

MINUTES OF THE SENATE EDUCATION COMMITTEE

The meeting was called to order by Chairman Jean Schodorf at 1:35 p.m. on February 5, 2007, in Room 123-S of the Capitol.

Committee members absent: Barbara Allen- excused
Carolyn McGinn- excused
Ralph Ostmeyer- excused

Committee staff present: Sharon Wenger, Kansas Legislative Research Department
Michele Alishahi, Kansas Legislative Research Department
Ashley Holm, Kansas Legislative Research Department
Theresa Kiernan, Revisor of Statutes
Shirley Higgins, Committee Secretary

Conferees appearing before the committee: Senator Dennis Wilson
Kyle Kessler, Kansas Department of Social and
Rehabilitation Services
Michael L. Wasner, D.V.M.
Dr. Carol B. Garrison, Children's Mercy Hospital & Clinics
Joe Fiorella
Jim Leiker, Capper Foundation Easter Seals

SB 138 – Autism Task Force

Senator Dennis Wilson testified in support of **SB 138**. He commented that it has been proven that children with autism who receive early treatment from experienced professionals can be saved from a very debilitating life. Additionally, the parents could be relieved from a tremendous financial burden. He noted that the intent of the bill was to help state legislators make good public policy for dealing with autism. (Attachment 1)

Kyle Kessler, Deputy Secretary for Public and Governmental Services, Kansas Department of Social and Rehabilitation Services (SRS), testified in support of **SB 138**. He explained that SRS has set many goals to address the significant growth of autism and the existing gaps in services for children with autism. SRS believes that early intervention will not only enhance the life of the child but also prevent many children from accessing SRS caseloads later in life, which could help avoid significant costs to the state. Mr. Kessler suggested that **SB 138** be amended to include SRS, the Kansas Department of Health and Environment, and the Department of Education as ex-officio members, by requiring that both an occupational therapist and a speech language pathologist be appointed to the task force, and by providing that all appointing authorities make the appointment of a parent of a child of an ASD to the task force. (Attachment 2)

Michael L. Wasmer, DVM, testified in support of **SB 138** as a parent of a child with autism, as a member of the Kansas Governor's Commission on Autism, and as cofounder of the Kansas Coalition for Autism Legislation. He emphasized that autism is not a problem that can be solved by a single group or state agency. He explained that the bill acknowledged the complexity of autism by including a diverse group of members and supporting agencies. Noting that the prevalence of autism in Kansas and nationwide is increasing in epidemic proportions, he suggested that a state registry of individuals with autism that includes children who have not yet entered the public school system is needed to provide a more accurate accounting of individuals with autism spectrum disorders in Kansas. He noted further that the cost of early intensive intervention for a child with autism can exceed \$30,000.00 per year; however, health insurance companies generally do not provide coverage for these services. Because of the importance of the health insurance issue, he asked that the bill be amended to include the Kansas Department of Insurance in Section 1(d) as an agency that will provide information and supporting documentation at the request of the task force. He went on to explain that the proposed task force would be charged with considering all treatment methods and asked to develop a consensus statement regarding best practice. In conclusion, Dr. Wasmer asked the Committee to consider amending the bill to include in the task force an appointee from the Kansas Governor's Commission on Autism. (Attachment 3)

CONTINUATION SHEET

MINUTES OF THE Senate Education Committee at 1:30 p.m. on February 5, 2007, in Room 123-S of the Capitol.

Dr. Carol B. Garrison, a neurodevelopmental pediatrician at Children's Mercy Hospitals and Clinics, testified in support of **SB 138** on behalf of individuals with autism, their families, and professionals who serve them. She explained that autism is a neurologic developmental disorder, and treatment for autism is consistent with the concept of "rewiring" the neuronal networks of the brain. Because treatments for children with autism are outside the traditional medical model, the children and their families are caught in the middle and remain underserved. She emphasized that autism is a medical condition; however, insurance will not cover services on the grounds that the services are educational in nature. She explained that the bill addressed the important issue of private insurance contributing to the diagnosis and treatment of autism. She pointed out that, in other areas of the country, children with autism are receiving services from the time of diagnosis, but services are currently inconsistent across the state of Kansas. She commented that professionals are anxious for the time when families can be served efficiently and effectively upon diagnosis of their child. (Attachment 4)

Joe Fiorella, a parent of an autistic child, testified in support of **SB 138**. He explained that he worked 14 years within the insurance industry, which included active involvement in claims processing. He noted that the diagnosis of autism, unlike other afflictions, does not come with standard "generally accepted medical practices," and there are multiple hurdles in even securing a diagnosis. His company availed the services of their general counsel to assist him with claims to his insurance company for coverage for his child. Each time one issue was resolved, his insurance company fabricated another one. All of his appeals were denied even though an outside board unanimously recommended payment for services provided to his child. He then turned to the Kansas Department of Insurance for assistance. The Department informed the insurance company that they had to pay; however, the company continued to fabricate reasons for not paying. He noted that, without an established best practices standard, confusion will continue for parents and providers, and insurance companies will continue to use this void as an excuse to not cover any services. He contended that a registry would not only identify those who need help but would be a mechanism to better address and service children with autism. (Attachment 5)

Dr. Wasmer distributed copies of written testimony in support of **SB 138** by Dr. Kathryn Ellerbeck, M.D., Assistant Professor of Pediatrics at the University of Kansas School of Medicine. Dr. Ellerbeck addressed the difficulties families have experienced in their attempts to access the medical system for diagnosis and treatment of autism. (Attachment 6)

Jim Leiker, President and CEO of the Capper Foundation Easter Seals, testified in support of **SB 138**. He recommended that more parents of children with autism be represented on the proposed task force because they know first hand what they need. In this regard, he recommended Brad and Linda Sloan, parents of a child with asperger syndrome and volunteers at the Capitol Area Asperger and Autism Resource Center. He also recommended that a community provider of autism services be represented on the task force. In this regard, he recommended the Caper Foundation Easter Seals, the leading non-profit provider of services for individuals with autism throughout the country. (Attachment 7)

There being no further time, the hearing on **SB 138** was continued to the February 6 meeting.

The meeting was adjourned at 2:30 p.m.

The next meeting is scheduled for February 6, 2007.

**SENATE EDUCATION COMMITTEE
GUEST LIST**

DATE: February 5, 2007

NAME	REPRESENTING
Eric Van Allen	SRS-HEP
Kyle Kessler	SRS
Joe Gamble	KBOE
Linda Sloan	Capitol Area Autism/Asperger
J. Decker	The Copper Foundation Resource Center EASIER SEALS
✓ Laura Higbee	myself.
Josie Torres	3/1CK
BILL REARDON	USD 500
Diane Gjerstad	Wichita Public Schools
Dan Morin	KS Medical Society
Casey Spencer	TFI Family Services
Andy Schlapp	Sedgwick County
Joe Finckh	Parent of autistic child
DONALD BONDANK	KEAL CO-FOUNDER
Stuart Little	Shawnee Mission 512
Val DeFera	Schools for Quality Ed
Michael Wasmer	parent, co founder KEAL
Ka May	LGA
TERRY FORSYTH	KWLA

STATE OF KANSAS

DENNIS M. WILSON
SENATOR, 37TH DISTRICT
JOHNSON COUNTY
11925 GILLETTE
OVERLAND PARK, KANSAS 66213



TOPEKA

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**Testimony in Support of Senate Bill 138
Presented to the Senate Education Committee
By Senator Dennis Wilson**

February 5, 2007

Chairman Schodorf and members of the Committee:

Thank you for scheduling this bill on autism and for allowing me to add my support for the passage of this bill.

My interest in this subject started about three years ago when I spoke with a parent of a child with autism. Like many of you, I had heard of this mental disorder but knew very little about it or about how wide spread it is becoming. But the good news is we can drastically curve the effects of this disorder by early intervention.

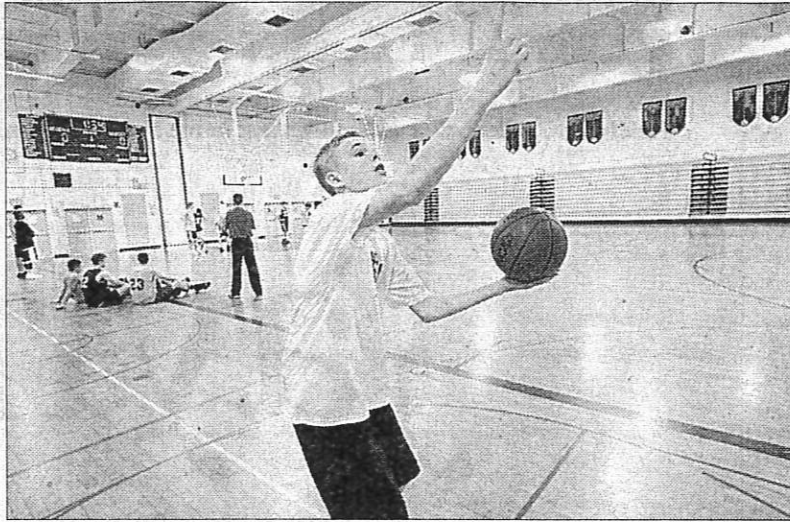
I now have made a personal commitment to the advocacies group in Kansas that I will do everything in my power to facilitate their cause, and to bring hope and even a cure for this disorder through early intervention. There are several ways we as legislators can be of help. One would be to pass this bill to set up a TASK FORCE that is made up of professionals in the area of autism, parents of autism children and legislators who have an interest and knowledge in this area.

The information that you have heard and will hear today will prove that if we can get the experienced professionals involved early we will save these children from a very debilitating life and their parents from financial ruin. As you can see when you read this bill, the TASK FORCE will be charged with many objectives. But the main objective would help us as state legislators make good public policy dealing with autism.

I have included an article about a teenager with autism and the miracle that took place last year in a high school. I hope it will give you the same encouragement it did me when I first heard about this extraordinary feat. This bill will give hope and encouragement to all of our citizens who face this tragedy daily, and to the unexpected parents who will face this problem in the future.

I will stand for questions at the appropriate time. I will now yield my time for the other conferees.

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2-5-07
Attachment 1*



The Associated Press

Back in his familiar role, team manager Jason McElwain shot baskets alone Monday as the Greece Athena High School team ran drills.

Hoops hero goes back to old job

He hit a three-pointer, a double-pump layup and a free throw in practice Monday.

Then **Jason McElwain** charged back into the locker room and back to his job as team manager. McElwain is the autistic teen who snuck into America's heart last week with a 20-point performance when he was allowed to suit up and play in his team's final game.

But Monday, he was back to handing out water bottles, helping run drills and exhorting his teammates on the eve of Greece Athena High School's sectional game Tuesday night in the New York state playoffs.

"You've gotta give it everything you got!" he sang in a rap verse. "The winner goes home all happy/ The loser goes home and says/ Mommy we lost the game, wah wah wah!"

McElwain — or at least his story — may become the next "Rudy."

Or "The Rookie" — movies based on real-life situations.

After his feat — six three-pointers that were caught on a student video that made the rounds of the television networks — the school was besieged with calls and e-mails from parents of autistic children.

His parents have received inquiries from about 25 production companies ranging from The Walt Disney Co. and Warner Bros. to independent documentary filmmakers.

Meanwhile, Jason is back in school. He's apparently not upset that he is ineligible to suit up for the sectional game because he played in only one game all season. He's hanging with his friends.

"I'm not really that different," he said. "I don't really care about this autistic situation, really. It's just the way I am. The advice I'd give to autistic people is just keep working, just keep dreaming; you'll get your chance and you'll do it."

Kansas Department of

Social and Rehabilitation Services

Don Jordan, Secretary

Senate Education Committee

February 5, 2007

SB 138

Public and Governmental Services

Kyle Kessler, Deputy Secretary

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For additional information contact:
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*Senate Education Committee
2-5-07
Attachment 2*

**Kansas Department of Social and Rehabilitation Services
Don Jordan, Secretary**

Senate Education Committee
February 5, 2007

SB 138

Chairperson Schodorf and members of the Committee, my name is Kyle Kessler. I am the Deputy Secretary for Public and Governmental Services at SRS. I appreciate the opportunity to appear before you today to provide testimony on SB 138 which would establish the Autism Task Force. We very much support this concept.

SRS has set many goals to address the significant growth of autism cases and the existing gaps in services for this population. For many years, we have proposed as a part of our budget an autism waiver that would provide early intervention services to kids who have autism spectrum disorders (ASDs). We have established a multi-disciplinary group which includes individuals from the fields of mental health, developmental disabilities, physical disabilities, and child welfare along with parents who have children with ASDs to work on the blueprint for an autism waiver. The larger group has been meeting since September. A smaller subgroup has been formed to work on the specific components of the waiver and report back to the larger group. Our goal is that the work on the waiver be completed by May with the anticipated submission to the Centers for Medicare and Medicaid Services (CMS) by June of this year. With a successful submission, we hope to offer enhanced services through this waiver starting in January 2008. We believe that by using early intervention, this will not only enhance the life of the child and his or her family, but also prevent many of the children from accessing SRS caseloads later in life which could help avoid significant costs to the state.

According to our research, five other states have established Autism Task Forces that have representatives from the respective human services agencies. SRS supports SB 138 with the following suggested amendments: the inclusion of SRS, KDHE, and the Department of Education as ex-officio members; the requirement that both an occupational therapist and a speech language pathologist be appointed to the task force, rather than one or the other; and lastly, that all appointing authorities make the appointment of a parent of a child of an ASD to the task force. Although this final recommendation raises the number of members from thirteen to eighteen, some of the most valuable feedback SRS has received in studying the gaps in services to this population has been from parents. Prior to the establishment of our current work groups, we held Parent Forums in August in the communities of Topeka, Hays, and Wichita. These were sponsored by the Governor's Commission on Autism which SRS staffs.

In closing, SRS expresses its support for a task force with the multi-disciplinary membership that is recommended. We acknowledge that no one agency and no one field of expertise will be able to address autism spectrum disorders but through the kind of thoughtful

collaboration that is suggested by the establishment of this task force, we may be able to offer greater solutions for persons with ASDs in the future. This concludes my testimony, and I would be happy to stand for questions.

February 5, 2007

**Testimony to the Senate Education Committee
in support of Senate Bill No. 138**

Michael L. Wasmer, DVM
14617 S. Garnett St.
Olathe, KS 66062
913-233-9101

My name is Mike Wasmer and I appreciate the opportunity to speak in support of Senate Bill 138, the Autism Task Force Bill. As the father of a child with autism, a member of the Kansas Governor's Commission on Autism, and cofounder of the Kansas Coalition for Autism Legislation, I view Senate Bill 138 as a critical first step toward clarifying the scope and magnitude of the issues facing the autism community in Kansas; and legislative change to address the problems.

Autism awareness campaigns frequently use a puzzle piece to symbolize the complexity of autism and many unanswered questions. Autism is not a problem that can be solved by a single group or state agency. The composition of the Autism Task Force as proposed by Senate Bill 138 acknowledges the complexity of autism by including a diverse group of members and supporting state agencies, which can contribute unique perspectives on this issue.

Autism encompasses a spectrum of disorders that includes classical autism, Asperger's Syndrome and Pervasive Developmental Disorders*. The prevalence of autism in Kansas, and nationwide, is increasing in epidemic proportions. In April 2004, the Centers for Disease Control reported the prevalence of autism spectrum disorders as 1 in 166. Ten years ago, the prevalence was approximately 1 in 10,000. In Kansas, from 1997 to 2004, the number of children with autism as reported under Part B of IDEA increased by 471%.

The needs of the autism community in Kansas are many. Of particular concern is the inconsistent delivery of services across the State, and meeting the expense of adequate therapy. Three of the more critical charges of the proposed Task Force will address these issues: creation of an autism registry, investigation of the availability of insurance coverage for children with autism, and development of a consensus statement on best practice for educating children with autism.

We can estimate the number of affected individuals with autism in Kansas based on the CDC's national estimate of 1 in 166. However a State registry, that includes children who have not yet entered the public school system, is needed in order to provide a more accurate accounting of individuals with autism

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2-5-07
Attachment 3*

spectrum disorders in Kansas. Without a registry, it will be very difficult to accurately budget for the cost of providing services across the State. A registry would also facilitate equitable distribution of service providers throughout Kansas, as well as allow researchers to complete epidemiologic surveys of the disorder.

The cost of early intensive intervention for a child with autism can easily exceed \$30,000 per child per year. Despite the fact that cost-benefit studies** have demonstrated tremendous cost savings over the lifetime of an individual with autism if an early diagnosis and appropriate therapy is received, health insurance companies generally do not provide coverage for these services. There is currently no legislation in Kansas that addresses the complexity of this issue. Any legislation to address the problem of health insurance coverage for autism must be very carefully constructed to ensure access to all necessary services.

Because of the importance of the health insurance issue, I would ask that the Committee consider amending Senate Bill 138 to include the Kansas Department of Insurance in Section 1(d), as an agency that will provide information and supporting documentation at the request of the Task Force.

Despite a large body of evidence-based research, there remain differences of opinion as to what methods of treating children with autism are most effective. This may be a contributing factor to inconsistent health insurance coverage for autism spectrum disorders. The proposed Task Force would be charged with considering all treatment methods, and asked to develop a consensus statement regarding best practice. In addition to the potential benefit of facilitating health insurance coverage, a consensus statement from a state-legislated task force would also provide a useful guideline for parents of newly diagnosed children. Frequently, parents are overwhelmed into inaction by too many differing opinions on how best to treat autism. Additionally, parents are often given incomplete or inaccurate information, including recommendations that have come from our own state agencies such as Infant and Toddler Services.

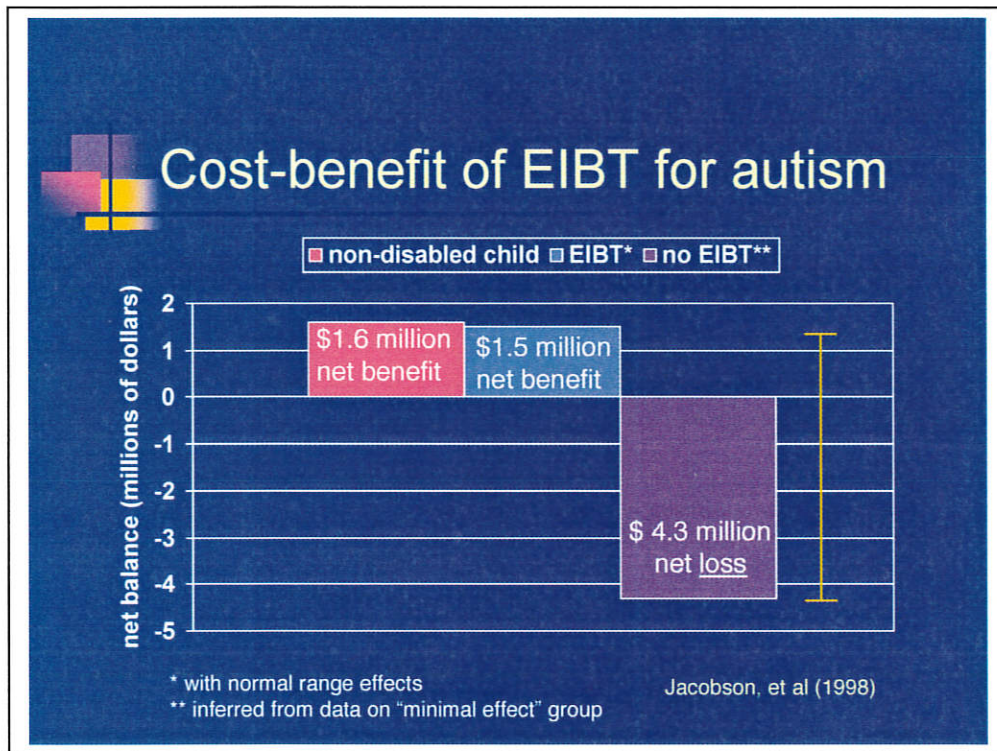
The passage of Senate Bill 138 plays the pivotal role of allowing Kansas to take a more proactive position in combating the crisis of autism.

I would ask that the Committee consider amending Senate Bill 138 to include an appointee from the Kansas Governors Commission on Autism (KGCA), or include the Governor's Commission as a resource in section 1(d). Although the Chairperson of the Governor's Commission on Autism has clarified that the responsibilities of the Task Force proposed by Senate Bill 138 are beyond the scope of the Governor's Commission to perform, this group remains a valuable resource for information.

I sincerely appreciate the Committee's interest in this very important issue and ask for your support of Senate Bill Number 138.

* Pervasive Developmental Disorder (PDD), Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS)

** see attachment, "Cost-Benefit of EIBT for Autism"



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

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

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

The area in purple represents the net costs associated with NOT providing EIBT to a child with autism. This demonstrates a net LOSS of \$4.3 million and an overall difference of \$5.8 million between the two groups.

Reference:

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



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February 5, 2007

**Testimony to the Senate Education Committee
in support of Senate Bill No. 138**

Carol B. Garrison, M.D.
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Shawnee, KS 66216
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Good Afternoon. My name is Carol Garrison. I am grateful for the opportunity to speak in support of Senate Bill 138, the Autism Task Force Bill.

I am a Neurodevelopmental Pediatrician, with Board Certification in Pediatrics, Neurodevelopmental Disabilities, and also in Developmental Behavioral Pediatrics. I evaluate children for developmental disabilities at Children's Mercy Hospitals and Clinics in the Section of Developmental and Behavioral Sciences and I am presently the Fellowship Director for our accredited Developmental Behavioral Pediatrics Fellowship. I have been in this field for 17 years.

I speak on behalf of individuals with autism, their families, and professionals who serve them.

I have been a member of the Governor's Commission on Autism since January 2001. Throughout this time, we have discussed concerns related to individuals with autism and their families. Through yearly updates, the Commission advises and makes recommendations to the Governor. This has been a satisfying process, yet at times frustrating – due to the limited scope of the Commission. Senate Bill 138 allows action beyond the scope of the Governor's Commission. Action which we believe is necessary to improve the quality of services and ultimately the functional outcome of individuals with autism and their families.

Autism is a neurologic developmental disorder. The brain does not process information in a normal manner. The nature of the primary treatments for individuals with autism is consistent with the concept of "rewiring" the neuronal networks of the brain – thus impacting the outcome of the individual. Yet, the primary treatments for these individuals are outside of the traditional medical model. This establishes a false

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2-5-07

Attachment 4

dichotomy: is it medical, or is it educational? Children and their families are caught in the middle, and remain underserved.

Autism is a medical condition. As professionals in the field, we continue to hear that insurance will not cover services – as they are “educational” in nature. Even diagnostic studies to determine an underlying etiology – studies presently recommended by one of several medical Practice Guidelines (Neurology, Genetics) – may not be covered – as the diagnosis of autism may fall under “mental health”. Senate Bill 138 allows the important issue of private insurance contributing its portion of revenues in the diagnosis and treatment of this neurologic disorder.

As a professional in the field, it is frustrating to know that in other areas of the country, children with this diagnosis are receiving evidence-based services from the time of diagnosis. At this time, services are inconsistent across the state of Kansas. “Turf wars” regarding which intervention (if any) preclude optimizing needed therapies to children. Establishing an Autism Task Force, as an independent body, to develop evidence-based recommendations for best practices for early interventions is necessary to provide accountability to the groups which are providing services.

The registry is a vital issue from many perspectives. It allows for long-term planning, tracking of information and epidemiologic information. As the Autism Commission has worked over several years, one critical piece of information requested has always been “What are the numbers?” We appreciate that SRS is hoping to address the needs for an autism registry. However, our understanding is that this may be limited in scope. Including the registry in this bill allows the Autism Task Force to have critical input into any registry developed.

The personal experiences that you hear today from Dr. Wasmer and Mr. Fiorella are not isolated. Professionals in our section routinely encounter the frustration of families who are dealing with these same issues. We are anxious for the time when families can be served efficiently and effectively upon diagnosis of their child.

I respectfully appreciate the Committee’s interest in this issue and ask for your support of Senate Bill Number 138.

Carol B. Garrison, MD
Neurodevelopmental Pediatrician
Children’s Mercy Hospitals and Clinics

- SENATE BILL 138 -
February 5, 2007
TESTIMONY BY JOE FIORELLA

- My name is Joe Fiorella. I thank you for the opportunity to speak to you today.
- First and foremost, I come to you as a parent of an autistic child. However, I spent 14 years working within the insurance industry, eight of which as a Chief Operating Officer of a health insurance organization including active involvement in claims processing.
- As both a parent and an officer of a health insurance organization, I have a balanced view of the issue. While certainly concerned with my child's welfare, I understand balancing the cost and treatment.
- Recently a couple informed me their child is on the autistic spectrum. I recognized not only their shock and grief, but also the look of confusion and frustration. And that is because my wife and I had the same look. Unfortunately it is all too common and increasing dramatically.
- Autism, unlike other afflictions does not come with a standard "generally accepted medical practices" of how to address autism. Even before the diagnosis, there are multiple hurdles in even securing a diagnosis.
- Sequentially,
 - Natural dismissal of warning signs by all who come in contact with children including parents.
 - Roadblocks to diagnosis (Infant Toddler Services practices, waiting lists for evaluations)
 - As a result of the lack of best practices consensus, there are diametric opinions as to what therapy may best treat their child.
 - A lack of providers who have specific training for autistic children. Also as in our case - a premium charge per hour of service due to the diagnosis.
 - Little if any oversight of those providers addressing autism and then
 - Dead ends with insurance companies

Now consider all of these together –

- shock of your child having a life long affliction
- a tremendous financial burden
- endless conflicts with your insurance company even for services not related to autism.
- the professionals disagree what should be done to best help your child
- there is a lack of therapists specifically trained to deal with your child's affliction

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Attachment 5*

- I was fortunate from several aspects.
 1. While an extreme financial hardship, I had the ability to retain therapists outside of any insurance.
 2. As COO of a health insurance company, my company availed the services of their General Counsel to assist me in dealing with the insurance company. (Since we adjudicated claims, we didn't want our associates to handle insurance issues for their coworkers so we secured another company's insurance plan.)
- What we found were repeated and inconsistent run-arounds for the insurance company not to pay.
 - Each time an issue was resolved, another was fabricated.
 - While I followed all ERISA guidelines, the insurance company violated multiple federal and state laws with no consequence.
 - All appeals were denied even after the insurance company retained an outside board of physicians.
 - “Based on this, the medical policy of Blue Cross Blue Shield of Kansas City with regard to the denial of speech to children with Autism is not in sync with current standards of medical care.”
 - This outside board unanimously recommended payment of the services provided.

RESULT: APPEAL DENIED

- The insurance company claimed they were unaware of legislation requiring them to pay yet it was proven that they were registered lobbyists against the act. (The Kansas Mental Health Parity Act)
 - I turned to the KS Department of Insurance for assistance.
 - Yes, they agreed with me and informed the insurance company they had to pay.
 - The insurance company still fabricated reasons for not paying
 - Example: Provider not in database. What does it take to get them in your database? Among other things, their license. Both provider and I submitted multiple copies (I did via certified mail). They then came back asking for the same license but attached to their request was a copy of the license they were requesting.
 - To date, only a nominal amount has been paid and they've reverted to the same excuses.
- The General Counsel who is very experienced in these issues was astounded at the repeated handling.
 - I bring this to your attention that even with knowledge and resources (including the support of the KS Department of Insurance), I was unsuccessful in dealing with the insurance industry.

- And this leads to yet another issue encountered by parents – many have been advised that it is not wise to proactively offer the diagnosis of autism to insurance companies under a twofold threat both of which came true in my case:
 1. Therapy claims will be blanketly denied. (I was told by one provider that my case clearly has been red flagged.)
 2. Other non-autism related claims may be denied.

- Without an established best practices standard,
 - confusion will continue both for both parents and providers.
 - Insurance companies will continue to use this void as an excuse to not cover any services.

- Autistic children, if denied services, will place a greater financial burden upon the state. Initially through the school systems, but ultimately throughout their lives they will be the long-term responsibility of the state. Studies have proven that appropriate services can address many of the issues.

- Autism is a neurodevelopmental abnormality but there is currently some relief under the Kansas Mental Health Parity Act. In addressing this issue, **coordination** with all legislation will be required.

- The registry will not only identify those that need help but will be a mechanism to better address and service these children.

- I ask you to support Senate Bill 138 for not only parents of autistic children but for all the taxpayers of Kansas.

- Again, I thank you.



February 5, 2007

Re: Senate Bill No. 138

To the Members of the Senate Education Committee:

I am pleased that you are considering Senate Bill No. 138 which would establish a Kansas autism task force. I am writing to provide my support for the bill. Mike Wasmer, Cofounder of KCAL, asked that I address some of the difficulties our families have with access to the medical system for diagnosis and for treatment.

I am a developmental-behavioral pediatrician at the Developmental Disabilities Center. I am part of an interdisciplinary autism diagnostic team under the direction of Matt Reese, Ph.D., Deputy Director of the DDC. Much has changed in the twelve years since I finished my fellowship and moved back to Kansas City. We know that autism is much more common than previously thought. One in every 166 children is believed to have an autism spectrum disorder. In 1995, autism clinics were just beginning to be set up across the country. Today the Developmental Disabilities Center (DDC) runs several state-of-the-art autism diagnostic teams. When I came to Kansas City in 1995 – even children with severe autism might not be diagnosed until they were four or five years of age. We now know that we *are* able to diagnose children early. And we know that we must. Today we understand that early intervention makes a significant difference in the life of a child who has autism and in the lives of the families who love them.

Early diagnosis is critically important – and so, in 2004, the Centers for Disease Control and Prevention (CDC) with the support of the American Academy of Pediatrics launched the “Learn the Signs. Act Early” campaign to help doctors and parents recognize the signs of autism and other developmental disability. Screening guidelines from the American Academy of Pediatrics recommend that all 18-month-old children be screened for autism. Screening, however, is only the first step. Both the family of a child with symptoms of autism – and the primary care provider who screens that child – face a daunting task with respect to getting a formal diagnosis. And formal diagnosis is often the key to appropriate early intervention. Autism is often a complicated diagnosis to make. Clinical practice guidelines recommend that children suspected to have autism be referred to interdisciplinary diagnostic teams expert in autism. (Practice parameter: Screening and diagnosis of autism. Report of the Quality Standards Subcommittee of the

American Academy of Neurology and the Child Neurology Society. *Neurology*. 2000; 55: 468 – 479).

In Kansas, there is much to be done in terms of training. Many more providers need to be trained, and we hope that eventually there will be regional diagnostic teams across Kansas. *However, a major barrier to progress in early diagnosis and treatment has to do with how medical insurance covers the "autism" diagnosis.* Reimbursement issues pose a major barrier to progress in (1) screening rates in primary care physician offices (2) early diagnosis by a trained diagnostic team and (3) appropriate early intervention. I will limit my testimony today to reimbursement issues as they affect the interdisciplinary diagnostic process at the Developmental Disabilities Center.

As providers, we have difficulty in delivering the current standard of care in terms of a comprehensive interdisciplinary evaluation for a child suspected of having an autism spectrum disorder. We have the following difficulties:

- (1) Insurance companies do not recognize an interdisciplinary evaluation. To control costs, most insurance companies have dedicated vendors to provide mental health services or allied health (Speech & Language, Physical Therapy, Occupational Therapy). The number of dedicated vendors per geographic area are restricted. This translates to many families having to pay out of pocket for the psych testing portion, or allied health evaluation services if they have an HMO or PPO with no out of network benefits (for services at the DDC). Yet, these dedicated providers admit themselves that they are unable to provide the same service that the Developmental Disabilities Center provides. For example, we had approached BCBS asking that we be recognized and contracted as a facility that provides comprehensive evaluations, but they refused. Their preference is that their subscribers be referred to each discipline individually so that they do not violate their contracts with their dedicated vendors. This of course allows them to control costs. For a parent, this may entail several visits to different providers, each with a fragmented view of their child. Often there are conflicting treatment recommendations.
- (2) Exclusionary diagnosis within policies apply also to initial evaluations. For example, Blue Cross and Blue Shield has actively marketed policies that exclude the diagnosis of autism. For many parents, it is a roll of the dice. If their child is diagnosed with autism, the insurance company will not pay for any part of that evaluation. If their child is diagnosed with something else, the insurance will pay. When parents find out about their exclusions, many decide to delay an evaluation which could significantly hinder intervention efforts (depending upon the age of the child). This seems to be at odds with the State of Kansas Mental Health Parity Act.
- (3) More recently, we are seeing an alarming trend in how claims for developmental medicine are being processed by the insurance companies. The majority of medical insurance providers contract with another organization to manage their

participant's mental health benefits. We will see a child to provide a medical service, but because the diagnosis is considered a "mental health" diagnosis, we are advised that their participant's benefits are provided by another "plan administrator". The claim is then sent to the mental health carrier, is processed, and we are told that payment is denied because we failed to obtain preauthorization from the mental health plan to provide our medical service. The providers and patients must then appeal the insurance company's decision – which can be an endless pursuit, as they are referred back and forth between the two insurance plans.

Research has shown that with early diagnosis and intervention, many children with autism spectrum disorders can join his/her peers with little to no educational accommodations by the 2nd grade. Early intervention can also decrease disruptive behaviors. Instituting preventative measures that include early diagnosis and intensive intervention for children with autism will save Kansas hundreds of thousands of dollars.

The health insurance system is difficult for many Americans. The system is almost impossible for the family of the child with autism. It is ethically unacceptable to delay diagnosis and treatment for a treatable condition. And autism, while generally not curable, *is* treatable.

Respectfully submitted,

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The Capper Foundation



February 5, 2007

Good Afternoon Senators -

My name is Jim Leiker. I am the President & CEO of The Capper Foundation Easter Seals. Our organization was founded by Arthur Capper, Kansas Governor, U.S. Senator Representing Kansas for 30 years, Publisher and Philanthropist. For more than 86 years, we have been offering help and hope to children and adults with disabilities, and to the families who love them. The Capper Foundation Easter Seals is Arthur Capper's living legacy and like him, we continue carrying on his commitment to enhancing the independence of people with disabilities and ensuring that all people enjoy access, opportunities and independence.

As indicated in our name we are affiliated with Easter Seals, The leading non-profit provider of services for individuals with autism, development disabilities, physical and mental disabilities, and other special needs. Through therapy, training, education and support services, Easter Seals creates life-changing solutions so that people with disabilities can live, learn, work, and play in their communities.

Easter Seals affiliates across the country together offer 45 different kinds of interventions to address the affects of autism. For example, The Capper Foundation Easter Seals is a regional service provider located in Topeka, Kansas and provides number of services for children with autism spectrum disorders, families and professionals. These included childcare services, occupational therapy for sensory processing disorders, speech therapy, therapeutic recreation, summer camps and substantial professional and family training.

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2-5-07

Attachment 7

Regarding Senate Bill 138 establishing the Kansas Autism Task Force and its powers and duties and duties, we are excited for the individuals and families in Kansas affected by autism spectrum disorders, that this legislation has been introduced. It is overdue. Since autism is an epidemic of our time, this legislation is a modest first step in moving forward in Kansas with this task force and them seeking input into recommendations for legislative and operational changes for support, services and funding.

We recommend that more parents of children with autism be represented on this task force. They know first-hand what they need from practical, everyday 24/7 experience. We specifically recommend Brad & Linda Sloan, parents of a child with asperger syndrome and volunteer leaders of the Capitol Area Asperger & Autism Resource Center. We have worked closely with them and continue to be impressed with their dedication and commitment to helping individuals and families affected by autism spectrum disorders.

We recommend that a community provider of autism services be represented on the task force. We specifically recommend that The Capper Foundation Easter Seals be appointed to the task force. This is based on our knowledge and experience in providing services in this area for many years and our affiliation with Easter Seals, the leading non-profit provider of services for individuals with autism throughout the country.

We would appreciate your serious consideration of these recommendations. Thank You.