

MINUTES

KANSAS AUTISM TASK FORCE

August 13, 2007
Room 313-S—Statehouse

Members Present

Dr. Bill Craig, Chairman
Ms. Sarah Bommarito
Mr. Jarrod Forbes
Dr. Kathy Ellerbeck
Ms. Denise Grasso
Ms. Louise Heinz
Dr. Linda Heitzman-Powell
Ms. Yeyette Houfek
Secretary Donald Jordan
Ms. Linda Kenney
Ms. Tracy Lee
Mr. Jim Leiker
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
Dr. Michael Wasmer
Dr. Jane Wegner
Ms. Jeannie Zortman

Member Absent

Senator Donald Betts

Staff Present

Sharon Wenger, Legislative Research Department
Martha Dorsey, Legislative Research Department

Renae Jefferies, Revisor of Statutes Office

Nobuko Folmsbee, Revisor of Statutes Office
Rose Marie Glatt, Committee Assistant

Conferees

Senator Dennis Wilson
Linda Kenney, Director, Bureau of Family Health, KDHE
Mary Ann Keating, Executive Director, TARC
Colleen Riley, Director, Student Support Services, Kansas State Department of Education
Margaret Zillinger, Director, Community Supports and Services, Social and Rehabilitation Services
Donald Jordan, Secretary, Social and Rehabilitation Services
Tom Laing, Executive Director, InterHab

Monday, August 13, Morning Session

The meeting was called to order at 10:00 a.m. by Bill Craig, Chairman, who welcomed and thanked the Task Force members for serving on the Autism Task Force. Senator Dennis Wilson welcomed everyone to the Capitol and expressed optimism for their work ahead. He challenged them to develop and present positive work products that will be presented and discussed during the 2008 Legislature. Chairman Craig invited members to introduce themselves.

Sharon Wenger, Legislative Research Department, reviewed the background of Senate Bill 138, which establishes the Kansas Autism Task Force with 20 voting members and 4 ex-officio members. The charge of the Task Force is to study and conduct hearings on the issues relating to the needs and services available for persons with autism as categorized below:

- What is available compared to what is needed?
- What are the “best practices” for early evidence-based intervention for children with autism?
- What organization or structure could best deliver these services?
- What are specific proposals pertaining to autism registry, hotline, and regional centers of excellence?
- To what extent are financial resources available and needed to assist families of children with autism?

The reporting requirements of SB 138 specify that reports of the Task Force’s activities and recommendations are to be given to the Legislative Educational Planning Committee. A preliminary report is due by November 15, 2007 and the final report is due by November 15, 2008. The Task Force expires on December 31, 2008 ([Attachment 1](#)).

Suggestions on subjects for further study or requests for additional information by members are:

- Definition of terms to include adults;
- Definition of rating system that will be used by Task Force members;
- Availability of services statewide;
- Practices used in other states and countries;
- Funding sources—insurance and private sector;
- Utilization of enhanced technology for communication and guidelines; and
- Summary and status of current federal legislation expanding the Autism Act.

Linda Kenney, Director, Bureau of Family Health, Kansas Department of Health and Environment, provided an overview of Infant-Toddler (IT) Services in Kansas, which is in conformance with Part C of the Individuals with Disabilities Education Act (IDEA). Infant-Toddler Services is a comprehensive, statewide system of 36 self-defined community networks, which are providers of family-centered, individualized services for eligible children and their families. Personnel that provide services meet the highest requirements in Kansas applicable to a specific profession or discipline. Children in need of early intervention services are located through a system of Child Find services at the state and local levels. A variety of evaluation/assessment tools are used to determine eligibility. Funding for services comes from federal, state and local sources. Annual total funding in the state system is \$18 million or approximately \$3,000 per child, per year. Additional information about IT services can be found at the KDHE website www.kdheks.gov/its (Attachment 2).

Discussion followed regarding procedural safeguards, processes for parental grievances and source of dollars for funding and litigation matters. Several requests for additional information were made including:

- Copies of “parents rights” currently being used in Kansas;
- The legal definition of “research” and “best practices”—Carolyn Nelson, Director, Children’s Developmental Services, agreed to provide that information;
- Outcome measure reports on existing programs; and
- Chart of 32 service areas currently serving the public. Linda Kenney agreed to provide copies for the Task Force.

Mary Ann Keating, Executive Director, TARC, a community service provider in Topeka, provided a brief history and overview of TARC services offered to families. In 2006, TARC’s Children’s Services Program was awarded a statewide best practices honor. She said that the following issues are important in the delivery of service for infants and toddlers: funding, lack of child care options, respite services for families, staff training, and additional research for early identification of autism (Attachment 3).

Colleen Riley, Director, Student Support Services, Kansas State Department of Education, explained that the federal funding for IDEA does not begin to cover costs of educating students with disabilities which are facilitated through the Kansas Instructional Support Network (KISN). She agreed to provide data on breakdown of the dollars spent on various programs and how many due process cases currently are being litigated in Kansas.

Ms. Riley introduced Lee Stickle, Co-Director, Kansas Instructional Support System (KISN), who explained the services available through the Kansas Department of Education. She said the

mission of KISN is to develop local capacity to serve the needs of children with disabilities. She described the training series and curriculum, offered quarterly, in conjunction with the Regents' institutions across the state. She noted that all training is videotaped and available through the lending library, for the cost of postage, to anyone in the state of Kansas. She reviewed the services offered in regional offices. She expressed concern over the issue of recruitment and retention of professional teachers in Kansas and described the current certification process. Discussion followed regarding the number of board-certified behavioral analysts currently in practice in Kansas (Attachment 4).

Afternoon Session

Margaret Zillinger, Director, Community Supports and Services, Social and Rehabilitation Services, spoke to the Task Force regarding three of the programs which are administered by SRS: (1) Targeting Case Management (TCM); (2) the Home and Community Based Services waiver (HCBS MR/DD) which provides services for individuals with development disabilities; and (3) the newly proposed autism waiver which will serve children with Autism Spectrum Disorders (ASD).

Ms. Zillinger explained the purpose, target population, eligibility criteria, services and funding for each program. She stated that there are approximately 600-700 people that are underserved or waiting to start a program. She explained how programs were developed, specific needs addressed by the programs, staffing challenges, and funding considerations. She explained the ASD bid process, January 1, 2008 implementation date, demographics, selection process of 25 candidates, availability of providers, and prevalence rate (Attachment 5).

Tom Laing, Executive Director, InterHab, described the DD and *Tiny-K* networks, which are community-based service networks most directly involved with persons with characteristics of the autism spectrum.

He identified three issues the Task Force should address:

- Financing—They must confront the reality of under-funding and its profound impact on the lives of persons with disabilities.
- Coordination—Publicly-managed and privately-managed service systems must assist families to easily transition from one needed network to the next as their children grow and require different services. There must be coordinated policy development that demonstrates to the advocacy community that there is a commitment to address the interests of all persons and families in need.
- Diversity—While diversity of opinion must be nurtured, separate schools of professional thought must not become intellectually armed camps of disagreement.

In conclusion, he urged the Task Force to develop proposals which would address funding needs, avoid new bureaucracies that merely reinvent existing network capacity and define goals in terms wherein all participants will recognize that their interests have been addressed (Attachment 6).

Jim Leiker distributed a memorandum, *Autism Spectrum Disorder (ASD) Roadmap*, as resource material. The report had been presented to the Interagency Autism Coordinating Committee, May 16, 2005 (Attachment 7).

Dr. Craig opened the discussion requesting suggestions on Task Force work process, *i.e.*, sub-committee assignments, topics, and scheduled meetings. He recommended that they start with three subcommittees:

- Best Practices—It was suggested that regional consultants currently working on “best practices” should be included in Task Force discussions when establishing guidelines. When developing benchmarks and best practices, define realistic goals and objectives, based on where the child is, with built-in flexibility for change when necessary.
- Professional Development Initiatives.
- Insurance Parity Legislation.

The following suggestions and comments were made by Task Force members that should be addressed in existing or additional subcommittee topics.

- Interaction with the public school system and how the best practices can be incorporated into the schools. Educate schools on resources available, *i.e.*, catastrophic aid, Kansas in-service programs, and re-insurance programs.
- Discuss the subject of an autism registry and how it would work.
- Service resources.
- Development of data to be presented to the Legislature regarding the amount of dollar savings that might be recognized from early intervention. (Nan Perrin suggested a study reported in *Research and Pediatric and Adolescent Medicine*).
- Define best practices to ensure they are measured by evidence or research-based information.
- Follow the money to ensure the dollars go to those intended.
- Public outreach or information dissemination subcommittee, *i.e.* waivers. Legislative Research staff agreed to provide information on how to navigate the system through a graphic presentation for next meeting.
- Presentations from SRS and Department of Education on *Keys for Networking and Families Together*. Other private providers also may have presentations that may be beneficial to committees.
- Michael Wasmer described a report, based on a need assessment by an outside consultant, for Children’s Mercy Hospital in Kansas City, for the bistate area

services for children with autism. There is a report on-line that he will email to the Task Force members.

- Funding Partnerships through insurance, waivers, Medicaid, federal and state government. Jeannie Zortman recommended a resource on line: www.developingchild@harvard.edu.
- Information needed from the Legislative Research Department for future meetings:
 - Report comparing various programs across the USA and other countries;
 - Assimilate autism specific legislation used in other states;
 - Provide a list of the locations of main offices of agencies participating in programs across the state and names of people in charge; and
 - Criteria to determine accuracy of data presented by different agencies.
- Public Forums—Report on the results of six public forums held statewide in the last two years is available. SRS provided a summary on those forums. Pros and cons of having public forums was discussed. There was a suggestion that time be allowed at the end of future meetings to hear public comments.

Dr. Craig advised that Task Force members would receive an email with subcommittee assignments soon. Staff will schedule the subcommittee meetings. Consideration of participation by phone by some members will be given. The next meeting of the Kansas Autism Task Force will be September 20, 2007, 9:30 a.m. in 313-S of the Statehouse. The meeting was adjourned at 4:00 p.m.

Prepared by Rose Marie Glatt
Edited by Sharon Wenger

Approved by the Task Force on:

September 20, 2007

(Date)