Date

MINUTES OF THE SENATE FINANCIAL INSTITUTIONS AND INSURANCE COMMITTEE

The meeting was called to order by Chairman Ruth Teichman at 9:30 a.m. on January 29, 2009, in Room 136-N of the Capitol.

All members were present.

Committee staff present:

Bruce Kinzie, Office of the Revisor of Statutes Melissa Calderwood, Kansas Legislative Research Department Terri Weber, Kansas Legislative Research Department Beverly Beam, Committee Assistant

Conferees appearing before the committee:

Matt Goddard, Heartland Community Bankers Assn. (Attachment 1)

Michael Wasmer, D.V.M., (Attachment 2)

Lorri Unumb, J.D.

Kathy Ellerbeck, M.D., Developmental Pediatrician, (Attachment 3)

James Sherman, PhD, Professor, (Attachment 4)

Joe Fiorella, (Attachment 5)

Stuart Jackson, (Attachment 6)

Carrie Wright, (Attachment 7)

Melissa Cooper, (Attachment 8)

Austyn "Carson" Alstrom, (Attachment 9)

Sheril Bergman, (Attachment 10)

Kellye Schroeder, Volunteer, Capper Foundation, (Attachment 11)

Tom Laing, Executive Director, InterHab, (Attachment 12)

Bill Sneed, America's Health Insurance Plans (Attachment 13)

Marlee Carpenter, Kansas Association of Health Plans, (Attachment 14)

Brad Smoot, Blue Cross & Blue Shield of Kansas and KC (Attachment 15)

Dan Murray, National Federation of Independent Business - Kansas (Attachment 16)

Natalie Bright, Wichita Independent Business Association (Attachment 17)

Rachelle Colombo, Kansas Chamber (Attachment 18)

Others attending:

See attached list.

The Chair called the meeting to order and welcomed everyone to the meeting.

Bill introductions

Matt Goddard, Heartland Community Bankers Association, introduced legislation providing consumers with better disclosures regarding unsolicited loan offers. Mr. Goddard said a "mortgage trigger" lead occurs when a lender obtains a credit report on a loan applicant from a credit reporting agency and the credit reporting agency then sells the applicant's information to another mortgage lender who in turn makes an unsolicited mortgage loan offer. He said this bill would require that anyone using a mortgage trigger must disclose to a consumer that they are not affiliated with the consumer's mortgage lender and that their solicitation is based on information purchased from a third party. (Attachment 1)

Senator Holland moved introduction. Senator Kelsey seconded. Motion passed.

Hearing on

SB 12 - Insurance; coverage for autism.

Melissa Calderwood, Research Department, gave an overview of the bill. Ms. Calderwood stated that <u>SB 12</u> came by way of the Legislative Educational Planning Committee. Autism Spectrum Disorder is defined as

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the following disorders within the autism spectrum, such as autistic disorder, Asperger's syndrome and pervasive developmental disorders not otherwise specified. SB 12 would allow coverage for ASD to be subject to appropriate annual deductibles and coinsurance provisions. Any employer with 50 eligible employees would be subject to a maximum benefit of \$75,000 per member per year through age 21. Employers with 50 or fewer employees and individuals could elect to exclude such coverage from their health benefit plans. SB 12 would require the Insurance Commissioner on or before November 30 of each year to adjust the maximum benefit using the medical care component of the Consumer Price Index and to publish the adjusted maximum benefit. The Insurance Department would also establish and administer an independent external review process for the denial of autism spectrum disorder claims. The Kansas Health Policy Authority states that with the enactment of SB 12, it would be required to provide coverage for the treatment of ASD under the State Employees Health Plan. Such coverage would be subject to annual deductibles and coinsurance provisions as appropriate and consistent with other benefits established under the State Employees Health Plan coverage. The State Plan currently covers hospital and physician care for ASD under the biologically based mental illness provisions of the plans. Kansas Health Policy Authority estimates that the cost to the state and non-state employee group coverage by adding ASD to the State Plan would be approximately \$4,671,000 for Fiscal Year 2010. Payments for benefits under the State Plan coverage are considered off-budget expenditures.

Michael L. Wasmer, DVM, testified in support of <u>SB 12</u>. Dr. Wasmer said in summary, enactment of <u>SB 12</u> is a critical step toward improving access to medically necessary services for individuals with autism spectrum disorders in Kansas. He said it would ease the burden on state funded programs and at the same time provide incentive for qualified service providers to remain in Kansas. (Attachment 2)

Lorri Unumb, J.D., Senior Council for Autism Speaks, testified in support of SB 12. Professor Unumb said she traveled here from South Carolina to show her support for this bill. She stated South Carolina is one of the states that has already passed similar legislation. She said she gave up her lucrative career to advocate for children with autism full time once she saw the inequities in the insurance arena. She said autism is a medical disorder for which there is no known cure, but it is treatable. She said standard treatment protocol involves therapy called Applied Behavior Analysis or ABA therapy. ABA has been used on kids with autism for many decades, but the insurance companies continue to deny coverage for it as experimental, she said. She noted further, this denial is simply not supported by the science. She said the American Academy of Pediatrics, the National Research Council and the Surgeon General have all endorsed ABA therapy for kids with autism. She noted that it is very effective for kids with autism, about 50% of the kids who get this treatment intensively will be indistinguishable from their peers by the time they reach first grade and can enter school without special educational support. But it has to be administered intensively, and that is quite expensive. My own son's treatment has cost \$75,000 to \$80,000 per year. We have been able to afford that because my husband and I are lawyers, but how many Kansas families do you know who can afford that kind of treatment for their child with a condition that they did nothing to invite into their family. She said Harvard estimated that the cost of caring for a child with autism who does not get treatment is \$3.2 million per person for their lifetime. So, it is a fiscally responsible thing to do to pass this legislation, she said. Other states have seen that, she noted. She said South Carolina passed the bill that she drafted in 2007. Seven other states have passed it since that time. Continuing, she said she seen the implementation of the bill in South Carolina and can tell the Committee that notwithstanding the doomsday predictions of the insurance lobbyists, there have been no mass exodus of insurers, nor have there been businesses throwing in the towel because of increased premiums. In conclusion, she said the Council for Affordable Health Insurance, which is the insurance industry's own association, projected that the cost impact on premiums from this kind of bill is less than 1%. Further, the impact on the overall economy has been good through job creation.

Kathy Ellerbeck, MD, Developmental-Behavioral Pediatrician Center for Child Health and Development, University of Kansas School of Medicine, testified in support of <u>SB 12</u>. Dr. Ellerbeck testified in summary that autism is a medical/neurobiological condition, and other neurological disorders are covered; autism should not be excluded. She said intensive intervention improves outcomes for children and for families and in the end, for the state of Kansas. (<u>Attachment 3</u>)

James Sherman, Professor, Department of Applied Behavioral Science, University of Kansas, testified in support of <u>SB 12</u>. Professor Sherman stated that early intervention means that the intervention should start

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Minutes of the Senate Financial Institutions And Insurance Committee at 9:30 a.m. on January 29, 2009, in Room 136-N of the Capitol.

as early as possible, ideally as soon as it is clearly recognized that the child has autism. He said this may be as early as when the child is one and one-half to two year s old. He said using an early intensive behavioral approach with children with autism is a long and hard road, but it's worth it. He said according to the evidence currently available, of the children with autism who received an intervention that started early enough, was intensive enough, lasted long enough and used systematic teaching methods to develop language, social behavior, self-help activities, and skills that replace problem behavior, 45 to 50 percent of the children were able to enter elementary school and progress normally through elementary school and the remainder of their schooling without any special supports. In conclusion, Professor Sherman stated that early intervention is worth it in terms of dollars and in terms of just basic humanity and care for the people who need our help. He said simply we need some way of paying for effective early intervention and insurance is one reasonable way of doing this for families who have insurance. (Attachment 4)

The following are parents of autistic children, an autistic child, and a volunteer who testified in support of <u>SB</u> <u>12</u>. Also, the Executive Director of Interhab who supplied written testimony only. Their testimony is also attached:

Joe Fiorella, Parent (<u>Attachment 5</u>)
Stuart Jackson, Parent (<u>Attachment 6</u>)
Carrie Wright, Parent (<u>Attachment 7</u>)
Melissa Cooper, Parent (<u>Attachment 8</u>)
Austyn "Carson" Alstrom (<u>Attachment 9</u>)
Sheril Bergman, Parent (<u>Attachment 10</u>)
Kellye Schroeder, Volunteer, Capper Foundation (<u>Attachment 11</u>)
Tom Laing, Excursive Director, Interhab (written only (<u>Attachment 12</u>)

Bill Sneed, on behalf of America's Health Insurance Plans, testified in opposition to <u>SB 12</u>. Mr. Sneed stated that due to the apparent increased prevalence of autism, policymakers must carefully evaluate all methods of funding autism treatment and services. He said various existing laws require schools to provide autism treatment and services and for outreach services to preschool-aged children. He said many health insurance plans currently provide benefits for medically necessary treatments for autism that are performed by licensed practitioners such as medication. He said it is the contention of America's Health Insurance Plans that expansion of coverage is not in the best interest of the insuring public. (<u>Attachment 13</u>)

Marlee Carpenter, representing Kansas Association of Health Plans, testified in opposition to <u>SB 12.</u> Ms. Carpenter stated that health insurance carriers already provide coverage for medically necessary services to children diagnosed with an autism spectrum disorder. She said in addition, state and federal mental health parity laws already require that these conditions be covered the same as any other medical condition. (<u>Attachment 14</u>)

Brad Smoot, on behalf of Blue Cross Blue Shield of Kansas and Blue Cross Blue Shield of Kansas City, testified in opposition to <u>SB 12</u>. Mr. Smoot said autism is a complex, life-long developmental disability but, one that is currently covered by the same medical coverage under BCBS plans that would be available to any other covered member. He said that coverage would typically include routine medical care, childhood immunizations, surgery, hospitalization and pharmaceuticals. He said more specifically, BCBS covers certain procedures determined to be medically necessary or assessment and treatment of ASD, including physical and speech therapy. He said Kansas law already mandates coverage for autism mental health services. Mr. Smoot said while <u>SB 12</u> 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. (Attachment 15)

Daniel Murray, State Director, National Federation of Independent Business - Kansas, testified that NFIB is greatly concerned by government imposed mandates that discourage consumer control and increase the cost of employee health plans, therefore, it is opposed to <u>SB 12.</u> He said mandate driven increases in premium costs might determine whether a small business is capable of providing insurance benefits to its employees. (<u>Attachment 16</u>)

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Minutes of the Senate Financial Institutions And Insurance Committee at 9:30 a.m. on January 29, 2009, in Room 136-N of the Capitol.

Natalie Bright, Wichita Independent Business Association presented written testimony in opposition to <u>SB</u> <u>12</u>. (Attachment 17)

Rachelle Colombo, Kansas Chamber of Commerce, presented written testimony in opposition to $\underline{\mathbf{SB~12.}}$ (Attachment 18)

The next meeting is scheduled for February 3, 2009.

The meeting was adjourned at 10:30 a.m.

NAME	REPRESENTING
Shanelle Dupree	KHPA
Sara Quice	CID - FCAP
Diane Banneman Twacek	CLO - Early Childhood Aut
Jennifer Smith Currier	K-CAL-Kateslaw
Spanne Wikle	KS Action for Children
Shannon Cotsoradis	ic r
Sarah Wasmer	KCAL - Parent of Kate
Sunee Mickle	RCRSKS '
Mehille Co combo	KS Chamber
Malle Carpender	KAHP
Sprak Tidwell	KSNA
Jame an Love	Actna
B.11 Sneed	AHIP
Alex Kotoyantz	P.I.A.
KEN DANIEL	TIBA
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James Sherman	Autism - Early Interestrain
Melissa cooper	LCMI- panered
Came Wright	KCAL'S Autism Task Force, paron
Mike Wasner	KCACK) Antism (ask torce, parow
John Marie Aloth	Peret
Rustyl Corsel	Sxu Jeh7
Sheril Berman	parents
Bill Robinson	Autism Society of America-Heartle. Grandparent KCAL + citizen of Kansas
	WPAL + citizen of Kansas

FINANCIAL INSTITUTIONS & INSURANCE COMMITTEE GUEST LIST DATE: _____/- 29-09_____

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Autism Speaks
Kearney & Assoc.
Center of Child Health Dev- Kunc
KCAL/Son with autism
KCAL/SON W/AUTISM
RCAC /Son ul outism
K(A(/ Son w/ arton
Office of the Ks Securities Commissioner
Autism Bournment Rolations
SES
KCAL
Parent of child with autism.
CLO ? ANTISM Task Force

FINANCIAL INSTITUTIONS & INSURANCE COMMITTEE GUEST LIST DATE: _____

NAME	REPRESENTING
Deede Waguez-Pera Ha	parent, Sen Wysons constr
Maglies Young	parent KCAL
Octily Rowland	Parent
Kriskay	Parent, KCAL
Sharon Wengu Chris Green	K5 Legislative Research
Chris Green	Harris Nex
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700 S. Kansas Ave., Suite 512 Topeka, Kansas 66603 Office (785) 232-8215 • Fax (785) 232-9320 mgoddard@hcbankers.com

To:

Senate Financial Institutions and Insurance Committee

From: Matthew Goddard

Heartland Community Bankers Association

Date: January 29, 2009

Re:

Bill Introduction Request

The Heartland Community Bankers Association appreciates the opportunity to appear before the Senate Financial Institutions and Insurance Committee to request introduction of legislation providing consumers with better disclosures regarding unsolicited loan offers.

The attached bill requires that anyone using a product known as a "mortgage trigger" must disclose to a consumer that they are not affiliated with the consumer's mortgage lender and that their solicitation is based on information purchased from a third party. A mortgage trigger lead occurs when a lender obtains a credit report on a loan applicant from a credit reporting agency and the credit reporting agency then sells the applicant's information to another mortgage lender who in turn makes an unsolicited mortgage loan offer. For enforcement purposes, the bill is made a part of the Unfair Trade and Consumer Protection Act which falls under the enforcement of the Attorney General.

We respectfully request the attached legislation be introduced and referred back to the Committee for hearings and deliberations. Thank you.

FI; I Committee 1-29-09 Attachment 1

Mortgage Triggers

SENATE DIED NO.	SENATE	BILL NO.	
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Section 1. K.S.A. 50-624 is hereby amended to read as follows: 50-624. As used in this act:

- (a) "Agricultural purpose" means a purpose related to the production, harvest, exhibition, marketing, transportation, processing or manufacture of agricultural products by a consumer who cultivates, plants, propagates or nurtures the agricultural products. "Agricultural products" includes agricultural, horticultural, viticultural, and dairy products, livestock, wildlife, poultry, bees, forest products, fish and shellfish, and any products thereof, including processed and manufactured products, and any and all products raised or produced on farms and any processed or manufactured products thereof.
- (b) "Consumer" means an individual, husband and wife, sole proprietor, or family partnership who seeks or acquires property or services for personal, family, household, business or agricultural purposes.
- (c) "Consumer transaction" means a sale, lease, assignment or other disposition for value of property or services within this state (except insurance contracts regulated under state law) to a consumer; or a solicitation by a supplier with respect to any of these dispositions.
- (d) "Family partnership" means a partnership in which all of the partners are natural persons related to each other, all of whom have a common ancestor within the third degree of relationship, by blood or by adoption, or the spouses or the stepchildren of any such persons, or persons acting in a fiduciary capacity for persons so related.
- (e) "Final judgment" means a judgment, including any supporting opinion, that determines the rights of the parties and concerning which appellate remedies have been exhausted or the time for appeal has expired.
- (f) "Lender" means a bank, savings and loan association, savings bank, credit union, finance company, mortgage bank, mortgage broker and any affiliate.
- (f) (g) "Merchantable" means, in addition to the qualities prescribed in K.S.A. 84-2-314, and amendments thereto, in conformity in all material respects with applicable state and federal statutes and regulations establishing standards of quality and safety.
- (h) "Mortgage trigger lead" means a consumer report obtained pursuant to Section 604 (c)(1)(B) of the federal Fair Credit Reporting Act, 15 USC 1681b, where the issuance of the report is triggered by an inquiry made with a consumer reporting agency in response to an application for credit. Any consumer report on an applicant obtained by a lender with whom the applicant has

initially applied for credit or with whom the applicant has an outstanding extension of credit is not considered a mortgage trigger lead.

- (g) (i) "Person" means any individual, corporation, government, governmental subdivision or agency, business trust, estate, trust, partnership, association, cooperative or other legal entity.
 - (h) (j) "Property" includes real estate, goods and intangible personal property.
 - (i) (k) "Services" includes:
 - (1) Work, labor and other personal services;
- (2) privileges with respect to transportation, hotel and restaurant accommodations, education, entertainment, recreation, physical culture, hospital accommodations, funerals and cemetery accommodations; and
 - (3) any other act performed for a consumer by a supplier.
- (j) (l) "Supplier" means a manufacturer, distributor, dealer, seller, lessor, assignor, or other person who, in the ordinary course of business, solicits, engages in or enforces consumer transactions, whether or not dealing directly with the consumer. Supplier does not include any bank, trust company or lending institution which is subject to state or federal regulation with regard to disposition of repossessed collateral by such bank, trust company or lending institution.
- Sec. 2. K.S.A. 50-626 is hereby amended to read as follows: 50-626. (a) No supplier shall engage in any deceptive act or practice in connection with a consumer transaction.
- (b) Deceptive acts and practices include, but are not limited to, the following, each of which is hereby declared to be a violation of this act, whether or not any consumer has in fact been misled:
 - (1) Representations made knowingly or with reason to know that:
- (A) Property or services have sponsorship, approval, accessories, characteristics, ingredients, uses, benefits or quantities that they do not have;
- (B) the supplier has a sponsorship, approval, status, affiliation or connection that the supplier does not have;
- (C) property is original or new, if such property has been deteriorated, altered, reconditioned, repossessed or is second-hand or otherwise used to an extent that is materially different from the representation;
- (D) property or services are of particular standard, quality, grade, style or model, if they are of another which differs materially from the representation;
- (E) the consumer will receive a rebate, discount or other benefit as an inducement for entering into a consumer transaction in return for giving the supplier the names of prospective

consumers or otherwise helping the supplier to enter into other consumer transactions, if receipt of benefit is contingent on an event occurring after the consumer enters into the transaction;

- (F) property or services has uses, benefits or characteristics unless the supplier relied upon and possesses a reasonable basis for making such representation; or
- (G) use, benefit or characteristic of property or services has been proven or otherwise substantiated unless the supplier relied upon and possesses the type and amount of proof or substantiation represented to exist;
- (2) the willful use, in any oral or written representation, of exaggeration, falsehood, innuendo or ambiguity as to a material fact:
- (3) the willful failure to state a material fact, or the willful concealment, suppression or omission of a material fact;
- (4) disparaging the property, services or business of another by making, knowingly or with reason to know, false or misleading representations of material facts;
 - (5) offering property or services without intent to sell them;
- (6) offering property or services without intent to supply reasonable, expectable public demand, unless the offer discloses the limitation;
- (7) making false or misleading representations, knowingly or with reason to know, of fact concerning the reason for, existence of or amounts of price reductions, or the price in comparison to prices of competitors or one's own price at a past or future time;
- (8) falsely stating, knowingly or with reason to know, that a consumer transaction involves consumer rights, remedies or obligations;
- (9) falsely stating, knowingly or with reason to know, that services, replacements or repairs are needed;
- (10) falsely stating, knowingly or with reason to know, the reasons for offering or supplying property or services at sale or discount prices;
- (11) sending or delivering a solicitation for goods or services which could reasonably be interpreted or construed as a bill, invoice or statement of account due, unless:
- (A) Such solicitation contains the following notice, on its face, in conspicuous and legible type in contrast by typography, layout or color with other printing on its face:

"THIS IS A SOLICITATION FOR THE PURCHASE OF GOODS OR SERVICES AND NOT A BILL, INVOICE OR STATEMENT OF ACCOUNT DUE. YOU ARE UNDER NO OBLIGATION TO MAKE ANY PAYMENTS UNLESS YOU ACCEPT THIS OFFER"; and

(B) such solicitation, if made by any classified telephone directory service not affiliated with a local telephone service in the area of service, contains the following notice, on its face, in a

prominent and conspicuous manner:	
п	IS NOT AFFILIATED WITH
(name of telephone directory service)	

ANY LOCAL TELEPHONE COMPANY"; and

- using, in any printed advertisement, an assumed or fictitious name for the (12)conduct of such person's business that includes the name of any municipality, community or region or other description of the municipality, community or region in this state in such a manner as to suggest that such person's business is located in such municipality, community or region unless: (A) Such person's business is, in fact, located in such municipality, community or region; or (B) such person includes in any such printed advertisement the complete street and city address of the location from which such person's business is actually conducted. If located outside of Kansas, the state in which such person's business is located also shall be included. The provisions of this subsection shall not apply to the use of any trademark or service mark registered under the laws of this state or under federal law; any such name that, when applied to the goods or services of such person's business, is merely descriptive of them; or any such name that is merely a surname. Nothing in this subsection shall be construed to impose any liability on any publisher when such publisher had no knowledge the business was not, in fact, located in such municipality, community or region.
- (13) making a written or oral solicitation for products or services based on a mortgage trigger lead unless the solicitation clearly and conspicuously states in the initial phase of the solicitation that the solicitor is not affiliated with the lender or broker with which the consumer initially applied and that the solicitation is based on personal information about the consumer that was purchased, directly or indirectly, from a consumer reporting agency without the knowledge or permission of the lender or broker with which the consumer initially applied.
- Sec. 3. K.S.A. 50-624 and 50-626 are hereby repealed.
- Sec.4 This act shall take effect and be in force from and after its publication in the statute book.

Kansas Autism Insurance Coverage

Social and Financial Impact of Senate Bill 12 (Kate's Law)

In Fulfillment of the Requirements of K.S.A. 40-2248 & 40-3349

Provided to the Members of the Senate Financial Institutions and Insurance Committee January 29, 2009



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

> FI&I Committee 1-29-09 Attachment 2

January 29, 2009

The Honorable Senator Ruth Teichman Chair, Senate Financial Institutions and Insurance Committee Kansas State Capitol Room 241 – E 300 SW 10th Street Topeka, KS 66612

Dear Senator Teichman,

I sincerely appreciate your thoughtful consideration of Senate Bill 12 (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 certified actuarial analysis of SB 12 has been requested but results are not available at the time of today's hearing. I will forward you this additional analysis as soon as it becomes available.

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

Impact Report for Kansas Senate Bill 12

In fulfillment of K.S.A. 40-2248 & 40-3349 January 29, 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.

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 estimates⁴, 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

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."

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.

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." 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

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)

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!"

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.

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

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

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

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.

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

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."

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. 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

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 Paid by Tri-Care		\$80 - 90 \$125	w 0 w
	Center-based autism treatment programs			\$45,000 - 120,000**
Speech and Language Therapy	Paid by ITS Private pay		\$68 Information not available	
Occupational Therapy	Paid by ITS Private Pay	(Ela e	\$68 \$100 - 432	

^{*} Provided by a board certified behavior analyst (BCBA)

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,

^{**} Depending on the level of severity of the affected child

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. 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.

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...."

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

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

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

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

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

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: Indiana⁴⁷, South Carolina⁴⁸, Texas⁴⁹, Arizona⁵⁰, Florida⁵¹, Louisiana⁵², Pennsylvania⁵³ and Illinois⁵⁴. 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,

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

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. 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. The cost of providing education services for children in special education is 2-3 times higher than for those in regular education.

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. 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

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

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." 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)

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.

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

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" 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

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)

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.

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:

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. 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.
- 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.

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. 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

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. 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. With proper treatment, children with autism can do better in school and can live healthier and more independent lives.

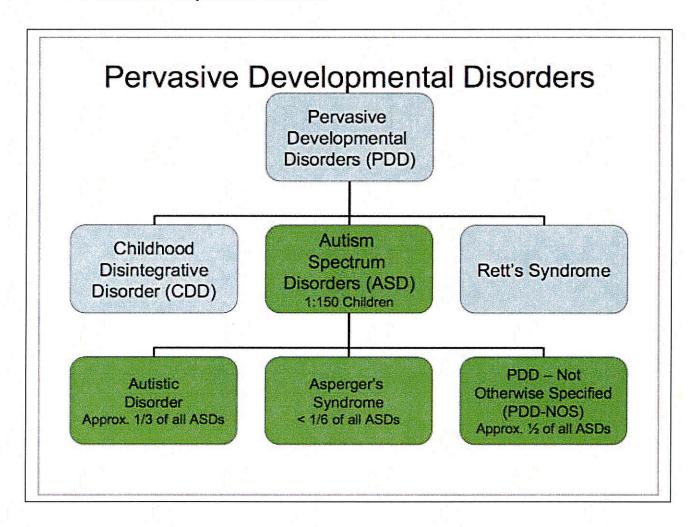
Autism Speaks believes that the pertinent question in the discussion of insurance reform is not whether we can afford to provide appropriate interventions to children with autism but, rather, whether we can afford not to. Autism is a financial drain on the health care system. Children with autism make 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.

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)

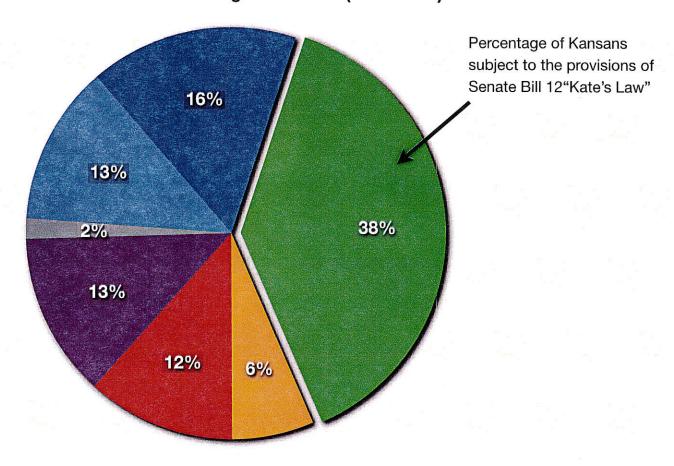
⁸³ Jacobson, supra note 22

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).



レモーン Appendix #2

Health Insurance Coverage in Kansas (2006-2007)



	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	a

- Employer sponsored / self fundedEmployer sponsored / fully insured
- Individual
- Medicaid/SCHIP
- Medicare
- Other Public (e.g. military)
- Uninsured

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

SCENAR	IO ONE	ASSUMP	TIONS

Estimated Cost per child with ASD
Est Cost Adjusted for Prevalence
Average monthly family premium
Medical Loss Ratio

7,000 Per IAN Kansas (2008)
47 CDC Prevalence 1:150
1,009 Per Kaiser Foundation (2008)
85.0% Estimated Medical Loss Ratio

7,000 Per IAN Kansas (2008)

18 Est Treatment Previnc 1:390

1,009 Per Kaiser Foundation (2008)
85.0% Estimated Medical Loss Ratio

Average monthly family premium Medical Loss Ratio	1,009 Per Kaiser Foundation (2008) 85.0% Estimated Medical Loss Ratio				1,009 Per Kaiser Foundation (2008) 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 Monthly Medical Cost Per Family Monthly Premium Costs	60 5 6	47	40%	3.2	23 2 2	18	40%	3.2
(Adjusted for Medical Loss Ratio) High Range Premium Increase Percentage	0.58%	1			0.22%			
Mid Annual Medical Cost Per Family Monthly Medical Cost Per Family Monthly Premium Costs (Adjusted for Medical Loss Ratio)	46 4 5	47	33%	3	18 1 2	18	33%	3
Mid Range Premium Increase Percentage	0.45%	1			0.17%	<u> </u>		
Low Annual Medical Cost Per Family Monthly Medical Cost Per Family Monthly Premium Costs (Adjusted for Medical Loss Ratio) Low Range Premium Increase Percentage	33 3 3	47	25%	2.8	12.6 1.1 1.2 0.12 %	18	25%	2.8
COENIA DIO TAVO ACCUMPTIONE								
SCENARIO TWO ASSUMPTIONS Estimated Cost per child with ASD Adjusted for Prevalence Average monthly family premium Medical Loss Ratio	118 1,009	Per Kaiser	alence 1:15 Foundation Medical Lo	(2008)	46 1,009	Per Kaiser	nent Prevince Foundation Medical Lo	1 (2008)
		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 Monthly Medical Cost Per Family Monthly Premium Costs (Adjusted for Medical Loss Ratio)	151 13 15	118	40%	3.2	58.4 4.9 5.7	46	40%	3.2
Premium Increase Percentage	1.47%				0.57%			
Mid Annual Medical Cost Per Family Monthly Medical Cost Per Family Monthly Premium Costs (Adjusted for Medical Loss Ratio)	117 10 11	118	33%	3	45 4 4	46	33%	3
Premium Increase Percentage	1.14%	16			0.44%			
Low Annual Medical Cost Per Family Monthly Medical Cost Per Family Monthly Premium Costs (Adjusted for Medical Loss Ratio)	83 7 8	118	25%	2.8	32.0 2.7 3.1	46	25%	2.8
Premium Increase Percentage	0.80%				0.31%			
SCENARIO THREE ASSUMPTIONS Estimated Cost per child with ASD Adjusted for Prevalence Average monthly family premium Medical Loss Ratio	500 1,009	Per Kaiser	expenditure alence 1:15 Foundation Medical Los	(2008)	193 1,009	Per Kaiser	xpenditure nent Previnc Foundation Medical Lo	(2008)
SCENARIO THREE		Cost per child	insured	Family Factor		Cost per child	insured	Family Factor
High Annual Medical Cost Per Family Monthly Medical Cost Per Family Monthly Premium Costs (Adjusted for Medical Loss Ratio)	640 53 63	500	40%	3.2	248 21 24	193	40%	3.2
Premium Increase Percentage	6.22%				2.41%			
<u>Mid</u> Annual Medical Cost Per Family Monthly Medical Cost Per Family Monthly Premium Costs (Adjusted for Medical Loss Ratio)	495 41 49	500	33%	3	191 16 19	193	33%	3
Premium Increase Percentage	4.81%				1.86%			
Low Annual Medical Cost Per Family Monthly Medical Cost Per Family Monthly Premium Costs (Adjusted for Medical Loss Ratio)	350 29 34	500	25%	2.8	135 11 13	193	25%	2.8
Premium Increase Percentage CPA 1/27/2009	3.40%				1.32%			

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

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	_ N	256,395
	-	
Total Risk Pool Based on National CDC Autism Prevalence Rate Estimate of 1/150 Ch	ildren 0.67%	1,709
http://www.cdc.gov/ncbddd/autism/fag_prevalence.htm		
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		
B		0.074
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

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

Health and Disability Working Group, "Catalyst Center State-at-a-Glance Chartbook" Boston University School of Public Health, Boston, MA (2007) p. 72 http://hdwq.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.

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 &}quot;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

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

				2 0	Low Avg Ann Out of Pckt Trtmt Cost per child in Kansas per IAN (2009)		Mid		Full Cap
							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	0/ Claima	47700		75000
	Linployees	Cilidren .50	Total Claims Falu	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

Autism Spectrum Disorders 2009

1. What is autism?

- Autism spectrum disorders (ASDs) are neurobiologic disorders defined by a cluster of symptoms which include impairments in social interaction and communication, and by the presence of restricted and repetitive behaviors.
- ASDs are relatively common disorders with the CDC estimating that 1 in every 150 children has some type of autism spectrum disorder
- Based on recurrence risk and twin studies, there is ample evidence that autism has underlying genetic causation. Like many other diseases, autism results from a variety of underlying genetic causes ("multifactorial").
- Although ASDs are neurobiologic conditions, there are no blood tests or brain scans that accurately diagnose autism; the diagnosis remains "behavioral."
- Genetic testing and brain scans may be necessary to diagnose the underlying cause for the impairments and behaviors we call autism: genetic testing is also necessary to define recurrence risk.
- ASDs often have associated medical problems (for example sleep disorders and epilepsy) that need to be addressed.
- ASDs often have associated behavioral problems (hyperactivity, obsessivecompulsive behaviors) that may respond to both behavioral management and medication.
- ASDs are chronic conditions that require high-quality longitudinal medical care in a medical home.

Why do we need to diagnose autism early?

- Autism symptoms can often be observed in very young children.
- Most parents have concerns before their child is 18 24 months old.
- There is substantial evidence that early intensive intervention improves developmental outcomes. Children with autism have impairments in attention to people and in imitation the foundations for learning. Structured educational interventions including behavioral strategies and habilitative therapies, can teach those skills, so that children don't fall further behind.
- There is increasingly good evidence that early intervention changes the biology even how genes are expressed in the brain as it is growing in the first years of life.

3. How should children with autism be identified and diagnosed?

• As of November, 2007 – the American Academy of Pediatrics recommends universal screening for autism at both the 18 month and the 24 month visit.

• There is no perfect screening tool – and a positive screen should initiate referral to early intervention services and to a diagnostic team with expertise in the diagnosis of autism.

FI:I Committee 1-29-09 Attach ment 3

- There are 3 major diagnostic challenges in the comprehensive assessment of a child with a suspected ASD: determining the child's overall level of functioning; making the categorical diagnosis of an ASD; and determining the extent of the search for an associated etiology. To accomplish these three goals, a comprehensive evaluation should include:
 - a. Health, developmental and behavioral histories
 - b. Physical examination including a thorough search for dysmorphic features and neurologic abnormalities
 - c. Developmental and/or psychometric evaluation
 - d. Determination of presence of a categorical DSM-IV-TR autism diagnosis, preferably with standardized tools.
 - e. Assessment of the parent's knowledge of ASDs, coping skills, and available resources and supports.
- 4. How does lack of adequate insurance impact diagnosis and treatment for children with autism (or possible autism)?
 - Pediatricians may resist screening for autism if they cannot be reimbursed
 - Pediatricians may resist screening for autism if they have no "back up" for timely definitive diagnosis. Wait lists at diagnostic centers are often more than six months.
 - Pediatricians may resist screening if they feel that families cannot afford recommended state of the art treatment for autism.
 - Families may delay diagnosis if costs (which can be \$1500 or more) for diagnosis are not covered.
 - Families often must travel hundreds of miles to find centers with diagnostic
 assessment teams, since poor reimbursement limits the growth of such centers.
 At the KU Center for Child Health and Development more than a third of claims
 are denied. The Center relies on training and research grant funding and would
 not be solvent if dependent on patient care.
 - Families often cannot afford to pay for the recommended intensive intervention services – delaying intervention and making it less effective.
 - Universities train bright young professionals in a variety of disciplines to diagnose and treat autism; however, once trained many providers are unable to make a living because of poor reimbursement. (*Kansas has the number 1 ranked school for Special Education n the country and yet, in many parts of Kansas there are not enough providers to treat children who are diagnosed).

5. Why Kate's Law?

- Autism is a medical/neurobiological condition, and other neurological disorders are covered; autism should not be excluded.
- Intensive intervention improves outcomes for children and for families and in the end, for the state of Kansas.

Respectfully submitted: Kathryn Ellerbeck, MD, MPH Developmental-Behavioral Pediatrician Center for Child Health and Development, University of Kansas School of Medicine.

Testimony presented to Kansas Senate Committee regarding Senate Bill 12 Jan 29, 2009

My name is James Sherman. I am a Professor in the Department of Applied Behavioral Science at the University of Kansas. I have been in the field of autism for the past 40 years. I testify on this basis, not as someone presenting the official views of the University of Kansas.

Autism is a very serious developmental disability. Unless a child with autism receives effective intervention early in life, it is highly unlikely that he will make normal progress in school or have a successful and fulfilling adult life.

The intervention that has the most empirical support of effectiveness is early intensive behavioral intervention, sometimes referred to as Applied Behavior Analysis or ABA. Official statements and policies by the Surgeon General's office and by several states, including New York and Kansas, express the same opinion.

Families with a child with autism face two formidable problems: (1) how to find therapists who can provide effective services; and (2) how to pay for these services.

There are very few families that can afford to pay for effective autism services -- it requires therapists to teach a child for 25 to 40 hours per week for two to four years. And, because few families can afford the services, there are only a few competent providers in Kansas.

Within the last two years Kansas, to its great credit, started a program that funds early intensive behavioral intervention, but only for a few children. Currently, funding provides services for approximately 45-50

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children with autism – approximately 2.5 % of the estimated 1890 children with autism in Kansas between the ages of 2 and 8 years old.

As long as there is little funding for effective autism intervention, the services will not exist. If there is funding, these services will exist. It may take several years, but it will happen: When funding became available in other states -- New York, Connecticut, California, New Jersey, Wisconsin, and Minnesota -- services became available.

For the past 15 years, my Department has provided training to prepare some of our graduates to provide effective intervention for children with autism. The great majority of our graduates are successfully employed, but in other states. Our graduates could and should be employed in Kansas and could and should be providing services to children in Kansas.

What will early intensive behavioral intervention do? The research indicates that approximately 45-50% of the children with autism will be able to attend school and be successful without any special supports. The remainder of the children with autism will need some supports, but the supports they need will be much less than if they had not received early intervention. The future savings to the State of Kansas of effective early intervention, in terms of adolescent and adult services not needed, as well the positive contributions of the people as workers and citizens when they become adults, is easily in the millions of dollars for each child served.

Written statement presented to Kansas Senate Committee regarding Senate
Bill 12

Jan 29, 2009

James A. Sherman

Families who have a young child with autism face a very difficult problem: unless their child receives effective intervention relatively early in life, it is unlikely that their child will make normal progress in school and equally unlikely that the child will eventually have a successful and fulfilling adult life.

There are many different types of early interventions that have been proposed to treat autism ranging from vitamin therapies to psychotherapeutic approaches to educational and teaching strategies. Families, however, face at least two major difficulties. First, in the face of conflicting claims by advocates of various types of interventions, families often do not know what interventions work and which do not. And, even if families receive good advice about which interventions work, they do not know to get these services. I try to address both problems.

Which interventions work and which do not? Unfortunately, many, indeed most, of the proposed interventions for early intervention for autism have not been empirically evaluated. For most interventions we do not know whether or not they substantially reduce the problem behaviors that children with autism display such as tantrums, self-stimulatory behavior, sometimes self-injurious behaviors and aggression. We do not know whether these proposed interventions teach the many skills that children with autism need to learn so that they can progress normally in school and live fulfilling lives into adolescence and through adulthood. Because of the wide variety of interventions that have been proposed, and because of the

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lack of clear evaluations of the effectiveness of many of these proposed interventions, parents are often at a loss regarding what to do when their child is diagnosed with autism. There is some hope, however.

A few interventions for young children with autism have been empirically evaluated. The results of the evaluations for an even smaller number of interventions have been very encouraging. One general type of intervention that has the most evidence for its effectiveness is a method I will label as early intensive behavioral intervention or teaching. It has been called other things as well, such as behavioral intervention, applied behavioral intervention, and applied behavior analysis or ABA. There are a number of empirical studies that support the effectiveness of this approach starting with research that was published in 1964 (Wolf, Risley, and Mees, 1964). The first major article reporting the results of a systematic clinical trial of this type of intervention was published in 1987 and a follow up evaluation was published in 1993 (Lovaas, 1987; McEachin, Smith, and Lovaas, 1993). Subsequently, a number of additional studies were conduced by various researchers. Two of the most recent studies were published in 2005 (Sallows and Graupner, 2005; Howard, Sparkman, Cohen, Green, and Stanislaw, 2005). The results of these two most recent studies were consistent with results from all of the earlier studies: children with autism could achieve substantial progress in both developing new skills and in reducing challenging or problem behaviors when the intervention was early, intensive, and used systematic teaching procedures. This body of research has been recognized by a number of professionals in the field of autism as the most effective empirically evaluated existing method of intervention. It has also been recognized by several states who have published clinical guidelines for early intervention for children with autism.

New York, for example, published an extensive document in 1999 that is available on their website

(http://www.health.state.ny.us/community/infants children/early interventio n/autism/ch4 pt2.htm). This document reviews a wide variety of interventions that have been used or proposed for young children with autism. The document was developed by a committee of 17 people selected by the state of New York. These people were respected clinicians and researchers in the field of early childhood, including autism. They were pediatricians, developmental psychologists, special educators, speech pathologists, and experts in early childhood education. Of the many types of interventions that were reviewed by the committee, the approach I have labeled as the early intensive, behavioral approach was one of the few interventions that was evaluated as having "strong" evidence for effectiveness. More recently, the Office of the Surgeon General of the United States posted on its website in the section on autism (http://www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html#au <u>tism</u>) that: "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior" in children with autism.

There are four basic elements of what I am calling the early intensive, behavioral method of intervention for children with autism.

First, <u>early</u>, means that the intervention should start as early as possible, ideally as soon as it is clearly recognized that the child has autism. This may be as early as when the child is one and one-half to two years old but, hopefully, no later than three or four years old. The available evidence suggests that when intervention is started later, say around seven or eight

years old, it is less effective, and it is even less effective when started when the child is nine or ten years old. I do not mean to imply by this that older children with autism cannot be helped by intervention. They can be helped considerably. But the magnitude of overall change that can be achieved by our current methods of intervention is much less when intervention starts later that when it starts as soon as it recognized that the child has autism.

Second, <u>intensive</u> means that there needs to be intervention taking place during a large proportion of the child's waking hours each day. Specific skills need to be taught to the child: language skills, such as following simple instructions and greeting other people; social behavior such as making eye contact, approaching and playing with peers, hugging their mother or father; self help skills such as feeding themselves appropriately, going to the bathroom appropriately, and brushing their teeth; and new behaviors need to be taught that replace problem behaviors such as tantrums, self-injurious behavior, aggression, and property destruction. All this requires a great deal of teaching time and it needs to be accomplished as quickly as possible. The window of opportunity for the greatest improvement is short and this critical period of time cannot be wasted. The most common recommendations are for somewhere between 25 and 40 hours each week of formal, structured teaching, with additional "incidental" teaching of 10 to 15 hours or more each week done by parents during the normal everyday activities that occur in the daily schedule of the family in the home and community.

Third is the length of the intervention. Effective interventions not only require 25-40 hours of structured systematic teaching and 10-15 hours of "incidental" teaching by parents each week, but it has to be done for a long time: two to four years. Of course, what is taught changes considerably

over the years as the child learns new skills. For example, we may start with teaching language by teaching the child to imitate simple sounds such as "aaa". Later, we may teach the child to imitate words. Then, we may teach the child to label objects in his or her home. Even later, we may teach the child how to approach another child and ask the other child to play.

Fourth, the intervention needs to employ <u>systematic</u> methods of teaching. This includes careful arranged sequences of tasks -- we need to teach the easiest and most basic skills first and then teach the more complex skills that build on the basic skills. We need to use positive motivational systems to encourage the child to participate and continue participating in the learning tasks. We need to establish clearly specified goals for teaching each day and each week. We need to collect reliable data that documents whether or not the child is learning. And, and we need to arrange regular meetings of the child's parents and teachers to review progress and establish new goals.

Using an early intensive behavioral approach with children with autism is long and hard road. But it's worth it. According to the evidence currently available, of the children with autism who received an intervention that started early enough, was intensive enough, lasted long enough, and used systematic teaching methods to develop language, social behavior, self-help activities, and skills that replace problem behavior, 45%-50% of the children were able to enter elementary school and progress normally through elementary school and the remainder of their schooling without any special supports. The remaining 50-55% of the children with autism required some type of special supports to progress adequately in school; however, almost all of these children required substantially less support that they would have

needed had they not received the early intensive behavioral intervention. That's the good news.

The not-so-good news is that it costs. One of my colleagues, Dr. Diane Bannerman Juracek, calculated the cost of implementing an early intensive behavioral intervention for children with autism in Kansas. Her estimate, done in 2004, was based on an assumption that the child with autism would receive four years of intervention that began when the child was about four years old. The minimum cost of the intervention was approximately \$205,000 in 2004 dollars. That is a lot of money. But consider the cost of not doing early intervention. Diane's estimate of the cost of not doing the intervention was between 1.3 and 3.8 million dollars for the lifetime of the person with autism if they were able to live in the community and between 5.8 and 7 million dollars if they lived in a state institution. This is the cost of providing services and support for the person with autism who does not receive effective early intervention from the time the person is 18 years old and beyond, with an assumption of a life expectancy of 70 years old. The range of the costs depend on the severity of the symptoms of autism. The higher costs of 7 million dollars was for people with the most severe symptoms of autism and the lower cost was for people with mild to moderate symptoms of autism. Please note that the cost of not doing the intervention did not include the costs to the school system of trying to address the educational and behavioral needs of a child with autism during the years from when the child was 7 or 8 years old to the time when the child reached 18 years old. And, the costs do not include the loss of income (and loss of taxes paid to the state and federal government) for a person who is completely or mainly unable to support themselves by working at a regular job in the community.

So, is effective early intervention worth it? I sure think so – I think it is worth it in terms of dollars, and I certainly think that it is worth it in terms just basic humanity and care for the people who need our help. We simply need some way of paying for effective early intervention. Insurance is one reasonable way of doing this for families who have insurance. And, requiring insurance to pay for effective early intervention for autism seems just as reasonable as providing insurance payments for effective early cancer treatment or for effective early diabetes treatment, or for effective early treatment of cardiovascular diseases. All of these are essentially medical problems, as is autism, that need treatment if the child is to have a chance at living a normal and fulfilling life.

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TESTIMONY BY JOE FIORELLA

January 29, 2009

Senate Financial Institutions & Insurance Committee

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.
- In the time allowed this morning, I cannot begin to convey what I and other parents have had to go through.

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.
- 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 auestion.
 - 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
 - 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

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

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 FI; I Committee 1-29-09 Attachment 5 Insurance. (Almost a year and ½ after the diagnosis)

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- 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:
 - 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. Officer of an Insurance Organization

- I will share with the committee that at the time of the diagnosis & throughout chronology of the claim, 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. Small Group Employer

- 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 12 not only for those children afflicted but for all Kansas taxpayers. THANK YOU

Testimony in Support of SB 12 "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 SB 12 "Kate's Law" on small to medium sized businesses. Judging by the experience of other states considering similar legislation, you may hear the following arguments from those opposed to SB 12:

- 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, or worse still, will cause more small companies to go out of business

Although intuitively they seem to make sense, both statements are incorrect. With regard to point (a), 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. This should not impact the ability of a viable small 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.

With regard to point (b), 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. 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

FI&I Committee 1-29-09 Attachment 6 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.

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.

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.

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 Senator Ruth Teichman and the Senate Finance Institutions and Insurance Committee for providing an early hearing on this bill, and I respectfully request that it be passed on to the Senate 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 Hello, my name is Carrie Wright and I am the mother of a 5 year old Autistic little boy. We live at 18804 W. 160th Ter., Olathe, KS. 66062 and are constituents of Senator Karin Brownlee in District 23. 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 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 Senate Bill 12 -Kate's Law to the senate floor.

Sincerely,

District 23

18804 W. 160th Ter. Olathe, KS. 66062

913-768-0729

FI&I Committee 1-29-09 Attachment 7

MRS. MELISSA COOPER

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

January 29, 2009

Dear Senate 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, Senate Bill 12, 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.

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, and Developmental Preschool part-time. As parents it didn't mater how many miles we

FI:I Committee 1-29-09 Attachment 8 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.

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 our School District Budget. We all know that Kansas has a budget shortfall. 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 before school age a child with Autism will and can drain school 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 school funding than they ever should have. I say this because the more therapies each school district has to provide a

child with Autism the more money it cost each child in that district. 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 SB 12, 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 Kansas Schools at the same time. 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 SB 12 on the Senate 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 State Senator.

Sincerely,

Melissa Cooper

Austyn 'Carson' Alstrom 811 Frank Marshall Dr. Marysville, KS 66508 (785) 629-8394 austyn.carson@gmail.com

Dears Sirs and Madams,

My name is Austyn. I am 15 years old and a freshman at Marysville High School. Last semester, I obtained a 3.4 GPA while attending all regular education classes. This included Algebra I and English.

I also participate in FFA and band. In fact, I play both the trumpet and baritone, and this school year I joined the drum line. I am a Boy Scout, and I volunteer weekly at the local food pantry. The skills I learned at the food pantry helped me land a job at the local grocery store where I work as a carryout. I attend church and youth group weekly. I am also a great swimmer – my best stroke is the breast stroke.

One of the reasons why I am excellent at- and nearly a league champion in the breast stroke is because I have poor posture. This is a characteristic of an Autism Spectrum Disorder. Another obvious symptom I have is limited eye contact. Formal measures indicate that I make eye contact about 10 percent of the time. And, when I do not make eye contact, I turn my head making it difficult for other people to understand me when I speak. Along with the typed copy of my testimony, I also included a handwritten copy to show you the difficulty I experience with my fine motor skills. As you can see, the legibility is not good, and being 15, it is still very hard for me to even button shirts. Again, these are all symptoms of ASD.

As I have grown older, a symptom that separates me most from my peers and work colleagues is my lack of social competence. I continue to have difficulty getting along- and making social connections with other people. And, although I have a strong moral sense, and I know right from wrong, I often "follow" others in an effort to fit in and be liked by my peers.

With the help of my parents, teachers, principal, and people in our community, I work daily on these challenges related to ASD. I know that my success as an adult ultimately depends on my capability to socialize- and get along with other people.

Fortunately, now there are more treatments that are much more effective and better than ever and these are available to the youngest children and their families who are also touched by ASD. Many of these interventions and therapies were not available when I was young.

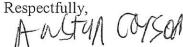
As I stand up here, a very successful young man with ASD symptoms, I challenge you to consider the thought that having had insurance and access to treatments when I was young, this

FI&I Committee 1-29-09 Attachment 9 school year I may have required less speech and language services, less social skills instruction, less academic accommodations and no need for a behavior plan. I could have fit in better with my peers – less of the target for others to tease - I could have been more like everyone else.

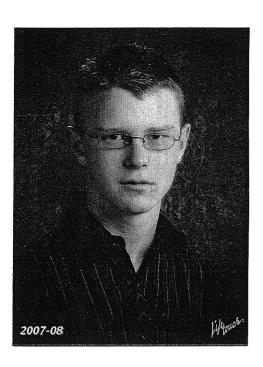
Do not get me wrong. I am not complaining – I am happy, and I have a great life. I look forward to the future – high school graduation, attending college, and a job. Yet I can tell you first hand the difficulties related to ASD that my family and I have experienced. Hard work and sacrifice by so many have helped make me the young man I am today.

Please, pass this law to help ensure even more success for children with ASD. You, ladies and gentlemen, hold futures in the palm of your hands. As you have seen today, kids like me can have contributions and strengths as well as weaknesses. Children need this insurance opportunity especially when they are young to increase their likelihood of involvement in the world of work as teenagers and adults. Please, do not hesitate to contribute to the betterment of children, families and society.

Thank you for your time today. If you have any questions or comments, please call or email me.



Austyn



WOTH SOMPLE

DROY SITS and moderns, My nome is Austyn. I om 15 years ord and a Freshmon of Morysville Highschool. Lost semesters I Obtained + 3.4 GPA while Atending out 1 regular education closses, this included Algebra ond english. I onso participate in FFA and Bond-Infact, I proy Doth the trumpet and Boritone, and this School year I Doined the Orapine. I am a BOY SCOUT , OAS I VOIMHEER ONE CHILD OF the KOOS 4000 PUNTED. THE SHILLS I recented at the food pontro helped long me or Job of the local grocery store Where I work or a corryant. I ottend charity Ind youth group needly, I am also a great Swimmer-my best Strotte is the browst strette. one of the reasons why I am except of onl nearly a reaside chameria in the breast strotte is become I have poly posture, this is o Choro Cteristic of on Autism spectrum disorder, Another obvious sumptom I have is timited Dye CONTOCT. FORMOT MEOSURES HAVICATE HAT I MOTHE eye confoct obout 10% of the time And when I do not Motte eye confocts I temm my head MOHING IT DEFFINALLYS FOR OHER PEOPLE to F understand me when I splatt

PERSONAL TESTIMONY THURSDAY, JAN. 29, 2009 SENATE BILL #12, KATE'S LAW

SHERIL BERGMAN 9377 MAIN ST. BENEDICT, KS. 66538

GOOD MORNING, Madam Chair/Members of the Committee:

My name is Sheril Bergman, and I live in the small, northeast Kansas town of St. Benedict. My husband, Steve and I raised six children, and in 2001 adopted our first grandchild, Sierra, who was diagnosed with autism on Jan. 21, 2005.

I thank you for allowing me this time to speak with you in support of the Accessing Autism Services Act, Kates's Law, SB#12. As a parent of a child with autism, I can tell you our story, which unfortunately is the story of all too many families in Kansas.

When Sierra was diagnosed with autism just before her fourth birthday, we set out to do what had to be done. We studied into the wee hours of the night, made countless phone calls during the days, and in general, spent every waking minute worrying if we were doing enough to give Sierra the best outcome for a productive life.

Everything we read told us that we had to hurry...the earlier these children received therapy...the better the outcome would be.

So...we did what we had to do...hired our own therapists to work with Sierra for 20-30+ hours per week, using scientifically proven therapies. Two years after her diagnosis, we found a doctor who works with autism to help us implement a strict dietary regimen in accordance with the most highly respected practices of Dr. Bernard Rimland and his DAN protocol.

And where are we now??? Well...Sierra "was" a 4-yr. old with less than 5 words that she could speak. She had full-blown tantrums 10-15 times per day, non-existent social functioning, no imaginative play skills, sleepless nights, no toileting skills, baffling sensory issues with light and sound, and she felt no pain from obvious injury. She also had a family who didn't see a light at the end of the tunnel.

Sierra "is" a polite, out-spoken, 7-yr. old second grader with non-stop vocabulary, top in her first grade class in reading, has wonderful imagination and play skills, with a family who is so proud of her accomplishments. She had her first girlfriend sleep-over this year, she tells corny jokes, gives wonderful hugs, and is the most loving person I know. She still has obstacles to overcome...but we are confident that she can have a very happy, healthy life as a contributing member to our society, if we continue to provide her with the medical, dietary, and behavioral treatments that have bought her this far.

Throughout our journey, insurance coverage for Sierra's treatments has been minimal at best. From diagnosis, costing almost \$2000, to in-home therapists, educational resources to use at home, doctor's exams, lab testing, and the nutritional therapy and diet, the strain on our family financially has been a difficult burden to bear.

FI;I Committee 1-29-09 Attackment 10 For the year 2007, our expenditures "after insurance" averaged \$1150 per month. That is money that will never be there for our retirement, for a 401K, or for our emergency funds if we get injured or suffer a debilitating illness. Families all over Kansas are making the same choice to put off worrying about their personal futures...to take care of the urgent, necessary needs of their children/grandchildren with autism. We have no other choice. We are doing what we have to do.

As the research continues to improve treatments for autism, more states are beginning to realize the effectiveness of early intervention and intense treatments. Autism is a medical condition, not a mental health disorder, and individuals with autism need comprehensive medical care. Of the four- A diagnoses of autism, ADHD, allergies, and asthma, autism is the only one not covered by insurance.

Sierra is proof that early, intensive intervention and therapy improves the quality of lives for children with autism. We have every confidence that she will be a fully-contributing member of our society IF we continue to provide her with the care she needs. We ask that every child be given this same chance at a productive life.

We are not asking for a handout. We just want a disease, the frequency of which now exceeds all types of cancer combined, to be given the same level of insurance coverage that other medical conditions are given...so that our children can be saved.

It is time for Kansas to do what needs to be done.

Thank you for listening.

Please pass Kate's Law.

Sheril Bergman Steve Bergman

· .

Dear Legislature-

I am writing you on behalf of my sister, Sierra Bergman, who is a child with autism. I have seen, first hand, the toll (financially and otherwise) that autism has taken on my parents ...on our family. I am asking that you pass KATE'S LAW....it is important in SO many ways. Do what is right for all these families....for these kids who will benefit tremendously from coverage.

Please say "YES" to Kate's Law...say "YES" to families in Kansas who are suffering.

Thank You,

Sarah Glendening

Dear Legislature-

I am writing you on behalf of my sister-in-law, Sierra Bergman, who is a child with autism. I have seen, first hand, the toll (financially and otherwise) that autism has taken on my in-laws ...on our family. I am asking that you pass KATE'S LAW....it is important in SO many ways. Do what is right for all these families....for these kids who will benefit tremendously from coverage.

Please say "YES" to Kate's Law...say "YES" to families in Kansas who are suffering.

Thank You,

Bret Glendening

January 25, 2009

Members of the Legislature

Dear Chairperson and Members of the Committee:

My name is Stacie Korte and I writing you today on behalf of my family and all families in Kansas impacted by autism to request your support of the current autism legislation before you Senate Bill 12 (Kates' Law). My son, Lucas, was diagnosed with autism in March of 2007 when he was 2 years old. We live near Seneca, Kansas which is a very rural area. Since we live in a rural community resources are very limited.

When given this diagnosis we were told he is to have 20-25 hours of week of intensive therapy. Providers do not cover cost of intervention, therapies, or services identified as medical necessities for a child like our son. We have been paying privately for therapists to help him. Communication with the school personnel and getting services has been quite challenging. We feel that early intervention is the key to helping these individuals. We are constantly wondering if we are doing enough to help him though. With insurance coverage in place we would be able to find more resources to help with progress and recovery.

The cost to provide therapy should not fall onto one sole entity. Families, schools, and government agencies should share the cost. Spending money now will save money over the lifetime of a child. Early identification, early intervention, and appropriate medical services will provide for decreased rate of human services support of individuals with autism in their adult years. Enhancing lives of all children in our state is something we can all work together to achieve and by doing so we can move forward to opportunities for adults with autism to live self-determined lives as healthy individuals within our communities. This is our dream for our son, Lucas.

Again, on behalf of my family, please support this important legislation that will provide hope and change the lives of individuals affected by autism.

Thank you for your consideration of this bill.

Stacie Hotte

Sincerely,

Stacie Korte

Alicia M. Keegan 2666 D Rd. Baileyville, Ks 66404-8645 785.336.6519 pandakeegan@networksplus.net

January 17, 2009

Dear Madam Teichman Chairperson,

1900年,1916年,1916年,1916年,1916年,1918年,1918年,1918年,1918年,1918年,1918年,1918年,1918年,1918年,1918年,1918年,1918年

I write to you today in hopes that you will support the Senate Bill #12, Kate's Law.

Let me tell you about our struggles without autism insurance..

Donovan is the oldest of three siblings in the family of Pat and Alicia Keegan. Donovan is 16, Kiera is 15, and Shea is 14. Donovan has high functioning ADHD, for this he takes medication; & PDD which covers high-functions autism & aspergers, with the disability being within his social skills. Donovan's story looks long on paper, but you have to remember that Donovan is about to turn 17!

We live in a very rural area, 6 3/4 miles north of Baileyville; and is 7 miles from Seneca where our family conducts business. Pat has two full time jobs; SKF of Seneca, and farming. Alicia is a stay at home mom. We also doctor in Seneca with a local MD. However beyond a MD you have to travel miles to the closest city for specialized services.

Donovan's story really started in kindergarten. Donovan was showing signs of being unable to set still in class; didn't have positive interactions with fellow students; and he perseverates before answering questions. He has a hard time staying seated on the bus and in a car. His speech development is delayed and hard to understand. Donovan had difficulties in retaining information, and was easily distracted.

In October '97 Donovan was diagnosed with ADHD, by Kanza Mental Health who does the assessments for the area schools under NM-MS Educational Coop. We were driving to Hiawatha for a psychologist appointment from October 1997...1998. Donovan's over all situation at school, was that he was dealing with more than ADHD & with the doctor agreeing, we were asked if we would like to go to Omaha or Menninger's in Topeka to do another type of evaluation Kanza wasn't equipped to perform.

We chose the Menninger's Foundation in Topeka, Ks since it was closer. We made trips every 2 weeks for a time then monthly for almost 4 years. Not only were these long distant trips but we had lost school hours, my husband had lost wages, and gas fill ups to all compensate for. These are dreaded stress filled days both financially as well as physically to us.

While doctoring at Menninger's Donovan's Diagnosis changed on 5-18-2000 to a (PDD) Pervasive Developmental Disorder, Language disorder and ADHD by William A Nathan, MD staff psychiatrist

Then Menninger's was closing and we had to again look elsewhere for trained psychological counseling. We made a connection with an office in Lincoln, Ne. call Catholic Social Services. Between 8-8-01 and 2007 we drove for counseling up to Lincoln, Ne. We also found out that there was an organization call Nebraska Farmer Hotline that would supply a voucher worth one hour's visit for the psychologist... as long as we own land in Ne., which we luckily do. So this was a pull for us to go out of state due to the funding by Nebraska Farmer Hotline Vouchers. Besides for us it was the same distance to Lincoln as it is to Topeka. We drove to Lincoln between the years '01-'05. But now we were only down to the cost of our time and gas. Dr Wilson added aspergers to Donovan's diagnosis. Which now states – ADHD/ADD, PDD = AUTISM & ASPERGERS.

In time we found out the vouchers had ran out, so I had mentioned this to the school psychologist and found out with her degree she could see Donovan and it would cost us nothing. So we went by this route and it was fantastic. No leaving school, no leaving work early, no extra gas, food or counseling cost at all. What a relief this gave us. This psychologist was very nice person whom we came to call friend.

There is always the school stress...starting with the kindergarten teacher who has no patience for children with troubles. But once he was under the care of the IRC, Donovan grew to like IRC in Kindergarten because he happened to be in there alone during his scheduled time. In grade school Donovan's IRC teacher changed about every year, for Donovan the bouncing around of IRC teachers was hard on him as a youngster. B&B always got the 'fill-in' teachers and the teachers coming in made 'noises' about there 'main' classroom, the one they were getting pulled from to cover B&B elementary that year. For 7 years (with repeating 2^{nd} grade), he had 6 different IRC teachers for $K - 6^{th}$ grade.

At the end of 1st grade and during his 2nd grade year we were experiencing frustrations. The regular Ed teacher was lax in expectations and giving credit where credit was due. We contemplated on several occasions on whether to hold him back. So at the end of his 2nd grade year we held him back to repeat it.

There is stress for Donovan by just being a member of this class, some have not accepted him for the past 9 years, but they have their own issues. We have taught Donovan to look the other way and he does this at school. There are times he has come home so ready to bust that he is crying. Which is a huge embarrassment to any teen even him. I have told the school about him coming home crying and that I will not have a depressed child (because he is turning the other cheek) on top of his other issues to deal daily with in his life.

We are at cross roads once again with Donovan and the Education Coop. If he would need therapeutic counseling this is no longer available through the Coop. Last school year they replaced the psychologist with one with a different degree in counseling. I was not made aware of this issue, till I asked her to talk to Donovan after an episode at school this school year. This means we go back to paying out of pocket plus traveling expenses again.

With all our frustrations and other families in the area we are learning what more we can do as individuals, families and as an organization. We have started our own support group called S.K.I.P. (Special Kids Informed Parents) to help area families through trying times and now have families in 6 counties.

Thank you for taking the time to read our story; and for serious consideration of bill #12. This bill will make a big difference to us as well as for many other families through out Kansas.

Alicia M. Keegan

10-5

Jan. 5, 2008

Dear Legislators:

I am a special education teacher of 20 years. In my profession I have worked with all types disablities from deaf, blind, Down's syndrome, and autism. I can say, without a doubt, that the struggles of autism leave many families feeling desperate and overwhelmed. The burden on families emotionally and financially is something many of us cannot imagine. Every minute of every day must be mapped out to insure that their autistic son or daughter will behave appropriately, communicate properly, and get the medical treatment necessary to help them function on a day to day basis.

I urge you to consider passing Kate's Law to help ease the burden on these families, but more importantly, to give these children what they need and deserve. Autism is no less important than being born blind or deaf and it is much more prevalent! Thank you for your consideration.

Sincerely,

Donna Elder

Early Childhood Special Education Teacher

Donna Elder

USD #336 Holton Special Education Cooperative

January 29, 2009

Kellye L. Schroeder 4750 SW 17th Terrace Topeka, Kansas 66604 Phone: 785.271.1356

To Committee members of The Accessing Autism Services Bill (SB 12), "Kate's Law",

I am writing as a constituent with hope, urging you to support SB 12, which would require health insurance to cover the diagnosis and treatment of autism spectrum disorders in Kansas.

I write to you as a mother of a child with an autism spectrum disorder. My son, Hunter, is seven years old. Our journey during diagnosis and since has been a grueling one. Our family has been sent from one doctor to the next just for diagnostic purposes. You may not be aware of the many complications that arise as to what insurance covers and the limitations on where to go and who to see and what an acceptable diagnosis is. We are told to go out of town to hospitals with long waiting lists or sign waivers for medical cards to try and receive therapies and we are told that we cannot use Hunter's autism spectrum diagnosis for treatment due to insurance and that we can get coverage with a different diagnosis. The disorders are just far too complex.

I am a stay at home mom. This is only feasible with a schedule of unpredictable and various appointments and my husband and I try to do home based therapies without the added stress of insurance conflicts. Financially and without professionals, we provide what we can, but it is not enough. Hunter's elementary school is now doing an evaluation to see what they are able to do for him. You may find it surprising that schools have such a burden forced upon them due to many insurance situations. As our battles with insurance persist, we will continue to pay for our son's therapies and medications the only ways we can. The expenses just multiply. We understand that Hunter is young and we have many years ahead. Insurance struggles that leave our child behind to be forgotten are not the future. The Accessing Autism Services Bill is his future. It is the future of all Kansas children being forgotten.

I hope I can count on you to support SB 12. Thank you for your consideration!

Kellye L. Schroeder

FI:I Committee 1-29-09 Attachment 11



700 SW Jackson, Suite 803, Topeka, KS 66603-3737 phone 785/235-5103 fax 785/235-0020 interhab@interhab.org www.interhab.org

January 29, 2009

TO: Senator Ruth Teichman, Chairperson

Senate Committee on Financial Institutions and Insurance

FR: Tom Laing, Executive Director

InterHab

RE: Testimony in support of Senate Bill 12:

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 SB 12 to establish a requirement that private health insurance companies cover the diagnostic evaluation and treatment for autism spectrum disorders for fully funded policyholders in Kansas.

A growing body of research-based information now documents that there exists services which, when available and applied in a timely and professional approach, 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 legislation establishes reasonable coverage limitations, allows small employer groups to be exempted, and is modeled after successfully enacted laws in other states.

All persons with health insurance have a right to expect that their most basic health-related needs would be a part of their health insurance package, and yet that has not been the case for families challenged by the difficulties facing persons with 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 should be covered by insurers.

We urge your thoughtful consideration and your timely passage of Senate Bill 12.

Thank you for your attention to this important matter.

FI:I Committee 1-29-09 Attachment 12

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Memorandum

TO:

THE HONORABLE RUTH TEICHMAN, CHAIR

SENATE FINANCIAL INSTITUTIONS AND INSURANCE COMMITTEE

FROM:

WILLIAM W. SNEED, LEGISLATIVE COUNSEL

AMERICA'S HEALTH INSURANCE PLANS

RE:

S.B. 12

DATE:

JANUARY 29, 2009

Madam Chair, 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 S.B. 12. Notwithstanding the good intentions behind the introduction of S.B. 12, 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

555 Kansas Avenue, Suite 101 Topeka, KS 66603-3443 Telephone: (785) 233-1446 Facsimile: (785) 223-1939

FI & I Committee 1-29-09 Attackment 13 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 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 S.B. 12 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 S.B. 12. I am available for questions at your convenience.

Respectfully submitted,

William W. Sneed

WWS:kjb

Independent Actuarial Analysis Reveals Cost of Insurance Mandate 1/7/2009 3:26:00 PM

CONTACT:

Jennifer Monies, Press Secretary Oklahoma House of Representatives Office of House Speaker Chris Benge

Office: 405-962-7679 Cell: 405-550-8144

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OKLAHOMA CITY (Jan. 7, 2009) – The costs of an autism insurance mandate would lead to at least a 7.8 percent increase in rates for insured Oklahomans and could be as high as a 19.8 percent increase, according to an independent actuarial study released today.

The report, conducted by Thomas Cummins, the actuary the House and Senate use jointly for all legislation requiring detailed financial analysis, shows that the autism mandate presented last year in Senate Bill 1537 would significantly drive up the cost of health insurance in Oklahoma. Last year's SB 1537 is identical to Senate Bill 1 filed for this legislative session.

"This report, unfortunately, confirms that adding this autism insurance mandate does in fact increase the cost of insurance and could lead to more Oklahoma families being forced to drop coverage, adding to our already high number of uninsured in our state," said House Speaker Chris Benge, R-Tulsa. "Despite claims otherwise, our goal has been to find ways to help Oklahoma families of children with autism, but to do so in a way that doesn't adversely affect other families currently struggling to pay for health insurance. But that takes time."

The actuarial analysis examines four scenarios assuming varying costs to determine the estimated percent increase policy holders could expect as a result of the autism insurance mandate.

The scenarios range from a \$40,000 average annual claim cost to an \$18,000 average cost. The report also takes into consideration an initial 10 percent contingency cushion insurance companies often add to their administrative and implementation costs until they know the true price tag of a mandate. A more long-term cost analysis is also included without the additional 10 percent administrative cost cushion.

According to the actuarial study, insurance costs would increase at a minimum of 7.8 percent assuming an \$18,000 annual claim, or about a \$141 minimum annual increase for a family with one child.

But, with a \$40,000 annual claim—which is more in line with the costs many families of children with autism face—the increase could be as high as 19.8 percent, or \$356 more a family with one child would have to pay to continue their insurance coverage whether they utilize the autism benefit or not. And the costs would likely increase with additional dependents included on the policy.

The Cummins' finding is consistent with other studies that show that mandates increase costs, with some even suggesting that for every \$25 increase in monthly premium passed on to a consumer, 10 percent of those experiencing such an increase will drop their coverage.

Proponents of the autism mandate often cite the cost analysis by James Bouder, an autism

advocate from Pennsylvania and parent of a child with autism. However, Bouder's analysis spreads the cost of the autism mandate among all insured Oklahomans to artificially lower the cost calculations. It is important to note that Cummins' independent actuarial analysis shows that in reality costs will only be spread to those policy holders with dependent coverage, since dependents are those able to utilize an autism benefit.

To further minimize the impact of an autism mandate, the Bouder study also assumes that literally 90 percent of children with autism in Oklahoma will not access any benefit from expanded coverage provided by the mandate.

Cost increases have also been seen in Texas as a consequence of their autism mandate. According to the Associated Press, Aetna, a health insurance company with policy holders in Texas and Oklahoma, said the company has tracked the cost of the autism mandate in Texas for the past year and found that it increased policy holder costs by \$379 a month.

"This documentation indicates that the proposed mandate in SB 1 would significantly increase the cost of insurance," said House Speaker Pro Tem Kris Steele, R-Shawnee. "I understand this is an emotional issue, especially to parents who are simply trying to take care of children affected by autism spectrum disorders. As lawmakers, we must focus on what is in the best interest for the state as a whole, and that includes solutions for these parents that will not price others out of the market."

In the coming weeks, House Republicans will announce a plan to help families of children with autism without imposing a costly mandate based on recommendations received in this year's interim study on the issue.

Kansas Association of Health Plans

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(785) 213-0185 marlee@brightcarpenter.com

January 29, 2009

SB 12 Before the Senate Financial Institutions and Insurance Committee Marlee Carpenter, Executive Director

Chairman Teichman 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 SB 12, the autism mandate. There are several reasons why we are here today in opposition of this measure. The KAHP believes that SB 12 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. In addition, KAHP believes that many of these services are already covered under current policies.

Historically, health insurance policies were taken to guard against catastrophic medical injuries or illnesses. The common definition of health insurance is "insurance providing compensation for medical expenses." SB 12 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. In a time when employers are struggling to maintain their current insurance policies, should we ask them to provide coverage for programs that should be provided though another source?

The current economic downturn has effected 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

FI & I Committee 1-29-09 Attachment 14 insurance premium costs, approximately 5,500 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. This would equate to more than 11,000 Kansans losing all medical insurance coverage and becoming uninsured.

Finally, health insurance carriers already provide coverage for "medically" necessary services to children diagnosed with an autism spectrum disorder. In addition, state and federal mental health parity laws already require that these conditions be covered the same as any other medical condition.

The KAHP requests that as you review SB 12 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.

BRAD SMOOT

ATTORNEY AT LAW

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Statement of Brad Smoot, Legislative Counsel
Blue Cross Blue Shield of Kansas
Blue Cross Blue Shield of Kansas City
Regarding 2009 Senate Bill 12
Senate Financial Institutions & Insurance Committee
January 29, 2009

Madam Chair and Members:

On behalf of BCBSKS and BCBSKC, we appreciate the opportunity to comment on SB 12, 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 about 700,000 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. Senate Bill 12 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, commonly known as "adverse

FI&I Committee 1-29-09 Attachment 15 selection," the product is no longer real insurance and prices for those who do opt for coverage skyrocket.

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 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 SB 12 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. In any case, the bill will have a fiscal note for the state and many municipalities (those that can't opt out). We imagine that you will want to examine that fiscal note before advancing SB 12.

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. SB 12 needs a lot of careful attention to detail or it may end up being something no one wants. Thank you.

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Senate Financial Institutions & Insurance Committee Daniel S. Murray: State Director, NFIB-Kansas Testimony in Opposition to SB12 January 29, 2009

NFIB-KS advocates free-market reforms that allow small-business owners to decide which benefits they can and cannot afford to offer.

Madam 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 SB12

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 SB12.

NFIB-KS applauds the ultimate goal of SB12. 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, SB12 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, increasing costs of fuel and other commodities, 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 SB12, we urge you to consider the impact on small business. Thank you for the opportunity to comment.

FI $\stackrel{?}{=}$ I Committee

1-29-09

Attachment 16



Wichita Independent Business Association

THE VOICE OF INDEPENDENT BUSINESS

Senate Financial Institutions and Insurance Committee Written Testimony in Opposition to SB 12 (Autism Mandate) January 27, 2009

Presented by Natalie S. Bright

The Wichita Independent Business Association (WIBA) is here today to provide written testimony in opposition to SB 12, coverage for autism spectrum disorder. WIBA represents small and independently owned businesses located in South Central Kansas.

A recent survey of our members indicates that the number one concern of our members is managing the rising cost of health care and their ability to continue to provide health insurance to their employees. For the second year in a row their concern about the cost of health care insurance has topped their concern over taxes. In fact, 51% of our members who responded to the survey indicated health insurance as their greatest cost of doing business after their payroll expenses.

In addition, the Kansas Health Institute provided information to the Interim Committee indicating that 25% of Kansans work for small businesses and that they are seeing a 7%-12% increase per year in health insurance premiums. This health insurance mandate will increase the cost of health insurance to small businesses. The bill provides an opt-out for businesses in the small group market 2-50. While this opt-out provision is helpful, not all businesses will opt-out and the cost for these services will increase premium costs among this group.

WIBA members are typically small businesses, but our membership does include many businesses that have more than 50 employees. This measure would not opt-out groups of 50 or more employees, thus increasing the costs of health insurance for this employment segment.

In this time of economic uncertainty, we believe that the Kansas Legislature should enact policies that reduce the cost of health insurance for employers, not increase the costs so that more Kansans are covered and not priced out of the health insurance marketplace.

Thank you for your consideration of this issue and please feel free to contact me if you have any questions.

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Legislative Testimony



SB 12

January 29, 2009

Senate Financial Institutions and Insurance Committee

Rachelle Colombo, Senior Director of Legislative Affairs

Chairman Teichman, members of the Committee:

We appreciate the opportunity to provide written testimony in opposition to SB 12 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 SB12 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.



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