

MINUTES

KANSAS AUTISM TASK FORCE

September 20, 2007
Room 313-S—Statehouse

Members Present

Dr. Bill Craig, Chairman
Dr. Kathy Ellerbeck
Mr. Jarrod Forbes
Ms. Denise Grasso
Ms. Louise Heinz
Dr. Linda Heitzman-Powell
Ms. Yeyette Houfek
Secretary Donald Jordan, *ex officio*
Ms. Linda Kenney, *ex officio*
Ms. Tracy Lee
Mr. Jim Leiker, *ex officio*
Senator Julia Lynn
Dr. Martin Maldonado
Representative Melody McCray-Miller
Dr. Dee McKee
Representative Judy Morrison
Ms. Nan Perrin
Dr. Matt Reese
Ms. Colleen Riley, *ex officio*
Dr. Michael Wasmer
Dr. Jane Wegner
Ms. Jeannie Zortman (present by telephone)

Members Absent

Senator Donald Betts
Ms. Sarah Bommarito

Staff Present

Sharon Wenger, Kansas Legislative Research Department
Martha Dorsey, Kansas Legislative Research Department
Rena Jefferies, Revisor of Statutes Office
Nobuko Folmsbee, Revisor of Statutes Office
Rose Marie Glatt, Committee Assistant

Conferees

Stephanie A. Bryson, LISW, KU School of Social Welfare
Susan K. Corrigan, Ph.D., KU School of Social Welfare

The meeting was called to order at 9:30 a.m. by Bill Craig, Chairman, who welcomed the Task Force back for their second meeting of the Kansas Autism Task Force. The agenda was approved as presented. After a review of the minutes of the August 13, 2007 meeting, they were approved by consensus of the Task Force ([Attachment 1](#)).

Stephanie Bryson, a Ph.D. candidate, and Susan K. Corrigan, Ph.D., KU School of Social Welfare, presented the results from the study *Research Summary: Service Challenges for Children with Autism Spectrum Disorders* ([Attachment 2](#)). In FY 2006, through a contract with the Kansas Department of Social and Rehabilitation Services, Health Care Policy Division, the University of Kansas School of Social Welfare undertook a study of service provision to children with autism spectrum disorders (ASDs). Through a power point presentation, the researchers explained the purpose of the study:

- Clarify service delivery to children with coexisting mental health needs and an ASD diagnosis;
- Evaluate present and future collaboration between the Community Mental Health Center (CMHC) and Community Developmental Disability Organization (CDDO); and
- Assess the need for innovative funding streams.

Data for the report was collected from: 1) Review of literature; 2) best practices; 3) waivers; and, 4) analysis of one year (2004) of Automated Information Management System (AIMS) data. Additional information was gathered from response to surveys of CDDO and CMHC directors, four parent focus groups, and ten phone interviews with parents.

Three research questions were discussed:

- What characterizes the population of Kansas children and youth with an autism spectrum disorder? How are they currently served by Kansas CMHCs?
- How does treatment differ in CMHC and CDDO systems? What are the main service barriers encountered by each system? What collaborative service options exist?
- What barriers do parents face in: 1) Identifying the need for services? 2) obtaining services; and 3) financing services.

An overview of systems problems and service level problems was provided, followed by nine parent recommendations and requests including:

- Provide monies for in-home and out-of-home supports;
- Provide early intervention services with sufficient intensity;
- Address gaps in current services and funding sources;
- Train the providers;
- Increase school-based supports;
- Support practices that lead to great continuity of care-givers;

- Address geographic disparities in resources;
- Fund statewide resource centers with expertise in ASDs; and
- Fund transitional services and lifespan supports for adults with an ASD.

A short video was shown of a young boy's activities and behavior before diagnosis and after therapy through the services of applied behavior analysis (ABA). (A file copy of the entire report *Service Challenges for Children with Autism Spectrum Disorders and Mental Health Needs* is on file with the Kansas Legislative Research Department).

After discussion, Ms. Bryson and Ms. Corrigan concluded by saying they were continuing their research in four community centers and will focus on what is working and how they can replicate those practices. Dr. Craig thanked them for their presentation.

Kansas Autism Task Force Subcommittee Reports

A summary of five Subcommittee activities were distributed (Attachment 3).

Registry/Information

Dr. Michael Wasmer, parent, presented the report from the September 7, 2007 Subcommittee meeting. He explained the two issues the subcommittee addressed, *i.e.* discussion of a possible autism registry in Kansas and creation of a central resource of information regarding autism and related services for the state.

Subcommittee members concluded if individual privacy could be assured, members would support a mandatory autism registry in Kansas. The information gained from such a registry could provide critical information that would allow more equitable allocation of resources and further the understanding of autism. The Kansas Cancer Registry appears to be an ideal model for a potential autism registry.

Discussion followed regarding possible inclusion of an autism registry in the Kansas Cancer Registry, process for participants to get off an autism registry, benefits to parents from the registry, who would be included in the registry, and the benefits/cost ratio.

Regarding an information resource, the Subcommittee concluded that a centralized source of information regarding autism and autism-related services that is readily accessible to the majority of Kansans is a vital need of the autism community. It appears that a combination of a website and the United Way 2-1-1 of Kansas may be the most effective solution.

Secretary Jordan suggested that the Subcommittee look into a comprehensive service locator system, developed in California. He agreed to bring information to the next task force meeting.

Afternoon Session

Best Practices

Dr. Linda Heitzman-Powell reviewed the progress made during two meetings on September 6 and 17.

- **Subcommittee Goals.** At its initial meeting, members established the following goals to be accomplished over the course of a year:
 - Determine what level of evidence is recommended in determining whether an intervention is evidence-based;
 - Determine what interventions are not evidence-based; and
 - Determine what are evidence-based interventions to be used over the life span of an individual with Autism as supported in literature or in other states.

The Best Practices Subcommittee developed criteria for ranking evidence-based interventions using a scale ranging from “no evidence” to “strongest evidence.” The Subcommittee also developed the following goals for its coming year’s work:

- Review literature from 2000-2007 to identify effective strategies and identify gaps for best practices.
- Review and summarize other states recommendations.
- Produce a document by November 28, 2008, that presents information on:
 - Best practices, gaps in the literature on best practices, and recommendations for intervention services.

In order to provide a broad representation in all of the different disciplines on the subcommittee, Dr. Heitzman-Powell made a request of the Task Force as follows:

- Submit research to this subcommittee that is discipline specific in the form of a pdf file with a reference page;
- Identify someone from the State Board of Education that would be able to attend Subcommittee meetings to provide input from the educational stand point; and
- Identify someone from the Tiny-K program that would be able to guide and direct identification of current research in the birth-to-three literature.

Given the broad range of topics, Dr. Heitzman-Powell requested Task Force guidance in terms of final outcomes for recommendations, for example, should the Subcommittee synthesize the research and define the “world” of best practices, or make recommendations about how to review the literature on a practice to determine if it is a best practice.

Dr. Wasmer suggested that from a parent's viewpoint, there are two important elements to consider: 1) what questions parents should be asking of service providers; and 2) making service providers accountable for their recommendations. He added that defining best practices *and* providing recommendations on how to review the information are *both* important. Discussion followed regarding other resources for best practices and the criteria used for their recommendations. Dr. Heitzman-Powell requested that Task Force members send her additional resources.

Professionals and Paraprofessionals Subcommittee

Dr. Matt Reese provided the report for the Subcommittee. The Subcommittee made the following recommendations:

- Recommend incentives be developed to encourage professionals to practice in particular areas of the state. Scholarships are now available for linkage of professionals to underserved areas.
- Recommend training be developed for an autism endorsement or certification for professionals, *i.e.*, traditional training, on-line, or telemedicine-like technology.
- Recommend training at community colleges, backed by incentives that could lead to four year degrees; 2) Increased pay; and 3) Training done via traveling training or interactive television.
- Adding an autism continuing education requirement to certification, licensure, or education for service providers, and making education easy to obtain via on-line or other readily accessible technology.
- Broadening the scope of early childhood Kan Be Healthy, mental health, and other screenings to include screening for autism, and supporting primary care physicians in screening for autism.
- Increasing the use of telemedicine, and developing regional centers that could provide diagnosis services via satellite.

Autism Waiver Funding

Dr. Craig said that implementation of the program begins January 1, 2008; however budgeting must be done now for FY 2008/09. He asked Louise Heinz to explain a budget request proposal (Attachment 4). She said the Autism Waiver is a fiscally responsible initiative as the state potentially saves \$1.5 to \$2.5 million overtime on every child that undertakes early intensive behavioral intervention. She explained the number of eligible children using figures from the 2000 census and IDEA data. Based on those projections she said they need to significantly increase the funding level from the current 25 children to 100 for FY 08/09, 200 children FY 09/10 and 400 children FY 10/11. An Autism Waiver multi-year funding plan was distributed (Attachment 5). Secretary Jordan advised the Task Force that SRS had recently submitted budget recommendations for 2008/09 and had officially requested funding for 100 children.

Discussion followed regarding responsibility and accountability of parents and service providers and expectations of the program.

Ms. Houfek made a motion that the Task Force support fully funding the Autism Waiver for 100 children FY2008/09. Representative Morrison seconded the motion. After discussion the motion carried. Dr. Craig will draft a letter to the Governor regarding this recommendation.

Insurance Subcommittee

Dr. Wasmer gave a brief overview of the September 7 meeting. The Subcommittee's goals include a review of the adequacy of existing legislation regarding health insurance coverage for autism-related services in Kansas and throughout the U.S.

The Subcommittee heard from the following individuals:

- Barbara Torkelson, Kansas Insurance Department, reviewed the Kansas Mental Health Parity Act;
- Joe Fiorella testified regarding personal difficulties with their carrier, Blue Cross Blue Shield;
- Ken Wilke, Revisor of Statutes Office, reviewed recent legislation in Senate Bill 380;
- Laura Lillich, University of Kansas, who compiled the results and presented a summary of a KU insurance questionnaire mailed to 443 parents/guardians of individuals with ASD; and
- Comments from two insurance industry lobbyists who voiced opinions and concerns over changes in the existing policies.

The Subcommittee submitted six conclusions:

- Health insurance coverage is inconsistent at best, and is both a direct and indirect factor in children receiving inadequate and delayed services.
- The existing Kansas Mental Health Parity Act appears to be of minimal practical benefit to families affected by autism.
- The number of formal complaints regarding coverage for autism-related services filed with the Insurance Commissioner's office likely is a gross underestimate of the problem due to lack of awareness of recourse available, and the time and stress associated with the appeals process.
- Disagreement between the insurance lobby and Kansas Department of Education is a significant impediment to accessing appropriate services.
- Efforts of this Subcommittee need to be closely coordinated with Best Practice and Education/Funding Subcommittees.

Copies of the following were distributed:

- A copy of Dr. William Craig's letter sent to Governor Sebelius on August 28, 2007, regarding funding for the Autism Waiver, were distributed (Attachment 6).

- Memorandum from Colleen Riley, Director of Student Support Services, regarding information pertaining to:
 - Federal Funding;
 - State Funding;
 - Kansas Autism Child Court; and
 - Due process hearings fully adjudicated in Kansas (Attachment 7).

Memorandum from Renae Jefferies, Assistant Revisor of Statutes, regarding *Combating Autism Act of 2006 Summary* (Attachment 8).

Future Task Force Committee dates are October 25 and November 13, 2007. The meeting was adjourned at 3:45 p.m.

Prepared by Rose Marie Glatt
Edited by Sharon Wenger

Approved by the Task Force on:

October 25, 2007
(Date)