Approved: Jehnsy 22 2011
Date

MINUTES OF THE HOUSE CHILDREN AND FAMILIES COMMITTEE

FEBRUARY 8, 2011

The meeting was called to order by Chairman Kiegerl at 9:07 a.m. on February 8, 2011, in Room 142S of the Capitol.

All members were present.

Committee Staff Present:

Martha Dorsey, Kansas Legislative Research Department Jay Hall, Intern, Kansas Legislative Research Department Renae Jefferies, Office of the Revisor of Statutes June Christensen, Committee Assistant

Others attending: See attached list.

Conferees appearing before the Committee:

Linda Heitzman-Powell, BCBA, University of Kansas Dr. Mike Wasner, President, Kansas Coalition for Autism Legislation Dr. Bill Craig, President and CEO of Lakemary Center

Chairperson Kiegerl announced that today's information on autism will be continued on Thursday. A bill was drafted yesterday that would eliminate the autism waiver for 264 children for \$2,200,000, but the problem will be finding the funding.

Chairperson Kiegerl introduced Ms. Linda Heitzman-Powell for testimony. Ms. Powell gave a slide presentation and information regarding her activities with both the University of Kansas and her intervention services to children with Autism Spectrum Disorder (ASD) (Attachment 1). She emphasized the benefits of early childhood intervention and presented several examples of children's progress being much more effective than those who received treatment at a later age. Most children benefit when treatment begins at the age of a few months to a few years, as they will age-out of the system by age six.

Dr. Mike Wasmer, President of the Kansas Coalition for Autism Legislation, gave a presentation on health insurance for ASD in Kansas, comparing it with legislation passed in Missouri (<u>Attachment 2</u>). He noted that 2010 HB2160 that the Kansas Legislature passed last year was helpful but not adequate He presented data regarding the cost and said it was not cost-prohibitive if a bill similar to Missouri's were to be enacted.

He also informed the committee that his daughter had autism, which was not diagnosed until she was over two years old, and treatment was not started for four months. After intervention, she became very proficient in reading skills, more so than her classmates, and is now in the sixth grade with no help at this time.

Dr. Bill Craig, President and CEO of Lakemary, said that he has a 32-year-old son with autism who did not benefit from training because of his age. He presented data showing the increase in autism diagnosis over the last several years, formerly 1 in 500 and now 1 in 110 (Attachment 3).

It is predicted this may increase to 1 in 50 in the future. He urged expanded funding to decrease the number of children on the waiting lists and said areas, such as the western part of the state, have fewer resources. He compared autism with that of a child who had a cancerous tumor left untreated and said every day without intervention is a lost day that cannot be made up.

CONTINUATION SHEET

MINUTES OF THE HOUSE COMMITTEE ON CHILDREN AND FAMILIES Room 142S, Statehouse, at 9 a.m., February 8, 2011

Committee members asked several questions that were answered by the three conferees.

Representative Melody McCray-Miller distributed copies of the *Kansas Governor's Commission on Autism* (Attachment 4).

The next meeting will be held Tuesday, February 15, 2011, at 9 a.m., Room 142S, and will include hearings on bills that will continue at the February 17 meeting.

The meeting was adjourned at 10:25 a.m.

CHILDREN AND FAMILIES COMMITTEE GUEST LIST

DATE: _____February 8, 2011

NAME (Please Print)	REPRESENTING
Tom KREBS	Kasis
LINDAS. HEStrman-Perus 11	Autism
TERRY FORSYTH	KWEA
Nancy Zosleman	Polsinelli.
Sinal Heres farmer	12.00
Kan Prestry	Kearney & Associates
Mat Tabo	RSDD
Robin Climits	OCCCA, INC
ShannonBell	LGR
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Health Insurance for Autism Spectrum Disorders in Kansas

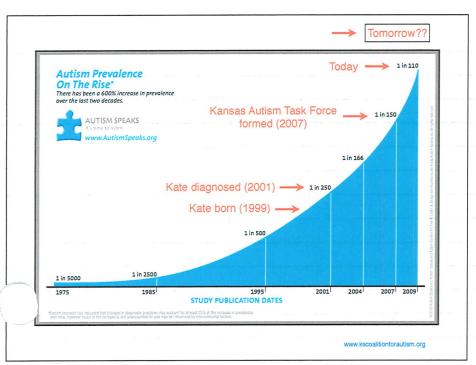
A Discussion of HB 2160 and the Need for Improved Legislation

Presented to the House Children & Families Committee February 8, 2011

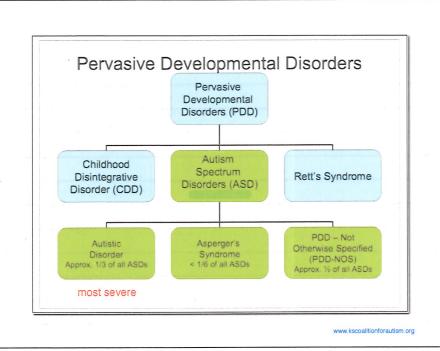
Michael L. Wasmer, DVM, Dipl ACVIM Founder, Kansas Coalition for Autism Legislation



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		HOUSE CHILDREN AND FAMILIES DATE: FEBRUARY §, 2011 ATTACHMENT NO. 1
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Autism Facts

- Early diagnosis and treatment are critical to a positive outcome for individuals with an autism spectrum disorder (ASD)
- · With appropriate treatment
 - 47% will mainstream in regular education without an aid (vs 2% without appropriate treatment)
 - 42% will require low level intensity SPED
 - 11% will require high intensity SPED

Kansas Autism Task Force Findings

- inequities in health insurance coverage create one of the most significant barriers to appropriate early intervention for children with autism spectrum disorders in Kansas.
- No private health insurance carrier in Kansas consistently covers the diagnosis and medically necessary treatments for ASD.

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What happens when insurance companies deny coverage for the treatment of autism?

Financial Ruin

- The out of pocket cost of treatment often exceed \$50,000 per year
- Financially devastating to families most go without or receive a fraction of prescribed treatment
- Without appropriate treatment, the lifetime cost to the state has been estimated to be \$3.2 million per child with ASD

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KS Task Force Recommendation

- SB 12 & HB 2367
- financial cap of \$75,000 only on ABA
- unlimited coverage for other medically necessary autism treatments (e.g. ST, OT)
- through age 21
- exempt from the "pilot project" statute

The "Pilot Project" Statute

240-2249n. Same; state employee group pilot project for new mandated health bene-fits. (a) After July 1, 1999, in addition to the requirements of K S.A. 40-2248 and 40-2249, and amendments thereto, any new mandated health insurance coverage for specific health services, specific diseases or for certain providers of health care services approved by the legislature shall ap-ply only to the state health care benefits program, ply only to the state health care benefits program, K.S.A. 75-6501, et seq., and amendments thereto, for a period of at least one year beginning with the first aninversary date of the state health care benefits program subsequent to approval of the mandate by the legislature. On or before March I after the one year period for which the mandar has been applied, the Kansus state employees health care commission shall submit to the preshealth care commission shall submit to the pres-ident of the senate and to the speaker of the house of representatives, a report indicating the impact such municated coverage has had on the state health care health program, including data on the utilization and costs of such mandated cover-age. Such report shall also include a recommen-dation whicher such mandated coverage should continue for the state health care henelits pro-gram or whether additional utilization and cost data is required. data is required.

(b) The legislature shall periodically review all health insurance coverages mandated by state law.

- KSA 40-2249a
- to assess cost and utilization of proposed coverage

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KS House Bill (HB) 2160

- Effective January 1, 2011
- · Only applies to State Employees as per the pilot project
- Very low financial caps on services



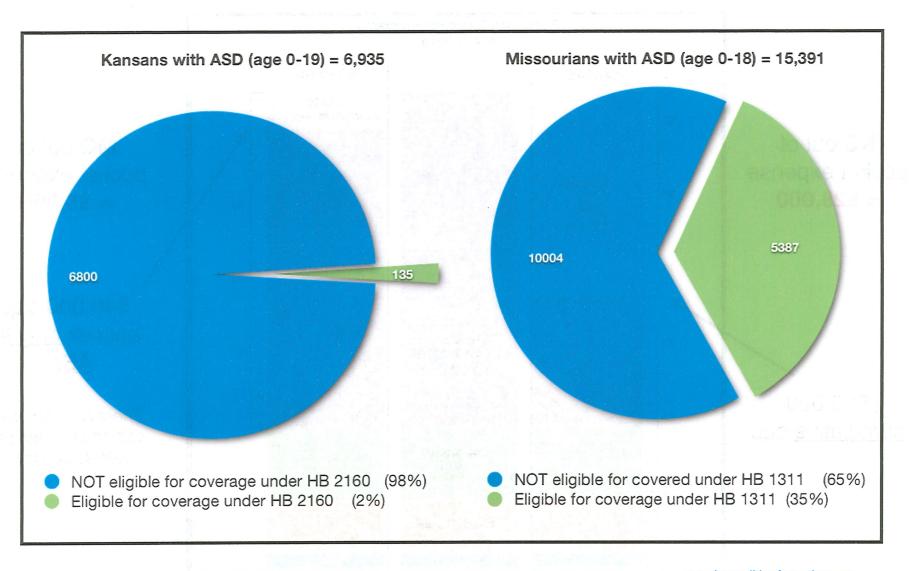
Governor Mark Parkinson April 19, 2010

KS HB 2160 vs MO HB 1311

	KANSAS	MISSOURI
BILL NUMBER	HB2160	HB1311
DATE PASSED	Apr 19, 2010	Jun 10, 2010
DATE EFFECTIVE	Jan 1, 2011	Jan 1, 2011
SCOPE OF COVERAGE		
	State Employees ONLY	Fully funded insurance plans and State employees; must be offered to individual plans but does not apply automatically
LIMITATIONS ON COVERAGE		
Age limits	Under 19	ABA is limited to age 18 Other treatments are <u>not</u> limited by age
	- age 0 to 6: \$36,000 per year - age 7 to 18: \$27,000 per year	ABA is limited to \$40,000 per year* No dollar limits on other therapies
Annual dollar limit	Limits are <u>cumulative</u> (i.e. all services count towards the dollar cap)	* maximum benefit limit may be exceeded, upon prior approval by the health benefit plan, if the provision of applied behavior analysis services beyond the maximum limit is medically necessary for such individual

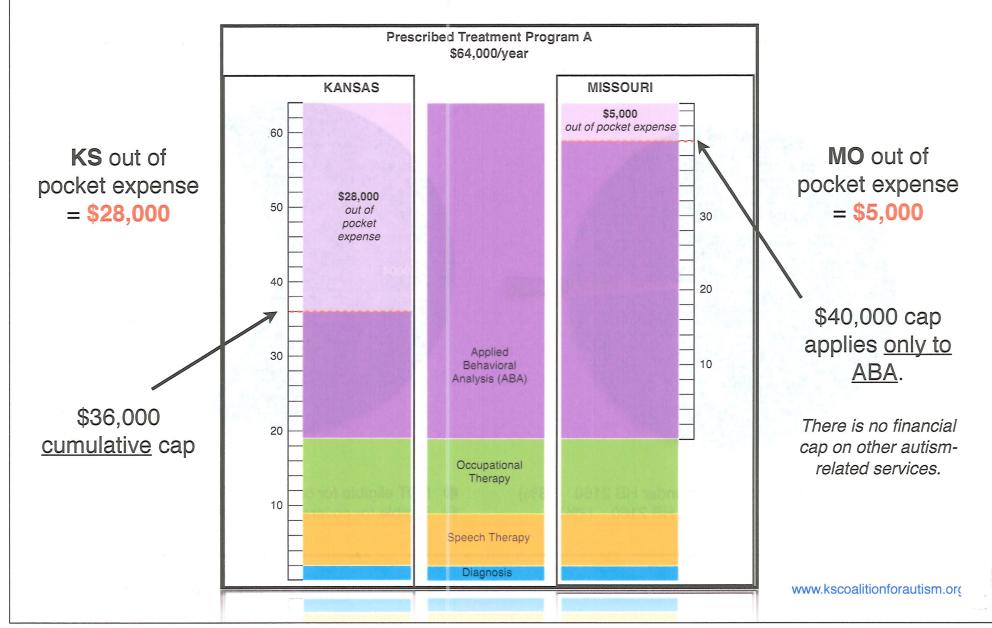
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Scope of Coverage: KS vs MO



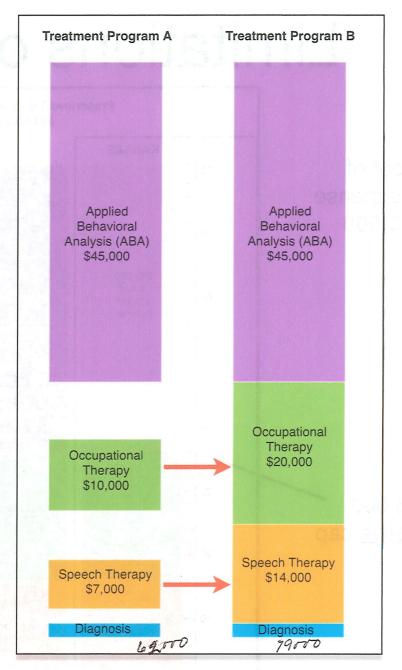
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Limitations on Coverage



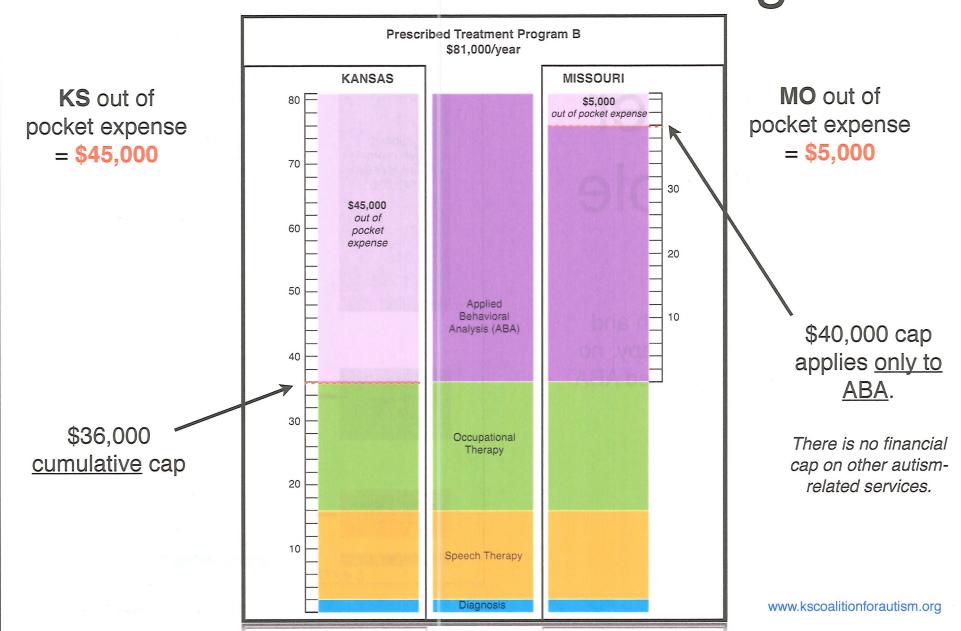
Another Example

Increased Speech and Occupational therapy; no change in prescribed ABA

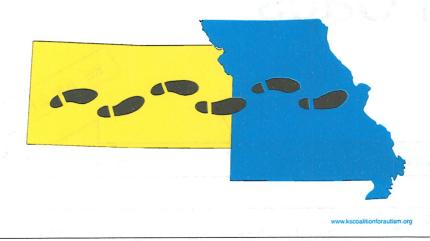


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Limitations on Coverage





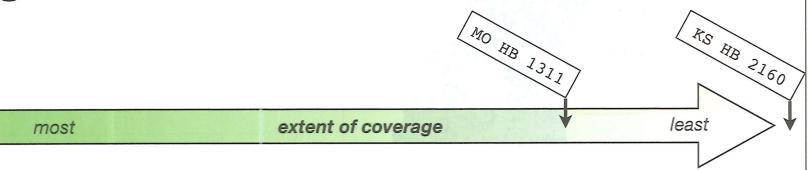


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It is imperative that the 2011 Kansas Legislature enact a bill that is comparable to Missouri HB 1311 this session

Arguments in favor of

Higher Financial Caps



	Indiana 2001	Minnesota 2001	SB 12 (HB 2367)	South Carolina	Texas (2007)
Annual Cap	none	none	\$75,000 (for ABA therapy)	\$50,000 (for ABA therapy)	none
Age Limit	no age limit	no age limit	21	16	6
Treatment Covered	includes ST, OT and ABA	includes ST, OT and ABA	includes ST, OT and ABA	includes ST, OT and ABA	includes ST, OT and ABA
existing data on impact on premium	NA	83 cents per member per month	:011 :ta	20 cents per member per month	<0.1% impact on premiums
data source	NA	2007 Blue Cross Blue Shield (BCBS) Minnesota Actuarial reports		APS Healthcare	Aetna of Texas

ST = speech therapy; OT = occupational therapy; ABA = Applied Behavior Analysis therapy

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The New Bill should be

Exempt from the Pilot Project

- 173 members of SEHP with ASD < age 22
- 154 diagnosed
- o 135 < age 19
- 20% of children diagnosed with ASD (i.e. 27 children on the SEHP) will utilize behavioral treatments such as ABA (Minnesota)
- Current capacity to serve children with ASD in all areas of Kansas?

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After the pilot project?

March 1, 2012

legislature will receive 2011 claims data from SEHP for review.

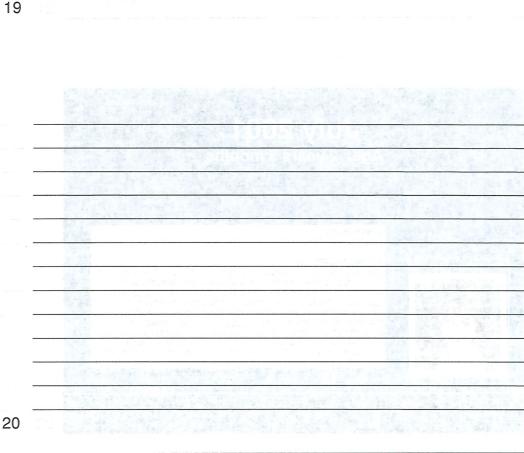
Will provisions of HB 2160 continue for SEHP and extend to fully funded insurance policies?



10-2249a. Same; state employee group pilot project for new mandated health bene-fits. (a) After July 1, 1999, in addition to the requirements of K.S.A. 40-2245 and 40-2243, and amendments thereto, any new mandated health insurance coverage for specific health services, insurance coverage for specific froatile services, specific diseases on for certain providers of health care services approved by the legislature shall apply only to the state health care benefits program, K.S.A. 75-6501, et seq., and amendments thereto, for a period of at least one year beginning with the first anniversary date of the state health care benefits program subsequent to approval of the mandate by the legislature. On or before March 1, after the one year period for which the mandate has been applied, the Kansas state employees has been appied, the tender to the president of the senate and to the speaker of the house of representatives, a report indicating the impact such mandated coverage has had on the state health care benefits program, including data on the utilization and costs of such mandated coverage. Such report shall also include a recommen-dation whether such mandated coverage should continue for the state health care benefits program or whether additional utilization and cost data is required.

(b) The legislature shall periodically review all health insurance coverages mandated by state law.

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What is 2 years for a child with autism?

- A chance for mainstream regular education versus special education
- A chance to be a productive tax-paying Kansan versus a dependent upon lifetime of adult disability services

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July 2001

Age: 2 years 3 months

Diagnosed with Autism



ASSESSMENT:

Autism (Autistic Disorder)

RECOMMENDATIONS:

"Kate would benefit from intensive early intervention services. Best practices for very young children with autism suggest 30-40 hours of home and/or centerbased programming per week...The program should consist of 1:1 and very small group activities. New skills should be introduced and trained in 1:1 teaching opportunities, with planned generalization to small group activities. Both facets of the program should be highly structured with predictable routines and consistent expectations...Skills and consequences should be predetermined and structured. Formal data collection procedures should be an integral part of the program. Routinely schedule team meetings will be necessary to promote consistency of expectations and training opportunities across environments."

Oct 1, 200

Jul 1, 2002

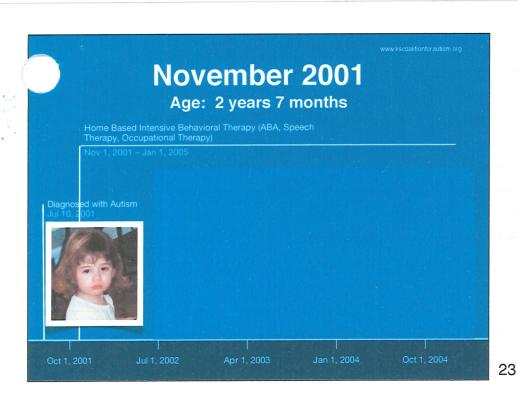
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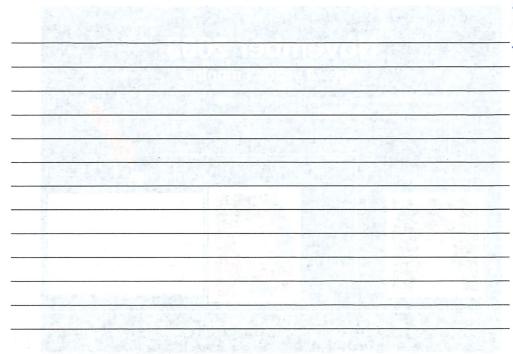
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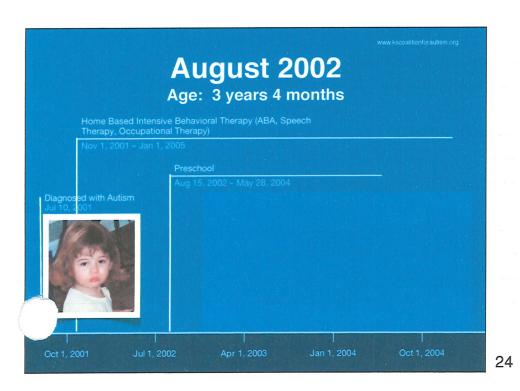
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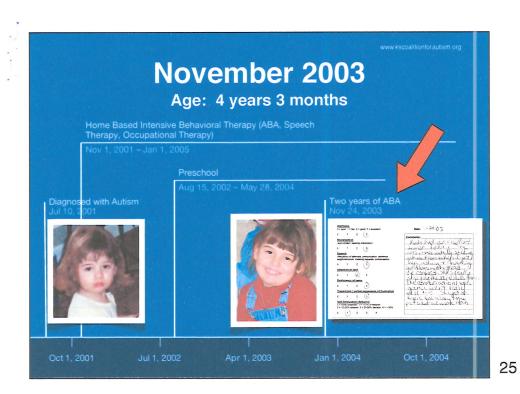
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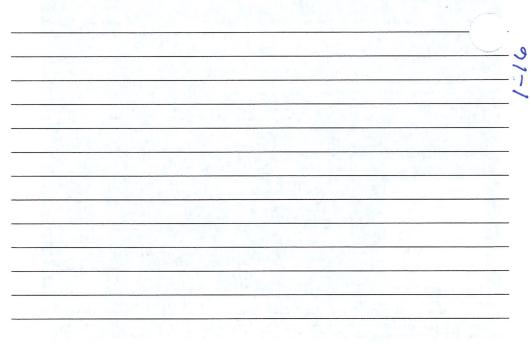


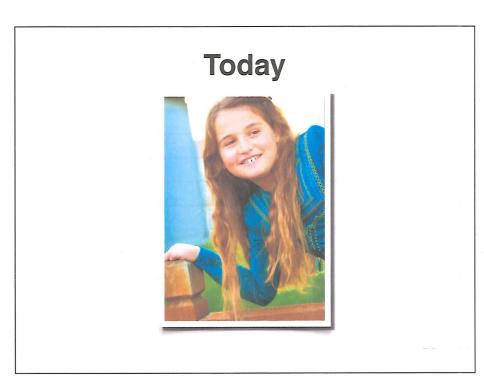


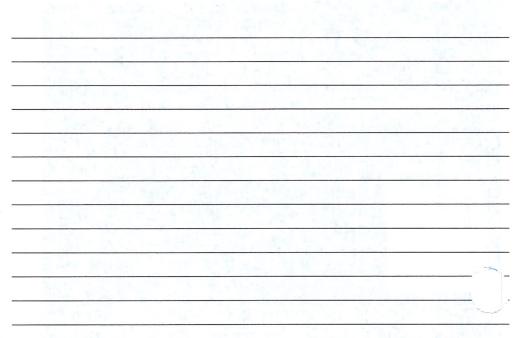


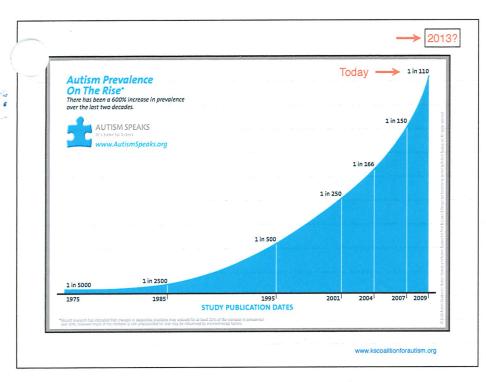












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Summary

- The disparity between Kansas and Missouri autism insurance legislation is deleterious to the Kansas autism community and the Kansas economy
- If any financial cap is imposed on covered treatment, it must not be cumulative
- A "pilot project" is not necessary for this issue and delays provision of appropriate treatment to <u>thousands</u> of Kansas children with autism for at least 2 years
- Enacting a bill comparable to Missouri is not cost prohibitive

The Kansas Coalition for Autism Legislation (KCAL)

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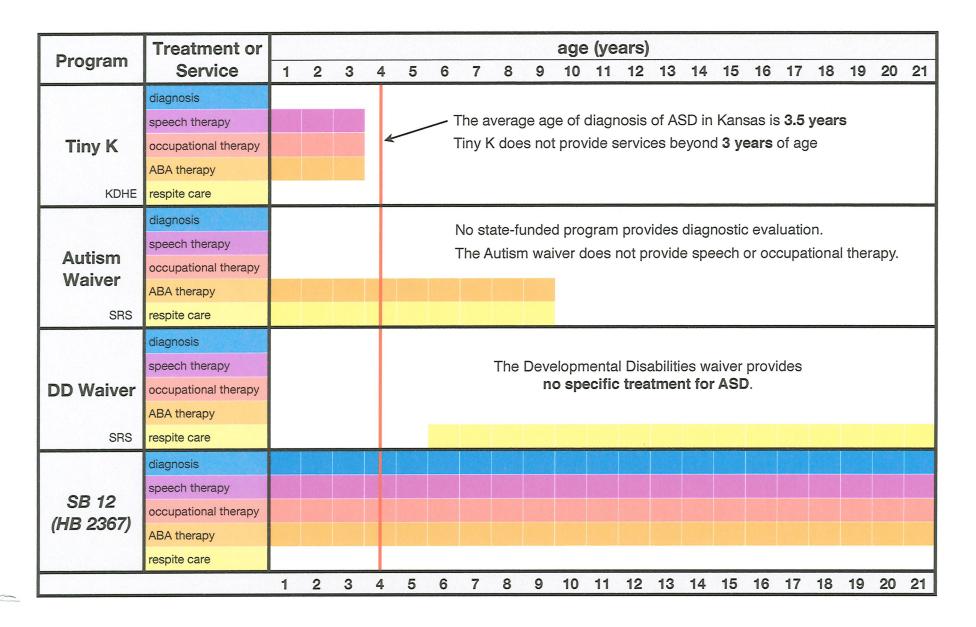


Michael Wasmer wasmer_ms@mac.com 913-626-0668

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State Funded Programs for Autism Spectrum Disorders (ASD) versus SB 12 (HB 2367)





HOUSE COMMITTEE ON CHILDREN & FAMILY ISSUES CHAIR: REP. MIKE KIEGERL FEBRUARY 8, 2011

The 2007 Kansas Legislature created the Kansas Autism Task Force for the purpose of studying the issues related to the needs of persons with autism in Kansas and making recommendations to address those needs.

At that time it was noted that the prevalence of Autism Spectrum Disorders in Kansas, and nationwide, appeared to be increasing in epidemic proportions. The Centers for Disease Control reported the prevalence of these disorders as 1 in 150 births. Most recently that number has been revised to 1 in 110. While greater awareness and early identification certainly plays a part in these numbers it by no means accounts for the astounding increase.

The more than 3,000 individuals waiting for developmental disability services in the State represent a scandal that will not go away until it is addressed. A recent snapshot of the individuals on that waiting list indicates that as many as 30% of them carry an Autism Spectrum diagnosis. So the magnitude of the problem and the obligation that it carries forward for this State is increasing at alarming proportions.

The Autism Task Force completed its work in December of 2008 and provided a report to the 2009 Kansas legislature. Among its findings, the following are key: Autism Spectrum Disorders are biologically based neural developmental disabilities with a strong genetic component. Their prevalence is increasing in epidemic proportions. There is no proven cure for autism; however, the effectiveness of early, intensive intervention is proven to reduce the effects of this disorder and as many as half of the individuals who receive this level of intervention may not require subsequent special education and support services.

Expanded funding for the autism waiver to fully serve the waiting list was one of the key recommendations of the Task Force. The autism waiver program in Kansas is one of the more innovative approaches to providing early intervention through Medicaid waiver services in the country. That is the good news. The bad news is the tragic fact that after creating this program the State has not funded the individuals who are eligible for its services. Currently more children are aging out of the waiting list than are entering service as they grow older without the benefit of early intervention. This is a shameful situation.

The Autism Waiver can be viewed as a companion piece to Kate's Law, as it provides a publicly funded option to those who do not have insurance governed by Kansas State regulation or any insurance at all. The current underutilization of the Waiver by those few lucky enough to have received it can largely be explained by the shortage of qualified providers. This issue is in the

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extreme in the Western part of the state. While a supply/demand conundrum, the only solution to developing this market will be fully funding the waiver AND passing Kate's Law.

The time has come in Kansas for *waiting lists* to be considered an anachronism, a thing of the past. For the child whose brain is failing to develop during the critical early stages of life because of Autism, and for their parents, the **urgency** for intervention is no less great than that for the child with a cancerous tumor. Every day without that intervention is a lost day that can never be recovered.

I would like to thank you, Mr. Chairman and members of the committee, for devoting your time to this critical issue.

Testimony provided by:

William Craig, Ph.D. President/CEO Lakemary Center Paola, Kansas

Kansas Autism Task Force

FINAL REPORT

CONCLUSIONS AND RECOMMENDATIONS

As a result of its findings, the Kansas Autism Task Force recommends that agencies which serve as support systems for families and children with autism (*tiny-k*, Department of Education, Department of Social and Rehabilitation Services) should incorporate the guidance of the "Best Practices in Autism Intervention for Kansas" handbook (attached) produced by this Task Force into their administrative guidelines.

As a result of its findings in other areas, the Kansas Autism Task Force recommends the Legislature consider and adopt legislation as follows:

- Create a specific mechanism in the *tiny-k* funding formula to support local *tiny-k* providers who must provide high cost, intensive services when they are required by a child's Individualized Family Service Plan (IFSP).
- Expand funding of the Autism Medicaid Waiver to fully serve the current waiting list and transfer the future funding of this program to the consensus estimating process, where anticipated need will be the basis for funding. A waiting list is not an acceptable option.
- Pass legislation which requires that health insurance policies cover the diagnosis and appropriate treatment of individuals with autism.
- Pass legislation which creates and funds a scholarship program to support the education of professionals in the field of autism who agree to serve in underserved areas of the State.
- Pass legislation to fully fund the Mental Retardation/Developmental Disabilities Home and Community Based Waiver (HCBS) waiting list and create adequate rates for the Developmental Disability system.
- To complete the objectives set for it by the Legislature, the Kansas Autism Task Force must have its term extended for an additional year. The necessary legislative authorization to accomplish this should be made retroactive to January 2009. (Please see the "Task Force Activities" section, page 4, for the complete rationale for this extension.)

In addition, the Department of Education should strive to ease the access to Catastrophic Aid funds for school districts who serve high-cost students, such as those with autism.

It is incumbent on the three state agencies primarily responsible for services to individuals with autism (Kansas Department of Health and Environment, Department of Education, and Department of Social and Rehabilitation Services) to collaboratively maintain a dynamic mapping website of the availability of services and supports across the state with current contact information. This site should be readily available and usable by parents seeking information and service.

Proposed Legislation: The Kansas Autism Task Force has no authority to introduce legislation.

University of Kansas Medical Center Linda S. Heitzman-Powell, Ph.D. Board Certified Behavior Analyst Testimony to the House Children and Families Committee Tuesday, February 7, 2011

Representative Kiegerl and committee members: thank you for the opportunity to testify today. I am Linda Heitzman-Powell, Director of Community Research and Training at the University of Kansas Medical Center. I hold a faculty appointment in the Department of Pediatrics at the University of Kansas Medical Center, as well as an adjunct position in the Department of Applied Behavioral Sciences at the University of Kansas. I hold a Ph.D. in Developmental and Child Psychology from the University of Kansas and am a Board Certified Behavior Analyst. In addition to my university position, I have maintained an active role in providing intervention services to children with an autism spectrum disorder in Kansas for the past 13 years. I have worked diligently over this time to advocate for access to evidence-based practices for all Kansas families. I am here today on my own behalf, not on behalf of the University of Kansas.

Today, my testimony will focus on best practices for young children with an Autism Spectrum Disorder and the need to increase access to services. Autism Spectrum disorders, or ASD, encompasses more than just classic autism. The spectrum includes Aspergers Syndrome (no evidence of early language delay), and Pervasive Developmental Disorder Not Otherwise Specified. My remarks will specifically address the current availability of services that, to the best of my knowledge, use "effective" or evidence-based practices. Sources include input from published intervention research, knowledge from my colleagues, and my experience as a researcher and clinician actively engaged in providing intervention services to families and children with ASD. While we have made some gains over the past couple of years, there are still major gaps in services that need to be addressed by the 2011 legislature.

Three things are relevant:

How do we define effective practice? What are some effective, or evidence-based, practices specific to Autism Spectrum Disorders? What is the current state of evidence-based practices in Kansas?

How do we define effectiveness?

Standards for defining effective practice include both research and clinical practice. Sufficient research using appropriate methods to show evidence for the intervention or practice is critical. The data or outcomes for participants show a positive improvement in important behavior such as social communication, adaptive behaviors, or job skills. A second way is to have a number of "clinical replications." This means there are a number of people in different geographical locations using an intervention or method with outcome data showing improvement, but without the experimental methods.

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Note the use of *data* in both sources of information. It cannot be emphasized enough that an "evidence-based" approach relies on the use of data to determine what is effective. The effectiveness of what we do for persons with disabilities is as important as accessing services. In putting forth a systematic effort to build capacity in our systems for evidence-based services, it is imperative that we do it using effective techniques and the use of data for making intervention decisions.

In the field of autism, determining what is effective or what works is sometimes challenging. This is because of the unique characteristics of the disorder related to problems in 4 key areas:

Social interaction and developing relationships, Language and communication skills, Behavior patterns such as repetitive behaviors, obsessions or rituals, Sensory issues such as oversensitivity to bright lights, textures, noise levels.

In general, it is harder to reach, teach, and motivate individuals with an ASD, their behavior is resistant to change, and their behaviors can be much more challenging than those seen in their typically developing peers.

What works? What are some effective interventions for persons with ASD that are relevant to transition planning and services for adults?

Each individual with ASD accrues about \$3.2 million in costs to society over his lifetime (includes loss in productivity and adult care; Ganz, 2008)

In the business world, effectiveness means cost savings. It is not apparent that we apply a cost-benefits approach in our treatment decisions. The cost-savings to society with the implementation of an evidence-based approach is estimated to be close to \$33,000 per year or \$2.5 million over the course of the life time of the individual (Jacobson, Mulick & Green, 1998).

We all care about people and the quality of life for persons with disabilities, but we can do a better job if we pay closer attention to the effectiveness of service through the use of interventions that work. A critical part for determining the effectiveness of service is the accurate collection of data and the use of those data to modify the intervention if it is not working or to change the intervention to increase independence.

Interventions that help 'teach new skills' including those needed for successful integration into home, school, and community life:

From my work on the Best Practices Subcommittee of the Legislative Task Force on Autism (Heitzman-Powell, et. al, 2008) (provided), we synthesized the evidence available at that time. Our recommendations included:

Best Practice Recommendations based on a Synthesis of Sources

1. Use of <u>a model based on the science</u> of human behavior such as that found in an Applied Behavior Analysis model of intervention. Applied Behavior Analysis has been referenced

- throughout the literature as having the most scientific evidence to support the use of techniques found in intensive behavioral programs.
- 2. Entry into intervention as soon as an ASD diagnosis is seriously considered rather than deferring until a definitive diagnosis is made.
- 3. *Intensive early intervention* is recommended. Intensive intervention has been defined throughout the review as active engagement of the child at least 25 hours per week, 12 months per year, in systematically planned, developmentally appropriate community, home, and educational-based interventions designed to address identified objectives.
- 4. *Instructional programs and curriculum address all areas of delay* and specifically address core deficits of ASD (e.g., social, communication, and repetitive/stereotypic behaviors).
- 5. Ongoing measurement and documentation of the individual child's progress toward identified objectives are recommended.
- 6. Promotion of opportunities for interaction with typically developing peers.
- 7. **Problem or interfering behaviors are targets for reduction** and/or replacement by using empirically supported strategies to teach socially valid replacement behaviors.
- 8. The staff members delivering the intervention have received *specialized training* in ASD that includes an experiential component.
- 9. *Inclusion of a family component (including* parent training as indicated); must involve family participation in development of goals, priorities and treatment plans and provide ongoing parent support, training and consultation.

These recommendations were further supported from a significant national effort that was underway at the time, the *National Autism Center's National Standards Project* (2009) (provided). Two-thirds of the strategies that were identified by the *NAC* were from the behavioral literature, of the remaining third, 75% of the articles were primarily behavioral. The remaining research was from speech and special education with less that 10% from Theory of Mind. These interventions frequently included behavioral components (National Standards Project, 2009).

The strategies identified by the *NAC* as an "established" treatment included:

Skill Building Strategies

- 1. Behavioral package (231 studies in Applied Behavior Analysis, Behavioral psychology, Positive Behavioral Support)
 - > Choice
 - > Functional communication training
 - > Differential reinforcement
 - > Tokens
 - > Modeling
 - > Contingency management
 - > Schedules
 - > Redirection
- 2. Comprehensive Behavioral Treatment for Young Children (under age 8) (22 studies in primarily ABA using methods such as discrete trial and incidental teaching)
 - > Targeting symptoms of ASD
 - > Treatment manuals

- > Intensive
- > Measured overall effectiveness
- 3. Joint Attention Intervention (6)
- 4. Modeling (50 studies often combined with behavioral strategies such as prompting and reinforcement)

Problem Behavior Strategies

- 1. Antecedent Packages (99 studies in primarily ABA and Positive Behavioral Supports)
 - > Modifications of events that precede problem behavior
- 2. Behavioral package (Applied behavior analysis, Behavioral psychology, Positive Behavioral Support)
 - > See above

Specific recommendations made by the *NAC* further support the use of these *Established Treatments* when making treatment decisions for individuals with ASD.

In 2001 the *National Research Council* recommended that services begin as soon as a child is suspected of having an ASD and that those services should include a minimum of 25 hours per week, 12 months a year. The recommendations included guidelines that services be systematic and developmentally appropriate and treatment objectives should target the core characteristics of ASD including communication, socialization, cognitive development, and play skills throughout the day. These strategies should also take a proactive approach to behavior management.

Following the lead of the National Research Council's (2001) recommendations the NAC (2009) states:

"We argue that unless compelling reasons exist to do otherwise, intervention services should be comprised of Established Treatments and they should be delivered following the specifications outlined in the literature (e.g.., appropriate use of resources, staff to student ration, following the prescribed procedures, et.) (pg. 31)"

What's Available to all Kansas Children?

Military Demonstration Program

The Demonstration Program falls under the ECHO Military Insurance Program. This program serves any child with ASD provided one of the child's parents are active duty military. All Providers under this program must be approved and go through the credentialing process with TriWest. The amount of hours is based on a \$36,000 yearly cap of approved funds per client. The demonstration project pays for the following service providers and services:

- 1. Demonstration Project Tutor (range between 12 & 18 hours per week)
- 2. Demonstration Project Supervisor (approximately .5 hours per week)

An interesting note is the current estimate of the prevalence of ASD in American society are 1:110; in the military those numbers are 1:88. While there is no research aimed at determining the differences in prevalence rates, based on personal experiences, I am familiar with families that were reservists that went active duty for the benefits for their children. I also have personal experiences with families who delay retirement for the benefits for their children.

Thus, while this program is a significant benefit to military families, this program is not available to all Kansas children.

Kansas Early Autism Wavier Program

The Kansas Early Autism Wavier Program falls under the umbrella of Home and Community Based Services of the Kansas Medicaid Program. The program currently provides services for:

Respite (168 hours per year or 3.2 hours per week),

Intensive Individual Supports,

Parent Support and Training (25 hours per week),

Autism Specialist (50 hours per year, <1 hour per week), and

Family Adjustment Counseling.

To be eligible for the program, the child must have an autism diagnosis, and complete the application process. Once the application is completed and approved, they will then be placed on a proposed recipient list. The program serves children birth through age 6.

Kansas Department of Social and Rehabilitation Services was forward-thinking in the adoption of an evidence-based approach. SRS staff not only held focus groups to hear the needs of the community, they also looked to the research for sound recommendations. All recent recommendations have stressed the need for well-trained staff for intervention implementation. All service providers must be approved and attend training in order to provide services. Currently the University of Kansas Medical Center and the Kansas Center for Autism Research and Training (KU/Life Span Institute) provides the state approved training for individuals interested in providing services for the Early Autism Waiver.

While the KS Early Autism Waiver Program is extraordinarily helpful to recipients, currently there are 262 children on the proposed recipient list: only 45 positions have been funded. Thus, this program does not fill the gap in services experienced by Kansas families that have children with ASD. Even if only 5 additional families were added per year, this would begin to chip away at the number of families that are desperately waiting for funding so that their children may benefit from the effects of intensive early intervention services.

For families fortunate enough to receive services under the SRS Autism Waiver, as mentioned service providers need to demonstrate a basic knowledge of the use of an evidence-based approach. The collaborative K-CART training mission is to increase the number of qualified service providers to support home and community-based services, who can then facilitate program development, implementation, and coordination of interventions across multiple environments including home, community, and school settings.

Overall Objectives of the Autism Training Program

- To provide a structured learning program in the use of evidence- based practices with children with an autism spectrum disorder.
- To provide trainees an opportunity to engage with a child with an ASD to practice skills in a structured, supportive environment.
- To provide trainees with exposure to an interdisciplinary team approach to the treatment of children with an ASD.
- To provide trainees with exposure to multiple learning environments through on-the-job training placements.

Training consists of three components:

- 1. Training modules (ten) are web-based instructional units and provide the foundation for trainees to learn essential information for working with children and youth with autism (See Modules Content in Appendix A. Approx. 20 hours)
- 2. Experiential learning consists of hands on one-to-one teaching of a child with autism under the supervision of the K-CART Autism Training Program staff (Approx. 10 hours).
- 3. On the job training consists of hands on teaching of multiple children with autism in job sites. These job sites include home- and school-based sites that are recruited by the K-CART Autism Training Program staff (Approx. 18 hours).

Collaborating On the Job Training Sites

Kansas City Autism Training Center KcATC http://kcatc.net
Partners in Behavioral Milestones, Milestones Academy School http://www.behavioralmilestones.com/
Community Living Opportunities http://www.clokansas.org/

For related publications and research projects, see "Sources."

Insurance

Currently Kansas has enacted an insurance mandate for a pilot bill for state employees. This bill is designed to provide reimbursement for (among other services), 1) Autism Specialist services (for consultation, training, program development and oversight, and assessment), and 2) Intensive Individual Support services (for implementation of the programs developed by the Autism Specialist), building on the requirements set forth by the SRS Early Autism Waiver program.

While this pilot bill is a toe-in-the-door for service provision, it does not address the needs for the entire community of individuals with ASD in the state of Kansas.

Before I leave today, I would like to summarize the following:

1. Kansas has been responsive to the needs of the community in the enactment of an evidence-based approach for intervention services and training requirements for its' Early Autism Waiver. States from as far away as Alaska have contacted me in an effort to replicate Kansas' efforts. However, there are only 45 funded positions. This program needs to be fully funded to prevent

more children from "aging off" the waiver and to provide an opportunity for younger children to be able to access services.

- 2. While Kansas has begun to enact insurance reform which has the potential to affect more individuals with ASD, with the Pilot program, only members of the State employees' health plan are covered.
- 3. While there are other insurances, e.g. the Military's Demonstration project, they also are not available to non-military citizens of Kansas.
- 4. Finally, the beneficial impact of early, intensive intervention cannot be over stated. I would like to leave you with a look at the effects of this type of service on 2 children.

They say a picture paints a thousand words – and nothing can express this more than seeing the transformation over time.

View Video Clips

In close, I appreciate the opportunity to present information to you today and encourage you to explore ways to be able to help all Kansas Children benefit from the positive impact of intensive intervention services for ASD.

Respectfully submitted,

Linda S. Heitzman-Powell, Ph.D., BCBA-D Licensed Psychologist

Sources:

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- Heitzman-Powell, L.S., Perrin, N., Heinz, L., Wegner, J., Rinkel, P., Miksch, P., et. al. (2008). Best Practices for Autism Treatment in Kansas. Best Practices Subcommittee of the Kansas Legislative Task Force on Autism, Report of the Kansas Autism Task Force Submitted to the 2009 Kansas Legislature.
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- Luiselli, Russo, Christian, & Wilczynski, eds. (2008). Effective Practices for Children with Autism: Education and Behavioral Support Interventions that Work

National Autism Center, (2009). National Standards Project. Randolph, MA

National Research Council (2001). *Educating children with autism*. Committee on Educational Interventions for Children With Autism, Division of Behavioral and Social Sciences and Education. Washington, DC: National Academy Press.

Training

Related Publications

Buzhardt, J., & Heitzman-Powell, L. (2005). Training Behavioral Aides with a Combination of Online and Face-to-Face Procedures. *Teaching Exceptional Children*, 37, 5, 20-26.

Buzhardt, J., & Heitzman-Powell, L. (2006). Field Evaluation of an Online Foster Parent Training System. *Journal of Educational Technology Systems*, 34, 3, 297-316.

Related Research Projects

NIDRR/United States Department of Education

H133G090136, Heitzman-Powell, PI (10/01/2009-9/30/20012)

Evaluation of the Online and Applied System for Intervention Skills (OASIS) Training Program for Parents of Children with an Autism Spectrum Disorder via Telemedicine Service Delivery. NIDRR/United States Department of Education

H133G060238, Heitzman-Powell, PI (10/01/2006-9/30/2009)

Combining Technologies to Maximize Outcomes: Online and Telemedicine Training Program for Parents of Children with Autism.



Kansas Governor's Commission on Autism

January 12, 2011

Governor Sam Brownback Capitol, 300 SW 10th Ave., Ste. 212S Topeka, KS 66612-1590

RE: GOVERNOR'S COMMISSION on AUTISM 2010 REPORT and RECOMMENDATIONS:

In 2010 the Governor's Commission on Autism recognized the need to develop a state plan for Kansas. The focus of our efforts was to develop a comprehensive state plan to meet the needs of individuals with Autism Spectrum Disorder throughout the lifespan. The Kansas Governor's Commission on Autism State Plan further reveals a map of what has been accomplished across Kansas and what Kansans still need do to assure that all Kansans with Autism Spectrum Disorder and their families have equal access to opportunities and resources.

Autism in America:

In 1987 approximately 15 in every 10,000 children were diagnosed with autism. In 1998 resources from the Centers for Disease Control indicated that from 1987 through 1998 the incidence of autism increased 633%, and determined that 1 in every 500 children were diagnosed with autism. In 2007 the Centers for Disease Control reported that 1 in every 150 children were diagnosed with autism, the ratio of boys to girls was 4:1. December, 2009 the Centers for Disease Control reported the number of children diagnosed with autism had increased to 1 in every 110 children, 1 in every 70 boys. Today, In America 1%, of children are diagnosed with an Autism Spectrum Disorder.

http://www.cdc.gov/ncbddd/autism/data.html
http://pediatrics.aappublications.org/cgi/content/abstract/peds.2009-1522v1
http://www.autism-society.org/site/News2?page=NewsArticle&id=15065

Autism in Kansas

The Governor's Commission on Autism was established to monitor and report to the Governor, the current state and the future needs of Kansans with Autism. The Task Force of 1987 projected that 3,654 Kansas adults and children were identified with autism. In 2010, the Kansas University Medical Center, Center of Children's Health and Development reports that 900 inquiries were received from persons interested in an Autism Spectrum Disorder assessment; 600 of the children assessed were diagnosed an Autism Spectrum Disorder. The average age of those diagnosed was four. The Kansas Instructional Support Network's teams report approximately 118 requests for assessments of children throughout Kansas; 88 children assessed or 75% received a diagnosis of Autism Spectrum Disorder.

Serving the Southeast region of Kansas; Parsons State Hospital and Training Center formally started an Autism Clinic two years ago and dedicates one day per week to autism evaluations. The PSHTC Autism Clinic received **104** referrals and completed **90** autism evaluations. The clinic reports a **17%** autism diagnosis rate.

HOUSE CHILDREN AND

FAMILIES
DATE: FEBRUARY / 2011
ATTACHMENT NO 4

K.... Action and Accomplishments:

In developing the State Plan, the Governor's Commission on Autism recognizes the activities and efforts to support individuals with Autism Spectrum Disorder that are occurring across Kansas. These advocacy actions and accomplishments demonstrate an atmosphere of collaboration and accountability.

Autism Awareness: Kansas continues to be diligent in statewide action and achievements. There has been substantial work in improving Autism Awareness and in providing training on early identification and diagnosis. Collaborative efforts in 2008 and 2009 provided regional training for school and 0-3/Tiny K teams in 63 of the 105 counties throughout the state. Autism Diagnostic Teams (ADTs) were trained to identify and complete assessments on children suspected of having an autism spectrum disorder. Local physicians, school psychologists, special education teachers, speech pathologists and occupational therapists, work within their area schools and communities raising awareness and dissemination of "Learn the Signs, Act Early" information. Advances towards improving diagnostic capacity through statewide Outreach clinics; improving the use of technology and Tele-medicine; increased training opportunities for educators; coaching in transition assessment; KISN trainings on EBP; and the Summer Institute on Structured Teaching are some of the many examples of ongoing efforts across Kansas, to raise awareness of autism spectrum disorders.

Advocacy Efforts: Advocacy is a constant for parents, professionals and individuals with an Autism Spectrum Disorder. The Autism advocacy efforts of members of the Commission can be directly connected to an increase in awareness and improved outcomes in reducing the waiting periods for diagnostic assessments. In the past five years diagnostic appointment waiting periods have been reduced from **2 years to 45 days**. Individual and group advocacy efforts across Kansas have greatly improved educational and professional use of evidence-based practices, diagnostics, parental support, self-advocacy, and current legislative matters. Further, training continues to be made available statewide through conferences that feature experts in the field of Autism.

Legislation designed to improve the lives of those with Autism Spectrum Disorder has bipartisan support statewide.

Kansas Governor's Commission on Autism

http://www.srs.ks.gov/agency/css/Pages/Autismwaiver/KansasGovernor%27sCommissiononAutism.aspx

Established by House Concurrent 5071 by the Kansas Legislature in 1987; the Governor's Commission on Autism advises and makes recommendations to the Office of the Governor in regard to matters related to Autism, families with a child with an autism spectrum disorder, and service providers. The Commission consists of 15 members appointed by the Governor.

Kansas Instruction Support Network – KISN http://www.kansasasd.com

The Mission of KISN is to support Kansas school districts in building local capacity to serve students with diverse learning needs, through results based professional development training, and technical assistance. KISN maintains a lending library that is accessible online. Autism Diagnostic Teams have been developed through a two day training that is offered two times a year. Provided free of charge to school districts in Kansas. KISN provides ongoing training for parents and educators through the KISN Training Series that is presented through the ITV Network, broadcast to 13 regional sites statewide. The training series is developed each year with the assistance of the Autism Consortium that includes faculty from the Fort Hays State University, Pittsburg State University, University of Kansas, Emporia State University and Wichita State University. Those universities offer three hours of graduate credit for the completion of the

credit, the sessions are provided without charge; those who wish to earn credit are responsible for the costs associated with that endeavor. KISN staff is available to provide direct observation and consultation for individuals students when the local school districts have exhausted their resources. Regional Autism Consultants (RACs) are also able to provide services if a KISN member isn't available. The Regional Autism Consultants are full-time employees of school districts throughout the state. KISN purchases days from their contracts in order to share their expertise to other districts. When requested members and RACs also provide districts with training tailored to meet their specific needs.

Center Child Health and Development – CCHD - Kansas University Medical Center

http://www.kumc.edu/cchd/

Advancing the health, development, and well-being of children at risk or who have developmental disabilities and supporting their families through the provision of: (1) exemplary clinical service; (2) interdisciplinary leadership training; (3) outreach training and technical assistance and (4) collaborative academic research is the Mission of the CCHD.

Children seen at the CCHD often present with developmental and/or behavioral challenges that are challenging and puzzling to families, communities, and schools. The clinicians at the KU Medical Center CCHD evaluate and diagnose children who may have developmental disabilities (DD). In addition to diagnostic services, the CCHD works with families, schools, and communities to develop treatment plans. The goal at the CCHD is to accurately diagnose the child and recommend the most effective treatments.

The challenges, as well as the strengths, of the children served by the CCHD are assessed in order to understand the diagnostic picture. An interdisciplinary team approach to the diagnosis of DD means that children and families have access to professionals in a broad range of treatment areas.

Pittsburg State University Autism Certification

http://kcmetro.pittstate.edu/home/academic-programs/autism-certificate.dot

The 15-18 hour non degree program is designed to certify that participants have specialized knowledge and skills in working with children with autism. These classes are available online and via IDL offered at the KC Metro Center.

Kansas Center for Autism Research and Training Center - KCART http://kcart.ku.edu/

The Kansas Center for Autism Research and Training (K-CART) at the University of Kansas, established in 2008 with private and public funds, is a new multidisciplinary center that promotes research and training on the causes, nature and management of autism spectrum disorders (ASD). Committed to the highest standards of scientific rigor, K-CART will generate new scientific discoveries about ASD, disseminate research-based practices by training professionals, practitioners and families who serve children and adults with autism, and provide clinical services through the Center for Child Health and Development at the University of Kansas Medical Center.

Kansas Home Community Based Services Waiver (HCBS): Autism Waiver

http://www.srskansas.org/hcp/css/Autism/CMS Approved Autism Waiver application 9.25.07.pdf

Current Autism Waiver Application Map: http://www.srs.ks.gov/agency/css/Documents/Autism/Autism Map.pdf
Current Autism Waiver Providers: http://kansasearlyautism.org/information/locator map.aspx

of a child with autism spectrum disorders and early intensive intervention treatment for children with autism. Children may enter the program at the age of diagnosis through five years. In order to be eligible, the child must be diagnosed by a medical doctor or Ph.D. licensed psychologist using an approved autism screening tool (e.g., CARS, GARS, ADOS, ADI, ASDS) and evaluated for a Level of Care Determination to assess functional eligibility. Services are provided for three years and may be extended for one year if deemed medically necessary by approval of the review team. Covered services include consultative clinical and therapeutic services by an autism specialist, intensive individual supports, respite care, parent support and training, and family adjustment counseling. Commission advocates and Kansas Legislature passes Kansas Autism Waiver. Twenty-five slots were funded in 2007. In 2008, The Kansas Legislature approved funding for an additional twenty additional slots. Currently 254 Kansas children are on the waiting list for the Waiver. In 2010 the Autism Waiver was renewed and the addition of communication skills was included in covered services.

Kansas Autism Insurance Mandate House Bill 2160

http://www.kslegislature.org/bills/2010/2160.pdf

On March 16, 2010 a compromise bill was introduced as HB 2160. Because Kansas law requires that any health insurance mandate first apply only to state employees in the state employee health plan for at least one year in order to assess cost and utilization of the service, the insurance coverage for autism services first will be such a "pilot project." The benefits of HB 2160 apply only to members of the Kansas State Employees Health Plan (SEHP) who are less than 19 years of age. Covered services include diagnostic evaluation, Applied Behavior Analysis and any treatment "prescribed or ordered by a licensed physician, licensed psychologist or licensed specialist clinical social worker." Approved treatments must be "recognized by peer reviewed literature as providing medical benefit to the patient based upon the patient's particular autism spectrum disorder." The legislature will determine at a later date if the mandate should be expanded beyond the pilot project. HB 2160 passed the full Senate and House, and on April 19, 2010 Governor Parkinson signed the bill into law.

GOVERNOR'S COMMISSION ON AUTISM RECOMMENDATIONS:

1) Regional Autism Centers/Systems

The Governor's Commission on Autism remains steadfast in our recommendation and goal to establish regional diagnostic and outreach centers. The Commission believes building regional and local capacity across Kansas will provide the best possible outcomes for individuals with autism and their families. All regions of the state of Kansas require increased access to qualified diagnostic services, treatment and intervention providers.

2) <u>Seamless Transition Throughout the Lifespan</u>

The Governor's Commission on Autism recognizes that individuals with autism and their families require a seamless transition throughout the lifespan. The journey of autism in a continuum of transition. The Governor's Commission on Autism identifies that individuals and families must be provided support to navigate through diagnosis; early childhood; Early Childhood 0-5; school age through age 21; transition to adult; and geriatric life. Services for Kansans affected by autism spectrum disorder need to be provided throughout the lifespan. Throughout the life journey, individuals with autism and families require access to family support, counseling and respite care services. These services and supports should be completely individualized and integrated and

occur along a continuum services provided to our children, adults and families, throughout the entire state.

Kansas.

Developing Policy and Autism Awareness Adult Population

The Governor's Commission on Autism recognizes the need to establish policies to meet the needs for the rising population of adult individuals with Autism Spectrum Disorder. Our children grow up and seek independence and engagement in meaningful activities. Adults with Autism Spectrum Disorder desire to be productive, contributing members of their community. The Governor's Commission on Autism believes and makes recommendation to empower individuals with Autism with the right of knowledge and accessibility to opportunities for full participation in education, adult services, employment and community involvement. Additional independent living and employment opportunities throughout the state of Kansas are recommended for transitioning adult population.

- a. http://www.mandysfarm.org/index.html
- b. http://www.kansas.com/2010/09/02/1474579/cartridge-king-helps-disabled.html
 http://www.usatoday.com/news/education/2008-07-08-autistic-college N.htm
- c. http://www.ncset.org/
- d. http://www.srs.ks.gov/agency/css/Documents/Provider%20Lists/Licensed%20CSPs.pdf

3) Supporting Federal Legislation

The Governor's Commission on Autism supports the re-authorization of the Combating Autism Act. The original Combating Autism Act of 2006 was a bi-partisan effort that expanded federal investment for autism research through NIH; services, diagnosis and treatment through HRSA; and surveillance and awareness efforts through the CDC. In total, CAA authorized \$1 billion over five years, thereby having increased federal spending on autism by 50 percent. As part of the negotiations on the bill, however, an FY11 sunset provision was included on all authorizations. As a result, some existing federal efforts through NIH, HRSA and CDC would cease to exist in the coming fiscal year without any action. This reauthorization bill will not only extend these important authorizations, but also make exciting investments in service-related activities and create a new National Institute of Autism Spectrum Disorders within the NIH.

4) Support Funding 0-3 Early Childhood and Special Education

The Governor's Commission on Autism recognizes that the increased number of children diagnosed with Autism Spectrum Disorder makes further demands on our educational systems, and that increased funding subsequently needs continue. The gains made in childhood development awareness and early diagnosis also has increased the enrollment in 0-3/Tiny K programs. Funding is requires to be at a level commensurate with the needs of the child. Funding is not the only barrier in Kansas, our biggest hurdle is overcoming a shortage of qualified professionals. Resources need to be directed towards the development of talent in the area of teacher education, and specialized educational therapies such as Speech and Language Pathology and Occupational Therapy. Funding levels also affects Kansas' ability to recruit and retain special education and allied health professional. Kansas currently maintains highly recognized training programs.

Kansas HCBS Autism Waiver

The Governor's Commission on Autism recognizes that currently **254** Kansas children are on the waiting list for the Waiver. The number of children placed on waiting list for the Autism Waiver has remained consistent. Currently, **132** children have aged off the proposed Waiver recipient list without having received services; an additional **89** children will age out in 2011. The intent of establishing the Autism Waiver was to provide early intervention services. The Governor's Commission on Autism recommends full funding of the Waiver. Early intervention services covered by the Waiver should serve the individual needs of the child. Occupational therapy should be included as covered therapeutic services. Furthermore, substantial efforts must be accomplished to serve children throughout the state. Rural areas of Kansas have a woeful of lack adequate medical and professional providers trained in autism spectrum disorders. The Commission thus believes and makes the recommendation that training, recruitment and retaining these professionals in these areas must be prioritized.

6) Kansas Autism Insurance

The Commission on Autism recognizes and supports legislation that would expand required health insurance coverage for autism spectrum disorders (ASD) to all fully funded policyholders in Kansas, and to increase coverage limits to be more consistent with that offered under existing Missouri law (i.e. HB 1311). Existing Kansas autism health insurance legislation (i.e. HB 2160) only applies to members of the State Employees Health Plan (SEHP). Less than 2% of children with ASD in Kansas are members of the SEHP. Furthermore, the cumulative financial caps on coverage imposed by Kansas law are among the lowest in the country and are considerably lower than in Missouri. The difference in scope and limitations of mandated coverage between Kansas and Missouri is creating incentive for Kansas families to move across the state line in order to get coverage for autism-related services. The disparity between the two laws also creates a financial incentive for the large number of service providers who work in both states to preferentially see Missouri children rather than Kansas children with ASD so that they can be reimbursed for their services.

Therefore, in addition to the fact that Kansas children with ASD will receive inferior services relative to their neighbors in Missouri, Kansas is also losing tax dollars to Missouri as result of inadequate autism health insurance legislation in Kansas.

http://www.house.mo.gov/billtracking/bills101/biltxt/truly/HB1311T.htm

The advocacy efforts throughout the state have demonstrated the enduring character of Kansans. The Governor's Commission on Autism has applied Kansas determination and leadership to develop the Governor's Commission on Autism's State Plan. Continued advocacy action and demonstrable accomplishments are necessary to do what is right for Kansans. Implementation of the Governor's Commission recommendations will advance the best possible outcomes for Kansas.

Respectfully Submitted:
Jeanie Zortman, Chair
Kansas Governor's Commission on Autism

47.6% of students reported to KSDE with ASD live in these suburban areas.

USD 202	Turner	20	USD 229	Blue Valley	194
USD 233	Olathe	165	USD 259	Wichita	237
USD 305	Salina	49	USD 308	Hutchinson	34
USD 489	Hays	22	USD 497	Lawrence	126
USD 500	KCK	94	USD 501	Topeka	95
USD 512	SMSD	176			

Total: 1212

1,333 students live in rural areas of the state outside of these areas (Roughly **52**% of students reported to KSDE with Autism Spectrum Disorder.)

In 2000, 710 or 1.16% of children ages 3-21 who received special education services in Kansas have autism. In 2008-2009, 2,097 or 3.19% of children with disabilities ages 3-21 who received special education services had autism.

Table 1-1: IDEA Part B - Children with Autism in Kansas for 1999-2000 and 2008-2009 (Child Count by Age Group)

	Child Count in 1999-2000	Child Count in 2008-2009
Age 3-5	87	216
Age 6-11	424	942
Age 12-17	169	810
Age 18-21	30	129
Age 6-21	623	1,881
Age 3-21	710	2097

Source: Reported by the State of Kansas in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs

Table 1-2: IDEA Part B - Children with Disabilities in Kansas for 1999-2000 and 2008-2009 (Child Count by Age Group)

	Child Count in 1999-2000	Child Count in 2008-2009
Age 3-5	7,728	9,896
Age 6-11	25,892	27,183
Age 12-17	24,910	27,750
Age 18-21	2,737	2,901
Age 6-21	53,539	55,834
Age 3-21	61,267	65,730

Source: Reported by the State of Kansas in accordance with Section 618 of IDEA to U.S. Department of Education, Office of Special Education Programs

http://www.easterseals.com/site/PageServer?pagename=ntlc8 2010 state autism profiles kansas

http://www.autism-society.org/site/DocServer/Autism Kansas v3.pdf?docID=9846

http://www.thoughtfulhouse.org/tech-labs/disabilities/autism.php?s=KS