

**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:

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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.

Executive Summary

Best Practices for Autism Treatment in Kansas

Best Practices Subcommittee of the Kansas Legislative Task Force on Autism

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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.