Recommendations, (2008)

[47] Indiana Code 27-13-7-14.7

[48] Ryan's Law (S 20)

[49] HB 1919

[50] Steven's Law (HB 2847)

[51] Steven A. Gellar Autism Coverage Act (SB 2654)

[52] HB 958

[53] HB 1150

[54] SB 934

[55] Autism Votes, "State Initiatives", http://www.autismvotes.org/site/c.frKNI3PCImE/b.3909861/k.B9DF/State_Initiatives.htm, accessed January 25, 2009

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the viability of small business, or the ability of the state to attract large and small businesses to the state.[56]

In addition to laws both enacted and pending, several significant court decisions and arbitration awards also demonstrate the demand for insurance coverage for ASD.

> **Kunin v. Benefit Trust Life Insurance Co. (CA-1988),** which established that, because autism has organic causes, it is not a mental illness and so cannot be used as a basis for denying or limiting insurance benefit.
>
> **Jacob Micheletti v. State Health Benefits Commission (NJ-2007),** in which the court ruled that state workers' health insurance plans required coverage for a family member with autism, including sessions of ABA-based therapy, occupational therapy, and speech therapy.
>
> **Jill and Stephen Tappert v. Anthem Blue Cross Blue Shield (CO-2007),** [57] in which the arbitrator ruled that Applied Behavior Analysis (ABA) is not an experimental therapy, but in fact medically necessary for children with ASDs—and a service the insurer should cover. Judge William G. Meyer stated, "It appears both from the greater weight of the references and credible testimony that ABA therapy is the standard of care in treating autism."[58]

Public schools also recognize the need for private health insurance to cover the diagnosis and treatment of ASD. Kansas schools' ability to provide appropriate special education is strained when private health insurance fails to address the core symptoms of autism. Without appropriate treatment it has been reported that only 2% of children with ASD will mainstream successfully in a regular education setting.[59] However, *approximately 50% of children with ASD who receive appropriate early intensive intervention do not require special education services* and 80% show measurable reduction in symptoms.[60] The cost of providing education services for children in special education is 2-3 times higher than for those in regular education.

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[56] Michele Trivedi, Legislative Liaison, Autism Society of Indiana and Member, Autism Society of America's Government Relations Committee, personal email, (September 2008)

[57] Judicial Arbiter Group, Inc. Case No. 270779, Arbitration Award

[58] R. Craig Ewing, who represented the Tappert Family, interview with Michael Goldberg, http://autismbulletin.blogspot.com/2008/02/more-on-colorado-autism-insurance-case.html (February 2008)

[59] Lovaas, "Behavioral Treatment and Normal Educational and Intellectual Functioning in Young Autistic Children", *Journal of Consulting and Clinical Psychology*, Vol. 55, No. 1 (February 1987)

[60] Kansas Autism Task Force, supra note 1

By facilitating access to a timely diagnosis and appropriate treatment for children with ASD, enactment of Senate Bill 12 will improve educational placement and dramatically decrease special education costs for this vulnerable population of Kansans.

40-2249 (a) (7): ***The level of interest of collective bargaining organizations in negotiating privately for inclusion of this coverage in group contracts.***

There is no known interest in collective bargaining agreements as generally defined (that is, negotiation between organized workers and their employer or employers). The proponents of this bill strongly assert that legislative action is needed in order to effectively secure the intended coverage.

40-2249 (a) (8): ***The impact of indirect costs, which are costs other than premiums and administrative costs, on the question of the costs and benefits of coverage.***

(from Arguments in Support of Private Insurance Coverage of Autism-Related Services, Autism Speaks, October 24, 2007)[61]

A 1998 study by John W. Jacobson and others titled, *Cost-Benefit Estimates for Early Intensive Behavioral Intervention for Young Children with Autism – General Model and Single State Case,* examined the cost/benefit relationship of early intensive behavioral intervention treatment at varying levels of treatment success.[62] The study used estimates of costs for early intensive behavioral interventions (EIBI) from childhood (age three) through adulthood (age 55) based on prices in the Commonwealth of Pennsylvania and compared these costs with the expected amount of income the child would earn later in life to arrive at an estimated cost savings.

With a success rate of 47 percent for early intensive behavioral intervention therapy (as determined by Lovaas), Jacobson's study found that cost savings per child served are estimated to be from $2,439,710 to $2,816,535 to age 55.

The study also accounts for the initial investment in early intervention by

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[61] Autism Speaks, "Arguments in Support of Private Insurance Coverage of Autism-Related Disorders, http://www.autismvotes.org/atf/cf/{2a179b73-96e2-44c3-8816-1b1c0be5334b}/ARGUMENTS_FOR_PRIVATE_INSURANCE_COVERAGE.PDF, (October 2007)

[62] Jacobson, supra note 22

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concluding that, with an initial annual cost of $32,820, the total cost-benefit savings of EIBI services per child with autism or PDD for ages 3-55 years averages from $1,686,061 to $2,816,535 with inflation.

According to a 2005 Government Accounting Office (GAO) report, "the average per pupil expenditure for educating a child with autism was more than $18,000 in the 1999-2000 school year. This amount was almost three times the average per pupil expenditure of educating a child who does not receive any special education services."[63] With this insurance reform in place, more children would be able to access the early intervention services they need. That investment will, in the long run pay benefits, both economic and social, to the greater population.

The cost of autism is borne by everyone. Michael L. Ganz's study of the societal costs of autism, *The Lifetime Distribution of the Incremental Societal Costs of Autism*, examined how the large financial burdens of autism affect not only families with an autistic child but society in general.[64]

Ganz broke down the costs associated with autism into two distinct categories, direct costs and indirect costs. Direct costs include direct medical costs, such as physician, outpatient, clinic services, dental care, prescription medications, complementary and alternative therapies, behavioral therapies, hospital and emergency services, allied health, equipment and supplies, home health, and medically related travel, as well as direct nonmedical costs, such as child care, adult care, respite and family care, home and care modification, special education, and supported employment. Indirect costs include productivity losses for people with autism (calculated by combining standard average work-life expectancies for all men and women with average income and benefits and estimated age and sex specific labor force participation rates).

According to Ganz's study, direct medical costs reach their maximum during the first five years of life, averaging around $35,000. As the child ages, direct medical costs begin to decline substantially and continue to decline through the end of life to around $1,000. Ganz goes on to report, "The large direct medical costs early in life are driven primarily by behavioral therapies that cost around $32,000 during the first 5-year age group and decline from about $4,000 in the 8- to 12-year age group to around $1,250 for the 18- to 22-year age group." (Ganz, *supra* note 3)

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[63] United States Government Accountability Office, Special Education: Children with Autism (GAO-05-220 (2005)).

[64] Michael L. Ganz, "The Lifetime Distribution of the Incremental Societal Costs of Autism". *Archives of Pediatric and Adolescent Medicine*, Vol. 161 (2007)

In terms of direct medical costs "the typical American spends about $317,000 over his or her lifetime in direct medical costs, incurring 60% of those costs after the age of 65 years. In contrast, people with autism incur about $306,000 in incremental direct medical costs, which suggests that people with autism spend twice as much as the typical American over their lifetimes and spend 60% of those incremental direct medical costs after age 21 years." (Ganz, *supra* note 3)

The study also found the indirect costs of autism to be significant as well. While in the first 22 years of life, indirect costs are mostly associated with lost productivity for the parents of a child with autism, the costs from age 23 on are associated with lost productivity of the actual individual with autism as depicted in the chart below taken from the study. The impact of this lost productivity can have enormous ramifications for the tax base of an entire society and the future of the older generation as their children with autism transition into adult care.

Ganz posited that direct medical costs "combined with very limited to non-existent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general."(Ganz, *supra* note 3)

Without the help of private insurance coverage, families affected by autism may never be able to pull their heads above water and provide their children with the medically necessary, evidence- based treatments that they need. It is to the advantage of these families, to the 1 in 150 children affected by autism, and to all of society that private health insurance coverage is provided for these services.

Financial Impact of Senate Bill 12

40-2249 (b) (1): *The extent to which insurance coverage of the kind proposed would increase or decrease the cost of the treatment or service*

The demand for autism treatment exceeds the available supply. Part of the reason for this imbalance may be explained by distortions in the delivery of services. For the most part, families have difficulty accessing treatment through private insurance coverage. This leaves them at a competitive disadvantage in negotiating the price of services. A study of exclusions and limitations in behavioral health coverage concluded that policy restrictions drove prices upwards:

> Health insurance generally increases the affordability of children's behavioral health care, but the presence of benefit limits or diagnostic exclusions can mean that some children effectively become uninsured if they require more intensive services than those covered under the plan

> or if they need treatment for disorders that are excluded under the plan. Although current utilization management strategies employed by managed behavioral health organizations, through which few patients ever reach their benefit limits, render benefit parity almost irrelevant, some children do exceed their benefit limits. The cost of obtaining uncovered services can be very high, because *the price of services that are not billable to an insurance plan can be significantly higher than payments for those same services under negotiated agreements between insurers and providers.*

(citations omitted and emphasis added) .[65] Autism Speaks expects that the added bargaining power of private insurers will reduce the cost of autism services. We further anticipate that the purchasing power of private insurers will draw additional providers into the market, increasing the supply of services and reducing their costs.

40-2249 (b) (2): *The extent to which the proposed coverage might increase the use of the treatment or service*

The treatments and services SB 12 requires are the core treatments for autism. Coverage of these treatments by private insurance may not only drive these costs down but may also increase their appropriate use. An insurance company can help consumers make appropriate medical decisions (providing, of course, that the company adheres to the terms of its contract with a subscriber). Insurers often provide members with a range of benefits to better use their health care. These benefits may include the following:

- Care coordination, a program designed to help provide answers to members' questions as they navigate through the health care system;
- Member outreach, a proactive program design to promote, among other things, informed health care choices; and
- Case management, a voluntary service to members with chronic health problems.

With inadequate insurance coverage, families of children with autism spectrum disorders are forced to go it alone in making difficult health care choices. SB 12 could well provide families with additional assistance in looking after the needs of their children.

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[65] Peele PB, Lave JR, Kelleher KJ, "Exclusions and limitations in children's behavioral health care coverage." Psychiatric Services. 33 (2002)

40-2249 (b) (3): ***The extent to which the mandated treatment or service might serve as an alternative for more expensive treatment or service.***

The services SB 12 requires are services that children with autism currently receive. These services are likely to become less costly but otherwise will not change.

40-2249 (b) (4): ***The extent to which insurance coverage of the health care service or provider can be reasonably expected to increase or decrease the insurance premium and administrative expenses of policyholders.***

In order to calculate the estimated rate impact of SB 12 on private health insurance premiums, two factors must be considered:

1. What is the likely risk pool that will utilize treatment provided for in SB 12?
2. What is the average per capita expenditure of the treatment provided for in SB 12?

Question 1

What is the likely risk pool that will utilize treatment provided for in SB 12?

As stated earlier in this analysis, in the 2007 Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network, the CDC estimates that 1 in every 150 children have autism in the United States. Previous cost estimates in other states considering legislation similar to SB 12 have utilized the 1 in every 150 prevalence rate to calculate rate impact.

For example, in a March 6, 2008 letter to the Pennsylvania Health Care Cost Containment Council, regarding HB 1150, which would require private insurers to cover evidence-based autism treatments, Insurance Commissioner Joel Ario stated:

> Our analysis assumes that 1 in 150 children have an ASD diagnosis and will use a mix of services equivalent to those currently provided by the MA (medical assistance) program. We use a total cost of approximately $17,700 per child/per year which is approximately 20% more than the DPW (Department of Public Welfare) per child cost....We estimate the average premium rate increase for a family plan will be approximately $11/month or $137 annually.[66]

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[66] Letter from Joel Ario, Acting Insurance Commissioner, to Marc Volavka, Executive Director, Pa. Health Care Cost Containment Council p. 7 n. 33 (Mar 6, 2008) (on file with Judith Ursitti)

He concludes:

> The Department's best estimate is that HB 1150 would increase premiums approximately 1.1% for a $1,000 per month family plan.[67]

Unfortunately, what is lacking in this analysis is the fundamental consideration that autism is a spectrum disorder, and that resource usage varies depending on many variables, including the severity of the ASD as well as the age of the recipient of treatment. Several recent studies have addressed the accuracy of utilizing epidemiological data to estimate the likely risk pool and have instead calculated the actual *treated prevalence* (or those actually utilizing treatment) of those under the umbrella of an ASD diagnosis.

- In 2007, Douglas L. Leslie and Andres Martin compiled data from the Thomson/Medstat MarketScan database, "which compiles claims information from private health insurance plans of large employers ... across the United States ...with covered individuals including employees, their dependents and early retirees"[68] They found that the *treated prevalence* of autism in the claims database was 1 in 520.

- In a separate study, Gregory S. Liptak et al obtained data from three national surveys and identified a treated prevalence of autism of 1 in 476.[69]

- Additionally, David S. Mandell et al reported a treated prevalence rate of 1 in 500, when analyzing youth diagnosed with autism in Allegheny County, PA.[70]

- Most recently, the acting Pennsylvania Insurance Commissioner, Joel Ario, stated in the previously referenced March 2008 letter to the Pennsylvania Health Care Cost Containment Commission, that out of "the 3.2 million Pennsylvania children between the ages of 2 and 20, there would be approximately 21,300 children with autism or related disorders...The Department of Public Welfare (DPW) has identified 13,800 children currently receiving some autism—related services under

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[67] Ibid.

[68] Leslie, supra note 9

[69] Liptak, Gregory S., Tami Stuart, and Peggy Auinger, "Health Care Utilization and Expenditures for Children with Autism: Data from U.S. National Samples." *Journal of Autism and Developmental Disorders.* Vol 36 (2006)

[70] Mandell, David S., Juan Cao, Richard Ittenbach, and Jennifer Pinto-Martin (2006.) "Medicaid Expenditures for Children with Autistic Spectrum disorders: 1994-1999." *Journal of Autism and Developmental Disorders*, Vol. 36, No. 4, pp. 475-485.

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> the Commonwealth's unique program which waives income eligibility standards for those services."[71]
>
> What is important to note is that although 21,300 children have been identified as having an ASD diagnosis, only 13,800 are actually receiving services through the DPW. This difference reflects the level of need as it relates to severity of symptoms and indicates a treated prevalence of 1 in every 233 children (13,800/3.2 million).

Since actual treated prevalence numbers are not readily available regarding children with ASD in Kansas, an estimated treated prevalence was calculated for use in this cost analysis, averaging the above referenced treated prevalence rates as follows:

Table 1

Source	***Number of Children Receiving Treatment***	***Percentage of Children Receiving Treatment***
Per Leslie and Martin (2007)[72]	1 in 520	*0.19%*
Per Liptak et al 1/476 (2006)[73]	1 in 476	*0.21%*
Per Mandell et al 1/500 (2008)[74]	1 in 500	*0.20%*
Per Pennsylvania DOI (2008)[75]	1 in 233	*0.43%*
Average Treatment Prevalence 1/390	**1 in 390**	*0.26%*

Based on the above, it is estimated that **1 in every 390** children will make up the risk pool that utilizes treatment provided for in SB 12.

Question 2

What is the average per capita expenditure of the treatment provided for in SB 12?

Capturing an appropriate expenditure amount related to treatment costs for autism spectrum disorders is crucial in accurately estimating the cost impact related to mandated coverage. In this cost analysis, three different per capita expenditure estimates were utilized:

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[71] Ario, supra note 68

[72] Leslie, supra note 9.

[73] Liptak , supra note 71

[74] Mandell, supra note 72

[75] Ario, supra note 68

- Since April 2007, Interactive Autism Network (IAN) Research has been collecting information from families who have a child with an ASD. IAN Research is a study at the Kennedy Krieger Institute overseen by the Johns Hopkins Medicine Institutional Review Board. As of June 2008, IAN Research had collected a wealth of information from over 9,000 families on topics ranging from treatment use to parental depression.[76] IAN Research also collects data relative to particular states. IAN data specific to the state of Kansas indicates that in 2008, the average out-of-pocket annual treatment cost per child with ASD was **$6,874.**[77]

- As previously indicated, in his March 6, 2008 letter to the Pennsylvania Health Care Cost Containment Council, Insurance Commissioner Joel Ario indicated that a total cost of approximately **$17,700** per child/per year (approximately 20% more than the actual Pennsylvania DPW per child cost) was appropriate in calculating cost impact related to mandated insurance coverage for ASD's.[78]

- The full-capped expenditure as expressed in SB 12 is **$75,000** per year.

Calculation of Estimated Rate Impact:

As reflected above, an estimated **1 in 390** children with an ASD will utilize treatment covered under SB 12 and the estimated per capita costs related to such coverage will range from a low estimate of **$7,000** to a full cap expenditure of **$75,000.**

Other factors that must be considered when calculating the estimated rate impact of SB 12 are the cost of an average monthly health insurance premium for a family, the applicable medical loss ratio, the percentage of insured that are children and the family factor quotient of typical group rate filings.

In 2008, The Kaiser Family Foundation estimated nationally that the average monthly family health insurance premium costs $1,009.[79] Since the average medical loss ratio was not readily available for the state of Kansas, a national average of 85% was utilized. According to the Pennsylvania Department of Insurance's 2008 review of group rate filings, 33% of insured are children and the family factor equals approximately three times the single rate.

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[76] Interactive Autism Network, http://www.iancommunity.org/cs/for_researchers/ian_statestats

[77] "Interactive Autism Network StateStats. *Average Annual Overall Out-of-Pocket Treatment Costs (US$) per Child US v Kansas" Chart.* Kennedy Krieger Institute, http://www.iancommunity.org/cs/for_researchers/ian_statestats, Retrieved January 24, 2009

[78] Ario, supra note 68

[79] Gary Claxton et al. Kaiser Family Foundation and Samantha Hawkins, Health Research and Educational Trust, "Employer Health Benefits 2007 Annual Survey," available at http://www.kff.org/insurance/7672/upload/76723.pdf.

The following scenarios exhibit a mid-range estimated rate impact of SB 12 on private health insurance premiums:

Scenario One: $7,000 Annual Treatment Cost (Low Estimate)	
Estimated Medical Cost per child with ASD Per IAN Kansas (2008)	**$7,000**
Estimated Medical Cost Adjusted for Prevalence *($7,000*(1/390))*	$18
Average Monthly Family Premium Per Kaiser Foundation (2008)	$1,009
Medical Loss Ratio	85%
Annual Medical Cost per Family *$18 (Est. Medical Cost Adj for Prevalence) x 33% (insured children) x 3 (family factor)*	$18
Monthly Medical Cost per Family *($18/12)*	$1
Monthly Premium Cost per Family *$1 (Monthly Medical Cost)/85% (Medical Loss Ratio)*	**$2**
Estimated Premium Increase *($2/$1009)*	**0.17%**

Scenario Two: $17,700 Annual Treatment Cost (Mid-Range Estimate):	
Estimated Medical Cost per child with ASD Per PA DOI (2008)	**$17,700**
Estimated Medical Cost Adjusted for Prevalence ($17,700*(1/390))	$46
Average Monthly Family Premium Per Kaiser Foundation (2008)	$1,009
Medical Loss Ratio	85%
Annual Medical Cost per Family *$46 (Est. Medical Cost Adj for Prevalence) x 33% (insured children) x 3 (family factor)*	$45
Monthly Medical Cost per Family *($45/12)*	$4
Monthly Premium Cost per Family *$4 (Monthly Medical Cost)/85% (Medical Loss Ratio)*	**$4**
Estimated Premium Increase *($4/$1009)*	**.44%**

Scenario Three: $75,000 Annual Treatment Cost (High Estimate)	
Estimated Medical Cost per full cap expenditure in SB 12	**$75,000**
Estimated Medical Cost Adjusted for Prevalence *($75,000*(1/390))*	$191
Average Monthly Family Premium Per Kaiser Foundation (2008)	1,009
Medical Loss Ratio	85%
Annual Medical Cost per Family *$191 (Est. Medical Cost Adj for Prevalence) x 33% (insured children) x 3 (family factor)*	$191
Monthly Medical Cost per Family *($191/12)*	$16
Monthly Premium Cost per Family *$16 (Monthly Medical Cost)/85% (Medical Loss Ratio)*	**$19**
Estimated Premium Increase *($19/$1009)*	**1.86%**

As exhibited above, the likely range of cost impact based on actual intensive human service cost as well as peer reviewed literature is 0.17% to 1.86%, with a likely mid-range premium increase of 0.44%

40-2249 (b) (5): *The Impact of This Coverage on the Total Cost of Health Care*

By our calculation, the likely maximum premium impact of SB 12 will be significantly less than 1 percent. That cost will be far outweighed by the benefits to the families of Kansas from the legislation. Treating autism effectively will *reduce* the long-term cost of health care.

In 2007 Michael Ganz of the Harvard School of Public Health examined how the large financial burdens of autism affect not only families with an autistic child but society in general.[80] Ganz broke down the costs of autism into direct costs and indirect costs. He counted as direct costs physician services, outpatient care, clinic services, dental care, prescription medications, complementary and alternative therapies, behavioral therapies, hospital and emergency services, allied health, equipment and supplies, home health, and medically related travel, as well as child care, adult care, respite and family care, home and care modifications, special education, and supported employment. He counted as indirect costs productivity losses for people with autism (estimated by combining standard average work-life expectancies for all men and women with average income and benefits and estimates of age- and sex-specific labor force participation rates).

Ganz estimated that the total annual societal per capita cost of caring for and treating a person with autism was $3.2 million. For an entire birth cohort of people with autism, the cost would total about $35 billion. Ganz direly warned that these costs would burden every American:

> These results, especially on the substantial costs resulting from lost productivity of both individuals with autism and their parents and from rather large adult care costs, have important implications for those aging members of the baby boom generation approaching retirement. As those individuals retire, many of their adult children with autism will be transitioning into adult care settings. Those costs, combined with very limited to nonexistent income for their adult children with autism combined with potentially lower levels of savings because of decreased income and benefits while employed, may create a large financial burden affecting not only those families but potentially society in general.[81]

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[80] Ganz, supra note 66

[81] *Id.* at 348.

The financial burden that Ganz describes can be lessened by effective autism services. Researchers estimated that the state of Texas would save $208,500 per child across eighteen years of education with early intensive behavioral intervention.[82] An earlier study in Pennsylvania placed the cost savings from early intervention at $187,000 to $203,000 per child for ages three to twenty-two years and at $656,000 to $1,082,000 per child for ages three to fifty-five years.[83] With proper treatment, children with autism can do better in school and can live healthier and more independent lives.

Autism Speaks believes that the pertinent question in the discussion of insurance reform is not whether we can afford to provide appropriate interventions to children with autism but, rather, whether we can afford not to. Autism is a financial drain on the health care system. Children with autism make more emergency and non-emergency hospital visits and incur greater outpatient, inpatient, and medication costs.[84] An investment towards reducing these costs would benefit everyone.

Of course, the cost of health care and other services is but one measure of the cost of autism. Another measure is the emotional cost of the condition, a measure that cannot readily be quantified. Whatever calculus is used, there can be no doubt that savings lie in reducing autism's toll. Ensuring that Kansas children with autism receive appropriate health care is a wise investment.

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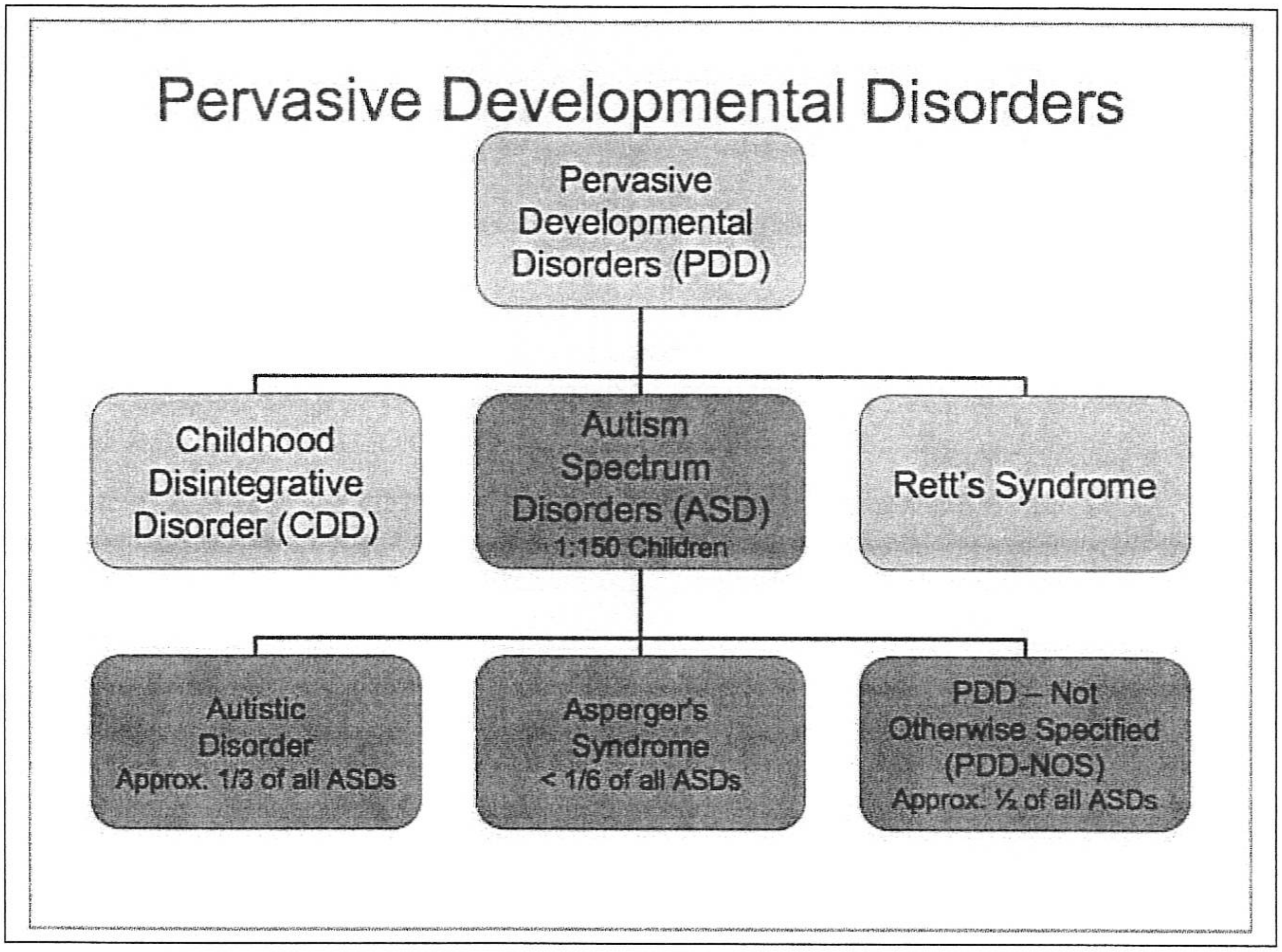
[82] Gregory S. Chasson, Gerald E. Harris, and Wendy J. Neely, "Cost Comparison of Early Intensive Behavioral Intervention and Special Education for Children with Autism." 16 *J. Child and Fam. Stud.* 401 (2007)

[83] Jacobson, supra note 22

[84] Lisa A. Croen, Daniel V. Najjar, G. Thomas Ray, Linda Lotspeich, and Pilar Bernal, "A Comparison of Health Care Utilization and Costs of Children With and Without Autism Spectrum Disorders in a Large Group-Model Health Plan," 118 *Pediatrics* 1203 (2006).

Appendix #1
Pervasive Developmental Disorders

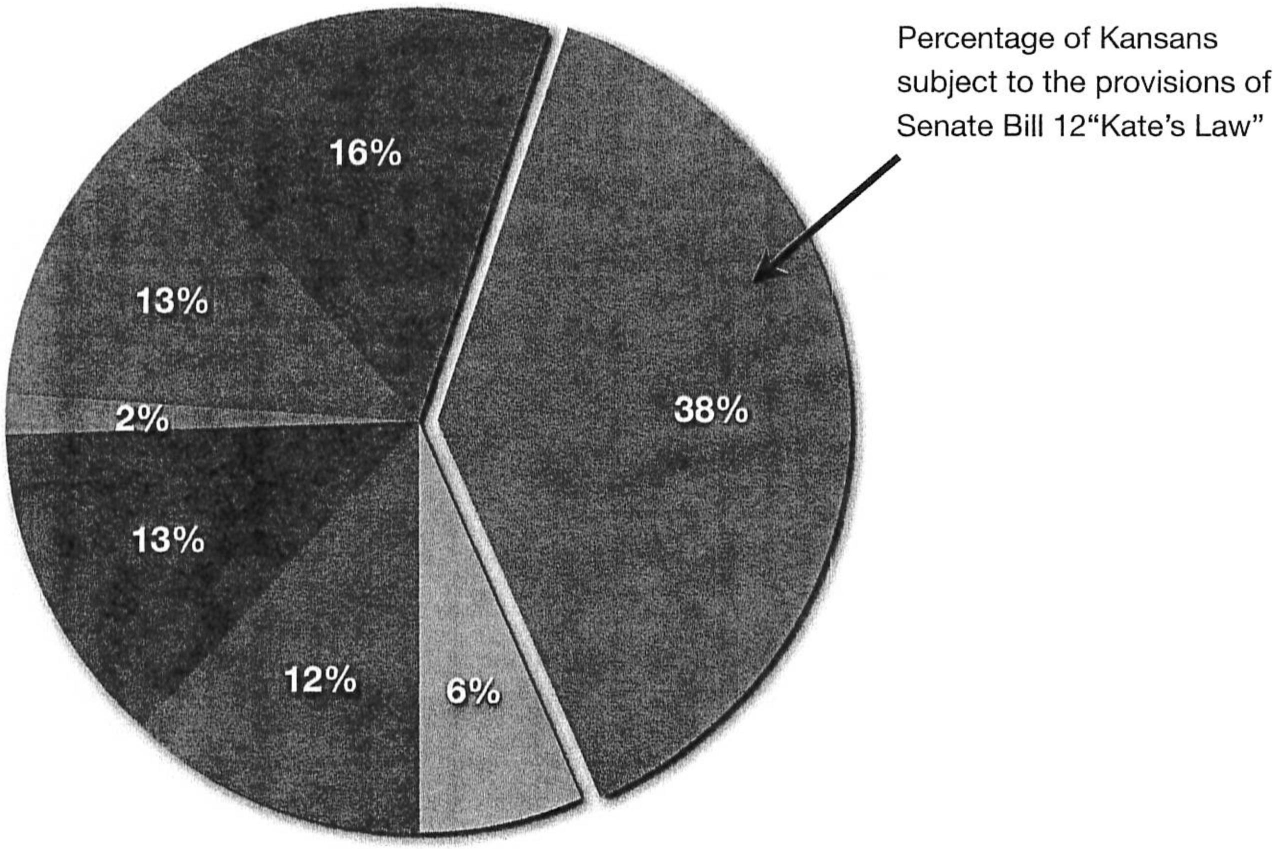


Pervasive Developmental Disorders

- Pervasive Developmental Disorders (PDD)
  - Childhood Disintegrative Disorder (CDD)
  - Autism Spectrum Disorders (ASD) 1:150 Children
    - Autistic Disorder Approx. 1/3 of all ASDs
    - Asperger's Syndrome < 1/6 of all ASDs
    - PDD – Not Otherwise Specified (PDD-NOS) Approx. ½ of all ASDs
  - Rett's Syndrome

Appendix #2

Health Insurance Coverage in Kansas (2006-2007)



Percentage of Kansans subject to the provisions of Senate Bill 12"Kate's Law"

	number	percent
Employer sponsored / self funded	445,813	16
Employer sponsored / fully insured	1,040,230	38
Individual	174,793	6
Medicaid/SCHIP	315,874	12
Medicare	349,542	13
Other Public (e.g. military)	42,776	2
Uninsured	340,373	13
Total population	2,709,401	

Source www.statehealthfacts.org

Exhibit One
Cost Analysis
Accessing Autism Services Bill (SB 12) Kate's Law
January 29, 2009

SCENARIO ONE ASSUMPTIONS

Estimated Cost per child with ASD	**7,000**	Per IAN Kansas (2008)	**7,000**	Per IAN Kansas (2008)
Est Cost Adjusted for Prevalence	47	CDC Prevalence **1:150**	18	Est Treatment Prevlnc **1:390**
Average monthly family premium	1,009	Per Kaiser Foundation (2008)	1,009	Per Kaiser Foundation (2008)
Medical Loss Ratio	85.0%	Estimated Medical Loss Ratio	85.0%	Estimated Medical Loss Ratio

		Cost per child	% of insured that are children	Family Factor		Cost per child	% of insured that are children	Family Factor
High								
Annual Medical Cost Per Family	60	47	40%	3.2	23	18	40%	3.2
Monthly Medical Cost Per Family	5				2			
Monthly Premium Costs	6				2			
(Adjusted for Medical Loss Ratio)								
High Range Premium Increase Percentage	0.58%				0.22%			
Mid								
Annual Medical Cost Per Family	46	47	33%	3	**18**	**18**	**33%**	**3**
Monthly Medical Cost Per Family	4				**1**			
Monthly Premium Costs	5				**2**			
(Adjusted for Medical Loss Ratio)								
Mid Range Premium Increase Percentage	0.45%				0.17%			
Low								
Annual Medical Cost Per Family	33	47	25%	2.8	12.6	18	25%	2.8
Monthly Medical Cost Per Family	3				1.1			
Monthly Premium Costs	3				1.2			
(Adjusted for Medical Loss Ratio)								
Low Range Premium Increase Percentage	0.32%				0.12%			

SCENARIO TWO ASSUMPTIONS

Estimated Cost per child with ASD	**17,700**	Per PA DOI (2008)	**17,700**	Per PA DOI (2008)
Adjusted for Prevalence	118	CDC Prevalence **1:150**	46	Est Treatment Prevlnc **1:390**
Average monthly family premium	1,009	Per Kaiser Foundation (2008)	1,009	Per Kaiser Foundation (2008)
Medical Loss Ratio	85.0%	Estimated Medical Loss Ratio	85.0%	Estimated Medical Loss Ratio

		Cost per child	% of insured that are children	Family Factor		Cost per child	% of insured that are children	Family Factor
High								
Annual Medical Cost Per Family	151	118	40%	3.2	58.4	46	40%	3.2
Monthly Medical Cost Per Family	13				4.9			
Monthly Premium Costs	15				5.7			
(Adjusted for Medical Loss Ratio)								
Premium Increase Percentage	1.47%				0.57%			
Mid								
Annual Medical Cost Per Family	117	118	33%	3	**45**	**46**	**33%**	**3**
Monthly Medical Cost Per Family	10				**4**			
Monthly Premium Costs	11				**4**			
(Adjusted for Medical Loss Ratio)								
Premium Increase Percentage	1.14%				0.44%			
Low								
Annual Medical Cost Per Family	83	118	25%	2.8	32.0	46	25%	2.8
Monthly Medical Cost Per Family	7				2.7			
Monthly Premium Costs	8				3.1			
(Adjusted for Medical Loss Ratio)								
Premium Increase Percentage	0.80%				0.31%			

SCENARIO THREE ASSUMPTIONS

Estimated Cost per child with ASD	**75,000**	Full Cap Expenditure	**75,000**	Full Cap Expenditure
Adjusted for Prevalence	500	CDC Prevalence **1:150**	193	Est Treatment Prevlnc **1:390**
Average monthly family premium	1,009	Per Kaiser Foundation (2008)	1,009	Per Kaiser Foundation (2008)
Medical Loss Ratio	85.0%	Estimated Medical Loss Ratio	85.0%	Estimated Medical Loss Ratio

SCENARIO THREE		Cost per child	% of insured that are children	Family Factor		Cost per child	% of insured that are children	Family Factor
High								
Annual Medical Cost Per Family	640	500	40%	3.2	248	193	40%	3.2
Monthly Medical Cost Per Family	53				21			
Monthly Premium Costs	63				24			
(Adjusted for Medical Loss Ratio)								
Premium Increase Percentage	6.22%				2.41%			
Mid								
Annual Medical Cost Per Family	495	500	33%	3	**191**	**193**	**33%**	**3**
Monthly Medical Cost Per Family	41				**16**			
Monthly Premium Costs	49				**19**			
(Adjusted for Medical Loss Ratio)								
Premium Increase Percentage	4.81%				1.86%			
Low								
Annual Medical Cost Per Family	350	500	25%	2.8	135	193	25%	2.8
Monthly Medical Cost Per Family	29				11			
Monthly Premium Costs	34				13			
(Adjusted for Medical Loss Ratio)								
Premium Increase Percentage	3.40%				1.32%			

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Exhibit Two
Cost Analysis
Accessing Autism Services Bill (SB 12) Kate's Law
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Estimated Number of children with ASD in the Commerical Insurance Market in Kansas

Kansas Population Between the Ages of 2-20[1]		740,469
Less Percentage Uninsured[2]	*13.0%*	96,261
Kansas Insured Population Between the Ages of 2-20		644,208
Less Percentage covered by ERISA/Self-Insured Plans[3]	*60.2%*	387,813
Kansas Non-ERISA Insured Population Between the Ages of 2-20		256,395
Total Risk Pool Based on National CDC Autism Prevalence Rate Estimate of 1/150 Children http://www.cdc.gov/ncbddd/autism/faq_prevalence.htm	***0.67%***	**1,709**
Likely User Pool Based on Actual Treatment Cost:		
Per Leslie and Martin 1/520 (2007)[4]	*0.19%*	493
Per Liptak et al 1/476 (2006)[5]	*0.21%*	538
Per Mandell et al 1/500 (2008)[6]	*0.20%*	513
Per Pennsylvania DOI 1/233 (2008)[7]	*0.43%*	1,100
Total Risk Pool Based on Average Treatment Prevalence 1/390 Children	***0.26%***	**661**

Average Per Capita Expenditure

Average Annual Out of Pocket Treatment Cost per child in Kansas per IAN (2009)[8]	6,874
Per Pennsylvania DOI (2008)[7]	17,700
Full Capped Expenditure	75,000

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[1] Source: US Census Bureau, "Age and Sex for States and for Puerto Rico April 1, 2000 to July 1, 2006," Release Date: May 17, 2007, http://www.census.gov/popest/states/asrh/SC-EST2006-02.html

[2] Health and Disability Working Group, "Catalyst Center State-at-a-Glance Chartbook" Boston University School of Public Health, Boston, MA (2007) p. 72 http://hdwg.org/files/resources/Catalyst_FInalChartbook2.pdf

[3] See Medical Expenditure Panel Survey Report (2005) at http://www.meps.ahrq.gov/mepsweb/data_stats/summ_tables/insr/state/series_2/2005/tiib2b1.pdf

[4] Leslie, Douglas L. and Andres Margin (2007) "Health Care Expenditures Associated with Autism Spectrum Disorders." *Archives of Pediatric and Adolescent Medicine*. Vol. 161, April 2007, pp. 350-355

[5] Liptak, Gregory S., Tami Stuart, and Peggy Auinger (2006), "Health Care Utilization and Expenditures for Children with Autism: Data from U.S. National Samples." *Journal of Autism and Developmental Disorders*. Vol. 36, pp. 871-879.

[6] Mandell, David S., Jun Cao, Richard Ittenbach, and Jennifer Pinto-Martin (2006). "Medicaid Expenditures for Children with Autistic Spectrum Disorders: 1994-1999." *Journal of Autism and Developmental Disorders*, Vol 36, No. 4, pp. 475-485

[7] Letter from Joel Ario, Acting Insurance Commissioner to Marc Volavka, Exectuive Director, Pennsylvania Health Care Cost Containment Council 7 n.33 (Mar 6 2008)
(13,800 children receiving autism related services from PA Department of Public Welfare out of 3.2 million PA children)

[8] "Average Annual Overall Out-of-Pocket Treatment Costs (US$) per Child US v Kansas" Chart. Kennedy Krieger Institute. Interactive Autism Network StateStats. Retrieved January 24, 2009 http://www.iancommunity.org/cs/for_researchers/ian_statestats

Prepared by Judith Ursitti, CPA 1/27/2009

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Exhibit Three
Cost Analysis
Accessing Autism Services Bill (SB 12) Kate's Law
January 29, 2009
State Employee Healthcare Program Coverage Claims Impact

					Low		Mid		Full Cap
					Avg Ann Out of Pckt Trtmt Cost per child in Kansas per IAN (2009)		*Per PA DOI (2008)*		*Full Cap per SB 12*
	Number of State Employees [1]	Assumed Number of Children .50	Total Claims Paid [2]	Number of Affected Children	7,000	% Claims	17700		75000
	88,006	44,003	285,872,000						
CDC Prevalance 1:150 Children				293	2,053,473	0.72%	5,192,354	1.82%	22,001,500
Treated Prevalence 1:390 Children				113	789,797	0.28%	1,997,059	0.70%	8,462,115

[1] *Kansas State Employees Health Care Commission 2007 Plan Year Annual Report*

[2] *State of Kansas Annual Financial Report 6/30/2008*

Prepared by Judith Ursitti, CPA 1/27/2009

10/12/2007

SUMMARY OF CLAIMS WITH DIAGNOSIS OF AUTISTIC DISORDERS AUGUST 2006 THRU JULY 2007

Overall Totals from Claims Data

Total # Members:	421	
Total # Claims:	2577	
Total # Providers:	359	
Total # Claims Denied	182	7%
Total # Claims Denied for reason related to benefit limit exceeded	109	4%
Total # Claims Denied for reason related to non-covered or not medically necessary	73	3%
# Members with Denied Claim(s)	41	10%
# Members with claims denied for reason of benefit limit exceeded	17	4%

Category Groups by Procedure Codes

Categories	#Claims	# Claims with denials (per category)	#Claims denied for reason related to benefit limit exceeded	% claims denied for reason related to benefit limit exceeded
Psychiatric	1459	98	61	4%
Special Otorhinolaryngology Services	260	36	36	14%
Central Nervous System Assessments/Tests	64	3	0	0%
Physical Medicine & Rehabilitation	261	13	12	5%
Office Visits	198	20	0	0%
Lab	251	8	0	0%
Miscellaneous (Scans, Medical Equipment, EEG, EKG, medication administration, anesthesia, lab collection)	77	4	0	0%
Inpatient	7	0	0	0%
Total	**2577**	**182**	**109**	

Queried for Diagnosis codes 299.0 thru 299.91

Diagnosis Codes found:	*Narrative*	*# Claims*
299.00	**Autistic disorder, current or active state** Childhood autism Infantile psychosis Kanner's syndrome	809
299.01	**Autistic disorder, residual state**	9
299.80	**Other specified pervasive developmental disorders, current or active state**	1684
299.81	**Other specified pervasive developmental disorders, residual state**	41
299.90	**Unspecified pervasive developmental disorder, current or active state** Child psychosis NOS Pervasive developmental disorder NOS Schizophrenia, childhood type NOS Schizophrenic syndrome of childhood NOS	34
Total		2577

(Summary Claims data with Autism diagnosis - continued pg 2)

CODES FOUND IN CATEGORIES

Psychiatry Category

Proc Codes	Narrative	# Claims
90801	Psychiatric diagnostic interview examination	102
90804	Individual psychotherapy, insight oriented, behavior modifying and/or supportive, in an office or outpatient facility, approximately 20 to 30 minutes face-to-face with the patient;	76
90805	Individual psychotherapy, insight oriented, behavior modifying and/or supportive, in an office or outpatient facility, approximately 20 to 30 minutes face-to-face with the patient; with medical evaluation and management services	29
90806	Individual psychotherapy, insight oriented, behavior modifying and/or supportive, in an office or outpatient facility, approximately 45 to 50 minutes face-to-face with the patient;	465
90807	Individual psychotherapy, insight oriented, behavior modifying and/or supportive, in an office or outpatient facility, approximately 45 to 50 minutes face-to-face with the patient; with medical evaluation and management services	108
90808	Individual psychotherapy, insight oriented, behavior modifying and/or supportive, in an office or outpatient facility, approximately 75 to 80 minutes face-to-face with the patient;	14
90809	Individual psychotherapy, insight oriented, behavior modifying and/or supportive, in an office or outpatient facility, approximately 75 to 80 minutes face-to-face with the patient; with medical evaluation and management services	31
90812	Individual psychotherapy, interactive, using play equipment, physical devices, language interpreter, or other mechanisms of non-verbal communication, in an office or outpatient facility, approximately 45 to 50 minutes face-to-face with the patient;	2
90813	Individual psychotherapy, interactive, using play equipment, physical devices, language interpreter, or other mechanisms of non-verbal communication, in an office or outpatient facility, approximately 45 to 50 minutes face-to-face with the patient; with medical evaluation and management services	11
90814	Individual psychotherapy, interactive, using play equipment, physical devices, language interpreter, or other mechanisms of non-verbal communication, in an office or outpatient facility, approximately 75 to 80 minutes face-to-face with the patient;	2
90815	Individual psychotherapy, interactive, using play equipment, physical devices, language interpreter, or other mechanisms of non-verbal communication, in an office or outpatient facility, approximately 75 to 80 minutes face-to-face with the patient; with medical evaluation and management services	5
90846	Family psychotherapy (without the patient present)	20
90847	Family psychotherapy (conjoint psychotherapy) (with patient present)	154
90853	Group psychotherapy (other than of a multiple-family group)	6
90862	Pharmacologic management, including prescription, use, and review of medication with no more than minimal medical psychotherapy	405
90887	Interpretation or explanation of results of psychiatric, other medical examinations and procedures, or other accumulated data to family or other responsible persons, or advising them how to assist patient	10
90899	Unlisted psychiatric service or procedure	19
Total		1459

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(Summary Claims data with Autism diagnosis - continued pg 3)

Special Otorhinolaryngologic Services Category

Proc Code	Narrative	# Claims
92506	Evaluation of speech, language, voice, communication, and/or auditory processing	3
92507	Treatment of speech, language, voice, communication, and/or auditory processing disorder; individual SPEECH THERAPY	197
90526	Treatment of swallowing dysfunction and/or oral function for feeding	57
92585	Auditory evoked potentials for evoked response audiometry and/or testing of the central nervous system; comprehensive	1
92587	Evoked otoacoustic emissions; limited (single stimulus level, either transient or distortion products)	1
92610	Evaluation of oral and pharyngeal swallowing function	1
Totals		260

Central Nervous System Assessment and Testing Category

Proc Code	Narrative	# Claims
96101	Psychological testing (includes psychodiagnostic assessment of emotionality, intellectual abilities, personality and psychopathology, eg, MMPI, Rorschach, WAIS), per hour of the psychologist's or physician's time, both face-to-face time with the patient and time interpreting test results and preparing the report	43
96102	Psychological testing (includes psychodiagnostic assessment of emotionality, intellectual abilities, personality and psychopathology, eg, MMPI and WAIS), with qualified health care professional interpretation and report, administered by technician, per hour of technician time, face-to-face	5
96105	Assessment of aphasia (includes assessment of expressive and receptive speech and language function, language comprehension, speech production ability, reading, spelling, writing, eg, by Boston Diagnostic Aphasia Examination) with interpretation and report, per hour	1
96110	Developmental testing; limited (eg, Developmental Screening Test II, Early Language Milestone Screen), with interpretation and report	4
96111	Developmental testing; extended (includes assessment of motor, language, social, adaptive and/or cognitive functioning by standardized developmental instruments) with interpretation and report	8
96116	Neurobehavioral status exam (clinical assessment of thinking, reasoning and judgment, eg, acquired knowledge, attention, language, memory, planning and problem solving, and visual spatial abilities), per hour of the psychologist's or physician's time, both face-to-face time with the patient and time interpreting test results and preparing the report	2
96155	Health and behavior intervention, each 15 minutes, face-to-face; family (without the patient present)	1
Totals		64

Physical Medicine and Rehab Category

Proc Code	Narrative	# Claims
97001	Physical therapy evaluation	2
97003	Occupational therapy evaluation	4
97004	Occupational therapy re-evaluation	5
97110	Therapeutic procedure, one or more areas, each 15 minutes; therapeutic exercises to develop strength and endurance, range of motion and flexibility	13
97112	Therapeutic procedure, one or more areas, each 15 minutes; neuromuscular reeducation of movement, balance, coordination, kinesthetic sense, posture, and/or proprioception for sitting and/or standing activities	19
97530	Therapeutic activities, direct (one-on-one) patient contact by the provider (use of dynamic activities to improve functional performance), each 15 minutes	216
97535	Self-care/home management training (eg, activities of daily living (ADL) and compensatory training, meal preparation, safety procedures, and instructions in use of assistive technology devices/adaptive equipment) direct one-on-one contact by provider, each 15 minutes	2
Totals		261

2-70

Lorri Unumb

Senior Policy Analyst and Counsel – Autism Speaks

Parent of a 7-year-old son with autism
Attorney: Senior Litigation Counsel with United States Department of Justice
Law Professor at George Washington University Law School

Autism is a medical condition, brought on through no fault of family. Diagnosed by a medical doctor. Treatment prescribed by medical doctor.

"Autism" is actually an imprecise term: some people use it interchangeably with "autism spectrum disorder" and others use it to mean one of the ASDs. In fact, there are three distinct diagnoses within the family of autism spectrum disorders. (See chart.) The umbrella diagnostic category is called Pervasive Developmental Disorder. Within that umbrella category are 3 conditions known as ASDs: Autistic Disorder (or "classic autism"), Asperger's Syndrome, and PDD-NOS. Across the spectrum, people vary greatly in terms of type and severity of deficits. Interestingly, 4 times more common in boys than in girls.

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. So, while they're not cured, they can overcome the disabling aspects of the condition.

The most commonly-prescribed treatment protocol involves a therapy called "Applied Behavior Analysis," or ABA. This is a therapy that has been used for many decades to treat autism, and yet the insurance industry continues to deny coverage for ABA therapy, often on the basis that it is "experimental." That self-serving conclusion is simply not supported by the science, and the Surgeon General, the National Research Council, and the AAP all have endorsed ABA. (Show sample coverage positions, which show blanket exclusion of ABA therapy.)

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)

As I mentioned, though, ABA must be administered intensively, often 40 hours/week. And this, of course, makes it expensive. My own son's autism is very severe, and his therapy has cost us, out-of-pocket $75,000 per year. (Because of this extraordinary medical expenses, we've been audited on our taxes 3 times.) Most kids don't require anything close to this much therapy, but the few, truly severe kids do. Fortunately, my husband and I are blessed with good jobs, and we were able to sacrifice to afford the therapy for our son. But how many Kansas families do you know that have that kind of money to sacrifice? Or even half that much? Most don't, and most of those children are going untreated. It's sad that in the USA, we know of a treatment that works, and yet we have kids who can't get the treatment they need because their parents aren't wealthy. And it's not only sad; it's unfair, given that these families are paying premiums every month to cover their kids. These are families who are doing the right thing, by buying insurance for their families to insure against exactly this kind of unforeseen & unprovoked medical disaster.

A 2006 study from the Harvard School of Public Health 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). In addition, a 1998 study for the state of Pennsylvania projected an actual direct cost savings to the state of over a million dollars per child. (Jacobson, Green 1998). Do the math: 1 in 150 Kansas kids diagnosed; only the wealthy few get treatment; and multiply each remaining child by over a million dollars. That's how much Kansas taxpayers will shell out if these kids don't get treatment. Lest you think, "We'll just handle these people in our budget the same way we've always handled it, think again. Just 10 years ago, the prevalence rate of autism was less than 1 in 1,000. Today, it is 1 in 150. Scientists don't know the reason for the increase, but we all understand the ramifications. There's a huge autism tsunami coming,

House Insurance
Date: 3-19-09
Attachment # 3

and it is going to cost the state an extraordinary amount of money in special education and adult care if the current generation of kids does not get the treatment they need. Without private insurance playing its part, the treatment is simply not going to happen.

Faced with this reality, other states – 8, to be specific – now require insurers to play their part. (See chart). Seven states have passed this legislation, or something very similar, in the past 2 years:

South Carolina (2007)
Texas (2007)
Arizona (2008)
Louisiana (2008)
Pennsylvania (2008)
Florida (2008)
Illinois (2008).

Indiana passed a similar bill 8 years ago – in 2001 – the same year the Attorney General in Minnesota entered into a settlement agreement with that state's major insurer (BCBS) to require coverage for autism, including coverage of Applied Behavior Analysis therapy. And many other states are considering similar legislation right now. Missouri, Montana, Utah, Minnesota, Georgia, New Mexico, and Kentucky have all passed committee and/or floor in past few weeks.

One of the reasons I'm here today is because I worked on the legislation in South Carolina that started the recent movement toward coverage, and I've seen it successfully implemented. 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. And I can tell you, despite the doomsday predictions from the insurance lobby that we've heard in state after state, none of our insurers have left the state and no businesses have thrown in the towel because of this benefit. Indeed, the impact on premiums has been negligible. In Indiana, the DOI called the financial impact "unmeasurable" even years after the coverage became effective.

The insurance industry's own association – the Council for Affordable Health Insurance – estimates that mandated autism benefits increase premium costs by LESS than 1%. (See chart)

Autism Speaks contracted with independent actuarial firm, Oliver Wyman, to conduct a cost analysis specifically for Kansas. The independent actuary also arrived at less than 1%. (See attachment.) A little over $2.00 per month.

The insurance industry is going around saying this will increase premiums 2-3%, and telling you that 5500 people will lose insurance for every 1% that premiums increase. Before you fall for that, I ask you to hold insurance industry's feet to the fire on this prediction of a devastating premium increase. Have they shown you the math they used to come up with a 2-3% prediction? Where's the study? You've got a 20-page document that shows our independent actuary's math and arrives at approximately $2-something/month. Better yet, why doesn't the insurance industry show you actual claims data? Insurance companies in Indiana and Minnesota have been tracking this data for years, and they know exactly how much it costs to fully cover autism. Do you wonder why the insurance industry hasn't produced that claims data for you to examine???

Fiscal note – Unclear whether appropriate assumptions were made:
Only 1/3 of Autism Spectrum Disorder is autistic disorder
Only a small fraction of those will need or be prescribed the maximum amount of therapy.
Average age of diagnosis -fixed in second analysis
Child's progress - only in rare cases does therapy extend beyond 2 or 3 years
Experience shows utilization projection (20-40%)

Thus, in addition to the general premium impact, the actuarial firm of Oliver Wyman also produced an independent assessment of the impact on the Kansas state employees health plan. Generous estimate of $1.7 million.

In states where this law has passed, the overall impact on the economy has been positive, particularly in terms of job creation. Thousands of people have been trained and are now working full-time as therapists with children with autism.

Scrivener's error.

Agree to do away with opt-out.

Question #1 Don't the schools provide this therapy? Or shouldn't the schools provide it?

Autism is a medical condition that is diagnosed by a medical doctor, not by a school principal. It is not a learning disability.

Federal law – the Individuals with Disabilities Education Act (IDEA) – does not charge the schools with ameliorating a child's medical condition; it charges the schools with providing the child a meaningful education.

Under IDEA, schools must accommodate disabilities in the course of educating children, but schools do not, cannot, and should not be tasked with treating the disabling condition.

For example, Schools accommodate a child with diabetes by allowing the child to receive insulin injections at school, so that the child can function and thus learn. But, just as society does not rely on schools to pay for the insulin, nor should we put the burden on schools to pay for the treatment a child with autism needs in order to function in a school setting.

Don't be confused by the fact that some of our teachers, in our best districts, use some of the same behavioral principles in a school setting that ABA therapists use at home or in a clinic; this does not magically render ABA therapy exempt from insurance coverage.

Further, even to the extent that a school district does have plentiful resources, allowing the district to employ a one-on-one trained therapist for each child with autism and a Board Certified Behavior Analyst to supervise in each district, the school therapists would only work on educational goals for the child. Children with autism still would need additional therapy in the home to acquire skills such a potty-training, dressing, use of utensils, toothbrushing, bathing, and other daily living skills that other children acquire naturally through imitation.

Calling ABA "educational" and thus not subject to insurance coverage is just another ploy to get out of paying for it. First it was covered because it was experimental; now it's not covered because it's educational. And yet, TriCare, the Department of Defense health insurance plan for military, has been covering Applied Behavior Analysis for years.

AAP report –

1 – Read the whole thing. Attached.

2 – In the list of "educational treatments," speech therapy and occupational therapy appear. Does that mean insurance should no longer cover them?

Question #2 Well, how about Medicaid?

Some states have attempted to handle this issue by creating autism-specific Medicaid waivers that cover ABA. Two problems with this approach, one practical and one philosophical.

1- Not enough funding. State must fund, and even with federal match, no state has been able to pour enough money into a waiver program to serve all of the kids with autism. Very long waiting lists, during which opportunity for maximum "recovery" disappears.

2- Socialized medicine

Question #3: Don't some insurers already cover autism?

Even to the extent that insurance policies currently cover autism, they do not cover the treatment that is most effective and most commonly-prescribed for autism. Perhaps there is no blanket exclusion in the policy for autism, but there are exclusions for behavioral therapy, for habilitative treatment, or any number of other things that make the treatment unavailable. Some insurers have specific written policy statements stating that ABA will not be covered. (See Cigna & BCBS coverage positions).

Cancer/chemo analogy.

I don't believe in telling insurance companies what they must cover.

Private contract between private parties.

I felt same way 5 years ago. But I've learned a lot in those 5 years. I've learned that the theories I studied in law school about market failure due to unequal bargaining power are true and real. This is a classic case of market failure. The industry has proven that it is not going to step up to the plate and do the right thing, thereby forcing your hand. And you know, granted they are contracts between private parties, but we as a society have already determined that we believe in some degree of interference in these particular contracts. If we didn't, we wouldn't need a DOI. The state regulates insurance affairs, and, because the insurance industry refuses to update its coverage positions to align with current science, the state should step in here.

Why should we single out this one disease for coverage?

What other disease do you know of that insurance purports to cover but doesn't cover the single most effective, accepted, and commonly prescribed treatment for? Name another disease for which we know of a treatment that undeniably works and that is evidence-based, but insurance won't cover that particular treatment.

Some insurers claim that the autism community is seeking special treatment by asking to have a particular treatment covered. They say we're seeking special treatment because ABA is not covered for any other diagnoses. Actually, we are seeking equal treatment. All we are asking is that insurance cover the standard treatment protocol for this condition. Would we tell breast cancer patients they were seeking special treatment if they asked to have masectomies covered? Would the insurance industry refuse to cover that particular treatment because they don't cover it for any other disease? Of course not. Equal treatment means covering for each disease the standard treatment protocol for that disease.

This law would not be very effective because only a small percentage of Kansas residents would be subject to its terms

The fact that many Kansas residents are governed by ERISA plans or other plans that are subject to federal, not state, regulation is not a reason to not help the residents you can reach. If you saw a sinking boat with 10 people on board on the verge on drowning, and you had 3 life jackets, would you toss the 3 life jackets, or would you hold onto them because you didn't have 10?

Effect on ERISA plans; many self-insured employers follow suit.

Further, if some coverage exists within the state, parents of autistic children can change jobs to find coverage. If none exists, they cannot.

Because there's no license for behavior analysts, we'd be forced to cover just anyone.

There is a well-established, national certification for behavior analysts that has already been accepted by states, by the military insurance (TRICARE), and by insurers who operate in states where this law has been passed. In those states, insurers have been able to limit payments only to board-certified providers (or equivalent), and the lower-level therapists who lack certification are paid through the board-certified provider. The requirements for board certification are extremely stringent and there are continuing education requirements. Many insurers have already examined these requirements and satisfied themselves that it is an appropriate credential for payment. (Show BCBS implementation documents from South Carolina).

Why aren't other therapies, such as Floortime, included?

This bill is written in such a way as to encompass evidence-based treatment. It is not meant to favor one brand over another, but at present, Applied Behavior Analysis (ABA) is the only treatment of its kind that is empirically validated. We do not question the judgment of parents who use or try other types of treatments; I've tried others with my own son. But we didn't think it was fair to ask insurance to cover treatments which are not yet validated with peer-reviewed research.

As to Floortime specifically (also known as DIR), we simply defer to the report of the American Academy of Pediatrics, which states:

"Published evidence of the efficacy of the DIR model is limited to an unblinded review of case records (with significant methodologic flaws, including inadequate documentation of the intervention, comparison to a suboptimal control group, and lack of documentation of treatment integrity and how outcomes were assessed by informal procedures) and a descriptive follow-up study of a small subset (8%) of the original group of patients."

Further, Floortime is often administered by parents, and we cannot ask insurers to reimburse parents for therapy.

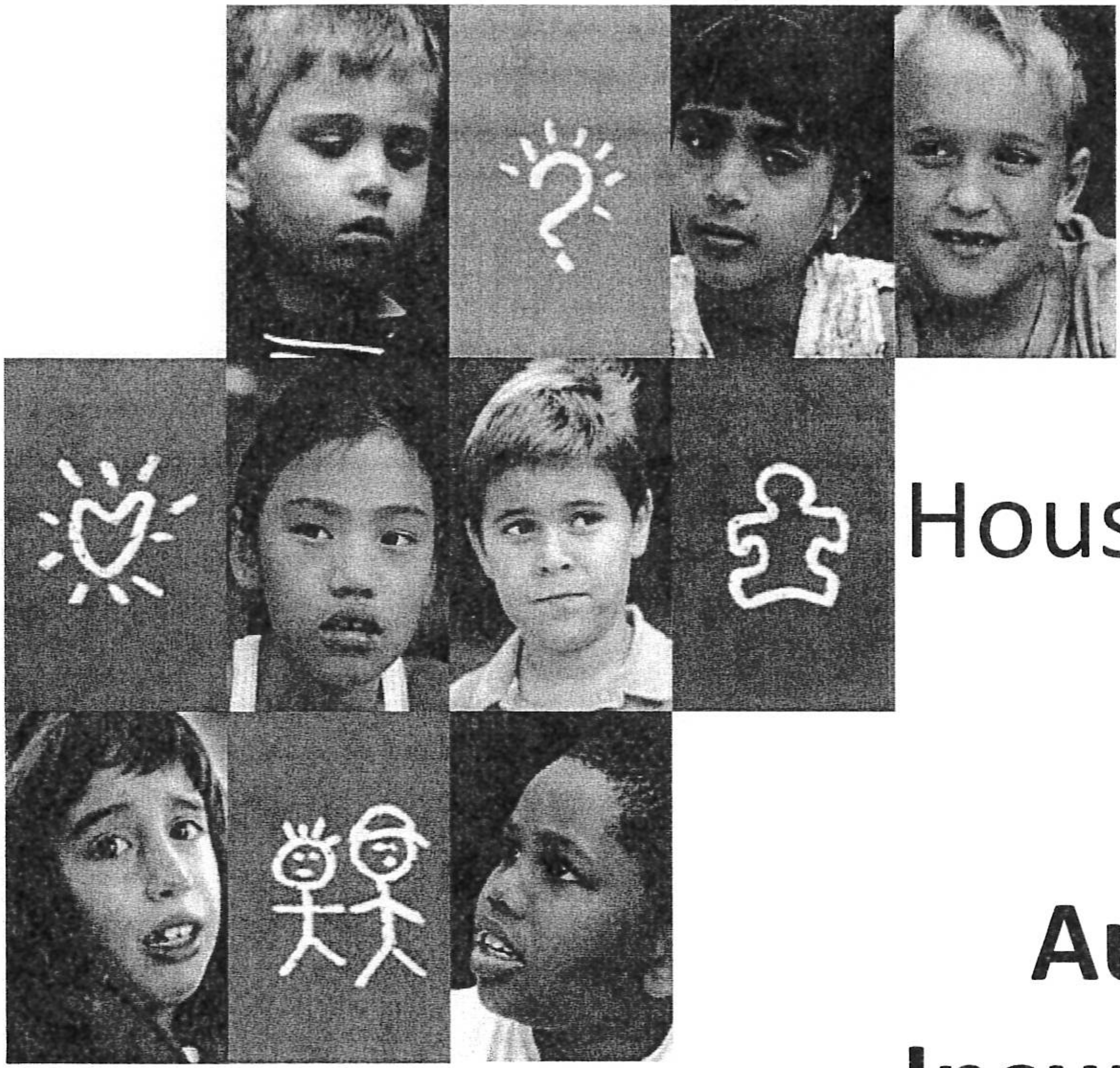
Does this bill take away the insurers' ability to use cost-control mechanisms? No. The bill neither indicates that insurers may not use their normal cost-control measures nor is it the intent of the autism community to remove their ability to do so. We are not asking for special treatment here; we are asking for equal treatment. We are asking to be treated equally in that insurance should cover the standard, well-accepted treatment for autism, just as it covers standard, accepted treatments for other diseases. But we're not asking to get out of deductibles, copayments, or even other typical cost-control mechanisms like coordination of benefits, restrictions on family members providing service, or reviews for medical necessity. (See treatment review clause).

SUM UP

I was a law professor for 7 years, and I spent much of that time thinking about this issue and how best to resolve it. [Medicaid? Education? May all have role to play and they're trying. But it is insurance industry that is most not doing its part. Getting off the hook scot-free and not paying its fair share of the burden]. After years of examining the issue, I've yet to come up with a better solution than what is being proposed here.

Finally, I would ask you to pass this bill because it is simply the right thing to do. I hear so many people complain about paying taxes and griping about how high taxes are. It is my dream for my son that someday he may get to pay taxes. And I bet many parents in this room share that dream.

Thank you for taking the first step toward giving Kansas children the treatment that kids in other states are now getting by voting this bill out of committee.



House Bill 2367

Autism Insurance in Kansas

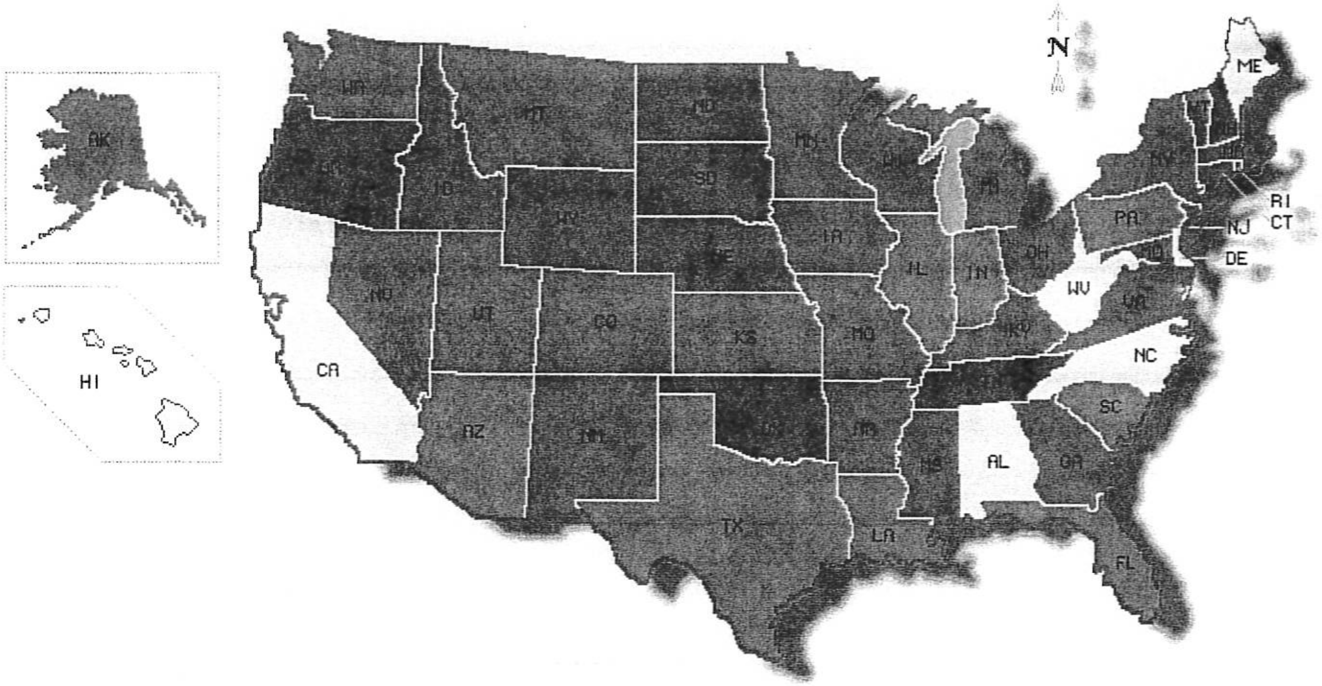
"[N]o disability claims more parental time and energy than autism."
- New York Times, 12/20/04

Lorri Unumb, Esq.
Autism Speaks

Autism Speaks
Government Relations Department

3/18/2009

Autism Speaks 2009 State Initiatives



States with Autism Insurance Reform	Introduced and Endorsed		Pending Introduction and/or Pending Endorsement	Bill Under Development	Little or No Activity
Arizona	Alaska	Mississippi	New Hampshire	Alabama	Idaho
Florida	Arkansas	Missouri	Oklahoma	California	Nebraska
Illinois	Connecticut	Montana	Oregon	Delaware	North Dakota
Indiana	Colorado	Nevada	Tennessee	Hawaii	Rhode Island
Louisiana	Georgia	New Jersey		Maine	South Dakota
Pennsylvania	Iowa	New Mexico		North Carolina	Vermont
South Carolina	Kansas	New York		Wash., DC	Wyoming
Texas	Kentucky	Ohio		West Virginia	
	Maryland	Utah			
	Massachusetts	Virginia			
	Michigan	Washington			
	Minnesota	Wisconsin			

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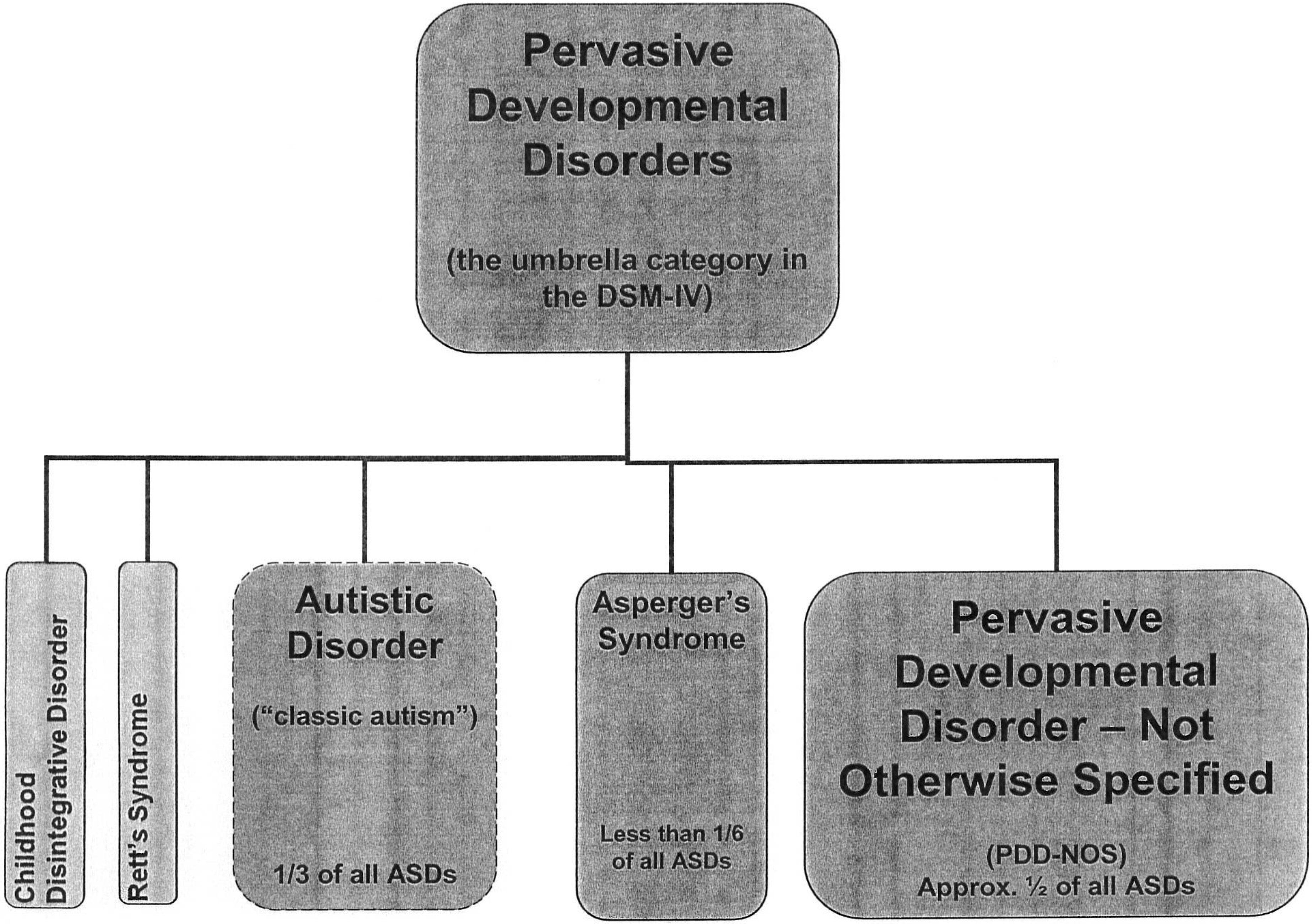

Pervasive Developmental Disorders

(the umbrella category in the DSM-IV)

- Childhood Disintegrative Disorder
- Rett's Syndrome
- **Autistic Disorder**
  ("classic autism")
  1/3 of all ASDs
- **Asperger's Syndrome**
  Less than 1/6 of all ASDs
- **Pervasive Developmental Disorder – Not Otherwise Specified**
  (PDD-NOS)
  Approx. ½ of all ASDs

Applied Behavior Analysis: A Sample Program

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

- Mid-level supervisor (lead therapist)
  - Highly educated and trained
  - May be board certified
  - Updates programming; trains; oversees
  - 6 hours per week
- Line therapists
  - May be college students, trained by above
  - Provide 40 hours per week of direct therapy, usually in 3-hour shifts

Applied Behavior Analysis: Cost of a Sample Program

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

- 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**

- Line therapists
  - 40 hours per week
  - $10 - $20/hour
  - 40 hours x $20 = $800/week
  - $800/week x 52 weeks = **$41,600**

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

Self-Funded ERISA Plans

- Microsoft
- Home Depot
- Intel
- Arnold & Porter
- Symantec
- Halliburton
- Eli Lilly
- Deloitte
- Ohio State University
- IBM
- Mayo Clinic
- Raytheon
- Symantec
- Lexington Medical Center
- University of Minnesota
- Progressive Group
- Michelin
- Greenville Hospital System

Excerpt from 2008 Report of Council of 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 Fert.	3-5%	13
Prescriptions	5-10%	2

Available at www.CAHI.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.

CIGNA HEALTHCARE COVERAGE POSITION

CIGNA

Subject **Autism Spectrum Disorders/Pervasive Developmental Disorders: Assessment and Treatment**

Revised Date 4/15/2007
Original Effective Date 4/15/2006
Coverage Position Number 0447

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Hyperlink to Related Coverage Positions

- Chelation Therapy
- Cognitive Rehabilitation
- Complementary and Alternative Medicine
- Genetic Counseling
- Genetic Testing
- Hyperbaric Oxygen Therapy
- Magnetoencephalography (MEG)
- Neuropsychological Testing
- Nuclear Imaging including Single-Photon Emission Computed Tomography (SPECT)
- Nutritional Counseling
- Occupational Therapy
- Preimplantation Genetic Diagnosis
- Secretin Acetate (Secreflo™)
- Sensory and Auditory Integration Therapy—Facilitated Communication
- Speech Generating Devices
- Speech/ Language Therapy
- Vision Therapy/Orthoptics

INSTRUCTIONS FOR USE

*Coverage Positions are intended to supplement certain **standard** CIGNA HealthCare benefit plans. Please note, the terms of a participant's particular benefit plan document [Group Service Agreement (GSA), Evidence of Coverage, Certificate of Coverage, Summary Plan Description (SPD) or similar plan document] may differ significantly from the standard benefit plans upon which these Coverage Positions are based. For example, a participant's benefit plan document may contain a specific exclusion related to a topic addressed in a Coverage Position. In the event of a conflict, a participant's benefit plan document **always supercedes** the information in the Coverage Positions. In the absence of a controlling federal or state coverage mandate, benefits are ultimately determined by the terms of the applicable benefit plan document. Coverage determinations in each specific instance require consideration of 1) the terms of the applicable group benefit plan document in effect on the date of service; 2) any applicable laws/regulations; 3) any relevant collateral source materials including Coverage Positions and; 4) the specific facts of the particular situation. Coverage Positions relate exclusively to the administration of health benefit plans. Coverage Positions are not recommendations for treatment and should never be used as treatment guidelines.*

Coverage Position

Some CIGNA HealthCare benefit plans specifically exclude therapy for learning disabilities, developmental delays, autism, and mental retardation or for that which is not restorative in nature. Please refer to the applicable CIGNA HealthCare benefit plan document to determine terms and conditions of coverage. Coverage for treatment of autism spectrum disorders (ASD) may also be mandated by state and/or federal mandates.

Services provided by a psychiatrist, psychologist or other behavioral health professionals are subject to the provisions of the applicable behavioral health benefit.

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Assessment and treatment for comorbid behavioral health and/or medical diagnoses and associated symptoms and/or conditions may be covered under applicable CIGNA HealthCare medical and behavioral health benefit plans.

When not otherwise excluded, CIGNA HealthCare covers medically necessary services for the treatment of autism spectrum disorders (ASD) when the criteria of the Diagnostic and Statistical Manual of Mental Health Disorders, Fourth Edition, Text Revision (DSM-IV-TR) are met.

Please refer to the CIGNA HealthCare Coverage Positions on Speech/Language Therapy, Occupational Therapy and Physical Therapy for specific coverage criteria for these therapies.

Services that are considered primarily educational or training in nature or related to improving academic or work performance are not covered under most CIGNA HealthCare benefit plans. CIGNA HealthCare does not cover the following services for the assessment and/or treatment of ASD because they are primarily educational and training in nature (this list may not be all-inclusive):

- education and achievement testing
- educational intervention (e.g., classroom environmental manipulation, academic skills training and parental training)

CIGNA HealthCare does not cover the following procedures/services for the assessment and/or treatment of ASD because they are considered experimental, investigational or unproven for this indication (these lists may not be all-inclusive):

Assessment:

- allergy testing (e.g., food allergies for gluten, casein, candida, molds)
- celiac antibodies testing
- erythrocyte glutathione peroxidase studies
- event-related potentials (i.e., evoked potential studies)
- hair analysis
- immunologic or neurochemical abnormalities testing
- intestinal permeability studies
- magnetoencephalography (MEG)
- micronutrient testing (e.g., vitamin level)
- mitochondrial disorders testing (e.g., lactate and pyruvate)
- neuropsychological testing
- stool analysis
- thyroid function testing
- urinary peptides testing

Treatment:

- auditory integration therapy
- augmentative communication devices
- chelation therapy
- cognitive behavioral therapy
- cognitive rehabilitation
- craniosacral therapy
- dietary and nutritional interventions (e.g., elimination diets, vitamins)
- facilitated communication
- hyperbaric oxygen therapy
- intensive intervention programs for autism (e.g., Lovaas therapy, applied behavior analysis [ABA])
- immune globulin therapy

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BCBS Medical Policy

Subject: Treatment of Autism, Asperger's Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (NOS)

Policy #: BEH.00004 Current Effective Date: 08/23/2007

Status: Revised Last Review Date: 08/23/2007

Description/Scope

This policy addresses a wide variety of pharmacotherapeutic, behavioral, educational, medical, and rehabilitative treatments and therapies used to treat Autism, Asperger's Syndrome, Rett Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder (NOS).

* * *

Medically Necessary:

Pharmacotherapy for management of comorbidities related to autism, Asperger's syndrome, Rett syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (NOS) is considered medically necessary when required for the treatment of mood disorders or other conditions where the potential for patients to harm themselves or others is present, or when such treatment would otherwise be considered medically necessary.

Behavior modification for management of behavioral symptoms related to autism, Asperger's syndrome, Rett syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (NOS) is considered medically necessary when required for the management of behaviors where the potential for patients to harm themselves or others is present, or when such treatment would otherwise be considered medically necessary.

Interventions to improve verbal and nonverbal communication skills for patients with autism, Asperger's syndrome, Rett syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (NOS) are considered medically necessary.

Physical and occupational therapy for comorbid physical impairments in patients with autism, Asperger's syndrome, Rett syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (NOS) is considered medically necessary when such treatment would otherwise be considered medically necessary.

Medical therapy or psychotherapy, as indicated for comorbid medical or psychological conditions is considered medically necessary when such treatment would otherwise be considered medically necessary.

Investigational/Not Medically Necessary:

The following treatments or therapies are considered investigational/not medically necessary for the treatment of autism, Asperger's syndrome, Rett syndrome, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (NOS):

* * *

Lovaas therapy (also known as applied behavior analysis (ABA), intensive behavioral intervention (IBI), discrete trial training, early intensive behavioral intervention (EIBI), or intensive intervention programs)

* * *

Indiana Code 27-8-14.2

Chapter 14.2. Insurance Coverage for Pervasive Developmental Disorders

IC 27-8-14.2-1

"Accident and sickness insurance policy" defined

Sec. 1. (a) As used in this chapter, "accident and sickness insurance policy" means an insurance policy that provides one (1) or more of the types of insurance described in IC 27-1-5-1, classes 1(b) and 2(a).

(b) The term does not include the following:

(1) Accident only, credit, dental, vision, Medicare supplement, long term care, or disability income insurance.
(2) Coverage issued as a supplement to liability insurance.
(3) Worker's compensation or similar insurance.
(4) Automobile medical payment insurance.
(5) A specified disease policy.
(6) A short term insurance plan that:
    (A) may not be renewed; and
    (B) has a duration of not more than six (6) months.
(7) A policy that provides indemnity benefits not based on any expense incurred requirement, including a plan that provides coverage for:
    (A) hospital confinement, critical illness, or intensive care; or
    (B) gaps for deductibles or copayments.
(8) A supplemental plan that always pays in addition to other coverage.
(9) A student health plan.
(10) An employer sponsored health benefit plan that is:
    (A) provided to individuals who are eligible for Medicare; and
    (B) not marketed as, or held out to be, a Medicare supplement policy.

IC 27-8-14.2-2

"Insured" defined

Sec. 2. As used in this chapter, "insured" means an individual who is entitled to coverage under a policy of accident and sickness insurance.

IC 27-8-14.2-3

"Pervasive developmental disorder" defined

Sec. 3. As used in this chapter, "pervasive developmental disorder" means a neurological condition, including Asperger's syndrome and autism, as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association.

IC 27-8-14.2-4

Group coverage required

Sec. 4. (a) An accident and sickness insurance policy that is issued on a group basis must provide coverage for the treatment of a pervasive developmental disorder of an insured. Coverage provided under this section is limited to treatment that is prescribed by the insured's treating physician in accordance with a treatment plan. An insurer may not deny or refuse to issue coverage on, refuse to contract with, or refuse to renew, refuse to reissue, or otherwise terminate or restrict coverage on an individual under an insurance policy solely because the individual is diagnosed with a pervasive developmental disorder.

(b) The coverage required under this section may not be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable to an insured than the dollar limits, deductibles, or coinsurance provisions that apply to physical illness generally under the accident and sickness insurance policy.

IC 27-8-14.2-5

Individual coverage required

Sec. 5. (a) An insurer that issues an accident and sickness insurance policy on an individual basis must offer to provide coverage for the treatment of a pervasive developmental disorder of an insured. Coverage provided under this section is limited to treatment that is prescribed by the insured's treating physician in accordance with a treatment plan. An insurer may not deny or refuse to issue coverage on, refuse to contract with, or refuse to renew, refuse to reissue, or otherwise terminate or restrict coverage on an individual under an insurance policy solely because the individual is diagnosed with a pervasive developmental disorder.

(b) The coverage that must be offered under this section may not be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable to an insured than the dollar limits, deductibles, or coinsurance provisions that apply to physical illness generally under the accident and sickness insurance policy.

As added by P.L.148-2001.

March 30, 2006

Bulletin 136

Insurance Coverage for Pervasive Developmental Disorders

This Bulletin is directed to all insurance companies that issue accident and sickness insurance policies as defined in IC 27-8-14.2-1 and to health maintenance organizations (HMOs) as defined in IC 27-13-1-19. Coverage for Pervasive Developmental Disorders (PDD) is a very complex issue. In 2001, the Indiana General Assembly passed P.L. 148-2001 adding IC 27-8-14.2 and IC 27-13-7-14.7. These provisions increased insurance coverage for persons suffering with PDD from what was available in the insurance market at that time. As is often the case, the bill that was passed contained compromises from the bills that were introduced, debated and amended. After a bill is passed and the statute is implemented it is not uncommon for interested persons to continue to dispute the meaning of the final language. The Department of Insurance is charged with implementing the provisions of Title 27. The Department must implement the statutes as they are written, giving meaning to each word of the statute. This Bulletin is intended to provide guidance to insurers and to consumers on contract language and administration of claims for the treatment of PDD as required by IC 27-8-14.2 and IC 27-13-7-14.7.

IC 27-8-14.2-4 requires that a group accident and sickness insurance policy must provide coverage for the treatment of PDD of an insured. IC 27-8-14.2-5 requires insurers that issue individual policies of accident and sickness insurance to offer to provide coverage for the treatment of PDD. And, IC 27-13-7-14.7 requires an HMO that provides basic health care services to provide services for the treatment of PDD of an enrollee. Neither insurers nor HMOs can deny or refuse to issue coverage on, refuse to contract with, or refuse to renew, or reissue or otherwise terminate coverage on an individual solely because the individual is diagnosed with PDD.

A written treatment plan for each individual with PDD must be developed and signed by the treating physician. The treatment plan should be submitted to the insurer or HMO as soon as possible after its development to facilitate the payment of claims. If a non-physician recommends the treatment plan, it must be approved and signed by the treating physician. The Department of Insurance recognizes the insurer's or HMO's right to review the services prescribed under the treatment plan as to medical necessity. The insurer or HMO shall consult with the treating physician in its consideration of the treatment plan. Any challenge to medical necessity will be viewed as reasonable only if the review is by a specialist in the treatment of PDD. A specialist includes a clinical employee such as a medical director or PhD clinical administrator, provider or consultant of the insurer or HMO, and has specialized and current knowledge of PDD. Any challenge to medical necessity will be treated the same as any other grievance, following the grievance and appeals process as defined in IC 27-8-28, IC 27-8-29, IC 27-13-10, and IC 27-13-10.1.

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The treatment plan must include all elements necessary for the insurer or HMO to appropriately pay claims. These elements include but are not limited to: a diagnosis, proposed treatment by type(s), frequency and duration of treatment(s), the anticipated outcomes stated as goals, the frequency by which the treatment plan will be updated, and the treating physician's signature. The insurer must provide, in writing, its determination regarding coverage for the services and supplies prescribed by the treatment plan within thirty (30) days of the insurer or HMO receiving the treatment plan. The insurer or HMO shall provide specific contact information for provider or member questions and shall facilitate filing of claims. An insurer or HMO that fails to provide its determination on the treatment plan within 30 days may be subject to enforcement action under IC 27-4-1-4.5.

Recognizing that PDD is a neurological condition, services will be provided without interruption, as long as those services are consistent with the treatment plan and with medical necessity decisions. Service exclusions contained in the insurance policy or HMO contract that are inconsistent with the treatment plan will be considered invalid as to PDD. However, coverage of services may be subject to other general exclusions and limitations of the contract or benefit plan, such as coordination of benefits, participating provider requirements, services provided by family or household members, eligibility, appeals processes, and carved out services (e.g. if the employer elects not to provide pharmacy coverage for any employees). IC 27-8-14.2-4(b), IC 27-8-14.2-5(b) and IC 27-13-7-14.7(c) and (e) state that the coverage or services that must be offered "may not be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable to an insured than the dollar limits, deductibles, or coinsurance provisions that apply to physical illness generally" under the accident and sickness policy or contract with the health maintenance organization. This provision allows the insurer or HMO to apply dollar limits, deductibles, co-payments and coinsurance as long as the application is consistent with coverage for physical illness generally. The Department considers dollar limits and visit limits to be synonymous for the purposes of this bulletin.

It is the Department's position that behavioral therapies such as Applied Behavioral Analysis Services may not be subject to limitations that apply to therapies such as physical, occupational or speech therapy. Further, Indiana does not currently have a licensing requirement for persons who perform Applied Behavioral Analysis Services. It is, therefore, inappropriate at this time for an insurer or HMO to deny a claim based upon the fact that the provider of Applied Behavioral Analysis Services does not hold a license.

The insurer shall have the right to request an updated treatment plan not more than once every six (6) months from the treating physician to review medical necessity, unless the insurer or HMO and the provider agree that a more frequent review is necessary due to emerging clinical circumstances. The cost of obtaining an updated treatment plan at the request of the insurer or HMO shall be borne by the insurer or HMO. This review does not alter the requirements and rights described in IC 27-8-29, IC 27-13-10 and IC 27-13-10.1.

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It is important for consumers to review their insurance coverage. For persons covered by individual policies, insurers are required to provide the insured with a copy of their insurance contract. For persons covered by group insurance policies or HMO contracts, the insurer or HMO is required to provide a copy of the certificate or evidence of coverage. While the insurer is not required to provide each covered person with a copy of the group insurance contract it should be made available if requested.

The insurance policies and HMO contracts affected by this Bulletin are required to be filed and approved by the Department. As guidance to the companies the Department approves the following language in its entirety:

1. Pervasive Development Disorder means a neurological condition, including but not limited to Asperger's syndrome and autism, as defined in the most recent edition of the Diagnostic and Statistical Manual of Mental Disorders of the American Psychiatric Association.
2. Coverage for services will be provided as prescribed by the insured's treating physician in accordance with a treatment plan.
3. Any exclusion within the policy, certificate or contract that is inconsistent with the treatment plan does not apply.
4. The benefits for Pervasive Developmental Disorder will not be subject to dollar limits, deductibles, or coinsurance provisions that are less favorable than the dollar limits, deductibles, or coinsurance provisions that apply to physical illness generally under the accident and sickness insurance policy, certificate or HMO contract.

Any form in conflict with this Bulletin should be revised and filed with the Department. Policies, certificates, contracts, endorsements, or riders already approved for use may be used until the employer contract is amended, renewed, or terminated. However, the Department requires effective with the date of this Bulletin any insurer or HMO that is interpreting its policies more restrictively than the standards of this Bulletin shall adjudicate claims consistent with the provisions of the Bulletin. The Consumer Protection Unit of the Department encourages individuals to contact the Department with any concerns over the payment of claims. Each complaint will be reviewed individually for compliance with all applicable statutes.

INDIANA DEPARTMENT OF INSURANCE

Atterholt

James Atterholt, Commissioner

APS HEALTHCARE
Healthy Together

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 Autistic 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 tests/screening tools:
    a. Autistic 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 Development 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.

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Medical Necessity Authorization:

Medical necessity authorizations for services to be covered under the State Health Plan ABA benefit must be requested by ABA providers contracted with APS. Before providers initiate the authorization procedure, they may call APS to confirm that the member is in fact covered by the State Health Plan. (Providers will want to make sure the member is not covered under the other State Employee Plans, which are HMO's BlueChoice and CIGNA.) Providers may also obtain information on coverage specifics from APS, such as member's deductible and benefit plan. Most members have a "Standard Plan" with yearly deductible of $350 and reimbursement at 80% of contracted network fees, up to an out-of-pocket maximum of $2000. After the out-of-pocket maximum is reached, reimbursement is 100% of network fees through the end of the year. A small number of members have the "Savings Plan" (identified on their ID card) which has a deductible of $3000.

APS will advise the provider of authorization details, and letters will be sent to the provider and to the member/parents. All services under this benefit must be rendered on or after January 1, 2009.

All documentation of eligibility requirements must be submitted by the ABA provider to APS for review for authorization. The first authorization will be for an initial assessment by the ABA provider for the purpose of development of the ABA Treatment Plan. After the initial assessment takes place and the ABA Treatment Plan is finalized, the ABA provider will request authorization from APS for parent/primary caregiver training and for recommended ABA therapy in six month increments.

Contracted providers will file claims to APS for ABA services, and reimbursement will be made directly to ABA providers in accordance with pre-authorization(s). Reimbursement to ABA providers will be at contracted network fees, minus deductibles and coinsurance. ABA providers may ask for payment of patient liability (deductible and 20% co-insurance) at the time of service. APS reimbursement will be limited to $50,000 for total ABA services per member per year, in accordance with medical necessity authorizations.

Medical Necessity Criteria:

1) In order for services to be considered medically necessary they must:
    a. Be for the purpose of diagnosis or assessment or treatment;
    b. Be identified as part of a written Treatment Plan;
    c. Include therapeutic goals which address cognition, behavior, communication, or social interaction skills;
    d. Be directed by a provider credentialed by and contracted with APS Healthcare;
    e. Meet all of the following:
        1. Be able to be coordinated with the member's Individualized Educational Program (IEP) if applicable;
        2. Have a specific plan for generalization to the member's home environment;
        3. Target observable, recordable, and measurable behaviors;
    f. Be implemented by trained behavioral staff.

2) In order for previously authorized services to be considered medically necessary on an ongoing basis they must:
    a. Demonstrate documented improvement over baseline and most recent measurement of targeted behaviors; and
    b. Begin being provided within sixty (60) days of being authorized; and
    c. Be provided with at least sixty percent (60%) of the frequency indicated in the written Treatment Plan; and
    d. Demonstrate that the parents/primary caregivers have been trained in all interventions identified in the written Treatment Plan, and actively involved in the member's Treatment Plan as evidenced by attendance at all team meetings and being present at scheduled therapy sessions to the extent recommended by the BCBA provider. The written Treatment Plan must include a section outlining a plan for parental/primary caregiver participation.

Questions may be directed to State of South Carolina APS Customer Service at 800-221-8699.

Revised 1/06/09

APS HEALTHCARE
Healthy Together

EXHIBIT 1
FEE SCHEDULE – Autism Spectrum Disorder Program
Under Utilization Management Products (South Carolina State Health Plan)

I. FEES

ABA is a covered benefit when provided and directed by a credentialed and contracted APS provider. Services eligible for reimbursement include periodic evaluation of the member, development of a written treatment plan, oversight of the written treatment plan, direct supervision, training of parents/primary caregivers to implement services in accordance with the treatment plan, and "hands on" or "line" therapy ABA services provided by behavioral health staff under the direction of the authorized BCBA provider.

APS will not pay for "hands on" or "line" therapy ABA services when provided by family members or other individuals who are not APS authorized providers.

Services must be directed and provided by an APS authorized provider on an outpatient basis and rendered in the member's natural environment. This includes services provided at home, at school unless educational in nature, or other locations suitable for the type of services being rendered.

Reimbursement for ABA services will be paid at a per diem rate to the APS provider that is directing the care. The per diem rate is inclusive for all ABA services including oversight, direct supervision, "hands on" or "line" therapy by behavioral staff, parent/caregiver training and periodic treatment plan review.

Reimbursement for ABA services will only be paid directly to an authorized BCBA provider. The BCBA provider is responsible for reimbursing all staff under their supervision.

Reimbursement for assessment for the purpose of development of the initial and annual treatment plan, and reimbursement for training are not included in the per diem rate and may be billed separately.

II. DEFINITIONS

In addition to the definitions set forth in the Agreement, the following definitions shall have the meaning ascribed hereto for the purposes of this Exhibit:

1.1 **"Usual and Customary Billed Charges"** means the reasonable and customary fees charged by Independent Provider which do not exceed the fees Independent Provider would charge any other person regardless of whether the person is a Covered Individual.

1.2 **"Utilization Management Product"** shall refer to Benefit Plans under which Affiliate Payor has contracted with APS solely for access to APS's Utilization Review services and/or network of Participating Providers.

III. REIMBURSEMENT RATE FOR UTILIZATION MANAGEMENT PRODUCTS

Reimbursement for the initial contract period to Independent Provider for Covered Services rendered to Covered Individuals, will be paid in accordance with the terms of this Agreement and the applicable Utilization Management Product, at the fee schedule set forth below, or Independent Provider's Usual and Customary Billed Charges, whichever is lower.

RATE	CPT CODE	DESCRIPTION
$116	99345-initial evaluation	This is the hourly rate for the initial assessment for the purpose of development of the initial treatment plan. Service will be authorized and reimbursed by the hour, with eight (8) hour standard maximum. The number of hours filed will be reflected in the Days/Units field of the claim form, and must correspond to the hours authorized.

$212	99347-initial training	This is the hourly rate for the initial parent/primary caregiver training. Service will be authorized and reimbursed by the hour, with eight (8) hour standard maximum. Exceptions for additional training will be granted on case-by-case basis. The number of hours filed will be reflected in the Days/Units field of the claim form, and must correspond to the hours authorized.
$207	99343	This is the daily rate for ABA services rendered at more than six (6) but not more than eight (8) hours per day, a maximum of five (5) days per week. This rate includes oversight, direct supervision, "hands on" or "line" therapy by behavioral staff, parent/primary caregiver training, and periodic treatment plan review.
$186	99342	This is the daily rate for ABA services rendered at more than five (5) but not more than six (6) hours per day, a maximum of five (5) days per week. This rate includes oversight, direct supervision, "hands-on" or "line" therapy by behavioral staff, parent/primary caregiver training, and periodic treatment plan review.
$165	99341	This is the daily rate for ABA services rendered at more than four (4) but not more than (5) hours per day, a maximum of five (5) days per week. This rate includes oversight, direct supervision, "hands-on" or "line" therapy by behavioral staff, parent/primary caregiver training, and periodic treatment plan review.
$144	99344	This is the daily rate for ABA services rendered at up to four (4) hours per day, a maximum of five (5) days per week. This rate includes oversight, direct supervision, "hands-on" or "line" therapy by behavioral staff, parent/primary caregiver training, and periodic treatment plan review.

CPT codes 99344, 99343, 99342 and 99341 represent four separate levels of care. At the time of authorization for each Covered Individual, the level of care (and corresponding CPT code) will be determined according to the number of treatment hours that are authorized. In order for claims to be reimbursable, they must be filed with the CPT code established at the time of authorization.

II. COMPENSATION PER CLAIM

The Compensation Per Claim payable by APS to Independent Provider, subject to the terms of this Agreement, the applicable Benefit Plan and corresponding Coordination of Benefit terms, shall be equal to:

A. The Reimbursement Rate for Utilization Management Products

B. <u>Minus</u> any applicable Copayments, Coinsurance and/or Deductibles

Independent Provider agrees that Covered Individuals shall not be billed for amounts in excess of the Deductibles, Copayments, and/or Coinsurance provided for in Covered Individual's Benefit Plan.

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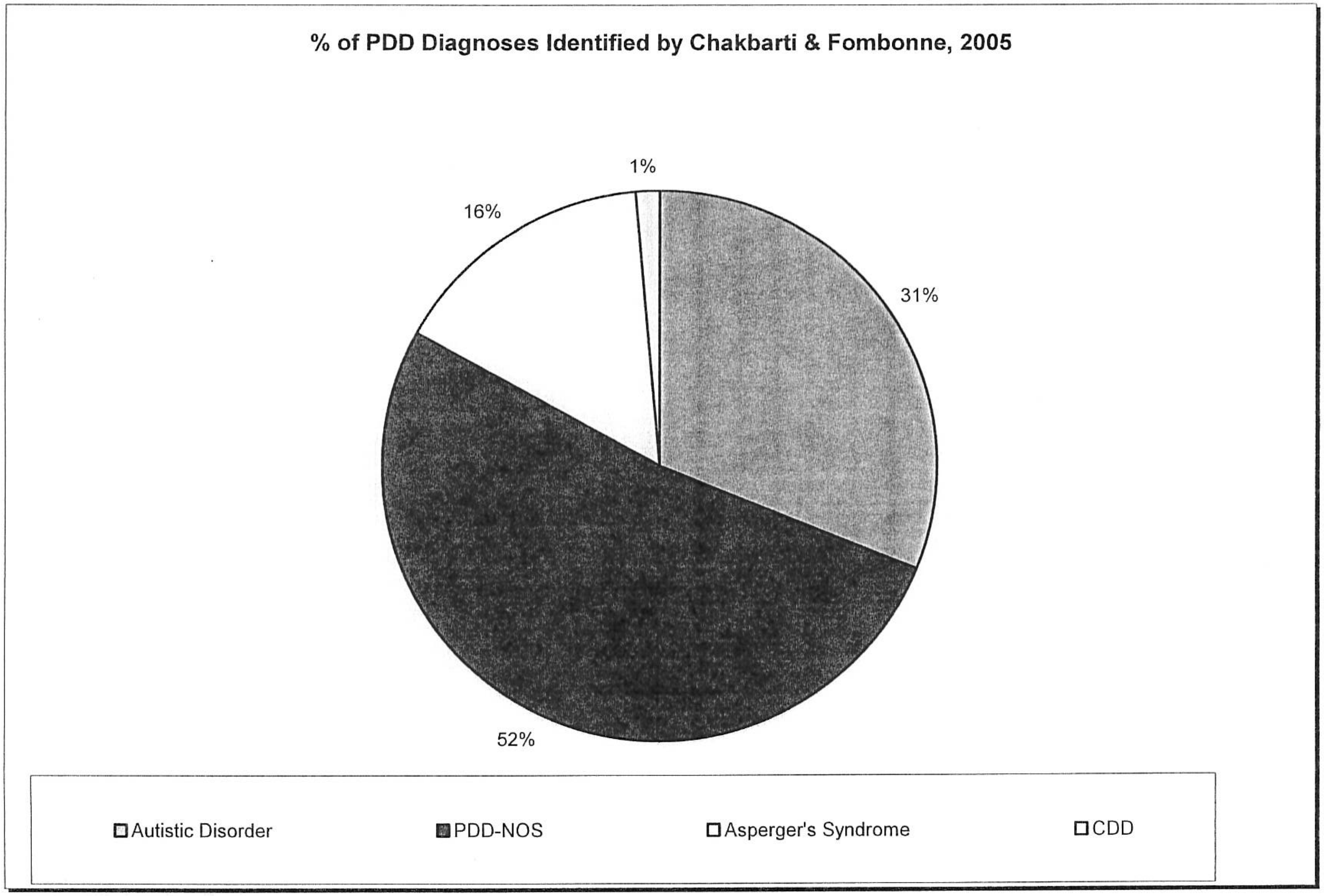
How Many Individuals are Diagnosed with Each Type of PDD?



Note: In this study, no individuals with Rett's Disorder were identified, suggesting a prevalence rate of < 1:10,000.

Consumer Information

Welcome to BACB.com, the web site of the Behavior Analyst Certification Board (BACB). We will use the page you are viewing now as our primary means for communicating news and information to consumers, and we invite you to check here often for new postings.

12/2008 **Board Certified Behavior Analyst-Doctoral** The BACB Board of Directors is pleased to announce the development of a new credential for qualified Doctoral-level Board Certified Behavior Analysts. BCBAs with doctorates should click here for additional information and application.

9/2008 **APBA Membership** The BACB has become an organizational member of APBA. The BACB's membership includes the option for you to be an APBA member. If you do not wish to be an APBA member, feel free to click here to opt out of APBA membership. You may opt back in at any time by sending an email to christine@bacb.com or by visiting the BACB's online certification management system and adding APBA to the list of organizations in your profile.

7/2008 **New BCaBA Supervision Procedures** The BACB has posted new procedures for implementing of supervision of BCaBAs by BCBAs. Supervision & documentation requirements will begin January 1, 2009. Click here for a document specifying the requirements and supervision reporting form.

6/2008 **New Professional Disciplinary Standards** The BACB will be implementing new Professional Disciplinary Standards effective 01/01/2010. Click here to view the new Standards.

11/2007 **Association of Professional Behavior Analysts** The BACB is pleased to provide the following two documents for your information: a unified statement of mutual support between three major behavior analysis organizations, and an announcement containing details on a new organization that will provide support for BACB certificants.Click here for the documents.

9/2007 **NCCA Accreditation** The Behavior Analyst Certification Board's BCBA and BCaBA credentialing programs are now accredited by the National Commission for Certifying Agencies in Washington, DC. The NCCA is the accreditation body of the National Organization for Competency Assurance.

8/2007 **Autism Task List** The BACB has decided not to pursue a credential in autism at this time, however valuable information regarding content for BCBAs working with persons with autism was obtained as part of the exploratory process. The BACB is releasing this information in the form of the *BACB Task List for Board Certified Behavior Analysts Working with Persons with Autism©*. Please click here for the Task List and click here for information on the exploration of an autism specialty.

8/2007 **Board Certified Associate Behavior Analyst** Effective January 1, 2009, individuals certified as Board Certified Associate Behavior Analysts will be certified as Board Certified Assistant Behavior Analysts and must document supervision by a BCBA. Please see newsletters for more details.

7/2007 **US Department of Defense Autism Report and Plan**The BACB provided information to the DoD to help DoD develop a report and plan of services for military dependent children with autism. This report and plan supports applied behavior analysis (ABA) and the BACB credentials. Please click here to view the report.

06/05 **Continuing Education Requirement**

Effective July 1, 2008, certificants recertifying must present 3 continuing education hours in ethics and professional behavior. Details will be posted when they are available.

06/05 **Test Administration Process**

Pearson VUE will administer BACB examinations in a computer-based format at its 200+ US and 150+ international sites. The BACB plans to test 3 times a year, by appointment, within 2-week windows.

06/05 **Supervisor Requirement**

All experience begun after September 1, 2006 to qualify individuals for certification examination must be supervised by a BCBA. Details will be posted when they are available.

03/05 **Consumer Representative Elected to the BACB Board of Directors**

Jennica Nill has been elected by the BACB Board of Directors to serve a second term as the Consumer Representative Director on the Board of Directors.

03/05 **Experience Standards**

New Experience Standards for qualification of individuals to take BACB examinations are posted with phase-in policy to be posted soon.

Please click below for the following:

- Certificant Registry This page allows visitors to find certificants by their last name, city, state (US), country (international), or to enter a zip code & mile radius to find up to 100 certificants, within the mile radius, closest to that zip code. Visitors may email individual certificants.
- Info on the Behavior Analyst Certification Board
- Registry of BCBAs and BCaBAs
- Universities with BACB approved course sequences
- Standards for becoming a BCBA or BCaBA
- Task Lists with content included in BACB exams
- Information on the pass rate of BACB examinations
- BACB *Guidelines for Responsible Conduct*
- Disciplinary Standards and Consumer Complaints
- Work Experience roles of BCBAs and BCaBAs
- Certification References

If you do not find the information you need on these pages or on the rest of this site, please click here to send us an email with your question or comment.

Thank you for your interest in the Behavior Analyst Certification Board.
Gerald L. Shook, Ph.D., BCBA
Chief Executive Officer
Metro Building - Suite 102
1705 Metropolitan Boulevard
Tallahassee, Florida 32308-3796

Comments?
Concerns?
Help us improve by giving your feedback

Written Testimony to
House Insurance Committee
Regarding HB # 2367 - Kate's Law

Estimating the Cost of Doing Nothing

As stated in the final report of the Kansas Autism Task Force, there is now conclusive evidence that early intensive intervention can substantially reduce the disabling effects of autism. The best estimate of this reduction with those receiving two years of intensive intervention is that 50% of those receiving these services are able to enter regular education without requiring an IEP. It is estimated that the lifetime cost savings for just one individual could be as much as $4 million in tax dollar funded services.

To understand the impact of not addressing this tragic disorder head on, we look at the adult DD system in Kansas which supports over 7,500 individuals. It has been estimated that under current diagnostic standards over one in three of these individuals would now be considered to be on the autism spectrum. With early intensive intervention, half of these individuals would not require State funded services. This represents an unneeded cost to the state of $45 million dollars! When the human cost is added to this calculation and unnecessary public treasury, the urgency of requiring a solution is apparent.

This issue must not be clouded by deflection of responsibility to schools or families. Nor can the response rely solely on the Medicaid waiver which is 100% tax dollar funded. Kansans must be able to count on health insurance that covers an established best practice for the treatment of a serious medical condition.

Thank you for your consideration.

Bill Craig, PhD.
Chair, Kansas Autism Task Force

House Insurance
Date: 3-19-09
Attachment # 4

Good afternoon. My name is Kathy Ellerbeck, and today I'd like to speak to you not only as a member of the Kansas Autism Task Force but as a developmental pediatrician and member of the American Academy of Pediatrics.

Autism is now recognized by the medical community as a complex neurobiological disorder. There is substantial evidence for multiple underlying genetic causes that result in abnormal brain development and the symptoms that we use to diagnose autism. Genetic testing is indicated in all children who meet criteria for ASD – and we're getting better at pinpointing causes and counseling about recurrence risk.

Still – right now, there is no blood test or neuroimaging test for autism. If it were only that simple! Autism remains a diagnosis based on a set of impairments and behaviors. Children with autism spectrum disorders all have some impairment in social interaction and communication as well as restricted or repetitive behaviors. Yet – we say in all seriousness – you see one child with autism – you've seen one child with autism. The diagnosis is difficult – particularly in very young children.

So – why bother? Why look for it early? Why do we need insurance companies to reimburse primary care physicians for screening for autism? Why do we need insurance companies to pay for definitive diagnosis and treatment?

There is urgency to early diagnosis because early diagnosis drives appropriate early intervention – and that appropriate early and intensive intervention *matters.* There is increasingly good evidence that early intervention changes brain circuitry. There is strong evidence that early intervention results in better functional outcomes.

And that is why in 2007 the American Academy of Pediatrics published new guidelines for the identification and management of children with autism spectrum disorders. Pediatricians are to do universal screening for autism at both 18 and 24 months. Children who fail screening need to be referred for diagnosis and for early intervention services. In medicine – when we adopt screening tests – we do so with the belief that screening results in action – and that action reduces the symptoms of disease. The science is there – the policy needs to be.

Why do the AAP's guidelines recommend a team of specialists with expertise in autism spectrum disorders? Why can't pediatricians do the diagnosis? There is no perfect screen for autism spectrum disorders –screening sometimes picks up other problems. Before assessing the child's behaviors and communication, the pediatrician needs to know the child's level of functioning. He or she needs to look at play and at measures of social interest and ability. This kind of assessment requires standardized tools that take considerable time and training to administer.

Inadequate insurance coverage costs children and their families at every turn. In the primary care physician's office - pediatricians often have difficulty getting reimbursement for screening for developmental disorders. And then, if a child screens positive – there are not adequate

House Insurance
Date: 3-19-09
Attachment # 5

resources for timely definitive diagnosis. And even after a child is diagnosed, in many parts of Kansas – particularly for young children – there is not adequate funding for treatment. The lack of resources for both diagnosis and treatment are directly related to lack of payment. After referral to the CCHD for definitive diagnosis, more than a third of claims are denied because autism is a non-covered condition – or because insurance companies don't understand or support the interdisciplinary team diagnostic model. Genetic tests – important for both prognosis and family planning are often denied. Claims for the medication management of comorbid symptoms are denied if "autism" is the primary code. And almost always – claims for treatment are denied.

I've been a developmental pediatrician now for more than 10 years. I watched some of the children diagnosed with autism as toddlers "grow up". Families who have means sometimes pay thousands of dollars for diagnosis, and tens of thousands of dollars for intensive behavioral treatment. Many of the children I see who get that type of treatment in the first years of life go on to regular classes. Some children improve so much with treatment that they lose their diagnosis. Many do not – but almost all children who have autism can learn new ways to engage in the world...they will live more independently and will be more productive – a good thing for families and for the rest of us. But so many families can't pay for diagnosis or for effective intervention....if it were your child – could you? Should you have to? The children of families without adequate insurance often get very little and what they get is often very late.

Insurance can't pay all costs for a child with autism – but **autism is a medical condition** – and treatment changes the biology – so insurance companies should certainly bear some responsibility. I see it as a matter of social justice – other neurological disorders are covered – autism should not be excluded. I want to imagine a world where all children are screened for autism at 18 and 24 months – and if they fail the screen – are evaluated and diagnosed within one month. And after they are diagnosed – that child receives state of the art autism treatment. And as that child grows up – autism won't be "held against him" in the health care system. He or she will be able to receive needed evaluations, and if necessary, medications for symptoms associated with autism.

I hope that you can imagine that too. Please support Kate's Law.

TESTIMONY BY JOE FIORELLA
March 19, 2009
Senate Committee – HB 2367

I. Introduction

- My name is Joe Fiorella. Thank you, not only for the opportunity to speak today but also, for allowing the presentation of this very important issue.

- I cannot begin to convey what I and other parents have had to go through. This afternoon, I'd like to share with you with just some of the obstacles I faced trying to secure prescribed therapy for my son, Michael.

- What is hard to comprehend is not the magnitude of the obstacles but the fact that many parents encounter similar obstacles routinely.

II. Abbreviated Claim Chronology

- Even though we were devastated by the diagnosis, I immediately contacted my insurer to identify an in-network provider solely for speech and occupational therapy. There was never a question about the ABA - out of my pocket.

- For the next month and a half, I responded to many requests for authorization. I continued to attempt to comply but the insurance company continued to request information.

Abbreviated Chronology

- August 18, 2003 - Diagnosis
- October 21, 2003 – Claim was denied. (2 months after diagnosis)
- November 6, 2003 - Submitted extensive appeal of the denial for speech therapy to Complaints and Grievance Unit.
- December 3, 2003 - Received letter denying the appeal and upholding the initial decision.
- February 19, 2004 - Submitted appeal for the denial for speech therapy to Second Level Appeal.
- March 18, 2004 - I attended the hearing at the insurer's office with my son.
  - They gave me an opportunity to speak but did not ask me one question.
  - I shared with them the existence and qualifications concerning the Kansas Mental Health Parity Act. They stated they were unaware of any such act. They were in fact, registered lobbyist against this Act.
  - During this hearing, they conferenced in an outside team of independent physicians. These physicians stated

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1. The insurer's medical policy was not in synch with the current standards of medical care.
2. The case warranted approval of the claim and therapy.
3. The lead person for the peer review indicated that the recommendations presented were unanimously supported by all three of the physicians participating.

We thought our nightmare was over until

- ➢ March 25 – despite the findings and recommendation of the physicians they hired, the denial was upheld.

Now this is the point in which others may need some insight - While unjust, my family was in crisis. We focused on the care of my son paying substantial claims out of our pocket.

- December 14, 2004 - I requested the assistance of the Kansas Department of Insurance. (Almost a year and ½ after the diagnosis)

- January 28, 2005 - The KDOI finds that BCBS's position to deny services is not justified.

- March 15, 2005 – Insurance company

  "Mr. Fiorella is asking that we cover speech therapy for his son, Michael, who has been diagnosed with autism. ***In this case*** [emphasis added] we will approve Michael's speech therapy."

At this stage, we again thought our nightmare was over. SECOND TIME

- Now the fun really starts. Once the KS DOI ruled, the insurer started an **endless request for information to process the claims – medical records, procedure codes, diagnosis codes, Tax ID numbers and multiple licenses of the therapists all of which were previously supplied multiple times by both me as well as the providers themselves.**

- All communication was sent certified registered mail as they often ignore communication or filings of claims.

- We now begin extensive communications repeatedly asking and receiving the same information. Additional communications dated

  April 7, 2005　April 26, 2005　April 28, 2005　May 10, 2005
  June 14, 2005　July 1, 2005　July 13, 2005　July 26, 2005
  August 13, 2005 (from insurer KS DOI "I have closed my file on this case".
  August 16, 2005　August 18, 2005 (2 years frm diagnosis)
  September 19, 2005

- An attorney assisting me with the issue cautioned me that I should anticipate correspondence that excessively and unnecessarily restated the contract terms.
  - September 26, 2005 from BCBS (70.9% was verbatim disclosure of contract)
  - November 21, 2005
  - December 5, 2005 – six pages of communications. The bottom of the first page states "The contract reads:" followed by five pages of contract terms including the highlighted reference "speech and hearing therapy must be Approved in Advance by Us."

- Late December, 2005 – I received a voicemail message from insurer's medical review unit asking the same questions that were asked in September of 2003.

- April 11, 2006. Again I sought the assistance of the KDOI. In my written communication, I referenced 11 (eleven) well documented violations to included:
  1. has repeatedly asked for the same information that had been previously submitted by both the provider and me several times, many of which via certified mail.
  2. sequentially asked for additional information once requested information had been received.
  3. carefully crafted wording such that compliance was not achievable regardless of the repeated attempts to supply the required information.
  4. conveyed untrue and certainly misleading comments.
  5. failed to properly acknowledge the receipt of claims nor did they appropriately deny selected charges.
  6. did not handle claims according to federal and state regulations.
  7. often referenced their certificate. Yet when countered on certificate language, they either failed to respond or were unable to locate an exclusion.
  8. violated K. S. A. 40-2442
  9. processed charges inconsistently.
  10. blanketedly denied charges due to autism
  11. reversed authorization after providing approval for service.

In the written request of the KS DOI, each of these issues was individually addressed and supported.

- **FURTHER TO A GREATER ISSUE, IT IS NOTED THAT THESE CHARGES WERE PROCESSED RIGHT UP TO THE DEDUCTIBLE AMOUNT. ONCE THE DEDUCTIBLE WAS MET, THEN ADDITIONAL INFORMATION OR QUESTIONS CAME INTO ISSUE THAT WAS INCONSISTENT WITH THE PRIOR PROCESSINGS.**

No it's not over – separate from any therapy issues. Claims for non-autism issues were challenged.

A. Item 1

- April 5, 2004 - submitted written diagnosis and therapy orders from BCBS approved orthopedic surgeon for physical/aquatic therapy. Included was both written and coded diagnosis of "Muscle Contractures (728.85)" and "Abnormal Gait (781.2)".

- April 8, 2004 - received written approval for evaluation and 4 physical/aquatic therapy visits.

- May 18, 2004 – More than a month later, we received a letter from BCBS rescinding the earlier approval.

- May 24, 2004 – initiated appeal process.

- May 24 through June 1, 2004 – several conversations with BCBS which indicated among other issues that aquatic physical therapy is not an approved physical therapy. Received email from owner of therapy company stating:

  > "FYI regarding aquatic PT. There is no longer any distinction made with insurance companies between aquatic and land-based physical therapy, especially as it relates to children."

  This was later confirmed by BCBS.

- May 24, 2004 - conversation with owner of physical therapy company. She conveyed that the condition is not related to autism but that they "clearly have a red flag" on Michael's file.

- May 27, 2004 - called insurer's customer service. WAS TRANSFERRED SEVEN TIMES. First talked to "Nicole" said that the denial was because while physical therapy is approved, aquatic therapy is not covered under our plan. I had a copy of our cert and asked her where that exclusion was located. After considerable time, she responded "I'm not seeing it". Nicole apologized and said she could not find any reason why this was denied and transferred me to the medical review department. Who transferred me, who transferred me and so on. On the second to last transfer, the person said "let me transfer you to the department that handles this." I questioned, "you're not transferring me back to customer service are you?" She responded, "no sir". Again on hold before reaching a live operator. When I explained the situation again, I heard the response 'Joe, this is Nicole. You talked to me about an hour ago." Same conversation, she apologized and gave me the direct fax number to file an appeal with the Complaint and Grievance Section of the Medical Management area.

- June 2, 2004 - received callback from May 24th fax. (Diana in Medical Management) Said they would mail form to appeal. Explained that the physical therapy had nothing to do with autism diagnosis. She basically conveyed that I had to prove it. Told her that I would as the prescribing doctor had conveyed this.

- June 11, 2004 - submitted appeal. Included a comprehensive report by physical therapists. Also included was a separate letter from prescribing physician (MD) addressing the issue in detail and further stating "Please take all consideration possible in allowing the providers to address Michael's non-autistic needs…"

- June 17, 2004 – letter informing that "the initial denial will be overturned".

B. Item 2

- On a Friday before a Monday appointment with his developmental pediatrician, we received Attachment 14 in the mail from them asking we sign a document stating:
    - ➢ The provider was notified that our insurance policy did not cover services and that we had to sign and agree to the statement that we would have to pay the discounted rate of $192.75 for simply a periodic office visit checkup. Now keep in mind that this was an in-network provider.

    - ➢ ***When I called the provider and talked to the individual responsible for sending the notification, he stated that he received a call from insurer who without a request, proactively notified him they would not cover any services. He apologized and said he did not understand but had no other choice.***

    - ➢ My wife was panic stricken and this event triggered a cascading gloom over our ability to provide care to our son.

    - ➢ Several calls to insurer did not resolve anything. Multiple customer service reps either said they didn't know why it wouldn't be covered or that it wouldn't be covered because the diagnosis was autism.

    - ➢ What has grown to be the usual case, we decided to pursue what was in our child's best interest even if we had to pay 100% out of our pocket.

    - ➢ Ultimately, we went to the appointment and I finally reached the individual claiming to have initiated the contact with the provider. She stated that the provider simply misunderstood and that insurer would not pay for the study which would yield the diagnosis. I questioned her why this would come up when he already had a diagnosis and that was a year and a half earlier. She responded that she simply was making it clear to the provider (who also generated the diagnosis).

    - ➢ I called the provider back to update the individual who sent the demand letter and shared with him the logic of the communication. He thanked me for the update but stated that he did this every day and recalled the conversation very clearly and that he did not misunderstand.
- Summer of diagnosis – proactively requested providers. From the list of approved list, I contacted no less than 20 different providers. Not one had more than an occasional session with a child diagnosed on the spectrum. In more than one case, a

provider in their network not only told me they had no experience with autistic children but they refused to work with an autistic child.

- I later discovered why this was the case. Providers with experience involving children on the spectrum were not in the network as they were never reimbursed by the insurance company. They would provide any information but the standard position was get paid up front and leave any handling of the insurance to the parents (insureds).

- I was advised very early in the process that insurance companies will simply wear you down by endless requests for information and will create every possible reason not to pay the claim. For that reason, no providers will work with them but will insist for payment directly from the family. Further, they will provide little if any support in the processing of the claim as there is a belief that no money will ever be paid. For that reason, therapists with relevant experience will not only not work with them but certainly will not even apply to become an in network provider.

III. <u>Officer of an Insurance Organization</u>

- I will share with the committee that at the time of the diagnosis and throughout the chronology of the claims presented , I served as the Chief Operating Officer of a health insurance organization which developed, sold and serviced only fully insured plans.

- Due to the financial and emotional drain, I share the issue with the owners & board. Our course plans and adjudication process had no such exclusion or handling of claims from children on the spectrum.

- They were dumbfounded not only at the handling, but also that a medical condition could be excluded.

- More common than pediatric cancer, diabetes, and AIDS combined.

- They the General Counsel to assist me on the issue.

IV. <u>Small Group Employer</u>

- Three years ago, I was recruited to be the Chief Operating Officer of a small, entrepreneurial company. My first charge from the owner/chairman was to secure health insurance benefits.

- While the health condition of the employees and their families is governed as Protected Health Information of (PHI), I knew that at least 3 of the 20 employees or 15% or the workforce had children diagnosed on the autism spectrum.

- Yet despite this fact, the group was fully medically underwritten and issued at the lowest possible rate.

- Now the company has grown several times as is now excluded from small group rate cap. However, this group has been renewed several times with the lowest possible rate increase. In essence, despite the inordinate frequency of autism, the claims expense is very favorable.

V. Closing

- Today I share with you not just my story, but common issues many parents of autistic children have repeatedly encountered.

- The Corrigan Report referenced in the impact report confirms:
  1. that the experiences I encountered are not isolated.
  2. That even after taking an insurance company to court or in a state ruling, the insurance company still did not pay.
  3. It even references the same act I presented to my insurance company and the KDOI.

- Dad & cancer. Imagine if care of one of your family was excluded from coverage of because there was some question that it would increase insurance costs.

- I ask you to advance Senate Bill 2367 not only for those children afflicted but for all Kansas taxpayers.

- Thank you.

House Insurance Committee March 19th 2009

Testimony in Support of HB 2367 "Kate's Law"

My name is Stuart Jackson, and I am the parent of a child with autism. My son Joshua is five years old and is on the severe end of the autism spectrum.

I am the President and CEO of AnalyzeDirect, Inc., a medical imaging software company that provides research solutions for scientists and physicians in universities, medical centers, pharmaceutical, biotechnology and medical device companies. Although we are a small company, we have a very wide reach, with customers in over 75 countries around the world. We have a very strong emphasis on exporting, and because of my company's experience in this area, I recently worked with the Kansas Department of Commerce Trade Development Division to help coach other small companies on how to effectively market to international customers.

In the ten years since I formed the company, I have personally been involved in all discussions regarding our benefits packages. As a result of this I have considerable experience in negotiating with health insurance companies to obtain the best policies for my employees. I would like to address the impact of HB 2367 "Kate's Law" on small to medium sized businesses.

You may hear the following arguments from those opposed to HB 2367:

a) Legislation such as Kate's law will increase health insurance premiums substantially

b) Rising premiums will force companies to stop offering health insurance to their employees

c) Rising premiums will cause more small companies to go out of business

d) Health insurance is the No. 1 concern of businesses today.

e) 5,500 Kansans lose their insurance for each 1% increase in premiums.

While this is powerful testimony, it is all incorrect or misleading.

Kate's Law will not dramatically increase insurance premiums

Eight states have enacted legislation similar to Kate's Law. In these states, the increase in insurance premiums attributed to covering the diagnosis and treatment of autism has been estimated to be less than $48 per year. Actuarial studies performed by Autism Speaks back up these numbers. This should not impact the ability of a viable business to provide health insurance coverage to its employees. Additionally, while Kate's Law would apply to small businesses by default, businesses with less than 50 employees may "opt out" of the coverage required by this legislation. Despite the high premium increases quoted by opponents to Kate's Law, no actuarial studies have been produced by them to back up their numbers.

Kate's Law will not force companies to stop offering health insurance

Health insurance premiums increase every year *regardless* of any new policy updates such as Kate's Law, and this *does not* generally cause companies to cancel healthcare coverage for their employees.

In a recent survey of 30 small to medium sized companies in the Kansas City Metro area, with revenues between $1m and $25m, CEO's were asked about health insurance in their companies and how they managed the annual renewal process.

- The top three reasons cited for offering health insurance were 1) employee recruitment, 2) employee retention, and 3) "it is the right thing to do".
- During the annual policy renewal process,
    - 23% of the companies reported proposed rates increases of 6% – 10%
    - 30% reported proposed rates increases of 11% - 15%
    - 33% reported proposed rates increases of 16%- 25%
- 90% of the companies changed health insurance companies at least once during the previous five years, and 51% had changed companies twice or more during the same period.
- None of the companies had cancelled health coverage in response to insurance premium increases.

This last point makes good sense, especially when combined with the reasons these companies provide health insurance. If companies want to attract and retain employees, they generally have to provide good health insurance as part of an acceptable benefits package, in the same way that they generally have to provide a decent salary, hourly wage or incentive based compensation.

Kate's Law will not force companies out of business

According to the National Coalition on Healthcare, all companies faced an average premium increase of 5% in 2008. Smaller companies faced an average premium increase of 6.8%. Although burdensome, there is no evidence to suggest that these health insurance rate increases increase the likelihood that a company will fold. Savvy company owners will simply not allow these rising costs to put their company out of business.

The argument could be made that for companies already under severe financial stress caused by the recent economic downturn, a health insurance premium increase such as that created by Kate's law, will push them over the edge and force them out of business. In reality, for companies in this situation, even if the insurance company were to somehow provide a health insurance policy completely free of charge for the next 12 months, the company would still go out of business. When health insurance rate increases can make a company go under, that company has significantly more problems than health insurance.

Health insurance is not the number one concern of businesses today

While health insurance is an important expense for many companies, in 2009 it can hardly be ranked as the number one business concern. In the survey of Kansas City companies referenced above, 26% of companies said that health insurance did not rank in their top ten concerns. 49% of companies ranked health insurance from number 5 to number 10 of their top ten business concerns. Not a single company ranked health insurance as its number 1 concern.

5,500 Kansans do not lose health insurance for each 1% of premium increase

Despite requests to insurance lobby organizations, the study which quotes the statistic "for every 1% increase in premiums, 5,500 Kansas lose health insurance" has not been forthcoming. The same statistic has been given in many states considering legislation similar to Kate's Law, and does not take into account differing overall populations or the size of the labor force in each state. In the absence of further information from the insurance lobby, we can make some assumptions as to how this statistic is calculated. In the NFIB study "Price Sensitivity in Health Care: Implications for Health Care Policy", the section on "Employee Premium Contributions and Take-Up Rates" quotes a study by Cutler (2002) on take-up elasticity. The study focuses on employees who are eligible for healthcare coverage within their company, but decline to accept the offer. The study quotes that for every 1% increase in employee premium (even though the plan is largely subsidized by the employer), a very small number of employees will voluntarily opt out of the plan and prefer to keep the money they would have contributed. The fraction of the workforce who voluntarily opt-out in this way is 0.0009, or 0.09 of 1% of the work force. This fraction can be applied to the US population and divided by the number of states to arrive at the "5,500 Kansans" figure. While we currently do not know the basis of the analysis, if this is indeed the method used to arrive at this statistic, it provides an incredibly misleading piece of testimony.

The real reason for rising premiums

Healthcare costs are of course increasing, primarily due to rising spending on prescription drugs, hospital care and the use of new medical technologies. Despite the increases in underlying costs, the health insurance industry is phenomenally successful. Over the past three years, revenues for the top 5 publicly traded health insurance companies have grown on average by 43%, while profits have grown by 49%. In 2007, these five companies generated profits of over $9 billion on revenues of $156 billion. Mergers and consolidation have reduced competition to the point where employers generally only have choices between a small number of mega-companies.

In the recent publication "Too Great a Burden: America's Families at Risk" published by Families USA, the growing advantage of the health insurance industry was stated as follows:

"A 2007 study found that there were more than 400 insurance company mergers in the last 12 years, resulting in near-monopoly power among insurance companies. In nearly two-thirds of major metropolitan areas, a single insurance company controls at least half of the market, and in 96 percent of metropolitan areas, a single insurer controls at least 30 percent of the market...**The near-monopoly power of insurance companies, coupled with little or no regulation of insurers, is a prescription for rising premiums**... Without appropriate consumer protections and rules to govern the influence and growth of large insurers, premiums are likely to continue their rapid ascent."

The bargaining advantage of the insurance companies is evident during the annual renewal process that all companies experience, in which double digit proposed rate increases are commonplace, as outlined in the results of the survey of Kansas City companies referenced above.

In my experience, it is very difficult to negotiate down a proposed rate increase, and insurance companies would rather lose you to a competitor than compromise on the new rate. One of the possible reasons for this is that they have a good chance of earning back your business during future renewal periods as there are so few competitors in the industry. While inconvenient for employer and employee alike, the ability to bounce from one insurance provider to another is one way that small companies can control health insurance costs.

In conclusion, experience in other states has shown that the health policy changes proposed by Kate's Law will have only a minimal impact on raising health insurance premiums. Premiums will however, continue to rise for employers, partly due to underlying health care costs, and partly due to insurance company practices during renewal. Despite this, small to medium sized businesses will not go out of business due *primarily* to rising health insurance costs, and will continue to offer good health insurance coverage for their employees.

I'd like to thank Representative Clark Shultz and the House Insurance Committee for providing a public hearing on this bill, and I respectfully request that it be passed on to the House Floor. I deeply appreciate this opportunity to testify in support of Kate's Law.

Stuart T. Jackson, Ph.D.
President and CEO
AnalyzeDirect, Inc.
7380 W 161st Street
Overland Park KS 66085

Chairman Shultz and members of the Committee. Thank you for taking the time to hear House Bill 2367 regarding autism. My name is Carrie Wright and I am the mother of a 6 year old Autistic little boy. We live at 18804 W. 160th Ter., Olathe, KS. 66062 and are constituents of Representative Rob Olson in District 26. I am writing this today to tell you my story and struggle with insurance coverage for my son.

This first began when at age 3 my son was exhibiting some classic signs of Autism, ie: lack of speech, social reciprocity, eye-contact and hand flapping. We notified our insurance of the need for an evaluation. They sent us to their doctors at Children's Mercy in Overland Park, KS. We waited over 6 months for an appointment. A week after his evaluation, the doctors on his team recommended at least 25 hours a week of intensive behavioral therapy (ABA-applied behavioral analysis). Now mind you the doctor didn't simply say this she slapped her hands down on the desk, leaned forward and said, "This is what you need and you need it today. There is no time to waste."

When I got home, cried myself silly and lamented the world. I then began the task of finding a therapist to give my child the treatment that he needed "today" to quote the doctor. Once I found a BCBA (board certified behavioral analyst-that is who does this therapy), I called the insurance company and began trying to make claims. I was first told that this therapist was out of network, so I then explained that per our policy, if there was no network of providers, then I could go out of network. Then their next denial was because the therapist was not licenced in Kansas. I then proceed to tell them that there is no license for BCBAs in Kansas. Then their third denial was because they felt that ABA was experimental. It has been practiced since the 1960's.

So there we were. The choice was to pay privately for this absolutely essential therapy or let Jake sit, stagnate and fade into the public school system, becoming a burden to our society for the rest of his life. That is a very hard sentence to write. It sends pain to my heart and tears to my eyes no matter how many times I say it. So you see, there simply was no choice for us. We would do what we had to. Put ourselves in financial ruin, sacrifice the future of us and our other child to give this little boy a chance at life. To not do this...that wasn't even an option. In our minds it would be just as neglectful to deny our child this therapy as it would to deny a child afflicted with cancer chemotherapy. We were fighting for his life.

Even with this determination, we had to find ways to pay for the therapy. Our credit cards maxed out pretty fast, the savings account was empty and my parents even, thank the Lord, took out a second mortgage. With all of this we still ran out of money. We put ourselves in the lottery for a spot on the Autism waiver list with the state. We were one of the lucky ones. There are three times more families on the waiting list than there are spots. I pray every day for those families that are in the same boat as us who just aren't as lucky to have gotten a spot on the waiver or had the

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finances to pay privately for this.

The thing is, most of those families do have private insurance. The vast majority of folks I talk to tell me that very fact. Just like us they pay their premiums diligently and just like us are discriminated against because of the name on the diagnosis. In these difficult financial times this state is making families choose harm over help, food over therapy and tax burden over tax payer. Families just like us are having to ask the state for help with these therapies instead of being able to manage the co-pays that should exist for them.

I, along with thousands of other Kansans, are asking you to make this gross negligence of our children right. Please pass House Bill 2367 -Kate's Law to the house floor.

Sincerely,

Carrie Wright

Carrie Wright
District 26
18804 W. 160th Ter.
Olathe, KS. 66062
913-768-0729

MRS. MELISSA COOPER
1631 South 105Th Terrace
Edwardsville, Kansas 66111
Wyandotte, County
(913) 441-1799
mucoop@att.net

March 19, 2009

Dear House Financial Institutions and Insurance Committee Members,

First of all I want to start out this morning thanking you for giving me the chance to explain why Kate's Law, House Bill 2367, is so important to my family and many other families in Kansas that live every day with Autism. I am a mother that has been blessed with three wonderful boys. My sons Gavin and Joshua are 5 year old twins and they are both Autistic. Gavin was diagnosed with Moderate Autism and Joshua was diagnosed with Severe Autism. My youngest son Garrison is 2 years old and we are now in the evaluation process of him being diagnosed on the Autism Spectrum. We just found out two weeks ago that he has a speech delay.

April 15th and 16th of 2005 will forever be burned in my heart and my mind. On April 15 the team of doctors at KUMD told us that Joshua had Severe Autism. The very next day my husband and I are just trying to deal with the news about Joshua. My husband Gary got on the phone to call our Health Insurance Provider to find out who in our area could provide all the therapies that the medical team wanted Joshua to start right away. The first person we talked to didn't even know what Autism was. After weeks of playing the "game" of red tape we got our answer from United Healthcare. They told us that they would never pay for Autism. They told us it was not a medical condition. After months of appeals we talked with one of the top officials of United Healthcare. She told us from her point of view as a doctor that Autism is a Medical Illness and not a Behavior Issue, but that United Healthcare would never pay for Autism Therapies. She also told us if Joshua had Brain Injury or had a Stroke then we could get the Insurance Company to pay for some speech therapy, but since that was not the case we would be out of luck and on our own. The very next week we found out that Gavin was also Autistic.

Just like any parent when the doctor tells you how to help your sick child of course you would do anything in your power to do it. No matter what the treatment is or how much it is going to cost. You would do it in a heartbeat, that is just human nature. Gary and I knew that we were on our own after many phone calls and letters to our Health Insurance Company. We believed the only way we could ever help Joshua and Gavin was to get them into ABA Therapy along with Speech Therapy, Occupational Therapy,

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and Developmental Preschool part-time. As parents it didn't mater how many miles we drove or how many therapy sessions it took. We just wanted a glimmer of hope for our boys. We didn't see dollar signs, we saw the chance to beat the odds. All we wanted was to have our boys have a chance to be valued members of society.

To pay for the therapies, we cashed in Gary's Retirement Fund. Gary is now 41 years old and we have nothing. We have so many bills to pay that we can't even take the chance of setting money aside from his paycheck to put in his retirement even though his company will match what we put into it. That money only lasted for 18 months so the next thing we did was go to the bank to get a 2nd mortgage on our home. It was hard to sit there in the Bank's Loan Office to ask for money to help our sons. The loan Officer couldn't understand how our Healthcare Insurance company could be so inhumane and not pay for our sons medical condition. It is hard enough to live with the fact that your sons have a medical condition you can't control, and there is no magic pill for it other than therapies that your Healthcare Insurance won't ever pay for. I stand here before you today two years later with no more money, but I still have medical bills. I am still paying out-of-pocket for therapies that the date of service was over a year ago. We had to stop all therapies this past summer. One of the hardest things I had to do was to tell Gavin you can't go to preschool today because mommy doesn't have any money to buy gas. It's not like we wasted all our money on careless items. We used all the money that we had to help our boys. The sad thing is, I just didn't have enough to spend on my boys to give them a chance to learn how to live with their Autism. I am sadden to say that Joshua has pay the ultimate price. Joshua is no regressing because we had to stop the therapy. This time last year I could say to Joshua mommy loves you and he would look at me and say me too during our night time routine and now when I say those words to him I get a blank stair. Tell me what is a mother is a mother suppose to do? I am loosing my child because I can't pay for speech therapy even thought I pay for medical insurance out of my husband pay check. I am paying for a service that I am not getting to use. I am sorry but in this mothers eyes that is against the law.

My Healthcare Insurance has taken way more than just money from my family. They have taken my husband's and my pride and our self-worth. There are not enough words to tell you what your heart feels when you know there is something out there that can help your child and it's within your reach but you can't get it because you don't have enough money. It makes you feel more than just a loser. Gary and I live paycheck to paycheck. We have a very strict budget and if one of us gets sick most of the time we don't have the money to go to the doctor, so we have to put it on a credit card. There have been times I have put food and gas on credit cards. That is no way to raise a family. For weeks at a time Gary and I only talk and think about money and Autism. There are many nights I lay in my bed wide awake thinking of ways to pay all of the bills for that week. The sad thing is that I am just one of thousands of moms in Kansas that lays awake at night worrying about how she is going to pay for Autism.

I blame United Healthcare 100% for my family putting a burden on family. When it comes right down to it, the Private Insurance Companies are not only hurting families with Autism, they are hurting every family in Kansas. Without private early intervention a child with Autism will and can drain State funding when they turn the age of three. If you have a child that can't talk at the age of three they will have to have more than just Speech Therapy once a week when they enter in the school system. My Insurance Provider alone has cost the State of Kansas more funding than they ever should have. When is the last time you heard United HealthCare not making a profit? The Children of Kansas are not making a profit with education funding being cut.

Since we live paycheck to paycheck, and I have no extra money for therapies, I can't even begin to give Garrison what he needs to help him. He is only two years old and I know first hand what early intervention did for Gavin and Joshua and with out Kate's Law HB 2367, Garrison will never get that chance. You have the power to give Garrison a chance. All of you on this committee can help Gavin, Joshua and Garrison Cooper. They are just three boys out of a thousand across the State of Kansas that are some how affected with Autism. You have the power more than just to help families that live with Autism, you have the power to help every family in Kansas . You are going to have dollar amounts thrown at you, but let me ask you how much is a 2 year olds life worth? You can do what is right and support and pass Kate's Law HB 2367 on the House Floor. In turn you will be able to help every child in Kansas. I don't know about you, but power like that would make me proud to be a Kansas House Member.

Sincerely,

Melissa Cooper

Melissa Cooper

NASW, KANSAS CHAPTER ...the power of social work
National Association of Social Workers

House Insurance
March 19, 2009

HB 2367
Insurance coverage; autism

Testimony submitted by:
Sky Westerlund, LMSW
Executive Director

The Kansas Chapter, National Association of Social Workers (KNASW) is the professional association working on behalf of the profession and practice of social work in Kansas. Social workers have been licensed to practice at three levels of expertise since 1976. These are the baccalaureate (LBSW), the master (LMSW), and the clinical social worker (LSCSW). The specialist clinical social worker is professionally and statutorily authorized to diagnose and treat persons with mental health conditions in an independent manner. The master social worker can do the same, under supervision and direction from an LSCSW. Social workers practice in all 165 legislative districts.

KNASW supports the concept of HB 2367 to provide the treatment necessary for a person who has been diagnosed with autism. **We have suggestions for balloon amendments to address the concerns with some of the language in HB 2367**.

The current language in HB 2367 excludes social work services and social workers from providing care to persons with autism. The attached materials include the balloon amendments to correct this problem.

Another problem with HB 2367 is that it would permit non-licensed individuals to treat persons with a diagnosis of autism.
This occurs through the definition: " 'Autism services provider' means any person, entity or group that provides treatment of any autism spectrum disorder." This language sets up a dangerous precedence in which non-licensed and, consequently, non-regulated persons are able to provide treatment to an individual with a diagnosis of autism.

The **remedy** is to delete the definition of "autism services provider" from the legislation. Or, an alternate is to modify the definition of "autism services provider" to mean an individual who is licensed to practice medicine or behavioral sciences in the state of Kansas and who has additional training in working with persons who are diagnosed with any condition included in the Autism Spectrum.

KNASW asks for your support to add these amendments to HB 2367.

House Insurance
Date: 3-19-09
Attachment # 10

Session of 2009

HOUSE BILL No. 2367

By Committee on Federal and State Affairs

3-5

AN ACT concerning insurance; providing coverage for autism spectrum disorder; amending K.S.A. 2008 Supp. 40-2,103, 40-2,105, 40-2,105a and 40-19c09 and repealing the existing sections.

Be it enacted by the Legislature of the State of Kansas:

New Section 1. (a) (1) Any individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides coverage for accident and health services and which is delivered, issued for delivery, amended or renewed on or after July 1, 2009, shall provide coverage for the diagnosis and treatment of autism spectrum disorders in any covered individual.

(2) Such coverage shall be provided in a manner determined in consultation with the autism services provider and the patient. Services provided by an autism services provider under this section shall be limited to those services prescribed by a licensed physician ~~or~~ a licensed psychologist. Such coverage may be subject to appropriate annual deductibles and coinsurance provisions as are consistent with those established for other physical illness benefits under the plan or coverage.

`a licensed clinical social worker, a licensed master social worker who is authorized to diagnose mental disorders under K.S.A. 65-6319, and amendments thereto,`

(b) Each individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides coverage for accident and health services and which provides medical and surgical benefits shall provide written notice, as currently required, to all enrollees, insureds or subscribers regarding the coverage required by this section.

(c) No individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides coverage for accident and health services and which provides coverage with respect to an autism spectrum disorder shall:

(1) Deny to a patient eligibility, or continued eligibility, to enroll or to renew coverage, solely for the purpose of avoiding the requirements

of this section;

(2) deny or refuse to issue coverage on, refuse to contract with, or refuse to renew, refuse to reissue or otherwise terminate or restrict coverage on an individual solely because the individual is diagnosed with an autism spectrum disorder;

(3) deny or refuse to issue coverage on, refuse to contract with, or refuse to renew, refuse to reissue or otherwise terminate or restrict coverage on an individual diagnosed with an autism spectrum disorder solely on the basis coverage is necessary to develop, maintain or restore skills of such individual or on the basis coverage is necessary to prevent the loss of skills or functioning of such individual;

(4) impose on the coverage required by this section any dollar limits, deductibles or coinsurance provisions that are less favorable to an insured than the dollar limits, deductibles or coinsurance provisions that apply to physical illness generally under the accident and sickness insurance policy;

(5) impose on the coverage required by this section any limit upon the number of visits that a covered individual may make to an autism services provider; or

(6) penalize or otherwise reduce or limit the reimbursement of an autism services provider, or provide incentives, monetary or otherwise, to an autism services provider for the purpose of inducing such autism services provider to provide care to covered individuals in a manner inconsistent with this section.

(d) For any employers that have more than 50 eligible employees, coverage for applied behavior analysis shall be subject to a maximum benefit of $75,000 per year through age 21.

(e) (1) Any employer that has 50 or fewer employees shall have the option to exclude the coverage required by this section from any health benefit plan, as such term is defined in K.S.A. 40-2209d, and amendments thereto, offered to such employees.

(2) Any individual with an individually underwritten health insurance policy shall have the option to exclude the coverage required by this section from such policy.

(f) The provisions of this section shall not apply to any policy or certificate which provides coverage for any specified disease, specified accident or accident only coverage, credit, dental, disability income, hospital indemnity, long-term care insurance as defined by K.S.A. 40-2227, and amendments thereto, vision care or any other limited supplemental benefit nor to any medicare supplement policy of insurance as defined by the commissioner of insurance by rule and regulation, any coverage issued as a supplement to liability insurance, workers' compensation or similar insurance, automobile medical-payment insurance or any insurance under which benefits are payable with or without regard to fault, whether written on a group, blanket or individual basis.

(g) This section shall not be construed as limiting benefits that are otherwise available to an individual under a health coverage plan.

(h) For the purposes of this section:

(1) "Applied behavior analysis" means the design, implementation and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce socially significant improvement in human behavior, including the use of direct observation, measurement and functional analysis of the relations between environment and behavior.

(2) ~~"Autism services provider" means any person, entity or group that provides treatment of any autism spectrum disorder.~~

~~(3)~~ "Autism spectrum disorder" means the following disorders within the autism spectrum: Autistic disorder, Asperger's syndrome and pervasive developmental disorder not otherwise specified, as such terms are specified in the diagnostic and statistical manual of mental disorders, fourth edition, text revision (DSM-IV-TR), of the American psychiatric association, as published in May, 2000, or later versions as established in rules and regulations adopted by the behavioral sciences regulatory board pursuant to K.S.A. 74-7507 and amendments thereto.

(3) ~~(4)~~ "Diagnosis of autism spectrum disorder" means any medically necessary assessment, evaluation or test to determine whether an individual has an autism spectrum disorder.

(4) ~~(5)~~ "Eligible employee" shall have the meaning ascribed to such term in K.S.A. 40-2209d and amendments thereto.

(5) ~~(6)~~ "Habilitative or rehabilitative care" means and includes any professional, counseling and guidance service and treatment program, including applied behavior analysis, that is necessary to develop, maintain and restore, to the maximum extent possible, the functioning of an individual.

(6) ~~(7)~~ "Insurer" shall have the meaning ascribed to it in K.S.A. 40-2118 and amendments thereto.

(7) ~~(8)~~ "Pharmacy care" means medications prescribed by a licensed physician and any health-related services deemed medically necessary to determine the need or effectiveness of the medications.

(8) ~~(9)~~ "Psychiatric care" means any direct or consultative service provided by a psychiatrist licensed in the state in which the psychiatrist practices.

(9) ~~(10)~~ "Psychological care" means direct or consultative services provided by a psychologist licensed in the state in which the psychologist practices.

(10) "Social work care" means direct or consultative services provided by a person who is licensed to practice social work.

~~(11)~~ "Therapeutic care" means services provided by licensed or certified speech therapists, occupational therapists or physical therapists.

~~(12)~~ "Treatment for autism spectrum disorder" includes all medically necessary services as determined by a licensed physician or a licensed psychologist, including, but not limited to:

, a licensed clinical social worker, a licensed master social worker who is authorized to diagnose mental disorders under K.S.A. 65-6319, and amendments thereto,

(A) Habilitative or rehabilitative care;

(B) pharmacy care;

(C) psychiatric care;

(D) psychological care; ~~and~~

(E) social work care; and

(F) ~~(E)~~ therapeutic care.

(i) The provisions of this section shall be applicable to the Kansas state employees health care benefits program and municipal funded pools.

(j) The provisions of K.S.A. 40-2249a, and amendments thereto, shall not apply to the provisions of this section.

(k) Except for inpatient services, if a covered individual is receiving treatment for any autism spectrum disorder, an insurer will have the right to request a review of that treatment not more than once every 12 months unless the insurer and the individual's licensed physician ~~or~~ licensed psychologist agrees that a more frequent review is necessary. The cost of obtaining any review shall be borne by the insurer.

, a licensed clinical social worker, a licensed master social worker who is authorized to diagnose mental disorders under K.S.A. 65-6319, and amendments thereto,

(l) On or before November 30, 2009 and annually on each November 30 thereafter, the commissioner of insurance shall adjust the maximum benefit for inflation by using the medical care component of the United States department of labor consumer price index for all urban consumers. The commissioner shall submit the adjusted maximum benefit for publication in the Kansas register annually no later than December 10 of each calendar year beginning with 2009, and the published adjusted maximum benefit shall be applicable on and after January 1 of the following year to each individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides coverage for accident and health services.

(m) (1) Upon an insurer's denial of a claim by a covered individual for diagnostic assessment of any autism spectrum disorder or for treatment of any autism spectrum disorder, such covered individual or such covered individual's authorized representative shall be entitled to an expedited internal review process, followed by an independent expedited external review process established and administered by the insurance department. The independent expedited external review process shall be provided in substantial compliance with the procedure established in K.S.A. 40-22a13 et seq. as amended and supplemented.

(2) The decision resulting from the independent external review process may be appealed in the manner provided in K.S.A. 40-22a16 and amendments thereto. Pending a final decision of the district court, the

insurer shall pay for those covered services previously denied and any additional services authorized by the district court.

(n) This section shall be known and may be cited as the accessing autism services act.

Sec. 2. K.S.A. 2008 Supp. 40-2,103 is hereby amended to read as follows: 40-2,103. The requirements of K.S.A. 40-2,100, 40-2,101, 40-2,102, 40-2,104, 40-2,105, 40-2,114, 40-2,160, 40-2,165 through 40-2,170, inclusive, 40-2250, K.S.A. 2008 Supp. 40-2,105a ~~and 40-2,105b~~, *40-2,105b and section 1*, and amendments thereto, shall apply to all insurance policies, subscriber contracts or certificates of insurance delivered, renewed or issued for delivery within or outside of this state or used within this state by or for an individual who resides or is employed in this state.

Sec. 3. K.S.A. 2008 Supp. 40-2,105 is hereby amended to read as follows: 40-2,105. (a) On or after the effective date of this act, every insurer which issues any individual or group policy of accident and sickness insurance providing medical, surgical or hospital expense coverage for other than specific diseases or accidents only and which provides for reimbursement or indemnity for services rendered to a person covered by such policy in a medical care facility~~;~~ must provide for reimbursement or indemnity under such individual policy or under such group policy, except as provided in subsection (d), which shall be limited to not less than 30 days per year when such person is confined for treatment of alcoholism, drug abuse or nervous or mental conditions in a medical care facility licensed under the provisions of K.S.A. 65-429 and amendments thereto, a treatment facility for alcoholics licensed under the provisions of K.S.A. 65-4014 and amendments thereto, a treatment facility for drug abusers licensed under the provisions of K.S.A. 65-4605 and amendments thereto, a community mental health center or clinic licensed under the provisions of K.S.A. 75-3307b and amendments thereto or a psychiatric hospital licensed under the provisions of K.S.A. 75-3307b and amendments thereto. Such individual policy or such group policy shall also provide for reimbursement or indemnity, except as provided in subsection (d), of the costs of treatment of such person for alcoholism, drug abuse and nervous or mental conditions, limited to not less than 100% of the first $100, 80% of the next $100 and 50% of the next $1,640 in any year and limited to not less than $7,500 in such person's lifetime, in the facilities enumerated when confinement is not necessary for the treatment or by a physician ~~licensed~~ or psychologist licensed to practice under the laws of the state of Kansas.

, a licensed clinical social worker, a licensed master social worker who is authorized to diagnose mental disorders under K.S.A. 65-6319, and amendments thereto,

(b) For the purposes of this section "nervous or mental conditions" means disorders specified in the diagnostic and statistical manual of mental disorders, fourth edition, ~~(DSM-IV, 1994) of the American psychiatric association~~ *text revision (DSM-IV-TR) of the American psychiatric asso-*

ciation, as published in May 2000, or later versions as established in rules and regulations adopted by the behavioral sciences regulatory board pursuant to K.S.A. 74-7507, and amendments thereto, but shall not include conditions:

(1) Not attributable to a mental disorder that are a focus of attention or treatment ~~(DSM-IV, 1994)~~; and

(2) defined as a mental illness in K.S.A. 2008 Supp. 40-2,105a and amendments thereto.

(c) The provisions of this section shall be applicable to health maintenance organizations organized under article 32 of chapter 40 of the Kansas Statutes Annotated.

(d) There shall be no coverage under the provisions of this section for any assessment against any person required by a diversion agreement or by order of a court to attend an alcohol and drug safety action program certified pursuant to K.S.A. 8-1008 and amendments thereto or for evaluations and diagnostic tests ordered or requested in connection with criminal actions, divorce, child custody or child visitation proceedings.

(e) The provisions of this section shall not apply to any medicare supplement policy of insurance, as defined by the commissioner of insurance by rule and regulation.

(f) The provisions of this section shall be applicable to the Kansas state employees health care benefits program developed and provided by the Kansas state employees health care commission.

(g) The outpatient coverage provisions of this section shall not apply to a high deductible health plan as defined in federal law if such plan is purchased in connection with a medical or health savings account pursuant to that federal law, regardless of the effective date of the insurance policy. After the amount of eligible deductible expenses have been paid by the insured, the outpatient costs of treatment of the insured for alcoholism, drug abuse and nervous or mental conditions shall be paid on the same level they are provided for a medical condition, subject to the yearly and lifetime maximums provided in subsection (a).

Sec. 4. K.S.A. 2008 Supp. 40-2,105a is hereby amended to read as follows: 40-2,105a. (a) (1) Any group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides coverage for mental health benefits and which is delivered, issued for delivery, amended or renewed on or after January 1, 2002, shall include coverage for diagnosis and treatment of mental illnesses. Except as provided in paragraph (2), such coverage shall be subject to the same deductibles, coinsurance and other limitations as apply to other covered services.

(2) The coverage required by paragraph (1) shall include annual cov-

erage for both 45 days of in-patient care for mental illness and for 45 visits for out-patient care for mental illness.

(b) Notwithstanding the provisions of K.S.A. 40-2249a, and amendments thereto, the state insurance department shall deliver to the president of the senate and to the speaker of the house of representatives on or before January 1, 2003, a report indicating the impact of providing mental illness benefits required by this act. Such report shall include information regarding access to and usage of such services and the cost of such services.

(c) For the purposes of this section, "mental illness" means the following: Schizophrenia, schizoaffective disorder, schizophreniform disorder, brief reactive psychosis, paranoid or delusional disorder, atypical psychosis, major affective disorders (bipolar and major depression), cyclothymic and dysthymic disorders, obsessive compulsive disorder, panic disorder, ~~pervasive developmental disorder, including autism,~~ attention deficit disorder and attention deficit hyperactive disorder as such terms are defined in the diagnostic and statistical manual of mental disorders, fourth edition, ~~(DSM-IV, 1994) of the American psychiatric association~~ *text revision (DSM-IV-TR) of the American psychiatric association, as published in May 2000, or later versions as established in rules and regulations adopted by the behavioral sciences regulatory board pursuant to K.S.A. 74-7507, and amendments thereto,* but shall not include conditions not attributable to a mental disorder that are a focus of attention or treatment.

(d) The provisions of this section shall be applicable to health maintenance organizations organized under article 32 of chapter 40 of the Kansas Statutes Annotated.

(e) The provisions of this section shall not apply to any medicare supplement policy of insurance, as defined by the commissioner of insurance by rule and regulation.

(f) The provisions of this section shall be applicable to the Kansas state employees health care benefits program and municipal funded pools.

(g) The provisions of this section shall not apply to any policy or certificate which provides coverage for any specified disease, specified accident or accident only coverage, credit, dental, disability income, hospital indemnity, long-term care insurance as defined by K.S.A. 40-2227 and amendments thereto, vision care or any other limited supplemental benefit nor to any medicare supplement policy of insurance as defined by the commissioner of insurance by rule and regulation, any coverage issued as a supplement to liability insurance, workers compensation or similar insurance, automobile medical-payment insurance or any insurance under which benefits are payable with or without regard to fault, whether

10-8

written on a group, blanket or individual basis.

(h) From and after January 1, 2002, the provisions of K.S.A. 40-2,105, and amendments thereto, shall not apply to mental illnesses as defined in this act.

(i) There shall be no coverage under this section for evaluations and diagnostic tests ordered or requested in connection with criminal actions, divorce, child custody or child visitation proceedings.

Sec. 5. K.S.A. 2008 Supp. 40-19c09 is hereby amended to read as follows: 40-19c09. (a) Corporations organized under the nonprofit medical and hospital service corporation act shall be subject to the provisions of the Kansas general corporation code, articles 60 to 74, inclusive, of chapter 17 of the Kansas Statutes Annotated, applicable to nonprofit corporations, to the provisions of K.S.A. 40-214, 40-215, 40-216, 40-218, 40-219, 40-222, 40-223, 40-224, 40-225, 40-226, 40-229, 40-230, 40-231, 40-235, 40-236, 40-237, 40-247, 40-248, 40-249, 40-250, 40-251, 40-252, 40-254, 40-2,100, 40-2,101, 40-2,102, 40-2,103, 40-2,104, 40-2,105, 40-2,116, 40-2,117, 40-2,153, 40-2,154, 40-2,160, 40-2,161, 40-2,163 through 40-2,170, inclusive, 40-2a01 et seq., 40-2111 to 40-2116, inclusive, 40-2215 to 40-2220, inclusive, 40-2221a, 40-2221b, 40-2229, 40-2230, 40-2250, 40-2251, 40-2253, 40-2254, 40-2401 to 40-2421, inclusive, and 40-3301 to 40-3313, inclusive, K.S.A. 2008 Supp. 40-2,105a ~~and 40-2,105b~~, *40-2,105b and section 1*, and amendments thereto, except as the context otherwise requires, and shall not be subject to any other provisions of the insurance code except as expressly provided in this act.

(b) No policy, agreement, contract or certificate issued by a corporation to which this section applies shall contain a provision which excludes, limits or otherwise restricts coverage because medicaid benefits as permitted by title XIX of the social security act of 1965 are or may be available for the same accident or illness.

(c) Violation of subsection (b) shall be subject to the penalties prescribed by K.S.A. 40-2407 and 40-2411, and amendments thereto.

Sec. 6. K.S.A. 2008 Supp. 40-2,103, 40-2,105, 40-2,105a and 40-19c09 are hereby repealed.

Sec. 7. This act shall take effect and be in force from and after its publication in the statute book.

40 YEARS
INTERHAB

WWW.INTERHAB.ORG

March 19, 2009

TO: Rep. Clark Shultz, Chairperson

House Committee on Insurance

FR: Tom Laing, Executive Director, InterHab

RE: Testimony in support of House Bill 2367:

The Accessing Autism Services Bill, also known as “Kate’s Law”

InterHab member organizations serve persons throughout Kansas with developmental disabilities and autism, among other disability categories, and support the passage of HB 2367 to require that private health insurance companies cover the diagnostic evaluation and treatment for autism spectrum disorders for policyholders in Kansas.

A growing body of research-based information documents that services are available, when applied in a timely and professional approach, which can ameliorate the challenges associated with conditions which are a part of the autism spectrum. This bill is intended to make such newly-documented services available to families in need of such services.

The reduction of long-term autism-related disabilities will save all Kansans millions of dollars into the future – in terms of costs now born by schools and community service networks. We should make every available and reasonable effort, such as this legislation, to tackle this growing challenge. Otherwise, the Legislature would be saying that the tiny costs we might save in premiums by defeating this bill would outweigh the increasingly enormous costs required to serve persons for whom early intervention would have made a dramatic difference. The math doesn’t lie. This law will save all of us money.

More importantly than the long-term costs, in real terms that the committee must consider, is the devastation of families who face the challenges of autism without the assistance they need. Please do not lose sight of that reality.

House Insurance
Date: 3-19-09
Attachment # 11

All persons with health insurance have a right to expect that their basic health-related needs would be a part of their health insurance package, and yet that is not the case for families challenged by the difficulties of autism spectrum disorders. Families have been devastated for years by the lack of success in the professional world in finding answers to meet their needs. There is no reason that they should be further devastated by the financial burden of unfunded services which could far more easily be covered by insurers.

Please examine the questionable opposition to this bill in the context it is presented:

The insurance industry opposes all coverage mandates. Always have, always will.

It is certainly their right to articulate such a philosophy, but that doesn't make them right to do so.

Each legislator can and should address this matter, by the passage of this legislation. We thank you for your thoughtful consideration and urge your timely passage of House Bill 2367.

achieve *more*

Legislative Testimony

HB 2367

March 19, 2009

House Committee on Insurance

Rachelle Colombo, Senior Director of Legislative Affairs

Chairman Shultz, members of the Committee:

We appreciate the opportunity to provide written testimony in opposition to HB 2367 which mandates the provision of coverage for the autism spectrum disorder. While this is an emotional subject that impacts a growing percentage of our population, it behooves the legislature to first consider the effectiveness and financial impact of mandating coverage.

The Kansas Chamber and its members believe that before we impose higher premiums on employers, additional mandates should meet the financial impact requirements laid out in statute so that their cost can be accurately determined.

Studies show that mandates increase the cost of health care and drive up premium price. Increasing premium price makes health care less affordable and results in a growing number of uninsured. In a recent study, the Pacific Research Institute found that if the cost of insurance premiums rises by 1 percent, the number of uninsured people increases by 0.5 percent. This illustrates the detrimental impact of even minor increases in premium price on the uninsured population.

Managing health care costs remains one of the top three issues affecting profitability as identified by Kansas CEOs surveyed in the Chamber's annual CEO poll. Kansas business owners tell us that they want to provide health insurance and remain competitive, but the cost is too high. Already the cost of health care put business owners at a competitive disadvantage. Until statutory financial impact studies are conducted additional coverage should not be mandated.

The Kansas Chamber opposes HB 2367 because the exact cost of implementing the coverage required has not yet been determined, but we do know that mandates increase the cost of health care. Before employers are burdened with increasing premium costs fattened by mandates and forced to shoulder the cost of an even heftier health care bill, we should study the financial and physical impact of new mandates on the market and the health of individuals.

Thank you for the opportunity to offer these comments today.

The Kansas Chamber, with headquarters in Topeka, is the leading statewide pro-business advocacy group moving Kansas towards becoming the best state in America to do business. The Chamber represents small, medium and large employers all across Kansas.

House Insurance
Date: 3-19-09
Attachment # 12

Kansas Association
of Health Plans

815 SW Topeka Boulevard, Suite 2C
Topeka, Kansas 66612

(785) 213-0185
marlee@brightcarpenter.com

March 19, 2009

HB 2367
Before the House Insurance Committee
Marlee Carpenter, Executive Director

Chairman Shultz and members of the Committee;

The Kansas Association of Health Plans (KAHP) is a nonprofit association dedicated to providing the public information on managed care health plans. Members of the KAHP are Kansas licensed health maintenance organizations, preferred provider organizations and other entities that are associated with managed care. KAHP members serve the majority of Kansans enrolled in private health insurance. KAHP members also serve the Kansans enrolled in HealthWave and Medicaid managed care.

The KAHP is here today to oppose HB 2367, the autism mandate. There are several reasons why we are here today in opposition of this measure. The KAHP believes that HB 2367 will broaden the definition of insurance by requiring reimbursement of educational programs and will increase the costs of health insurance so that it is out of reach for many Kansans.

Kansas health insurance carriers already provide coverage for "medically" necessary services to children diagnosed with an autism spectrum disorder. These services include initial screenings for autism, occupational therapy, speech therapy, physical therapy, and coverage for common medical issues suffered by individuals with autism. In addition, state and federal mental health parity laws already require that these conditions be covered the same as any other medical condition.

HB 2367 would require coverage for many services that do not fall under medical expenses. This bill would require that medical insurance policies pay up to $75,000 per year per individual for the coverage of educational programs. This $75,000 figure would increase yearly because the bill requires the Kansas Department of Insurance to adjust the maximum amount for inflation.

HB 2367 would affect very few Kansas families. Approximately 60% of Kansans covered by a group health insurance plan are covered through an employer who self-insures. That means that the employer makes all coverage decisions and these plans are exempt from state health insurance mandates. The bill also allows for the exemption of individuals and small groups, which are groups of 50 or fewer. HB 2367 would cover very few Kansas policies and the cost of the mandate would be spread among very few policies.

House Insurance
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The current economic downturn has affected all businesses, from large companies to very small family-owned businesses. These companies are cutting costs and must choose between laying off employees, providing less services and products or the continuation of employee benefits. In Kansas, for every 1% increase in medical insurance premium costs, approximately 2,500 Kansans lose all medical insurance coverage due to their employer dropping all medical coverage due to costs. It has been estimated that the cost of providing these services would add between 2%-2.3% to current premiums.

Finally, I have attached the Kansas Health Policy Authority's Fiscal Note to SB 12, which is very similar to HB 2367. The fiscal note states a $4.6 million cost to the state employee health plan for FY 2010 with a 6.5% increase per year and an estimated cost of $5.6 million in FY 2013. These increased costs would be paid for by the state.

The KAHP requests that as you review HB 2376 that you consider the impact it will have on the health insurance market and ability to offer cost effective insurance products to Kansas citizens.

Thank you for your time and I will be happy to answer any questions.

Coordinating health & health care
for a thriving Kansas
KHPA™
KANSAS HEALTH POLICY AUTHORITY

Fiscal Note: SB 12
Accessing Autism Services Act

Brief analysis of the proposed legislation.

Senate Bill 12 would require any individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society or health maintenance organization which provides for accident and health services to provide coverage for the diagnosis and treatment of autism spectrum disorders (ASD) in any individual covered by the plan. Autism spectrum disorder is defined as disorders within the similar to or related to autism including Autistic disorder, Asperger's syndrome and any pervasive developmental disorder not otherwise specified in the bill.

SB 12 would allow coverage for Autism spectrum disorders to be subject to appropriate annual deductibles and coinsurance provisions. Any employer with more than 50 eligible employees would be subject to a maximum benefit of $75,000 per member per year through age 21. On or before November 30 of each year, the Insurance Commissioner would adjust the maximum benefit using the medical care component of the Consumer Price Index..

How does the bill affect KHPA's responsibilities?

The provisions of this act would be applicable to the State Employees Health Plan (SEHP). This act would require the SEHP to cover the treatment for ASD, which includes all medically necessary services as determined by a licensed physician or a licensed psychologist, including, but not limited to:

- Habilitative or rehabilitative care
- Pharmacy care
- Psychiatric care
- Psychological care, and
- Therapeutic care

The SEHP currently covers hospital and physician care for ASD under the biologically based mental illness provisions of the plans. The plans, however, do not cover speech and behavioral therapeutic or rehabilitation services for ASD under the "cognitive therapy" exclusion clause.

Dollar effect on KHPA's budget (expenditures and receipts) by funding source.

The calculations below show the cost impact of adding ASD therapy to the SEHP. The proposed change would impact both the State and Non State entities.

The following estimates are based on assumptions listed below. To the extent these assumptions are not exactly met, the projected costs will increase or decrease accordingly.

Estimated FY 2010 additional total cost for ASD therapy	
a. Estimated FY 2010 additional cost per patient with ASD	$27,000
b. Estimated number of children with ASD in FY2010 in SEHP	173
c. Estimated FY 2010 additional total cost (a. x b.)	**$4,671,000**

Assumptions used to develop cost estimates or anticipated revenues.

1.	Estimated additional annual cost per patient with ASD Source: Archives of Pediatrics and Adolescent Medicine (April 2007), Study by Michael L. Ganz. Costs were projected to FY2010.	$27,000
2.	Estimated number of individuals with ASD per 1,000 lives Source: World Health Organization (2006)	6.50
3.	Estimated number of children with ASD in SEHP	
	a. Estimated number of children in SEHP	26,666
	b. Estimated number of children with ASD in SEHP (rounded) (2. / 1000 x 3.a)	173

Actual costs could vary significantly from the estimate due to factors such as:

- Improvements in the diagnosis of ASD
- Evolution of accepted treatments and technology
- Treatment plan breadth and depth
- Possible provider price increases in response to coverage availability
- Actual prevalence that is different from our population-based estimate

Can the bill be implemented within currently approved staffing and operating expenditures levels? Will additional staff or expenditures be requested?
No additional staffing or operating expenditures are required.

The long-range effect of the bill, including estimates for three fiscal years following the budget year.
The total increase in revenues (from participating employers and employees) and expenditures for the upcoming fiscal years based on expected utilization is projected as follows:

Estimated FY 2010 total additional cost for ASD therapy	**$4,671,000**
FY 2011 (6.5% increase over FY 2010)	**4,975,000**
FY 2012 (6.5% increase over FY 2011)	**5,298,000**
FY 2013 (6.5% increase over FY 2012)	**5,642,000**

Date: January 22, 2009

BRAD SMOOT
ATTORNEY AT LAW

800 SW JACKSON, SUITE 808
TOPEKA, KANSAS 66612
(785) 233-0016
(785) 234-3687 (fax)
bsmoot@nomb.com

10200 STATE LINE ROAD
SUITE 230
LEAWOOD, KANSAS 66206

Statement of Brad Smoot, Legislative Counsel
Blue Cross Blue Shield of Kansas
Blue Cross Blue Shield of Kansas City
Regarding 2009 House Bill 2367
House Insurance Committee
March 19, 2009

Mr. Chair and Members:

On behalf of BCBSKS and BCBSKC, we appreciate the opportunity to comment on HB 2367, a bill to dramatically change the scope of private health insurance coverage for autism patients and providers of services for autism spectrum disorders (ASD). As you know, BCBSKS, a mutual insurance company owned by its customers, provides health insurance to nearly 900,000 Kansans in 103 counties while BCBSKC, a nonprofit company, delivers similar policies in Johnson and Wyandotte Counties to nearly 300,000 customers.

Autism is a complex, life-long developmental disability but one that is currently covered by the same medical coverage under Blue Cross Blue Shield plans that would be available to any other covered member. That coverage would typically include routine medical care, childhood immunizations, surgery, hospitalization and pharmaceuticals. More specifically, we cover certain procedures determined to be medically necessary for assessment and treatment of ASD, including physical and speech therapy. Kansas law already mandates coverage for autism mental health services pursuant to K.S.A. 40-2,105a. House Bill 2367 is a very odd proposal. While it would dramatically expand coverage for some, it would allow for exclusion of coverage for others and while it would guarantee issuance of a policy to a family with autistic children it might price those same families out of all health care coverage completely. Allow us to briefly identify the troubling sections.

The bill states that insurers of group policies and individual policies cannot exclude or refuse to issue policies to applicants with autism (commonly known as guaranteed issue). See Section 1. However, the bill allows individuals and families (non group market) and small groups (below 50) to opt out of autism coverage altogether. Small groups are not allowed to do that today as such is prohibited by K.S.A. 40-2,105a, the mental health parity act. (See Section 3 striking autism as an illness subject to our mental health parity law.) As to families who receive coverage from the non group market, the bill guarantees coverage but doesn't say the carrier can't price the applicant out of the policy which will be very likely since families buying non group coverage can reject autism coverage. When only the people who need a particular service buy it, the product is no longer real

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insurance and prices for those who do opt for coverage skyrocket. This is commonly known as "adverse selection."

Next, the bill asserts in Section 1(c)(4) that no policy may impose dollar limits on coverage. However later on in that same Section 1(d), the law would impose a $75,000 cap per year up to age 21. To add to the confusion, the cap only applies to employer groups of 50 or more, apparently meaning that individuals (non group) and small groups who don't opt out of coverage must provide coverage with no limits whatsoever. While small groups 2-50 in size are not protected by the $75,000 cap they do have limited protection from rate increases by our existing small group rate reform laws. Non group individual policies, however, have no such protection and are subject to annual underwriting changes. These are the most vulnerable policyholders in our health insurance system. A group of 51, while subject to the $75,000 cap, would also lack rate controls since they too are underwritten. Add to this the prohibition on insurer review of claims to once per year [see Section 1(k)] and a prohibition on limiting the number of visits [Section 1(c)(5)]. Together these provisions make the costs for autistic services virtually unlimited. Such costs could easily drive families and some employers into much more expensive policies or force them to drop health coverage altogether.

In short, the structure of HB 2367 runs counter to the common understanding of insurance "as the pooling of risks." This bill fragments the pool and allows too many to drop out of coverage. We are fairly certain this bill does not do what the advocates want.

In addition, the bill exempts itself from our test track statute which allows lawmakers to know the true costs of any proposed mandate based on the state employees health plan experience [see Section 1(j)] but the bill mandates that the Kansas state employees health care benefits program and municipal funded pools will be subject to the new mandate. The fiscal note for the state employees health plan is $2.4 million annually and many municipalities (those that can't opt out) will see increased insurance costs as well. We imagine that you will want to examine the fiscal impact on both the public and private sectors before advancing HB 2367.

Finally, the bill either attempts to expand the scope of practice for psychologists by giving them authority to prescribe services (which only physicians and their supervised assistants may now do) or it inadvertently excludes all other providers (except physicians and psychologists) from providing services they now provide. Again, we doubt that either result was the intention of the proponents. HB 2367 needs a lot of careful attention to detail or it may end up being something no one wants. Thank you.

NFIB
The Voice of Small Business®

House Insurance Committee
Daniel S. Murray: State Director, NFIB-Kansas
Written Testimony in Opposition to HB2367
March 19, 2009

NFIB-KS advocates free-market reforms that allow small-business owners to decide which benefits they can and cannot afford to offer.

Mr. Chair, Members of the Committee: My name is Dan Murray and I am the State Director of the National Federation of Independent Business-Kansas. NFIB-KS is the leading small business association representing small and independent businesses. A nonprofit, nonpartisan organization founded in 1943, NFIB-KS represents the consensus views of its 4,000 members in Kansas. Thank you for the opportunity to comment on HB2367.

Small business owners want to and do offer healthcare plans that cover a wide variety of benefits such as preventive care and cancer screenings. Providing these types of benefits is important to the productivity of NFIB-KS members and their employees. However, NFIB-KS continues to be greatly concerned by government imposed mandates that discourage consumer control and increase the cost of employee health plans. Thus, we must oppose HB2367.

NFIB-KS is sympathetic to the ultimate goal of HB2367. That is, we truly hope that insurance companies will offer affordable benefit packages that include coverage for autism spectrum disorders. It is very likely that many of our members have family or friends that, in some way, have been affected by autism spectrum disorders. Such coverage, however, should not be compulsory.

Health insurance mandates reduce the ability of employers to tailor insurance benefits that fit their employees' needs. These constraints remove private solutions and likely increase the cost of benefits. Studies have indicated that each health insurance mandate can increase the cost of insurance premiums by 1%-3%.

Mandate-driven increases in premium costs might determine whether a small business is capable of providing insurance benefits to its employees. Indeed, HB2367 allows employers with 50 or fewer employees to exclude the coverage. This is an acknowledgement that an autism coverage mandate will increase premium costs for employers, and is an attempt to protect the smallest of small businesses from premium increases caused by the autism mandate.

However, our small and independent businesses with more than 50 employees will most surely experience an increase in the cost to provide insurance benefits to their employees. This could cause these employers to reduce or cut existing benefits. Further, in this current economy, most businesses are struggling with reduced sales, tight financial markets, etc. The last thing small and independent businesses need right now is a government mandate-driven increase in insurance costs.

NFIB-KS wants small business to have affordable benefit packages that can be tailored to their workforce needs. When contemplating HB2367, we urge you to consider the impact on small business. Thank you for the opportunity to comment.

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Polsinelli Shughart PC

Memorandum

TO: THE HONORABLE CLARK SHULTZ, CHAIRMAN
HOUSE INSURANCE COMMITTEE

FROM: WILLIAM W. SNEED, LEGISLATIVE COUNSEL
AMERICA'S HEALTH INSURANCE PLANS

RE: H.B. 2367

DATE: MARCH 19, 2009

Mr. Chairman, Members of the Committee: My name is Bill Sneed and I am Legislative Counsel for America's Health Insurance Plans ("AHIP"). AHIP is a trade association representing nearly 1,300 member companies providing health insurance coverage to more than two million Americans. Our member companies offer medical expense insurance, long-term care insurance, disability income insurance, dental insurance, supplemental insurance, stop-loss insurance and reinsurance to consumers, employers and public purchasers. Please accept this memorandum as opposition to H.B. 2367. Notwithstanding the good intentions behind the introduction of H.B. 2367, we believe its enactment would unwisely shift the cost of what is a very difficult public health challenge.

Due to the apparent increased prevalence of autism, policy makers must carefully evaluate all methods of funding autism treatment and services. Various existing laws require schools to provide autism treatment and services and for outreach services to preschool-aged children. Many health insurance plans current provide benefits for medically necessary treatments for autism that are performed by licensed practitioners such as medication. We would contend that this expansion of coverage is not in the best interest of the insuring public.

First, the bill states that the coverage shall be provided in a manner determined by the autism service provider and the patient. Under that scenario, the terms of a contract between an insurance company and, typically, an employer, would be dictated by a provider of services and the person receiving the services.

Giving this provider carte blanche on treatment, notwithstanding that it was prescribed by a licensed physician or psychologist, can only create additional costs far beyond what is typically considered part of a health insurance contract.

This particular mandate will certainly drive up the cost of insurance. I have attached a press release from the press secretary of the Oklahoma House of Representatives' Speaker of the House outlining that the Oklahoma bill, which was studied by an independent actuary, would lead to a 7.8% increase in rates, and could generate as high as a 19.8% increase. It is my

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understanding that others may testify today as to the rate increases that have been looked at based upon the bill in Missouri.

Next, only a small population will benefit from this mandate. In addition to the fact that mandates can only apply to products under state purview, it would appear that H.B. 2367 does not apply to employers of less than 50 employees, and it would not apply to individual contracts. Thus, it appears that the bill only applies to what is commonly referred to as "large" employers. However, as most of you know, in reality a "large" employer in Kansas (50-200 employees) has traditionally had a difficult time handling the increases in health insurance costs for their employees, and such increases will again hurt Kansas employers who, as I believe most would agree, are not in a position today to absorb any type of increase.

Additionally, regardless of the debate as to what percentage of increase such a mandate will cause per policy, it is very important to remember that this is only one component of the total increase in costs. The frequency with which a benefit is utilized also has a dramatic effect on the underlying rates for the policy. Therein lies the other issue with mandates: mandates are required to be in the policy regardless of how frequently such benefits are utilized. This frequency of utilization compounds the problem and substantially increases costs that are ultimately reflected in higher rates.

As discussed during the mandate review, increased costs lead to more people being priced out of coverage, which in turn leads to more uninsureds. Thus, by passing health insurance mandates, the Legislature is ultimately increasing the pool of uninsureds in the State, leading to a greater gap in coverage.

We appreciate the opportunity to present this testimony. Based upon the foregoing, we respectfully request that the Committee take no action on H.B. 2367. I am available for questions at your convenience.

Respectfully submitted,

William W. Sneed

WWS:kjb .

Written Testimony for the House Insurance Committee

March 19, 2009

Chairman Clark Shultz, Vice Chairperson Virgil Peck and Distinguished Committee Members:

The Kansas Autism Task Force extensively studied and conducted hearings on issues related to the needs of and services available for persons with autism. One of the key recommendations of this task force to the Kansas Legislature is to pass HB2367 Accessing Autism Services Bill, also known well as "Kate's Law".

The American Academy of Pediatrics defines autism as "a biologically based neurodevelopmental disability". Autism is not a mental illness – it is a neurobiological medical disorder. Insurance coverage should be provided for the diagnosis and treatment of autism of any covered individual.

There is no known cause or cure for autism and the effects of this disability are typically lifelong. However, effectiveness of early intensive intervention in reducing the effects of this disorder is supported by a growing body of scientific research. Half of the individuals who receive this level of intervention do not require subsequent special education services and 80 percent show measurable reduction in symptoms. The positive return on investment of insurance coverage of early diagnosis and treatment of individuals with autism will prove to be staggering for individuals, families, businesses and our state education and health care systems.

For this reason and many more, **nine states have passed autism insurance coverage legislation and in six states, including Kansas, new autism insurance reform bills have been introduced.**

Each day I see, speak, interact and listen to individuals and families with autism spectrum disorders. They share their moving, often heart-breaking stories about their world 24/7. Parenting a child with autism, they face stressful challenges at home, school, work, and in the community. Some are bankrupt emotionally and financially. They face many barriers frequently in pursuing supports and services for their children with autism. **They love and care about their children and want them to receive appropriate diagnosis and treatment so they can make progress and lead meaningful, productive lives. This is a social justice issue and good public policy.**

I and numerous Kansans in each district of the state passionately agree with the Kansas Autism Task Force recommendation to pass HB2367 Accessing Autism Services Bill – "Kate's Law" as good public policy to benefit citizens with autism and ultimately all Kansans.

Please vote Yes on HB2367. Thank You!

Jim Leiker
Kansas Autism Task Force Member

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