

MINUTES OF THE SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

The meeting was called to order by Vice Chair Senator Vicki Schmidt at 1:30 p.m. on February 10, 2009, in Room 136-N of the Capitol. Chairman Barnett was testifying at another Senate hearing.

All members were present.

Committee staff present:

Nobuko Folmsbee, Office of the Revisor of Statutes
Doug Taylor, Office of the Revisor of Statutes
Kelly Navinsky-Wenzl, Kansas Legislative Research Department
Terri Weber, Kansas Legislative Research Department
Jan Lunn, Committee Assistant

Conferees appearing before the committee:

Dr. Bill Craig, Chairman, Autism Task Force
Michael L. Wasmer, DVM, Appointed Member of Autism Task Force
Louise Heinz, Appointed Member of Autism Task Force and Parent

Others attending:

See attached list.

Senator Schmidt requested Nobuko Folmsbee brief committee members on **SB 83 - Autism task force**. This legislation would re-establish the Kansas Autism Task Force which was created in 2007 and expired on December 31, 2008. Its purpose is to study and conduct hearings relating to the needs and services available for persons with autism.

Senator Julia Lynn was recognized by the chair to introduce the conferees.

Senator Barnett arrived and assumed the chair. He recognized Dr. Bill Craig who spoke regarding the purpose, accomplishment, and the work remaining for members of the Autism Task Force. He indicated the members of the Autism Task Force include representatives and experts from varying fields/industries such as insurance, parents of autistic children, advocacy groups, special educators, regulatory agencies, legislators, etc. The Task Force developed key recommendations that fell into four areas: a handbook for parents with autistic children that details best practices within the field, the development of a scholarship program (through legislation) to include a human services specialist for autism to serve rural/underserved areas, open access to health insurance (through legislation) for autistic individuals, and full funding for individuals on the autism waiver waiting list. Dr. Craig submitted the full report to committee members (Attachment 1).

Senator Schmidt requested that if the task force is renewed, the group work with the State Board of Regents (postsecondary institutions) to develop the definition, role, and certification criteria of an autism specialist or human services specialist. Dr. Craig indicated willingness to move forward with that recommendation should the task force be re-established.

Senators discussed the current status of insurance coverage for autistic individuals, the scope of work included in re-establishing the task force, anticipated costs for renewing the task force, the autism waiver and potential for a sliding fee scale, and on-line resources for consumers, etc.

Dr. Mike Wasmer was introduced to speak in support of **SB 83**. His daughter, Kate (for whom the bill is named) was diagnosed with autism at age 2. Dr. Wasmer related his family's experience. Dr. Wasmer reported that with the appropriate treatment, his daughter has been mainstreamed in public school, requires no special services, and makes straight A's in school. He spoke about the value of early intervention and treatment not only to the autistic child but to the public in the form of dollar savings to the State (Attachment 2). It is projected that savings of approximately 4.4 million dollars in costs of adult services and lost productivity can be realized by utilizing early intervention and recommended treatment modalities

Chairman Barnett recognized Louise Heinz, the mother of an autistic child and appointed member of the

CONTINUATION SHEET

Minutes of the Senate Public Health And Welfare Committee at 1:30 p.m. on February 10, 2009, in Room 136-N of the Capitol.

Autism Task Force, who provided updated committee members on the current status of autistic children on the waiver waiting list. Ms. Heinz shared information regarding the progress of the Task Force and cited statistics related to the rising numbers of children being diagnosed with autism (Attachment 3). She reported that significant work has been done on the “best practices handbook” which will serve as a resource tool for parents and will provide evidence-based information to enhance decision-making (Attachment 4). The re-establishment of the Task Force will allow members to incorporate outcomes from a national project into “best practices handbook.”

Senator Barnett adjourned the meeting at 2:15pm.

The next meeting is scheduled for February 11, 2009.

Public Health & Welfare - February 10, 2009

NAME	Applicant
Katelyn Lutgen	KAC
D. Moyer	KHPA
Kari Presley	Kearney & Associates
Sandy Braden	Hacher, Braden & Assoc.
Tom Kutz	KASIB
Nancy Zogelman	Polsinelli
Susan W. Zelenka	gtg
Suzanne Winkle	KS Action for Children
David Borlay	Intern
FRANK STAHL	SRS/DBHS/CSS
Louise Hanz	AUTISM TASK FORCE.
Bill Craig	() () ()
Michael Walsmer	KS Autism Task Force
LINDA S. HEITZMAN-SWELL	KS Autism Task Force

Testimony Prepared for the Hearing of SB 83
Public Health & Welfare Committee
Senator Barnett, Chair
February 10, 2009

The Kansas Autism Task Force, established by Senate Bill 138, submitted its final report to the Legislative Education Planning Committee in November of last year. I have provided the committee a copy of that report.

In this report, the Task Force offered a vision statement for autism supports and services to which Kansas should aspire:

All children in Kansas will receive screening for a developmental delay within the first year of life and for an autism spectrum disorder (ASD) within the second year. Children with a positive ASD screen will be referred for evidence based intensive intervention immediately while undergoing a thorough diagnostic assessment within six months. Evidence based intervention services (defined as 25 hours a week of systematic intervention for a period of three years for a child under the age of 8) will be readily available for all Kansas children with an ASD.

High quality supports will be readily available to persons with autism who require them throughout the life span.

Families, public schools, state and federal programs, and private health insurance must each be fully participating partners in the achievement of this vision.

To further this vision, the Task Force focused its recommendation in four areas:

1. The development of a Best Practices Handbook which identifies those treatments and approaches to autism which have received solid research support. This easy-to-use document will be made available to families on-line and through the service access networks: Tiny K, Pre-Schools, and CDDOs.
2. Legislation (SB 10) to create a Scholarship Program to incentivize human service professionals to become autism specialists who agree to work in underserved areas of the State.
3. Legislation (SB 12 or Kate's Law) to ensure **open access to health insurance** for Kansans with autism. Currently, such access is not guaranteed and medically necessary services are denied under policies which fall within the purview of the Kansas Insurance Commission.

4. **Full funding of the Autism Waiver.** Kansas instituted a Medicaid waiver focused on early intervention for children with autism in January of last year. This waiver has receiving national attention for its design. Currently, 45 children have received the funding and about 160 remain on a waiting list. Six children have aged out off of the waiting list and will never benefit from this service. Because of the age dependent effectiveness of this type of intervention, a waiting list is simply not acceptable public policy.

Over, the course of the past year, the Task Force has heard from numerous state agencies, educators, scientists, business people and families. We have been impressed with the widespread awareness of the growing challenge of autism and willingness of Kansans to be part of the solution. We believe that by addressing the four areas above a foundation will have been laid to begin to successfully address this challenge.

Today, on behalf of the Task Force, I am here to seek your support for SB 83 which would extend the term of the Task Force through this calendar year. The rationale for this request is that we were unable to complete our work in the allotted eighteen months. What remains is not large, but is essential:

- the completion of the Best Practices Handbook
- identification of ways to better address the support and information needs of families
- liasoning with the Governor's Commission on Autism which will continue to function after the Task Force sunsets.

Thank you.

Dr. Bill Craig
Chair, Kansas Autism Task Force

**Report of the
Kansas Autism Task Force
to the
2009 Kansas Legislature**

CHAIRPERSON: Bill Craig

LEGISLATIVE MEMBERS: Senators Donald Betts and Julia Lynn; and Representatives Melody McCray-Miller and Judy Morrison

NON-LEGISLATIVE MEMBERS: Sarah Bommarito, Kathy Ellerbeck, Jarrod Forbes, Denise Grasso, Louise Heinz, Linda Heitzman-Powell, Yeyette Houfek, Donald Jordan, Linda Kenney, Tracy Lee, Jim Leiker, Martin Maldonado, Dee McKee, Nan Perrin, Matt Reese, Colleen Riley, Michael Wasmer, Jane Wegner, and Jeanie Zortman

STUDY TOPIC

The Kansas Autism Task Force is directed statutorily to study and conduct hearings on the issues related to the needs of and services available for persons with autism. State law requires that the Task Force submit reports to the Legislative Educational Planning Committee (KSA 46-1208d).

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 (Kansas Department of Health and Environment (KDHE), Department of Education, and the Department of Social and Rehabilitation Services (SRS)) 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 KDHE *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 (KDHE, Department of Education, and SRS) 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.

BACKGROUND

The Kansas Autism Task Force was established by 2007 SB 138 to study and conduct hearings into issues including but not limited to:

- The realignment of state agencies that provide services for children with autism;
- The availability or accessibility of services for the screening, diagnosis and treatment of children with autism and the availability or accessibility of services for the parents or guardians of children with autism;
- The need to increase the number of qualified professionals and paraprofessionals who are able to provide evidence-based intervention and other services to children with autism and incentives which may be offered to meet that need;
- The benefits currently available for services provided to children with autism;
- The study and discussion of an autism registry which would (a) provide accurate numbers of children with autism, (b) improve the understanding of the spectrum of autism disorders and (c) allow for more complete epidemiologic surveys of autism spectrum disorders;
- The creation and design of a financial assistance program for children with autism;
- The establishment of a hotline that the parents or guardians of children with autism may use to locate services for children with autism;
- Additional funding sources to support programs that provide evidence-based intervention or treatment of autism, including

funding for the development of regional centers of excellence for the diagnosis and treatment of autism; and

- Develop recommendations for the best practices for early evidence-based intervention for children with autism.

TASK FORCE ACTIVITIES

The Task Force and its subcommittees met frequently in 2008. For a detailed description of the activities of the Task Force, refer to the minutes of meetings dated March 5, April 14, June 12, July 16, August 22, September 17, and November 12, 2008.

The Task Force decided to make a request to the 2009 Legislature to extend the term of its activity for an additional year for the following purposes:

- A final edition of the "Best Practices in Autism Treatment in Kansas" handbook must await the incorporation of the soon-to-be released national standards manual. Subsequently, a readily accessible version of this document will be made available to all interested families, providers, and others.
- The Task Force believes it must be available as a resource to the 2009 Legislature during the Session as it deliberates the recommendations of the Task Force.
- At the conclusion of the extension year the Task Force will make a recommendation to the Legislature for a mechanism to provide ongoing advice and oversight for the concerns of Kansans with autism.

CONCLUSIONS AND RECOMMENDATIONS

Our Findings

- Autism spectrum disorders (ASDs) are biologically based, neurodevelopmental disabilities with a strong genetic component that are characterized by impairments in communication, social interaction and sensory processing. With varying degrees of severity, ASDs interfere with an affected individual's ability to learn and to establish meaningful relationships with others.
- The prevalence of ASDs in Kansas (and nationwide) is increasing in epidemic proportions. (The Centers for Disease Control currently report the prevalence of ASDs as 1 in 150 births. Ten years ago, this estimate was 1 in 2,500.)
- There is no proven "cure" for autism and the effects of this disability are typically lifelong. However, effectiveness of early, intensive intervention in reducing the effects of this disorder is supported by a growing body of scientific research. The costs of this intervention for at least three years during the crucial developmental age (1 through 7) may exceed \$150,000.
- Half of the individuals who receive this level of intervention do not require subsequent special education services and 80 percent show measurable reduction in symptoms. The cost of supporting an individual with autism who does not receive such intervention through age 55 is estimated to average \$4,400,000.

Current Barriers

The current barriers to individuals with autism and their families in Kansas include:

- Long wait times for thorough diagnostic assessments by properly certified

professionals.

- The *tiny-k* network which provides the front line for early identification and intervention in Kansas is not adequately funded and provides no allowance for the high cost of early intervention.
- There is a dramatic shortage of qualified personnel to implement early intervention.
- The qualified personnel who are available are concentrated in the urban areas and not accessible to vast portions of rural Kansas.
- Current funding for the newly created Autism Waiver is limited to fewer than 50 children. The current waiting list contains more than three times the current number served.
- The only source local school districts have for covering the expense of these high cost services is Catastrophic Aid funding through the Kansas Department of Education.
- Currently, the Kansas Insurance Department has no authority to require non-discriminatory coverage for Kansans with autism.
- Most Kansas families of individuals with autism eventually will need to look to the public Developmental Disability system for services. The current waiting list for needed service (2,233 individuals waiting for HCBS services and an additional 1,279 awaiting other services, for a total of 3,512) is growing each year as appropriations have failed to keep pace with the need. In addition, the inadequacy of reimbursement rates to cover the cost to recruit and retain direct support workers of acceptable quality has further rendered this system a broken resource.

Vision Statement

The Task Force expresses the following Vision Statement for autism supports and services to which Kansas should aspire.

All children in Kansas will receive screening for a developmental delay within the first year of life and for an autism spectrum disorder (ASD) within the second year. Children with a positive ASD screen will be referred for evidence-based intensive intervention immediately while undergoing a thorough diagnostic assessment within six months. Evidence-based intervention services (defined as at least 25 hours a week of systematic intervention for a period of three years for a child under the age of 8) will be readily available for all Kansas children with an ASD.

High quality supports will be readily available to persons with autism who require them throughout the life span.

Families, public schools, state and federal programs, service providers, and private health insurance carriers must each be fully participating partners in the achievement of this vision.

LEGISLATIVE 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 (KDHE, Department of Education, SRS) should incorporate the guidance of the "Best Practices in Autism Intervention for Kansas" handbook 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 KDHE *tiny-k* funding formula to support local providers who must support high cost, intensive services identified in 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 and a waiting list is not an 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 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 (KDHE, Department of Education, and SRS) 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.

Attachment: Executive summary of the "Best Practices in Autism Intervention for Kansas" handbook.

Testimony in Support of Senate Bill 83
Senate Public Health & Welfare Committee

February 10, 2009
Michael L. Wasmer, DVM

Thank you Senator Barnett and members of the committee for the opportunity to speak today in support of Senate Bill 83.

I am an appointed member of the Kansas Autism Task Force, Founder of the Kansas Coalition for Autism Legislation and proud father to Kate and Sam. Kate was diagnosed with autism when she was 2 years old. Since 1999 when Kate was born, the number of children with autism in Kansas as reported under Part B of IDEA has increased by over 230%. The most recent report from the Centers for Disease Control cites the prevalence of autism spectrum disorders as 1 per 150 children. A definitive cause for the rising prevalence of autism remains elusive.

There is no proven "cure" for autism. However as our next conferee will discuss in more detail, a large body of scientific research supports the effectiveness of early, intensive intervention in reducing the effects of this disorder. The cost of appropriate treatment varies with the level of severity of the affected child and can exceed \$50,000 per year. However, approximately 50% of the individuals who receive this level of intervention will not require special education services, and 80% show measurable reduction in symptoms. The cost of supporting an individual with autism who does not receive such intervention through age 55 is estimated to be as high as \$4.4 million.

Kate had been a typically developing, bright, verbal, and engaging child until shortly after her first birthday when her development started to regress. At the time she was diagnosed she had lost the ability to speak and was non-responsive to social interaction. Our health insurance denied coverage for her treatment. My wife and I drained our savings but were able to provide Kate with 25 hours/week of a home-based intensive behavior therapy program for 3 years. However, she now is among the 50% of children who, provided with appropriate early intervention, have mainstreamed in public school and does not receive special education services.

Kate is currently in 4th grade in a general education classroom without an aide. She has "straight A's" on her report card and achieved a score of "exemplary" in both the Math and Reading Kansas State Assessment Tests this year. She still struggles with the social deficits that come with the diagnosis of autism, but she has a small group of good friends and plans to be a writer and an actress when she grows up.

Dr. Craig asked me to speak to the value of early, intensive evidence-based intervention for autism. The value to my wife and I is that it gave us back our daughter and the promise of a happy, productive life for Kate. The value to our public school is that the cost of educating Kate is 2-3 times less than it would have been if she had not received appropriate treatment. The value to the State of Kansas is that it has saved an estimated \$4.4 million that it would have otherwise spent on Kate in adult disability services and lost productivity over the course of her lifetime.

Dr. Craig's summary of the work of the Task Force demonstrates the complexity of the issues faced by the autism community and the crisis that autism presents the State of Kansas. Clearly this cannot be solved by a single entity or state agency. Families, private health insurance carriers, government funded programs, and public schools must each be fully participating partners in the solution. This "4-legged stool" approach to the solution is reflected in the Task Force's recommendations to the legislature. If any one leg of the stool is not strong enough, the stool will topple over.

Unfortunately, the current economic crisis is jeopardizing the already underfunded tiny-K, Autism Waiver and Developmental Disability Waiver programs. Additionally, public school funding is being cut. Most families simply cannot afford to pay the expense of medically necessary treatment for their child with autism out of pocket. That is why enactment of Kate's Law (Senate Bill 12) is so critical. Senate Bill 12 addresses the fourth leg of the stool analogy - private health insurance.

The Autism Task Force found that inequities in health insurance coverage create one of the most significant barriers to appropriate early intervention for children with autism spectrum disorders in Kansas. This conclusion led to draft legislation that was endorsed by the Legislative Educational Planning Committee and introduced this session as Senate Bill 12. Enactment of Senate Bill 12 would require that private health insurance companies cover the diagnostic evaluation and treatment for autism spectrum disorders for fully funded policyholders in Kansas.

Easter Seals, in cooperation with the Autism Society of America, recently completed a nationwide survey of 1,652 parents of children with autism about several topics including finances and health care. In this survey, only 18% of parents of children with autism reported that they have health insurance that adequately covers their child's needs.

The Center for Child Health and Development at the University of Kansas (KU) Medical Center reports a 34% rate of denial of coverage from private health

insurance for children referred for a comprehensive team assessment after receiving a positive screening test for autism. The rate of denial reported by the KU Department Pediatrics, which sees largely typically developing children is 15%.

Very few private health insurance plans in Kansas cover Applied Behavior Analysis (ABA). ABA is often denied on the basis of it being “investigational” or “experimental”, notwithstanding the scientific evidence of its efficacy and its endorsement by the nation’s leading health authorities including the American Academy of Pediatrics and the Surgeon General of the United States. Tri-Care is the Department of Defense health insurance plan for military dependants. Federal Law prohibits Tri-Care from covering “unproven care or special education.” Applied Behavior Analysis is covered under Tri-Care Extended Care Health Option (ECHO).

Many private health insurance companies designate autism as a diagnostic exclusion, meaning that any services rendered explicitly for the treatment of autism such as speech therapy and occupational therapy are not covered by the plan, even if those services would be covered if used to treat a different condition.

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

Our analysis demonstrates the estimated increase in health insurance premiums as a result of services required by Senate Bill 12 to be 0.44%. This equates to \$48 per year per family premium. This estimate is consistent with that of the nine other states that have already enacted legislation similar to SB 12. Of these, Indiana’s autism mandate has been in effect the longest - over 8 years. It has no age limits or financial caps on coverage, and applies to both large and small businesses. To date, there has been no data presented by any government body or insurer to show that it has had negative effects upon health insurance premiums, the number of uninsured in the State, the viability of small businesses or the ability of the state to attract large and small businesses to the State.

The original fiscal note submitted by Kansas Budget Office for SB 12 estimates the cost of providing coverage for autism to the State Employees Health Plan (SEHP) to be \$4.7 million. However, we are currently reviewing with the Kansas Health Policy Authority (KHPA) some of the assumptions that were made when calculating this estimate and expect that a more accurate figure may be as much as 66% lower.

Even using what we expect is an inflated estimate of the cost to the SEHP in the following calculation, the cost savings that result from appropriate intensive early intervention are dramatic:

- The KHPA has estimated that there are **173 children** with autism spectrum disorder in the SEHP
- Research demonstrates that approximately **50% of these children** will mainstream in regular education classrooms without an aid if provided appropriate early intensive intervention.
- The future success of each of these **86 children** saves the State of Kansas an estimated \$4.4 million in lifelong adult disability services and lost wages, for a **total cost savings of over \$378 million dollars.**

Although it is important to ask whether the State of Kansas can afford \$4.7 million dollars today, a more critical question is whether it can afford spending \$378 million tomorrow.

For our children, for our families, for our school, and for the State of Kansas I pray that the Kansas Legislature sees the wisdom of enacting Senate Bill 12. In addition to the reasons cited by Dr. Craig for extending the term of the Autism Task Force, if Senate Bill 12 passes the combined knowledge and expertise of its members would be necessary to assist in the implementation phase of the process.

From a parent's perspective, one of the most important roles that the Task Force has served is increased awareness of the crisis of autism among our elected officials. There has been more discussion of autism in Topeka in last 2 years than ever before. The Autism Task Force has given voice to the parents of newly diagnosed children who are living this nightmare 24 hours a day and cannot be here to advocate in person. However increased awareness without concrete legislative action is not going to help our children. Please support Senate Bill 12 and Senate Bill 83.

Respectfully submitted,

Michael Wasmer
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**Testimony in Support of an Extension to the Kansas Autism Task Force
Senate Public Health and Welfare Committee**

February 10, 2009

Good afternoon. My name is Louise Heinz. I am a parent appointee to the Kansas Autism Task Force. I am Vice-President of the Lawrence Autism Society, a parent support group. And, most importantly, I am a parent of 3 children, one of whom, my 5 year old daughter, has autism.

I would like to thank Senator Barnett and members of the committee for the opportunity to testify today in support of an extension to the Kansas Autism Task Force.

The formation of the Autism Task Force allowed those who shared a common concern about the plight of the growing numbers of individuals with autism in Kansas to come together. Parents, legislators, professionals and agencies met on a regular basis to gather information, discuss options and ultimately produce recommendations for the Kansas legislature. I believe that the Autism Task Force accomplished a great deal in the time it was given, however, I also believe that we still have work to do.

Firstly, I would like to share some facts and figures with you:

- “Autism is the fastest growing serious developmental disability in the U.S. ...” – Centers for Disease Control;
- “Autism is a national health crisis, growing at an alarming 10-17% per year.” – Autism Research Institute;
- As of Dec 2007, the Kansas Department of Education reported that 1998 students with autism (ages 3-21) were enrolled in its school districts;
- As of September 2008, my own school district, USD 497 (Lawrence) reported that 169 students have a diagnosis of autism, that is 1:64;
- According to Kansas Department of Education figures, from 2001 – 2007, there was a 236% increase in the number of children with autism.

Since there is no known cause of autism, no preventative measures can be taken. Therefore it is fair to assume that the state of Kansas can expect the number of children diagnosed with autism to keep rising and, if the previous trends of this decade continue, at an average rate of 16% a year.

We do not know what causes autism, we cannot prevent it and we cannot cure it. However we can treat it. And we can treat it very successfully as long as the appropriate interventions are supplied to the children with autism at the appropriate time. This is why the work of the Best Practices Subcommittee is so important. We all (parents, educators, pediatricians, providers and legislators) need to know how to effectively treat autism in order to curtail this crisis.

Public Health and Welfare

Date:

Attachment:

02/10/09

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Best Practices Subcommittee – Work to Date

The charge for the Best Practices Subcommittee was What are the "Best Practices" for early evidence-based intervention for children with autism? In other words, what does the science tell us are the most effective interventions? Or, put another way, which treatments are going to give us the greatest return on our investment?

The Best Practices Subcommittee was subsequently assembled and included Autism Task Force appointees and guest-members. The team represented individuals from behavioral science, speech and language, special education, psychiatry, the Kansas Department of Education (representing school districts), the Kansas Department of Health and Environment (representing *tiny-k*) and included a parent representative. Thus the work, recommendations and final report of the Best Practices Subcommittee was a cross-disciplinary team effort. The subcommittee convener, Dr Linda Heitzman-Powell went to great lengths to ensure that the team and therefore the team's recommendations were representative of all invested parties in Kansas.

A document entitled "Best Practices in Autism Intervention for Kansas" was produced. A copy of the Executive Summary is attached to this testimony. Essentially, the document's purpose is to remove any guesswork when it comes to identifying those interventions that best serve children with autism in the state of Kansas. In order to produce the document the Best Practices Subcommittee agreed to review the following: other state documents; other completed comprehensive reviews; discipline-specific comprehensive reviews that were submitted to the subcommittee; and all key reports and scientific documents that have been generated in the last 5 years.

Once the research was complete, the subcommittee then produced its Best Practice recommendations. To clarify, "Best Practice" is a protocol or procedure that has been empirically validated and becomes the minimum or appropriate standard. The Best Practices Subcommittee found that its recommendations were similar to those set forth in other states reports (California Department of Education and Developmental Services, 1997; New Jersey Department of Education, 2004) as well as those identified by the National Research Council.

Best Practice recommendations include the use of:

1. intensive early intervention services based on the science of human behavior such as that found in an Applied Behavior Analysis, 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.
2. Instructional programs and curriculum to address all areas of delay and specifically address core deficits of autism (e.g., social, communication, and repetitive/stereotypic behaviors) with ongoing measurement and documentation of the individual child's progress toward identified objectives, while addressing problem or interfering behaviors for reduction and/or replacement using empirically supported strategies to teach socially valid replacement behaviors.

3. Involvement with typically developing peers.
 4. Staff members delivering the intervention must have received specialized training in ASD that includes an experiential component.
 5. Inclusion of a family component, including parent training, to ensure family participation in development of goals, priorities and treatment plans and to provide on-going parent support, training and consultation.
- (Executive Summary, Best Practices for Autism Treatment in Kansas, 2008).

Best Practices Subcommittee - What Next?

Given another year, the Best Practices Subcommittee would be able to accomplish the following:

- Incorporate the outcomes from the long awaited National Standards Project. This is a national effort to complete a thorough, first-hand review of the scientific literature regarding effective intervention for individuals with autism throughout the life-span. This would greatly enhance our research base for the “Best Practices in Autism Intervention for Kansas” document and would allow us to evaluate the science behind interventions for adults with autism.
- Incorporate the emerging literature on ways to effectively train individuals to work with those affected by autism and on ways to effectively teach families how to work with their family members affected by autism.
- Produce a Parent Handbook and Resource Guide, a document desperately needed by Kansans affected by autism and their families. This would help them navigate from first suspicion, through diagnosis, to accessing evidence-based intervention, and to access service-delivery systems (for example, currently funded agencies that provide support, such as the CDDOs).

It is our hope that this committee will consider extending the life of the Legislative Task Force on Autism so that we might complete our information gathering endeavors and be able to provide succinct recommendations to the Legislators, particularly in these tough economic times, on the most effective way to treat autism.

Best Practices for Autism Treatment in Kansas

Best Practices Subcommittee of the Kansas Legislative Task Force on Autism

Subcommittee members

Linda S. Heitzman-Powell, Ph.D., Convener

Adjunct Faculty, University of Kansas

Nanette Perrin, M.A.

Board Certified Behavior Analyst

Louise Heinz

Parent Representative

Jane Wegner, Ph.D.

Speech-Language-Hearing

Tracy Lee, M.S.

Special Education

Martin Maldonado, M.D.

Psychiatrist

Guest Members

Significant Contributors

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EXECUTIVE SUMMARY
Best Practices Subcommittee

The purpose of this report is to (1) synthesize the evidence regarding effective evidence-based interventions that guide best practices for the treatment of individuals affected by ASD; and (2) based on the findings, make recommendations on best practices for children with autism.

This report was generated from the ideology that our process and recommendations are based on the most current science.

Synthesis of Evidence-based Practices

The Best Practices subcommittee agreed to review: 1) other state documents; 2) other comprehensive reviews that have been completed; 3) discipline-specific comprehensive reviews that were submitted to the subcommittee by members of the committee or guest members, and 5) key reports or scientific documents that have been generated in the last 5 years. The subcommittee agreed with Horner and colleagues' (2005) definition of evidence-based practice:

“[evidence-based] Practice refers to a curriculum, behavior intervention, systems change, or education approach designed for use by families, educators, or students with the express expectation that implementation will result in measurable educational, social, behavioral, or physical benefit (pg. 175).”

The Best Practices subcommittee also defined criteria for strong, moderate, emerging, minimal and no evidence of interventions, and these criteria were used to make recommendations. These criteria were developed based on published criteria for reviewing evidenced based practices by prominent researchers and national scientific reviews including the National Standards Project (National Autism Center – <http://www.nationalautismcenter.org/>), the National Research Council, the American Speech-Language-Hearing Association's National Center for Evidence-Based Practice, and the Council for Exceptional Children. The agreed upon criteria were:

- Strongest evidence: more than six studies with more than 20 participants, with beneficial effects and no conflicting results or harmful effects, using Randomized Control Trials or single subject designs, and conducted by 3 researchers in 3 geographic regions.
- Moderate evidence: more than nine studies and the same criteria as used for 'strongest evidence, however one study showing conflicting results.
- Emerging evidence: four to five studies with more than 10 participants, the same benefits and scientific design as for strongest evidence but no criteria for the number or location of research.
- Minimal evidence: one to two studies, with four participants and the same benefits and scientific design as for strongest evidence but no criteria for the number or location of research.
- No evidence: no methodological criterion and no experimental control

Once these sources were identified, the recommendations cited as evidence-based were then synthesized. Interventions and program recommendations that adhered to the committee's criteria for "evidence" were then included in this report. Due to time and resources constraints, the Best Practices subcommittee procedures DID NOT include: 1) a comprehensive, first hand search and review of the scientific literature; 2) a review of all disciplines that could provide services for individuals with an ASD; and 3) a review of alternative medicines or techniques.

Findings and Recommendations to the Autism Task Force

Recommendations in this report are made with the understanding that each individual on the spectrum is unique. Given early diagnosis and intervention, outcomes will vary for individuals with an Autism Spectrum Disorder (ASD) just as outcomes for any child will vary based on individual characteristics. Individualized programs are recommended based on child needs and best available evidence of effective practices.

Recommendations are based on common elements of reported "best practices" and evidenced based programs: data collection and data-based decision making, structured and well-defined teaching procedures, use of procedures to increase desirable behaviors, function-based treatment of problem behaviors, and use of developmentally appropriate and well-rounded curriculum including peers when appropriate. Examples of evidence-based practices included: Applied Behavioral Analysis and Discrete Trial Teaching (e.g., University of California at Los Angeles, and replication sites); and 2 other intervention programs cited in a meta-analysis conducted by Simpson and colleagues (2005) Pivotal Response Training (PRT; University of California at Santa Barbara), and Learning Experiences: An Alternative for Preschoolers and Parents (LEAP). Examples of emerging or probably evidence-based (needing more research) included: Treatment and Education of Autistic and Communication Handicapped Children (TEACCH; University of North Carolina); and individual interventions such as assistive technology, augmentative alternative communication (AAC), incidental and naturalistic teaching, joint action routines, peer mediation intervention strategy, social stories intervention strategy, developmental play/assessment teaching, Picture Exchange Communication System (PECS), and video modeling.

Recommendations are also inclusive of general characteristics of quality programs based on syntheses provided of *Model Early Childhood Programs for Children with ASD* (see Boulware, et al. 2006; Dawson & Osterling, 1997; the National Research Council, 2001). Programs considered high quality by the reviewers (i.e., using evidenced-based practices, favorable reviews by multiple professional organizations) found a range of 15-40 hours per week of service, with average of 25 hours week. They found that the characteristics necessary for an effective program are: use of a comprehensive curriculum sensitive to developmental sequence, use of supportive, empirically validated teaching strategies, involvement of parents, gradual transition to more naturalistic environments, highly trained staff, and a systematic supervisory and review mechanism.

Finally, a large project sponsored by the National Autism Center, recently completed the National Standards Project, as an effort to use scientific merit to identify evidence-based guidelines for treatments of individuals with ASD younger than 22 years of age. The focus of the project was limited to “interventions that can reasonably be implemented with integrity in most school or behavioral treatment programs. A review of the biomedical literature for ASD will be left to another body of qualified individuals.” (Wilczynski, et al., 2008, p. 39). A panel of multidisciplinary autism researchers applied a rigorous scoring system to evaluate the quality and usefulness of interventions for individuals with ASD described in nearly 1,000 studies. Results of the project are expected before the end of 2008 (<http://www.nationalautismcenter.org>). A recent publication by those involved in the *National Standards Project* includes recommendations of the best practices listed above (e.g., discrete trial training). The report also recommends four key behavior support interventions including: antecedent (preventive) intervention, positive reinforcement to decrease challenging behavior, behavior-contingent (restrictive) intervention as a function-based approach, and family support.

The following recommendations are the results of the Best Practices subcommittee work for the Legislative Task Force on Autism.

Best Practice Recommendations based on a Synthesis of Sources

1. Use of a model based on the science 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 on-going parent support, training and consultation.

This report offers a synthesis of evidence-based practices and program characteristics for young children with ASD. Examples of quality programs are referenced, and characteristics described. Single intervention strategies with evidence supporting their effectiveness are also described. Recommendations to the Autism Task Force are provided as guidelines for practitioners to improve outcomes for children with ASD, and support for their families across the state of Kansas. Guidelines are based on current research and our review process of the research as described (review of state documents, reports from professional organizations, literature syntheses, and meta-analyses reports). A final recommendation is to provide periodic updates and supplements to the report as new research and treatment are developed.