

Autism Board Meeting Minutes
July 27, 2005

In Attendance:

Yeyette Houfek (Chair), Teri Keeton, Jamey Kendall, Stephen Stein, Dr. Carol Garrison, Mary Woodworth, Shirley Erickson, Dr. Matt Reese, and Lee Stickle. Guests included: Pamela Keller (HCP/CSS), Jeanie Zortman (Dodge City, Autism Society of Southwest Kansas), Donald and Cheryl Bondank (Lenexa, Autism Society of Johnson County).

Not In Attendance:

Rebecca Flaton (excused), Sarah Bommarito (excused), Karen Frye (excused), Michael Wasmer (excused), Ron Green

I. Introductions/Approval of Agenda:

Lee Stickle was introduced as the new commission member replacing Carol Dermeyer, who had retired from the Kansas State Department of Education. Lee explained her background and elaborated on a new idea to develop a comprehensive statewide plan to provide training and technical assistance for schools with students in the autism spectrum.

A motion to approve the agenda was made by Shirley Erickson, seconded by Carol Garrison.

II. Commission Members Updates:

Yeyette read letters from Becky Flaton, Sara Bommarito and Karen Frye who could not be in attendance for the meeting. Becky reported that Parsons is creating a DVD to explain individual rights to people with disabilities. The commission expressed a desire to view the DVD in the future. Sara suggested moving the "Legislator Cookie Day" to another time of the year.

Shirley Erickson reported attending the Kansas University's Autism Asperger Resource Center "State of Autism" meeting in the spring. She disseminated booklets from the meeting. She suggested making the "Legislators Cookies" shaped in the autism logo of a puzzle piece. She has a cookie cutter in the shape of a puzzle piece. Various members volunteered to check with local culinary schools for interest in participation of free donations to make the cookies for distribution.

Dr. Carol Garrison reported that Children's Mercy Hospital is actively exploring collaborating with a Phoenix, Arizona community group SARRC (Southwest Autism Research & Resource Center) that was initiated by parents for diagnosis and educating of parents with early interventions as well as transitions into adulthood. This group is funded through the community by fundraising. There is also a program for genetics study of autistic disorders by the name of TGen (Translational Genomics Research Institute) in Phoenix. Better tests and therapies based on knowledge of the underlying defect in autism is the outcome of these programs. She shared brochures and pamphlets from SARRC and TGEN.

Mary Woodworth reported she is part of a pilot program modifying a program supporting autism for inclusion from Larned High School at Hamilton Middle School in Wichita.

Jamey Kendall reported working on a generic state plan for October. It is a train the trainer model to educate physicians about the Infant Toddler program.

Pam Keller reported the Autism Waiver made it through the first cuts on the SRS budget. Many calls are being received from parents for autism resources, especially from the rural areas.

Steve Stein reported Arrowhead West is presently serving 18 people from 9 counties. The Autism Conference will be the first weekend in October and Temple Grandin's mother will be speaking. He recommended more representation is needed on the commission from southwest Kansas.

Dr. Matt Reese reported more networking is occurring at the Child Development Center at KU, especially collaboration with the Autism Asperger Resource Center. He told of the increase in tele-medicine with consultations and diagnosis.

III. Brad Kirmer, Interim Team Leader, Mental Health Services, shared with the commission a memo dated 6/21/05 intended to provide clarification to community mental health centers regarding the provision of services to youth with both serious emotional disturbance and developmental disabilities. The memo does clarify the position of SRS that Asperger's Syndrome is a diagnosable mental health disorder. He asked for commission members to send any autism resources to <mailto:bjk@srskansas.org> for use in the training of state employees in the mental health services. Online training is the predominant instruction presently.

IV. Jeanie Zortman, shared with the commission members her personal background in autism and ways the Autism Society in Southwest Kansas is educating parents on how to work with autism and various systems in Dodge City as well as the plans for the future.

- V. Donald and Cheryl Bondank, shared with the commission members how autism has touched their lives and each of their active roles in the Autism Society in Johnson County. They also spoke on their personal crusades with the legislators to ban the use of thimerosal. Don had attended the Power Rally in Washington D.C. this month. He did meet with United States Senators Dennis Moore and Sam Brownback during his trip.
- VI. Vision for the future: The three priorities of 1) Governor Awareness 2) Autism Medicaid Waiver 3) Regional Autism Centers are ongoing issues. The lack of funding is the major concern facing the commission. The commission would like to move ahead in developing a plan on how to advocate moving the Autism Waiver from the SRS wish list into action. Yeyette volunteered to contact the Governor's staff to ask for the best contacts and what the commission can do as there is a need for several partners to fund the waiver. There was discussion on the lack of adequate insurance coverage for families of children with autism. It was decided at the next meeting the guest speaker should be an insurance contact person to discuss funding options. Therefore, a meeting with the SRS Deputy Secretary Ron Denning should be scheduled as quickly as his schedule would allow assisting with this process. All commission members would be notified of the meeting date so that a large number could attend the scheduled meeting. It was determined a fact sheet needed to be created for the state parent autism societies and for the legislators. A committee was formed to create the fact sheets. The committee consists of Lee Stickle, Mary Woodworth and Dr. Carol Garrison, who will chair the committee. This committee will accomplish developing the two fact sheets by the next meeting. Commission members can approve of the sheets online. Yeyette will contact the Governor's office to set up another meeting with Governor Sebelius. She will also send commission members the list of facts that were sent to the Governor that are the major issues facing Kansans affected by autism spectrum disorders. She also reminded commission members to act on H. R. 2421, the Combating Autism Act of 2005.
- VII. Future business: Shirley Erickson recommended that a representative from SRS Vocational Rehabilitation speak to the commission in the future on transition from high school into the job market. Shirley suggested representation on the commission from this group.

The next meeting is scheduled for Wednesday, October 26, 2005, from 9:30 a.m. to 3:00 p.m. Please bring a lunch. Funding will be discussed with an insurance person.

The winter meeting is scheduled for Wednesday, January 25, 2006. An alternative date is scheduled for Wednesday, February 8, 2006, in case of snow on the scheduled date of January 25. This date will be the Legislators Cookie Distribution Day.

Conference call-ins will be available for future meetings.

Mary Woodworth motioned to adjourn and Jamey Kendall seconded.