

**PRELIMINARY  
MINUTES**

**KANSAS AUTISM TASK FORCE**

June 12, 2008  
Room 313-S—Statehouse

**Members Present**

Dr. Bill Craig, Chairperson  
Senator Julia Lynn  
Representative Judy Morrison  
Dr. Linda Heitzman-Powell  
Dr. Jane Wegner  
Nan Perrin  
Louise Heinz  
Dr. Matt Reese  
Denise Grasso  
Jeanie Zortman  
Dr. Mike Wasmer  
Dr. Kathy Ellerbeck  
Dr. Dee McKee  
Jarrod Forbes  
Yeyette Houfek  
Jim Leiker, Capper  
Margaret Zillinger, Department of Social and Rehabilitation Services  
Lee Stickle, Kansas State Department of Education  
Carolyn Nelson, Kansas Department of Health and Environment  
Representative Melody McCray-Miller, via conference call  
Senator Donald Betts, via conference call

**Staff Present**

Sharon Wenger, Kansas Legislative Research Department  
Nobuko Folmsbee, Office of the Revisor of Statutes  
Renaee Jefferies, Office of the Revisor of Statutes  
Ken Wilke, Office of the Revisor of Statutes

Chairperson Craig called the meeting to order at 9:35 a.m. *On a motion by Senator Lynn with second by Dr. Ellerbeck, the April meeting minutes were approved. On a motion by Nan Perrin, with second by Louise Heinz, the May meeting minutes were approved.*

### **Best Practices Subcommittee Update**

Dr. Heitzman-Powell reported on the work of the Best Practices Subcommittee. She indicated the Subcommittee would soon generate a Best Practice Guide. She invited all members of the Task Force to submit peer-reviewed articles to the Subcommittee for review. She said the Subcommittee had many articles and information from the speech pathology and behavioral intervention areas but very little from pharmacology and occupational therapy. She also indicated that studies were needed specific to children with autism. Dr. Ellerbeck commented that studies in the area of pharmacology were limited but evolving. Dr. Heitzman-Powell told the Task Force that a rough draft of the Best Practice Guide should be completed by August of 2008.

### **Registry Subcommittee Update**

Dr. Mike Wasmer discussed the Autism Registry. He told the Task Force that if the Autism Registry were to move ahead as the Cancer Registry had done, it would need to be established by law (as the Cancer Registry was done within the Kansas Department of Health and Environment (KDHE)) and funded with a combination of federal funds and State General Funds (the Cancer Registry is funded with federal funds from the Centers for Disease Control and Prevention and State General Funds). Dr. Wasmer recommended that a meeting be scheduled with the major administrators of the Cancer Registry and the Task Force's Autism Registry Subcommittee. Carolyn Nelson from KDHE agreed to research who from KDHE should be a part of such a meeting. Dr. Wasmer indicated that an estimated cost to establish an Autism Registry, based upon information from the Cancer Registry implementation, would be \$130,000 for the first year of operation and 1.25 full-time equivalent employees. Sue-Min Lai, Ph.D., MS, MBA, Associate Professor, Preventive Medicine Director, Kansas Cancer Registry, The University of Kansas Medical Center, made an unofficial agreement with Dr. Wasmer to share resources. Dr. Wasmer also mentioned that the Kansas Center for Autism Research and Training is becoming the "go to" place for autism issues in Kansas, so this might be a place for hosting an Autism Registry.

Lee Stickle from the Kansas State Department of Education (KSDE) described an Ohio Department of Education database ([ocali.org](http://ocali.org)) which includes the zip code for persons with autism. Early intervention providers can add information to such a database. Ms. Stickle indicated that KSDE is investigating such a system for Kansas.

### **Professionals Subcommittee**

Dr. Matt Reese reported on the activities of the Professionals Subcommittee. He told the Task Force that the concept of regional diagnostic centers was being developed this summer by developing regional capacity through KSDE treatment teams, even though these teams do not yet have diagnostic components. Ms. Stickle provided more detailed information on these teams. She indicated the teams could be linked to physicians and, in fact, during July and August, physicians and other providers will be given training on diagnosis of autism. She said that excellent work in this arena is occurring in Dodge City which could be replicated across the State. Ms. Stickle reported that the age for diagnosis was 18 months through two years. When asked whether KSDE was willing to work with children as young as 18 months, Ms. Stickle said that Colleen Riley at KSDE is working on this. Dr. Ellerbeck said that physicians must get assistance in diagnosis. Dr. Reese told the Task Force that, nationally, there is 13 months between screening and diagnosis. Dr. Reese indicated there was no way to measure this for Kansas; however, the goal was to allow no more than 30 days between a child's referral for diagnosis and readiness for diagnosis.

Ms. Stickle reported that there would be nine teams who will go through Dr. Reese's training. Teams are located in southwest and northwest Kansas, Concordia, Beloit, and the Three Lakes Educational Cooperative areas.

Dr. Craig inquired regarding the linkage between the tiny-k Program and the regional teams. Ms. Stickle reported that KSDE has recently hired a Kansas Instructional Support Network position to work with tiny-k. This staff member is starting work in July and will be working with KDHE providing training.

Ms. Stickle reported that she has been providing training for seven years to public school district professionals. Teams in schools consist of speech pathologists, school psychologists, educators, and occupational and physical therapists. The Wichita School District has its own team of five or six professional staff having masters' degrees. Teams are funded with federal Title VIB funds via a flow-through grant from KSDE. The KSDE is working with Dr. Reese to evaluate the program.

Senator Betts, via conference call, commended Senator Lynn on her attempts to obtain additional funding for the Autism Waiver. Senator Betts recommended that the Task Force consider advertising services for autistic children in neighborhood association newsletters. When Senator Betts requested information regarding where a constituent with an autistic child should go to find services, Chairperson Craig told him the local tiny-k Program or network was the best entry point for services.

### **Funding Resources for Families with Autism**

Margaret Zillinger, Department of Social and Rehabilitation Services (SRS), reported that the 2008 Legislature provided funding to service 20 additional children under the Autism Waiver. Assessments for these children will begin the end of June 2008. The current services contracts are being revised to add these children. The current Autism Waiver program is still serving 25 children. There are 26 certified Medicaid providers providing services under the Autism Waiver with five applications pending.

Dr. Craig asked to what extent, if the current Autism Waiver funding is underutilized, could additional children be served. Ms. Zillinger said that will not be known until SRS has a better idea of the amount services for the 25 initial children will cost. Ms. Zillinger indicated that only one provider application had been denied thus far. She told the Task Force that there currently were 151 children on the waiting list. She was asked to provide an indication of the age groupings of those on the waiting list.

Ms. Zillinger said some families may be slightly hesitant to accept Medicaid services. However, because the Autism Waiver program is targeting a population different from the regular Medicaid program, some education regarding the Medicaid application process is needed to encourage parents to apply for the Waiver. Ms. Zillinger indicated that there were probably no children who had "aged out" on the waiting list. However, some likely will age out within a year. SRS will notify those that do age out. Those children accepted in the Waiver program will get three years of funded services regardless of their age during those three years.

Task Force members discussed the feasibility of screening every child on the waiting list. Ms. Zillinger responded that each screening costs approximately \$300, so if all on the waiting list currently were screened, approximately \$45,000 would be used which could be better used providing services.

Dr. Craig posed this question for Ms. Zillinger. Would it be possible to put every child who ages out of the Autism Waiver onto the MR/DD Waiver?

Ms. Zillinger did not know what amount, if any, would be in the SRS budget request regarding the Autism Waiver in the SRS budget now under development.

Carolyn Nelson, KDHE, gave a legislative update regarding the tiny-k Program. She said the program received an additional \$1.0 million in Children's Initiative Funds (CIF) during the 2008 Legislative Session. This amount will be placed in the allocation which is distributed to the tiny-k networks via a formula. Ms. Nelson indicated the federal funding had decreased this year by \$6,000. Dr. Craig requested information on the increased amount per child that the additional CIF would provide.

### **Developmentally Disabled Waiver Update**

Ms. Zillinger reported there are approximately 1,300 unserved individuals currently on the Developmentally Disabled Waiver (DD Waiver) waiting list. Those individuals are receiving no services. The 2008 Legislature increased reimbursement rates two percent across the board for all services and added funding for 25 additional individuals. She indicated that the waiting list will most likely grow by about 280 individuals per year. She also indicated that the waiting list is growing in the number of children. Dr. Craig asked for age group breakdowns on the waiting list. Ms. Zillinger told the Task Force that individuals could remain on the DD Waiver waiting list even if they are in the Work Program, and they do not lose their place on the DD Waiver waiting list. Dr. Craig requested the age group breakdown for the Work Program waiting list.

### **Insurance Subcommittee**

Dr. Wasmer discussed insurance mandate work during the past legislative session. Dr. Heitzman-Powell told the Task Force that military insurance paid for autism services and might serve as a good model for a larger insurance mandate. She said she would send information regarding the military insurance to Dr. Wasmer. Dr. Wasmer said that six states have passed private insurance mandates covering autism services.

Jarrod Forbes reported that United Health Care supported the Autism Waiver during the 2008 Legislative Session and is sending information to legislative leadership indicating that the Autism Waiver is the best way to help those with autism.

### **Other Discussion**

Dr. McKee discussed catastrophic aid and indicated the importance of its continuation. Dr. McKee also mentioned the importance of dynamic mapping of a comprehensive listing of resources in order to ensure economical and effective use of resources.

### **Legislative Initiatives for the Future**

Dr. Reese reported on his contact with the Kansas Board of Regents in setting up a meeting to discuss scholarships for students interested in pursuing allied health degrees providing services to autistic individuals.

Ms. Stickle mentioned that Pittsburg State University has an autism specialist education track. KSDE could help pay for one scholarship to move a student through this program. In the Fall of 2008, Pittsburg State will offer this program over interactive television. Ms. Stickle said there would be a four-day autism workshop later this year which will be "streamed" to sites across the State.

Dr. Wasmer's advice for legislative action regarding an insurance mandate is to regroup and revise the bill from the 2008 Session.

Regarding added funding for the Autism Waiver, Senator Lynn said the Task Force should not feel too discouraged because many issues, including lack of funding for all State programs, affected this effort. She recommended that future advocacy involve those affected at the "grassroots" contacting legislators, not only Task Force members.

Mr. Leiker added the following comments. The past Legislative Session's preoccupation with a controversial issue, the coal-fired power plant in western Kansas, accurately describes the next legislative session as well, since a controversial issue usually dominates the session, the state economic forecast will be challenging, legislators constantly run for re-election, personal and legislative leader agendas and coalitions will be present. He said the Task Force must determine how it is going to move the Kansas Autism Task Force recommendations and related legislation forward in this environment of the next legislative session. We must be assertive with legislative leaders and legislators with personal communication and numerous visits, enlisting grassroots advocates throughout the state to do the same. There is ample money in the state budget to pass, implement and fund the Kansas Autism Task Force recommendations. It is a matter of priorities. The Task Force was established to expand access to autism screening, diagnosis, services and capacity for the growing number of Kansans with autism. This is an important and high priority. Waiting lists for people with disabilities in our state are shameful and should not be tolerated. It was determined that the Kansas Statehouse renovations were a priority. These renovations were originally budgeted at \$90 million and over \$280 million has been spent to-date on this and counting. Legislators must be convinced that if statehouse renovations are a priority, services for people in Kansas with autism is a higher priority than limestone and mortar. Autism legislation must be passed and funded. It is a matter of priorities and most Kansans would favor a common sense approach to getting our priorities straight at the Kansas Statehouse that is People First.

Discussion ensued regarding various advocacy tactics to take leading up to the 2009 Legislative Session.

The meeting adjourned at noon. The next meeting will be July 16, 2008, in Topeka.

Prepared by Sharon Wenger

Approved by Task Force on:

July 16, 2008  
(Date)

