

Kansas Governor's Commission on Autism
Minutes
October 26, 2005

In Attendance: Yeyette Houfek (Chair), Jamey Kendall, Stephen Stein, Dr. Carol Garrison, Mary Woodworth, Shirley Erickson, Dr. Matt Reese, Lee Stickle, Mike Wasmer, Sarah Bommarito and Rebecca Flaton (by phone).
Guests included: Pam Keller (HCP/SRS), Susan Corrigan and Stephanie Bryson (from KU School of Social Welfare).
Not in attendance: Karen Frye (excused) and Teri Keeton (excused).

I. Introductions/Approval of Minutes

Yeyette began the meeting with a letter from Ron Green announcing his resignation from the commission. Yeyette asked him to notify the Governor's office. He suggested several items that we will discuss later in the meeting. Agenda was approved. Minutes from last meeting were discussed and motion made to accept as corrected by Shirley and Jamey seconded. Teri was unable to attend the meeting so Jamey agreed to assist with taking minutes.

Commissioners were asked to introduce themselves and give report of any new activities related to autism. Yeyette reported that Hays has developed an Autism Team for schools. Lee – KSDE has 4 training set up statewide that will take place by ITV for school districts. The ITV sites are in 9 geographic areas around Kansas and the first training will take place December 9, 2005. It will originate from Edwards Campus in Overland Park and will feature Shawn Henry from the Iowa Center on Autism. He takes IEP's and breaks them down. It has been hard to coordinate all of the meetings and sites. The trainings will focus on priority for districts without Autism Teams. Working on Practicum's for Education Students interested in Autism. Steve – The conference scheduled earlier with Temple Grandon's mother in Dodge has been rescheduled for 4-22-06. Shirley – Nightline recently did a program on older adults with autism and how little support etc is done with them. Lee added that only 10% of autism population is school age. Matt – 3 potential projects, 1) Working with CSHCN program to put 10 polycam devices in primary care physician offices throughout KS that will help in Telecommunication and outreach to Western KS. Family Practice calls concept Chronic Disease and Pediatrics call it Medical Home, 2) Looking at gap between diagnosis and services, and 3) Centers for Excellence – NIH is transitioning to practice issues. Vanderbilt and KU are looking at research on language. Mike – Professor at Juniper Gardens (Kathy Thiemann) will be doing an in-service at KU Edwards campus on November 5, 2005 related to training peers to interact with children with autism. Carol – continue to work with Fellows and look forward to new ones coming on board. Jamey – Caring for Infants and Toddler (CFIT) training is in planning process and will be coming this spring. It is targeted to Pediatricians and Family Practice physicians to encourage recognition of developmental delay and referral to early intervention. Sarah – last Friday attended Autism Spectrum Conference. Sarah is also seeing also of children at Kindergarten enrollment without diagnosis of Autism who have had no intervention but suspect diagnosis. Mary – last year School Psych role changed to working with 2 middle schools who were in crisis. Now have been ask by one of the parents to present at Families Together Conference on 12-5-05 and their school team will discuss inclusion. Early this fall she was also ask by a family she had previously worked with to help with consultation to help with student who is 10 with football and process. He is doing extremely well and has reportedly been noticed by Junior College. Becky – still a lot of referrals from birth to 3. New admissions of children with autism continue at Parsons State. continue work on DVD that explains patient rights and have supported this effort with a handbook. Also residents have started a self advocacy group.

II. Meeting with SRS: Yeyette,

Carol and Pam met with Ron Denning (Deputy Secretary of SRS) and Margaret Zillinger regarding Autism needs and they were encouraged to contact advocacy groups like Interhab and Mike Hammond with Association of Community Health Centers. They felt getting parents involved would strengthen the message. The meeting went well, they listened well to the concerns but stated they need evidence based information such as numbers and commission members did explain how difficult it is to get the numbers. They also discussed taking advantage of the university system, continue contacts with the Governor, and talked about the waiver (ages and what numbers to start with). Discussion then continued on how we can get parents involved in our message.

III. Guest Speakers from KU School of Welfare- Stephanie Bryson and Susan Corrigan.

Discussed research they are doing upon request of SRS and passed out a handout explaining the research. The question is How are persons with Autism served and where are they ultimately best served? They ask who are the groups we suggest they talk with. State ICC, Early Intervention Networks, Support Groups. How do you get to those families not involved with services? They want to touch base with the commission as they go along and commissioners welcomed that.

IV. Recent Findings on Autism:

Various books were discussed and Yeyette passed around a publication out of North Carolina that lists a large amount of publications. Jeannie Zortman was unable to attend but sent an email to Yeyette to report her progress on meeting with Senator Roberts. She will be meeting soon with Mike from his Washington DC office where they will present the proposal for funding of regional centers. She recommends that site for regional center be in Dodge instead of Hays. An in-service is planned for 4-22-06 when they will also have an outreach clinic.

V. Vision for the Future:

At the last meeting we created a committee to work on fact sheets and this has not been started yet. Is this the right time to do this? Have ask to meet with the Governor when we have the next meeting 1-25-06. Mary brought up the concern that since the last time we met with her there is no news. When we deliver cookies she may have already done the State of the State address which outlines her budget, so it was suggested that we send her a letter soon that will update on the Kansas activities from the proclamation signing on. Mike will research (Susan and Stephanie will assist) on what other states have in place related to Standards and Waivers. Lee reported that KSDE reports show 1,389 students with Autism and the number should be around 2,000. Even if you add the other health impairments (OHI) it still does not add up to 2,000. Talked about addressing Ron's concerns in his resignation letter (which was passed out). The concerns are felt to be so large and the same ones we have been working on. Discussed need to continue to try for the waiver, but once we get it are we prepared with persons who can serve those with autism. Training and education are necessary to provide continuity and regional centers can help with this. Lee gave example of how she is now only able to provide assistance to school and not community based providers. Our overall goals are important but if they were written like an IEP would we have measurable steps. Do we have legislators attend our meetings? It was decided for families on the commission to invite their legislators from 1-2 pm for the next meeting and we will do presentation (Carol has one she recently did with Neurologist and KU School of Welfare will also do update). Mike will also work on a rough draft of what is to be presented. May want to provide pictures and personal stories. Yeyette will work on letter for the Governor to outline our accomplishments. Cookie delivery – Toni has confirmed that Shawnee Mission Culinary Department will bake 200 cookies. It was discussed and decided that we will try to get 400 so that legislative secretaries could also have a cookie at delivery time. Shirley will call Teri to see if this is possible and will locate the cookie cutter. Discussed why we don't use person's with autism to deliver and it was decided that logistically it is difficult so will continue with Commissioners doing delivery. Yeyette asked for Future agenda items: Rehab services (Voc Rehab) Jamey asked if we are interested in trying for a permanent counselor to set on the commission and it was decided this would be positive. She will contact Eunice Thompson to see if she can identify a counselor who has an interest in Autism. Insurance Commission (Matt did report that box is getting more narrow when it comes to billing even for Diagnosis let alone intervention) Keys for Networking REACH (formally Children's Benefit Services) have assisted families to access insurance benefits. Names have been submitted for replacement of Commission vacancies and Yeyette will follow to see the status as now we have 2 vacancies.

Mary Woodworth moved to adjourn and Sarah Bommarito seconded.