

MINUTES

KANSAS AUTISM TASK FORCE

January 9, 2008
Room 313-S—Statehouse

Members Present

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

Members Absent

Senator Donald Betts
Dr. Kathy Ellerbeck
Dr. Martin Maldonado
Dr. Jane Wegner

Kansas Governor's Commission on Autism

David Cunningham, Acting Chairperson
Shirley Erickson
Mimi French
Pamela S. Keller

Jamey Kendall, Kansas Department of Health and Environment
Mary Schlyer Woodworth
Stephen Stein

Staff Present

Sharon Wenger, Kansas Legislative Research Department
Martha Dorsey, Kansas Legislative Research Department
Ken Wilke, Office of the Revisor of Statutes
Renaee Jefferies, Office of the Revisor of Statutes
Nobuko Folmsbee, Office of the Revisor of Statutes
Dianne Rosell, Office of the Revisor of Statutes
Jackie Lunn, Committee Assistant

Morning Session

The meeting was called to order at 9:40 a.m. by Dr. Bill Craig, Chairperson. Dr. Craig stated the Task Force would be following the agenda from the December meeting, which was cancelled due to weather, with considerably more urgency with the 2008 Legislative Session upon the Task Force.

Chairperson Craig called the members' attention to the minutes of the last meeting for their approval. After a brief discussion it was noted that the minutes should be corrected on the vote of the insurance bill to show that Mr. Jarrod Forbes entered a "nay" vote. With this noted, *Mr. Jim Leiker made a motion to approve the minutes of the November meeting with the noted change to be made. Sarah Bommarito seconded. The motion carried.*

Dr. Craig called the Task Force members' attention to the legislation the Task Force would be recommending to the Legislature this session, and introduced Mr. Ken Wilke, Office of the Revisor of Statutes, to explain the bill concerning insurance coverage for autism (Attachment 1). Mr. Wilke stated that this bill is an act concerning insurance; providing coverage for autism. He explained each section of the bill, highlighting the following:

- Any individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society, or health maintenance organization which provided coverage for accident and health services and which is delivered, issued for delivery, amended or renewed on or after July 1, 2008, shall provide coverage for the treatment of autism.
- Written notice shall be provided to all enrollees regarding the coverage of autism.
- No individual or group health insurance policy, medical service plan, contract, hospital service corporation contract, hospital and medical service corporation contract, fraternal benefit society, or health maintenance organization which provided coverage for accident and health services which provides coverage with respect to autism shall deny a patient eligibility, to enroll or renew coverage solely for the purpose of avoiding the requirements of this section; deny or refuse to

issue coverage, because the individual is diagnosed with autism; deny or refuse to issue coverage on, to contract with, or refuse to renew or reissue or otherwise terminate or restrict coverage because of the individual being diagnosed with autism.

- Impose on the coverage required by this section any dollar limits, deductibles or coinsurance provisions that are less favorable to an insured than the dollar limits, deductibles or coinsurance provisions that apply to physical illness generally under the accident and sickness insurance policy or penalize or otherwise reduce or limit the reimbursement of a health care provider or provide incentives to a health care provider, to induce such health care provider to provide care to an individual participant or beneficiary in a manner inconsistent with this section.

Upon the conclusion of Mr. Wilke's explanation of the bill, there was discussion. The bill had been assigned a number of SB 398. There also was discussion regarding page 6 of the bill, and it was the consensus of the Task Force it should be stricken. It was noted that changes to the bill could only be made during the legislative process.

With no further discussion, Dr. Craig introduced Nobuko Folmsbee, Office of the Revisor of Statutes, to explain the second bill establishing the autism service scholarship program (Attachment 2). Ms. Folmsbee stated the bill included the definitions of "autism," "qualified student," and "underserved area." Ms. Folmsbee went on to state the bill established the autism service scholarship program that could be awarded to any qualified student and may be renewed for each student who remains qualified for the scholarship. She also stated the number of scholarships awarded and the amount awarded to each applicant shall be determined by the executive officer of the Kansas Board of Regents. The amount awarded for academic year 2008-2009 shall not exceed \$2,500 each semester or its equivalent. For academic year 2009-2010 and each year thereafter, the maximum amount that may be awarded shall be increased by an amount equal to the percentage increase in the Consumer Price Index-Urban during the preceding fiscal year as certified to the executive officer by the director of the budget on August 15 of each year.

Upon the completion of Ms. Folmsbee's explanation of the bill, a discussion followed. It was noted that this bill also has been assigned a bill number of SB 406 and that the bill can only be modified in legislative committee. Several of the Committee members have concerns with the bill and had ideas on how to improve it.

Upon the completion of the discussion regarding the proposed scholarship legislation, Chairperson Craig introduced Margaret Zillinger, representing Secretary Donald Jordan, Department of Social and Rehabilitation Services (SRS), to give an update on the Autism Waiver implementation. Ms. Zillinger gave a brief update stating as of 5:00 p.m. January 8, 2008, SRS had received 84 applications for the Autism Waiver Program. The deadline for application is January 11, 2008. Applications must to be postmarked or faxed by that date to meet the deadline. The official selection will be on January 17 by a computer program randomly picking 25 applicants. Ms. Zillinger stated SRS would respond to every applicant as soon as possible to let them know if they were selected or not. At this time, SRS staff are working on recruiting providers. The program manager, Pam Keller, will be going out to meet with providers regarding the program and also will be trying to recruit new providers. She noted that SRS had received applications from across the entire state.

Dr. Craig asked Ms. Zillinger to take the Committee through the process step-by-step. Ms. Zillinger stated that once 25 applicants have been selected, they will have 5 to 7 days to get an assessment. Medicaid eligibility will be discussed; and if they do not have a Medicaid card, they will

put them in touch with the proper department to obtain a card. After all this is done, they will begin a process selecting providers. Ms. Zillinger stated income is not a factor if the child is eligible, and SRS staff are trying to get the word out to families. Case management is not available with this program. It was noted that the family would have a choice of "ultimate specialists" choosing from the providers in the program. She also stated that if applicants did not make the first group of 25, they would be given notification of where they rank on the waiting list.

There was a lengthy discussion regarding this program and ways to increase the knowledge of the program to the public. Chairperson Craig inquired if SRS could encourage the families in the program to contact their legislators to make them aware of the program. Chairperson Craig felt it might help awareness and also will help in getting needed legislation passed.

The Task Force thanked Ms. Zillinger for all her hard work in getting this program established.

With no further questions or discussion, the Task Force took a brief break. Upon return, Chairperson Craig read an e-mail from Carolyn Nelson with the *tiny-k* Program. She had spoken with their network about getting families to sign up for the Autism Waiver Program. They also have been encouraging the networks to have appropriate providers.

Chairperson Craig introduced Lesli Girard to give an update on Families Together, Inc. Ms. Girard presented a copy of the organization's newsletter (Attachment 3). Ms. Girard explained that they are the parent training and information center of Kansas and are federally designated by the Department of Education. They are staffed by parents of children with disabilities, and there are four centers; Topeka, Wichita, Garden City, and Kansas City. Their main responsibility under the federal guidelines is to train and inform parents on what their rights and responsibilities are under the special education statute at the federal and state level. They are continually training and having workshops. She stated that 23 percent of the calls they get are from families having a child with autism.

Ms. Girard stated that the Kansas Department of Health and Environment (KDHE) has contracted with Families Together, Inc. to coordinate the Child Advocate Program for infants and toddlers birth to the age of three. If a child meets the criteria for the appointment of a child advocate, a referral is made to the Child Advocate Coordinator at Families Together, Inc.

Questions and answers followed regarding what offices served what areas. It was noted Families Together has toll-free numbers in each center and also e-mail. They have four staff that serve the entire state. Dr. Craig asked Ms. Girard if she would send the Task Force a map electronically, and she said she would.

Ms. Girard introduced a parent of an autistic child to explain how Families Together, Inc. has helped her family through the Parent-to-Parent Program. This Program puts parents together with other parents with similar needs. She told what a help it was to talk to other parents with children with autism and to find out that she was not the only parent with a child with autism. She realized through her contact with this Program they were not an autistic family, but a family with amazing strengths and really unique needs. In closing, she stated that at this time her son is a freshman in high school and on the swim team in general education classes and is doing awesome. She stated that the Parent-to-Parent Program is what got her family out of that autistic world, and she works for them now.

A short question and answer session followed regarding insurance coverage. The parent stated that the Parent-to-Parent Program helped her family get coverage through their military insurance.

The discussion turned to what the Task Force could do to alert legislators of the Task Force's recommendations. Chairperson Craig suggested that the two pieces of autism-related legislation offered this session may be the best way to promote the cause through targeting members of the Legislature with the legislation and put legislators in touch with families from their home district.

Chairperson Craig stated the Task Force would review the preliminary report that was submitted and the executive summary after the lunch break. Chairperson Craig broke for a short lunch.

Afternoon Session

Chairperson Craig called the Task Force members' attention to the *Report of the Kansas Autism Task Force to the Legislative Educational Planning Committee (Attachment 4)*, noting this was a preliminary report with the final report being due in November 2008. He also called their attention to the *Executive Summary (Attachment 5)*. Chairperson Craig called for comments or discussion regarding the preliminary report. There was discussion on *Recommendations Regarding Quality Providers* on the definition of "Highly trained." Chairperson Craig introduced Patty Gray representing Colleen Riley with the Department of Education and asked her to enter the discussion. Ms. Gray stated that whether or not to change the current structure for teaching licensure for special education is an area with several things to consider.

Chairperson Craig called the Task Force members' attention to a handout (Attachment 6) which is a draft copy of *National Teacher Standards: Autism Spectrum Disorders Under Review by the Council for Exceptional Children (CEC), Fall 2007-Spring 2008*. A discussion followed regarding the one-stop centers. It was noted that Jeannie Zortman would be willing to chair a subcommittee regarding regional centers.

Chairperson Craig referred the Task Force back to the executive summary and to the section, "A Vision for Autism Services in Kansas," highlighting the evidence-based, data-driven intervention services. A discussion followed regarding changes that should be made in the future regarding the appropriate program for each child. The discussion continued on the subject of regional centers and the need for those across the entire State.

During the discussion regarding the Regional Centers, Dr. Dee McKee referred Task Force members' attention to *Kansas Unified School Districts-Parents as Teachers* handout (Attachment 7), *Locations of Selected Early Childhood Services (Attachment 8)*, *Descriptions of Select Early Childhood Programs (Attachment 9)*, *Smart Start Program Sites-Children's Cabinet (Attachment 10)*, regarding educational programs available across the State and the locations covered. Dr. McKee asked Ms. Rosell to explain the attachment. She stated that Legislative Research might have the capabilities to make an overlay map using the information she has compiled.

Chairperson Craig recognized Dr. Linda Heitzman-Powell, who wished to give a review of the *Best Practices Subcommittee's Report to the Task Force*. Dr. Heitzman-Powell stated the report covered the meetings of December 5, 2007 and January 8, 2008 (Attachment 11). She stated in order to provide the best recommendations for evidence-based practices for individuals with an autism spectrum disorder (ASD) in Kansas, it is necessary to establish what has already been accomplished by other states and professional organizations; what comprehensive literature reviews have already been conducted; and how the process that resulted from those documents and efforts coincide with requirements for a practice to be considered evidence-based. In order to accomplish

this goal, the Subcommittee has developed a review process to determine how other states have reached their conclusions for what is deemed an evidence-based or “best” practice. She stated Subcommittee members realize they are taking on a task of tremendous proportion. Because this task requires a significant amount of time to accomplish, the Subcommittee would like to request volunteers from the larger Task Force assist with the review process. Chairperson Craig was the first to volunteer to assist with the review process and other Task Force members followed. Dr. Heitzman-Powell referred the Task Force to the table attached to the Subcommittee report and gave a brief review.

Upon the completion of Dr. Hietzman-Powell’s review, Chairperson Craig announced to the Task Force that during the upcoming legislative session the Task Force on Autism could meet every two months. He also stated that the Task Force should keep communicating regarding the hearings for the autism-related legislation, and do everything they could to support the efforts in getting the bills passed.

Chairperson Craig asked the Task Force what items need discussion or action. They are:

- Best practices reviews;
- Paraprofessional training scholarships;
- Definition of “highly trained”;
- Parent education and support;
- Education of physicians;
- Best practices for diagnosis and quicker referral;
- Availability of diagnostics across the State;
- Continued work on better access to services available;
- Self-funded and military insurance policies;
- Develop novel funding streams;
- Information dissemination and registry development;
- Mapping (perhaps on the internet) to determine if better alignment of resources is necessary;
- Explore adult services for autism funding; and
- How to be legislative advocates for the support of Task Force legislation.

Upon completion of discussion on the above items, Chairperson Craig adjourned the meeting at 2:10 p.m. with the next meeting scheduled for March 5, 2008 at 9:30 a.m. He stated the agenda and meeting place would be sent to all the members.

Prepared by Jackie Lunn
Edited by Sharon Wenger

Approved by the Task Force on:

February 22, 2008

(Date)

