MINUTES

KANSAS AUTISM TASK FORCE

August 22, 2008
Room 783—Docking Building

Members Present

Dr. Bill Craig, Chairperson
Senator Julia Lynn
Representative Judy Morrison
Sarah Bommarito
Dr. Kathy Ellerbeck
Jarrod Forbes
Denise Grasso
Louise Heinz
Dr. Linda Heitzman-Powell
Yeyette Houfek
Jim Leiker
Dr. Dee McKee
Nan Perrin
Dr. Matt Reese

Lee Stickle, Kansas Department of Education

Dr. Mike Wasmer

Margaret Zillinger, Department of Social and Rehabilitation Services Jeanie Zortman (via conference call)

Staff Present

Martha Dorsey, Kansas Legislative Research Department Sharon Wenger, Kansas Legislative Research Department Nobuko Folmsbee, Office of the Revisor of Statutes Renae Jefferies, Office of the Revisor of Statutes Ken Wilke, Office of the Revisor of Statutes Jan Lunn, Committee Secretary

Chairperson Craig called the meeting to order at 9:40 a.m., and announced the Task Force has been approved for an additional three meetings. Questions were raised whether limiting the meetings was an issue related to lack of funds for travel reimbursement and whether subcommittees could continue to meet (without reimbursement). Martha Dorsey, Legislative Research Department, clarified budget constraints were responsible for the decision and Subcommittee meetings could continue without reimbursement. Nobuko Folmsbee, Office of the Revisor of Statutes, added that

public notice is required by law for all Committee or Subcommittee meetings, or both. Members were asked to notify Ms. Dorsey of any Task Force or Subcommittee meeting dates, times, and places, so that appropriate notification can occur.

Members attending reviewed the minutes of the June 12, 2008, meeting. Mr. Leiker requested the minutes be corrected to reflect the spelling of his name as Leiker and not Leikert. It was moved and seconded to approve the June minutes, as corrected. Motion carried.

Ken Wilke, Revisor of Statutes Office, summarized a draft of a proposed bill, "AN ACT concerning insurance; providing coverage for autism; amending KSA 2008 Supp. 40-2,103, 40-2,105, 40-2,105a and 40-19c09 and repealing the existing sections," (Attachment 1). Members reviewed the draft page-by-page with Mr. Wilke highlighting revisions, deletions, and additions. He commented that all changes must be made prior to placing the bill into final format. Mr. Wilke and Dr. Wasmer both indicated that many of the changes contained in the proposed bill are similar to existing legislation in other states.

A major change to the previous draft creates a tiered approach to coverage for businesses that employ more than 50 eligible employees with a maximum benefit of \$50,000 for each eligible person who has not attained age nine years and \$25,000 for each eligible person who is at least nine years old but who has not attained age 16 years. The next tier applies to businesses which have not less than 25 nor more than 50 eligible employees with maximum benefits of \$25,000 for each eligible person who has not attained nine years and \$10,000 for each eligible person who is at least nine years but who has not attained age 16. For businesses with less than 25 eligible employees, no coverage shall be required. Mr. Wilke noted the proposed legislation applies to private insurance providers, the Kansas state employees' health care benefit program, and municipal-funded pools. In addition, this legislation does not apply to those policies which provide coverage for a specified disease (*i.e.*, cancer), accident or accident-only coverage, credit, disability income, and long-term care insurance, among other things.

Another new addition, patterned after other states, includes language preventing denial of coverage, refusal to renew coverage, or termination insurance for persons diagnosed with autism. The "Applied Behavioral Analysis" definition is included along with other definitions contained in the Model Autism Act. The autism spectrum disorder definition was retained on a broad basis, including Autism, Asperger's, Rett's and others listed in the draft. This ties to the Diagnostic and Statistical Manual (DSM) of the American Psychiatric Association so that the Behavioral Sciences Regulatory Board can update rules and regulations, as it is required to do.

The definition of an eligible employee was reviewed as well as the definitions of other terms such as rehabilitative care and habilitative care, a health care provider, insurers, psychiatric care, therapeutic care, and treatment for autism spectrum disorder, among other things.

New language was added to provide for expedited claim review/process in the event a claim is denied.

Following Mr. Wilke's comments, considerable discussion ensued relating to the financial caps. Mr. Forbes indicated that, in his experience, most policies contain lifetime caps. In addition, discussion was heard on the age groups included in the tiers. Several suggestions were heard relative to revising the dollar caps contained in the proposed bill. Mr. Forbes suggested that insurance carriers might be more amenable to the legislation if lifetime caps or current lifetime maximum limits (as defined by the provider) were included in the legislation. In addition, it was suggested to revise the second tier limit to include language that reflects eligibility for coverage is "dependent on provisions in the parent's policy." For example, for children who are at least nine years but have not attained 16 years, the 16 years would be changed to be whatever age limit is

contained in the provisions of the parent's policy. Many children are covered on parents' policies up to age 21 years or 23 years. The decision of the group was to perform additional research on insurance companies' "lifetime maximum limits" policies and create a "placeholder" in the proposed bill for inclusion of those numbers using the tiered approach as well as increasing the age limit in tier two that age limit provisions are dependent on the parent's policy. Mr. Wilke indicated that even after the bill is finalized and introduced, an insurance impact study will be required by Kansas law.

Dr. Heitzman-Powell suggested revising the definition of "applied behavior analysis." Discussion followed in which members encouraged development of a simpler definition. The consensus of the group was to request Ms. Perrin and Dr. Heitzman-Powell collaborate on a more concise definition, and that they submit a revised definition to Task Force members.

Dr. Craig inquired whether introduction of the proposed legislation would affect mental health law. Mr. Wilke responded that all references to autism or related subjects are extracted from existing statutes based on amending KSA 40-2,105a and repealing existing sections. This, in effect, places all autism requirements into the proposed bill and reduces potential conflict. Concerns were expressed that many autism-affected children have dual diagnoses, and Task Force members want to ensure those children are not at risk for losing mental health benefits. Mr. Leiker suggested contacting Dr. Ira Stamm, local mental health professional and legislative activist, for his opinion.

Dr. Craig asked that Dr. Wasmer and the Insurance Subcommittee have the finalized draft of the proposed legislation by the next meeting in order that it can be presented to the Legislative Educational Planning Committee by the October 9, 2008, meeting.

It was suggested that changes to the "applied behavior analysis" definition and changes to Section (3)(A)(ii) on page 1 of the proposed bill be sent to Dr. Wasmer, and Dr. Wasmer will forward them to Mr. Wilke.

Task Force members discussed the strategic planning phase for introduction of the proposed bill into the Legislature, and whether a subcommittee should be appointed to begin this process. There was no final action or decision on this issue.

Dr. Matt Reese reported he had met with the Board of Regents and proposed the creation of a scholarship bill that is focused on allied health professionals in the community for the provision of autism-related services, particularly in underserved or frontier areas in Kansas. The Board of Regents was supportive of the concept and encouraged continued work; however, with current budget constraints, funding could present a challenge and suggestions for co-funding plans by private sources were heard as well as a loan payback program.

As a starting point, it was suggested to revise the bill produced last year including suggestions as discussed for presentation at the next Autism Task Force meeting.

Dr. Heitzman-Powell distributed the following documents for Task Force review:

- "Best Practices for Autism Treatment in Kansas—A Guide for Parents" (<u>Attachment 2</u>);
- "Guiding Forces in Early Intervention and Early Childhood Special Education" (Attachment 3);
- "Council for Exceptional Children" (Attachment 4);
- "The Early Intervention/IFS Process" (Attachment 5);
- "Bureau of Family Health—Part C Infant-Toddler Services" (Attachment 6); and
- "The Division for Early Childhood" (Attachment 7).

Dr. Heitzman-Powell indicated that the "National Autism Center National Standards Project" also will be included upon receipt of that document, and that all of the documents named above are to be included in the "Parent Packet."

The following document was distributed and will be the subcommittee's report submitted to the Legislative Task Force on Autism:

 "Best Practices for Autism Treatment in Kansas – Submitted to the Legislative Task Force on Autism" (<u>Attachment 8</u>).

Dr. Heitzman-Powell indicated this is a comprehensive compilation of information to assist parents in obtaining information related to early childhood education programs and flow of process within those programs, early intervention and early childhood special education, agencies and resource information, tools for assessing quality and key interventions, among other things.

The document to be submitted to the Kansas Autism Task Force is similar to the Parent Handbook containing the same information in summary form.

Dr. Heitzman-Powell requested that all Task Force members carefully review the distributed documents and provide feedback by August 31. Feedback should be specific, referencing the name of the document, page number, suggested changes, and additions. All feedback can be sent to Dr. Heitzman-Powell at lhpowell@ku.edu. She introduced and thanked Nathan Waffe, a volunteer, who is assisting members of the subcommittee in collating and compiling information for the Parent Handbook and the legislative report. Discussion was heard related to the need for occupational therapy evidence-based practice documents for inclusion in the Parent Handbook.

Ms. Houfek encouraged members of the Best Practices Subcommittee to consider a "Guide at a Glance" with references to agencies and a glossary of acronyms in an effort to ensure concise, accurate, and meaningful information is presented in a simple form.

Dr. McKee reported this subcommittee has recommended dynamic mapping as a method of providing succinct, comprehensive information on agencies, resources, schools, special education offices, and services, and that the mapping could be linked to other sites such as the "Autism Speaks" website. In addition, Dr. McKee has talked with the Kansas Health Foundation to discover ways to publish early childhood screening. It was recommended to collaborate with journalism schools throughout Kansas universities to develop public service announcements.

Dr. Craig requested that Margaret Zillinger, Department of Social and Rehabilitation Services, provide updated information on the Autism Waiver and any related expenditure information at the next meeting.

Ms. Houfek distributed an article from the *Wall Street Journal* entitled, "New Ways to Diagnose Autism Earlier" (Attachment 9).

Dr. Craig reported he had attended and had provided testimony at the last Legislative Educational Planning Committee meeting. He introduced the possibility of extending the Task Force, and to date there has been no feedback from the LEPC related to his suggestion. Tentatively, the next Autism Task Force meeting is scheduled for September 17, 2008.

Representative Morrison inquired whether there was a national or state autism group dedicated to economically assisting families with autistic children. Dr. Wasmer stated there was a national Autism Society of America (ASA) with state chapters whose mission is to support families. Other discussion was heard on various fund raising activities. Dr. Craig requested Ms. Dorsey provide the link to the Autism Walk scheduled in October.

The meeting was adjourned at 12:43 p.m.

Prepared by Jan Lunn Edited by Martha Dorsey

Approved by Task Force on:

September 22, 2008
(Date)