

MINUTES

KANSAS AUTISM TASK FORCE

November 13, 2007
Room 313-S - Statehouse

Members Present

Dr. Bill Craig, Chairman
Ms. Sarah Bommarito*
Mr. Jarrod Forbes
Dr. Kathy Ellerbeck
Ms. Denise Grasso (present by phone)
Ms. Louise Heinz
Dr. Linda Heitzman-Powell
Ms. Yeyette Houfek
Ms. Linda Kenney, *ex officio*
Mr. Jim Leiker, *ex officio*
Senator Julia Lynn
Representative Melody McCray-Miller (present by phone)
Dr. Dee McKee
Representative Judy Morrison*
Ms. Nan Perrin
Ms. Colleen Riley, *ex officio*
Dr. Michael Wasmer
Ms. Jeannie Zortman
Ms. Margaret Zillinger (representing Secretary Donald Jordan, *ex officio*)

* member of Governor's Commission on Autism

Members Absent

Senator Donald Betts
Ms. Tracy Lee
Secretary Donald Jordan, *ex officio*
Dr. Martin Maldonado
Dr. Matt Reese*
Dr. Jane Wegner

Kansas Governor's Commission on Autism

Mr. David Cunningham, Acting Chairperson

Shirley Erickson
Jamey Kendall, Kansas Department of Health and Environment
Mary Schlyer Woodworth
Stephen Stein
Mimi French
Pamela S. Keller

Staff Present

Sharon Wenger, Kansas Legislative Research Department
Martha Dorsey, Kansas Legislative Research Department
Ken Wilke, Revisor of Statutes Office
Renaë Jefferies, Revisor of Statutes Office
Nobuko Folmsbee, Revisor of Statutes Office
Rose Marie Glatt, Committee Assistant

Morning Session

The meeting was called to order at 9:30 a.m. by Bill Craig, Chairman, who welcomed members from the Kansas Governor's Commission on Autism to the third meeting of the Autism Task Force. Introductions were made. He reminded members that this is the last meeting before submission of the preliminary report to the Legislative Educational Planning Committee (LEPC). The goal of the meeting is to reach a consensus on the content of the preliminary report to be presented to the LEPC.

Last week at the Legislative Educational Planning Committee, Bill Craig presented a draft of the progress report (Attachment 1). He thanked members of the Task Force who had attended the meeting, and said he appreciated their moral support. He believed that the reception from the Committee was positive and supportive, with no hard questions; the LEPC Chairperson expressed appreciation for the work of the Task Force.

The draft of the Preliminary Report is organized around the subcommittees' topics. He called attention to the graphics (page 3) that illustrate the importance of all stakeholders in finding the solution to the autism challenge. At this time, he asked for comments and observations on the draft report. The following points were made:

- It was noted that in the financial portion of the report a recommendation was made regarding the "mapping of resources" and there was a question about its inclusion. The Chairman agreed to review the report.
- One observation was that there is a lack of understanding of the autism issue and education is necessary to illuminate legislators, as well as Kansans across the state. Thanks were given to Dr. Craig for his hard work.
- Another observation was made by an attendee of the LEPC who said the Committee seemed responsive to the draft report, but questioned how they can keep the momentum moving forward throughout the session. He sensed interest in introducing legislation to address the topic.

Bill Craig turned the Task Force members' attention to the draft of the Autism Task Force Preliminary Report (Attachment 2). He explained that it is a concept paper showing how the preliminary report might look, with the goal of developing a format that is more accessible to the average person. It is organized around issues followed by details from the subcommittees. He thanked Louise Heinz for her help in the development of the Report. He explained the elements of the report. The topic areas are intended to capture the Legislature's charge to the Task Force, including: Early Identification; Best Practices; Quality Providers; Statewideness; Funding; and Information Access. Under each topic, there will be three sections: Vision; Barriers; and Recommendations. He asked for feedback on the format and the following points were made:

- An introductory session should be added giving a brief definition of autism, the prevalence, and why it is an issue.
- The estimated cost of programs should be attached to recommendations, as well as an estimate of the projected costs if money is not spent for early intervention.

Early Identification. Bill Craig directed attention to the Vision statement. *“All children in Kansas will be seen within the first year of life by a pediatrician who is trained in screening techniques for the early signs of Autism Spectrum Disorder.”*

The following suggestions were offered:

- The term “medical home,” which includes a pediatrician or family physician, should be used instead of “pediatrician.” Dr. Kathy Ellerbeck said the definition of “medical home” is a primary care practice that coordinates the medical care for an individual. For autistic children, it offers continuity of care and is comprehensive in that it is connected to all agencies related to children's issues. It is a chronic care model which is accepted in both pediatric and general practices for children with chronic illness.
- Caution was voiced over making definitions too specific.
- There are a large number of agencies that are already providing autism-related services, and they need to be held accountable for what they are supposed to be doing.
- There is a need for a viable mapping process that states the places providing services related to autism. This would serve as a resource for parents who have difficulty following a prescribed plan for their child.

“All Kansas children with a provisional ASD diagnosis will be referred for early intervention even before a definitive diagnosis is made. A thorough diagnostic assessment by trained professionals will be available to autistic children within two months of referral.”

The following key points were made:

- There was a question about whether a thorough diagnostic assessment could be done in two months.
- Additional language “that is evidence-based” should be added after “early intervention” in the first sentence.

- It was suggested that the terms “screening” and “diagnosis” need to be carefully used.
- Discussion followed regarding the issue of accountability. Several suggestions to provide oversight were given including: creating a new agency; using existing agencies; including the Kansas Health Policy Authority; and forming a new subcommittee formed from current Task Force that deals with accountability. It was suggested that Sharon Wenger research what other states have done regarding an oversight committee. Legislators said that without a central authority named, legislation put forth during the next session will not be successful. Bill Craig reminded members to e-mail other suggestions to Sharon Wenger.
- Do not piecemeal legislation - it should include all aspects of autism: medical, educational, and social.

Best Practices. Bill Craig reviewed the vision statement: "Intensive intervention with active engagement with the child for at least 25 hours per week for 12 months of the year in a systematically-planned, developmentally-appropriate service setting be provided to all Kansas children who have received either provisional or a final ASD diagnosis. Specific intervention and techniques will be guided by a living document entitled "Best Practices in Autism Intervention for Kansas Children."

Dr. Craig said there are two elements involved: the American Academy of Pediatrics recommendation; and reference to the document that will become the work product of the Best Practices Subcommittee.

The following key points were made or asked:

- Intervention must be evidence based.
- Where will the recommendations go and how are they assured they will be implemented?
- Recommendations should be for all ages, not just for children. Look at gaps across the entire life span, beyond early intervention. Use the word Kansans, not children.
- Stress cost savings with early intervention.
- A toolkit needs to be developed on best practices.
- There needs to be a scoring system using levels of evidence regarding early intervention and service providers.
- The mission is to identify, based on research, the practices that have been demonstrated to have successful outcomes.

Quality Providers

The vision statement: "An adequate number of highly-trained professionals and para-professionals will be available throughout Kansas to provide the best practices and state-of-art interventions as needed."

The following key points were made:

- The definition of "quality providers" is too broad.
- The definition of "highly trained" was discussed, and it needs to have a universally-understood meaning.
- The idea of "special education" needs to be elevated to the same par as "higher math and science standards."
- What are the credentials for an "autism specialist"? This needs to be governed by an oversight committee. It is difficult to identify and certify "specialists."
- Generic licensing is not adequate to be identified as an autism specialist. Each discipline needs to look at definitions for which each license is given. Perhaps the Board of Regents should be questioned as to existing training programs for services from the Department of Education.

Statewideness

The vision statement: "Participation in the vision of this project shall not be hindered by a resident's location in the State of Kansas."

The following key points were made:

- This should be written in a positive rather than negative form.
- Educational roll-out programs must be delivered to all Kansans.

Afternoon Session

Minutes from the October 25, 2007 meeting were reviewed. *Yeyette Houfek made a motion to approve the minutes. Jim Leiker seconded the motion. The motion carried.*

Funding

Vision Statement: "Funding shall not be a barrier to the access of every Kansas child with an ASD diagnosis to early identification, intervention, and ongoing support. Families, public schools, state and federal programs, and private insurance companies will play a responsible, proactive role in assuring the accomplishment of this goal."

The following key points were made:

- The legal definition of ASD was discussed. Bill Craig turned attention to the issue of autism mandated insurance legislation. Dr. Michael Wasmer reviewed the key points submitted from the Insurance Subcommittee:
 - Definition of autism - According to the American Academy of Pediatrics, autism is "a biologically based neurodevelopmental disability with a strong genetic basis." Although autism is not a mental illness, in the Kansas Mental Health Policy Act, autism and pervasive developmental disorder are included among the disorders defined as "mental illness." This is a major source of confusion for all parties concerned.
 - Course of action - Consider a proposal for a state health insurance mandate specific to autism spectrum disorders that would include coverage for intensive behavioral treatments such as applied behavior analysis (ABA).
 - Increased health insurance costs - Arguments that raised concerns over possible increased premiums were with an autism insurance mandate found to have no impact on overall health care costs, according to a 2004 report by the Kansas Department of Insurance.
 - Language - Dr. Wasmer said the Indiana Autism Mandate, passed in 2001, was intentionally vague with regard to details of services covered; however, the Subcommittee recommended the administered therapy must be ordered by the primary care physician and must be demonstrated to be effective upon regular review of the treatment plan.
 - Cost Analysis - The cost to the State of not providing early and appropriate intervention for an individual with autism has been estimated to be \$4.3 million over their lifetime. Autism-specific health insurance legislation is a fiscally responsible consideration.

Senator Lynn moved the Kansas Autism Task Force vote to approve the text of the preliminary report, submitted to the committee last week, with the understanding that the Insurance Subcommittee will be developing a specific recommendation for an autism insurance mandate to be recommended for introduction in the 2008 Session. The motion carried on a voice vote. There were no negative votes.

Discussion followed regarding limitations of services by providers and the strategy on whether to propose legislation this year or next.

It was noted that insurance companies prefer more specific guidelines as recommended by the Best Practices Subcommittee rather than including every type of therapy available to be covered by insurance companies. It is important to be prepared to answer tough questions with the rationale behind the answers.

Dee McKee said the Funding Subcommittee had discussed the issue of catastrophic aid. She explained that Kansas has a funding mechanism within the special education funding program, that allows for reimbursement (currently at 75/25 ratio) after \$25,000 is spent by a school district on an individual child. The consensus of the Subcommittees is that it is available from three years of age through graduation at 21. This access to additional funds provides a positive reason for educators/administrators to offer this program. She said there has been talk about changing the program and, based on its importance to many educators, she made the following recommendation.

She made a motion that the Task Force, through the Funding Subcommittee, recommend that the Legislature retain catastrophic aid at its current level. Yeyette Houfek seconded the motion. After discussion, the motion carried. Colleen Riley asked to be recorded as an abstention.

Information Access

Vision Statement: "All Kansans will have ready access to an information source for services, best practices, quality providers, and local resources. In addition, a database will be maintained that will track numbers of individuals with autism."

Bill Craig said that the vision statement is intended to encompass the mandate from the enabling legislation that includes a registry, centralized resource centers, and centers of excellence.

The following key points were made:

- The vision statement should state "information sources."
- Dynamic mapping of where agencies are located and how resources are currently being spent should be included.

Bill Craig reminded everyone to e-mail their suggestions regarding the draft report to Sharon Wenger as soon as possible.

Bill Craig suggested that the Task Force discuss the proposed administrative home for the tiny-k program. He said the program's location was discussed in 2006, at which time the Interagency Coordinating Council dealt with the question of whether it might be better managed elsewhere. There were extensive hearings on the topic and the group arrived at a split decision to place tiny-k in the Department of SRS. The Governor did not make a recommendation and left the agency with the Department of Health and Environment.

Sharon Wenger provided the background on other recent legislative committee actions. She said the 2010 Commission looked at early childhood programming, per 2006 legislation. As part of that recommendation, there were three programs that the 2010 Commission recommended move to the Department of Education, and tiny-k was one of them. In turn, that recommendation was brought to the Legislative Educational Planning Committee, and the LEPC agreed, so legislation is being drafted to that end.

Dr. Craig invited the three Task Force *ex officio* members, who represented the three agencies involved, for their comments.

Ms. Linda Kenney, Department of Health and Environment (KDHE), provided the history of the oversight of tiny-k. The tiny-k program is administered by the state agency, through multiple agencies and in partnership with local agencies. She said that if it is determined that the program would be better served in another lead agency, KDHE will give its support for continuation of services to Kansas families.

Margaret Zillinger, Department of Social and Rehabilitation Services, and Colleen Riley, Department of Education, both voiced their support of Linda Kenney's comments. Ms. Riley commended the service providers in the field for their continuation of providing the needed care, regardless of administrative changes.

Discussion followed regarding the administrative home for various programs and problems that occur during transition periods from one agency to another. Doug Bowman, State Interagency Coordinating Council, came to the podium to speak briefly on the process of the two proposals before them. He answered members' questions on the need to change agencies, and why the Governor declined to make a recommendation. Mr. Bowman spoke of a seven-page work document that addressed compliance issues, followed by side-by-side comparisons of programs. It was noted that the work document will be e-mailed to Task Force members.

Discussion returned to the morning's discussion on accountability. The following key points were made:

- For legislation to be successful, there must be an accountability piece.
- The question was whether an oversight entity should be public via legislative oversight, or via regional centers.
- It was suggested that regional centers that work directly with local providers would be in the position to know whether the work is being done.
- Accountability should be with an entity having authority and responsibility of related programs, not in the hands of a new agency.
- The Task Force should remain in force throughout the Legislative Session in order to bring the issue forward.
- Oversight by the Governor's Commission on Autism was suggested.
- An ongoing entity, such as the Task Force, could serve as an advisory group to the Kansas Health Policy Authority.

The next meeting of the Task Force will be December 12, 2007. The meeting was adjourned at 3:00 p.m.

Prepared by Rose Marie Glatt
Edited by Sharon Wenger

Approved by the Task Force on:

January 9, 2008

(Date)