

**KANSAS INTERAGENCY COORDINATING COUNCIL ON  
EARLY CHILDHOOD DEVELOPMENTAL SERVICES**

MINUTES

FEBRUARY 1, 2008  
Topeka and ITV

MEMBERS PRESENT IN TOPEKA

Dr. Linda Mitchell, Chair, Public Member  
Cynthia D. Price, KS Insurance Department  
Deb Voth, Provider Member  
Carolyn Nelson, KDHE Representative  
Tom Laing, Public Member  
Sharon Hixon, Public Member  
Dr. Eva Horn, Public Member-KU  
Tiffanie Krentz, Parent Member  
Dave Lindeman KU/Regents Representative  
Bobbi Mariani, SRS Representative  
Susan Carriger, Provider Member  
Representative Melody McCray-Miller  
Maria Martinez, Parent Member  
Scott Bruner, KHPA-Medicaid Rep.  
Colleen Riley, KS Bd of Education

MEMBERS PRESENT IN LENEXA

Letitia Holub-Taylor, Provider Member  
Julie Broski, Parent Member

MEMBERS PRESENT IN HAYS

Jennifer Rojas, Parent Member

MEMBERS PRESENT IN CLEARWATER

Nancy Krase, Child Start, Provider Member

MEMBERS NOT IN ATTENDANCE

Richard Martinez, Parent Member  
Kate Wolff, Governor's Representative  
Thomas Kohmetscher, Provider Member  
Senator Julie Lynn, Senate Appointee

NON-MEMBERS IN TOPEKA

Doug Bowman, Staff Coordinator  
Jean Wilson, Senior Admin Assistant  
Carolyn Weinhold, HSSCO/SRS  
Misty Van Nostrand, Families Together  
Anne Aytes, Leavenworth Co  
Dawn O'Brien, Tiny-K, Leavenworth Co  
Tiffany Smith-Birk, SRS  
Jennifer Spencer, KS Dept Education

NON-MEMBERS PRESENT IN HAYS

Vicki Runge, Kid-Link  
Cathy Estes, Sunflower Early Ed

NON-MEMBERS PRESENT IN  
LENEXA

Amy Owens, Infant-Toddler Services  
Phoebe Rinkel, KITS/Kansas University  
Liz Stone, Lakemary Infant/Toddler  
Teresa Gahagan, Parent/IB Provider

NON-MEMBERS PRESENT IN  
CLEARWATER

Homer Welker – Rainbows United  
Sonja Ostrander – Rainbows United  
Jennifer Francois – Rainbows United  
Chelie Nelson – Harvey County  
Paco Price – Rainbows United

NON-MEMBERS PRESENT IN  
DODGE CITY

Deanna Berry, Russell Child Dev. Ctr.

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Dr. Linda Mitchell, Chair, called the meeting to order with a welcome and introduction of all present in Topeka, and all remote sites.

ADOPTION/APPROVAL OF MINUTES

Tom Laing moved to adopt the minutes of the SICC Meeting of January 11, 2008, as written. Bobbi Mariani seconded the motion. Motion passed unanimously.

PUBLIC FORUM

Carolyn Weinhold of SRS, reminded everyone of the upcoming Kansas Fatherhood Summit beginning in Kansas City, KS on April 2-3, 2008, at the Jack Reardon Center. The cost is \$25.00 for parents and \$75.00 for practitioners. Registration brochures will be out in 10 days to sign up. There will be several sessions for fathers with special needs and/or children with special needs.

SRS PRESENTATION ON INFANT MENTAL HEALTH

Tiffany Smith-Birk of Kansas SRS' Early Childhood Mental Health gave a presentation on Infant Mental Health. This year, the Therapeutic Pre-School and School Violence Prevention Programs were not recommended and were cut out of Year 2009 Budget. Other funds cut were \$7 million to the Community Mental Health Centers.

An early childhood mental health endorsement system was purchased from Michigan. Tiffany passed out handouts of this system for all to review. This identified the mental health services needed in early childhood, and how mental health services could be improved.

INFANT MENTAL HEALTH GOALS:

- Goal No. 1: "that every community has access to well-qualified early childhood consultants working with young children, families, and providers, with listed strategies".
- Goal No. 2: "structured coordinated communication systems that bring people and resources together through a head agency overseeing the work".
- Goal No. 3: "high quality services delivered in multi-tiered pyramid approach including promotion, prevention, and treatment".
- Goal No. 4: "that young children and families have access to services in their natural environments".

Some of the members and guests present provided information about how important infant-mental health services are in Kansas. Many encouraged Tiffany to continue her important work in trying to secure the funds needed to carry out the work.

The SICC members encouraged Tiffany to keep the Council informed of the progress in continuing to gain funding and support for infant-mental health, and 13 mental health consultants, and others, now in Kansas.

Dave Lindeman made a motion that SICC form an Ad-Hoc Committee of volunteers to come back with recommendations to help support Infant Mental Health. Motion was seconded by Tom Laing. Vote was unanimous with no dissenters. Volunteers: Tiffany Smith-Birk, Tom Laing, Letitia Holub-Taylor, and one person each, from KSDE and KDHE will be chosen.

#### AUTISM TASK FORCE PRESENTATION

Bill Craig, Chair, spoke for the Autism Task Force (ATF) which began meeting last August 2007. They are a short-term group whose life ends in November 2008 when they will make a final report to the legislature. The existence of this group is due to the frustration of parents with kids with autism in dealing with the system not responding to their needs. Bill spoke as a parent and as a part of the system and understood both ends of frustration. The tiny-K is part of this system and part of this frustration and Bill has operated a tiny-K program and is very proud of it. Two things autism parents are aware of:

1. There is an epidemic of autism in this country.
2. There is a growing body of evidence-based research that Early Intensive Intervention can make a difference to some kids.

Bill conceded that it could be disputed how many kids have autism and on the different varieties of autism, but early intensive intervention seems to make real differences in some children.

In response to questions about the ATF from the SICC, Bill reiterated that he wanted to form a dialog with our group. The report focuses on deficits. Not excluding the broader positive approach, Bill's group believes that in the early phase these deficits, (attention, communication skills, and socialization) are important.

Another question Bill had from the SICC questioned the purpose of a referral to tiny-K or the schools. The ATF believes that the autism waiver (when fully funded) will be the vehicle to activate this vision of intensive evidence-based intervention upon early diagnosis. It is hoped that tiny-K networks (and all its systems) will embrace the opportunity the waiver presented in a creative and collaborative way. The ATF will not tell the SICC how to do this, but invited the Council to review the waiver system. The assumption is that tiny-K and the schools are not prepared to provide appropriate services with current resources.

Another comment received from the Council was that there are many other systems of services that would benefit from awareness training. The ATF completely agreed that

training of pediatricians, family practice physicians, and other primary care providers, is to be pursued.

Another concern brought up by the SICC, is of a possible conflict with requirements or expectations with the Individuals with Disabilities Education Act, known as IDEA. This concern is understood, but so far, the Autism Task Force does not see any conflict. Referrals to Part B and Part C are supported. The Best Practices Subcommittee is going to produce a handbook designed for easy use by parents providing detailed information for referral to Part B and C networks. Future website linkages for this information, is in the planning.

A question that goes to the core of many people's concerns is the 25-hour a week minimum and there is not unanimous agreement on this. The Best Practices group does state that 25 hours a week of evidence-based intervention for a minimum of 3 years is the gold standard and was accepted by SRS in the guidelines of the autism waiver and been also accepted by CMS in the approval of that waiver. Some parents will not want this level of intervention and it is not required. We are asking that it be available.

The Autism Task Force' intensity of service is based on numerous literature reviews, (including those supported by the National Research Council,) in educating children with autism. One of the concerns this expectation creates is that autistic children are not the same and cannot be treated with a "cookie-cutter" approach. This was not the intention as every single child would be treated with an individualized program incorporating a number of different practices. It should be noted that never is it specified to use any particular approach and many approaches will evolve dramatically as research develops.

The ATF is an advocacy organization that believes that only a collaborative effort with other agencies such as SICC will produce the best possible outcome. The first success story has been demonstrated with the autism waiver program that the group endeavors to expand funding for waivers for 100 total children starting in July 2008. The Governor's budget did not include this recommendation but as the legislative session proceeds funding will be sought for 100 children. The reason more funding was not asked for was that there is presently no capacity to back it up. Kansas has before the legislature, Senate Bill #398, which would mandate for insurance policies to cover autism services. It is hoped the SICC will support the ATF in these specific activities and for Senate Bill #406 for tuition assistance for professional expertise levels in the autism field.

Bill stated that the Best Practices subcommittee will publish their findings and enlisted SICC's assistance on the use of terms, research conclusions, and findings.

Eva Horn and Deb Voth both volunteered to assist Bill in gathering information.

Bill mentioned Senate Bill #406's assistance for tuition incentives for those in social service which is broadly defined to include work with individuals with autism, and is to cover even a graduate degree.

### Chair and Staff Reports

Linda Mitchell announced meetings through the State of Kansas on the process for being approved for the autism waiver. Also to be discussed is the criteria to be named “specialist”, and how to obtain these credentials.

### Funding Committee

Doug Bowman talked about the Governor’s proposal for creating a new block grant for early childhood. Later, the Funding Committee convened by phone call and agreed to defer to the next meeting for a suggested ICC position on a new block grant for early childhood in a written letter form.

Tom Laing noted that children with disabilities don’t fall within “at risk” kids, the confusion of this term. The committee discussed how future block grants are set up on a competitive nature and how this could affect various communities’ capabilities to get block grants. Tom stated his gratefulness for the Governor putting money into the system but with concerns about end results. The Council still actively advocates for additional funds for tiny-K but the state level block grant system is not an appropriate funding stream for mandated services.

Carolyn Nelson was concerned that the block grant would become the means to distribute future funds in early childhood.

### Budget Hearings for KDHE

Doug Bowman sent emailed notices out to members of the Council and the 36 Networks, about the Budget hearings for the Department Health and Environment. They started the following Monday, Tuesday, and Wednesday at 3:30 PM. Doug’s testimony was over the nature of the valuable services of the tiny-K program and explained our request for the \$2.1 million funding increase. At least one parent also testified.

Deb Voth asked that Doug Bowman make a very strong message. Parents could make emails and calls; they did not have to be there in person (which was the best plan).

Doug Bowman then brought up other hearings the following week in Senate Education on Senate Bill #408 proposing a move to the Department of Education for Part C.

Tom Laing recommended that the SICC send a strong message focusing on the funding by indicating that the most important issue coming up in this session is funding.

Maria Martinez asked about the impetus for this bill and how they made that determination. Doug explained that federal law was quite clear that it is the Governor’s decision in designating the lead agency. Kansas decided to take this a step further and put into our state statute that the lead agency is KDHE. So, when the 2010 Commission and the Legislative Education Planning Committee (LEPC) made recommendations last fall, they introduced a resolution (has not had a hearing yet,) urging the Governor to change the lead agency. At that time, they also introduced a bill to change that statutory language.

Tom Laing stated that this bill has come up for hearings now; this was to be a clean up bill in case the Governor acts to clean up the statutory language.

Linda Mitchell stated that the networks should be notified of this hearing coming up and they should write and call expressing their points of view.

Doug Bowman is still working on the document/draft of the SICC Annual Report. Linda Mitchell suggested that a template be put together and given to the Executive Committee. Deb Voth suggested the importance of putting in the document the child population numbers who were touched by services (birth to 5) – and what SICC does.

#### Committee Reports

Maria Martinez and the Partnerships Committee are working on strengthening communication and leadership and are to send an email out concerning the upcoming meeting.

Nancy Krause represented the Advocacy Committee and relayed discussions covering block grants funding. March 12<sup>th</sup>, 2008, is our Tiny-K Day.

#### Agency Reports

Tom Laing reported on the School Readiness Coalition meeting about the Governor's block grant. He questioned that a program required to serve children should still have to compete for funding. Operating dollars should not be in the competition where children are mandated to be served.

Dave Lindeman also asked that SICC send and approve the letter being directed to the Children's Cabinet on what Block Grants look like, with the assurance in this letter, stating "children with disabilities be included". He also talked about Medicaid and the CMS issue – habilitative and rehabilitation. The council is to send an email to Local 36 Networks for CMS Rules; there is a six months moratorium, and this information is with Carolyn Nelson. He also interpreted this action - meaning that they do not want to pay and there is only six months to figure this out and advocate for our funds.

Sharon Hixon stated that she had a copy of the Medicaid letter to the Kansas Health Policy Agency (KHPA), and wished Mr. Bruner had heard about the defense for case manager's services with Medicaid; it is only allowable to bill for one case manager.

Carolyn Nelson remarked that CMS had been approved for Part C, so unless what is proposed changes, the special instruction is going to be deleted. KHPA needs help writing and advocating what is right and what is wrong.

Tom Laing suggested that perhaps SICC needs to continue raising our voices that case management is collapsing. The attitude that everyone just has to live with it means that kids are really getting harmed by these cuts.

Carolyn Nelson of KDHE talked about the initiative to increase screening for 29 metabolic conditions. She also passed out a brochure on a Kansas Nutrition Council Conference coming up on April 17, 2008, to be at the Geary County Convention Center, Junction City, Kansas.

Colleen Riley brought information on the APR she has worked on and told the SICC that the Eighth Annual Performance Report to OSEP is due today. Dave Lindeman stated that part of our previous discussions were reviewing the SICC Budget. Doug put together a small committee to look at the SICC Budget.

Insurance and KHPA Report

None

Linda Mitchell announced that the next ICC Meeting will be at the KDEC Conference on March 7, 2008, at the Wichita Airport Hilton. At this SICC Monthly Meeting, we can do telephone remote calls only. There will be no Interactive Television (ITV).

Meeting Adjourned

**TESTIMONY PRESENTED TO  
THE KANSAS COORDINATING COUNCIL ON EARLY CHILDHOOD  
DEVELOPMENTAL SERVICES  
BY THE KANSAS AUTISM TASK FORCE  
BILL CRAIG, CHAIR  
FEBRUARY 1, 2008**

**Opening Statement:** Thank you for offering the Autism Task Force (ATF) the opportunity to discuss the details of its preliminary report to the Legislative Education Planning Committee. The Autism Task Force is delighted to hear that the Kansas Coordinating Council on Early Childhood Developmental Services (KCC) supports many of the items recommended in the preliminary report and feels that they are appropriate for young children with an Autism Spectrum Disorder (ASD).

As expected, the KCC has raised some questions and has requested clarification of certain sections of the Preliminary Report. The following is the Autism Task Force's response :

**Autism Task Force Response**

*Comment 1:*

*KCC: Early childhood recommended practices assert that services and supports are individualized and based on the child's strengths and needs (DEC Recommended Practices, 2000). In the vision statement under Early Identification section (p. 6), the report suggests that intervention should be deficit focused. Can the task force provide the literature that supports a deficit only approach to intervention?*

ATF: This may be confusion with the wording. The preliminary report does state that, "early intervention should focus on the child's deficits and should begin before the child has a definitive diagnosis". However, this is not to imply a deficit only approach, but to state that it is important to work on the skill areas that are identified as having delays, and therefore contribute to the potential diagnosis of autism; i.e. joint attention, communication skills, socialization, repetitive behavior. The ATF would be able to provide empirical references for evidence-based services for children with ASD, should the KCC request.

*Comment 2:*

*KCC: One of the recommendations in the Early Identification section is that awareness training for tiny-k programs and school district personnel will be made available to ensure timely referral. As the primary services providers to children with ASD it is somewhat unclear as to the purpose of referral. Are we to assume this referral would be to the "highly trained professional" and for what purpose?*

ATF: The *Early Identification: Recommendations* section page 7, bullet point 2 does state that the ATF feels that Tiny-K and school district personnel should be able to access awareness training for timely referral. "Timely referral" in this section refers to ensuring

that *tiny-k* and school district personnel are provided with adequate knowledge (via training opportunities etc.) to identify a child suspected of having an ASD and therefore ensure a *timely referral* for diagnosis. The ATF does recommend that children are diagnosed by properly qualified personnel.

As to “what purpose”: the core vision of the ATF is a future where intensive, evidence based intervention will be available to all eligible Kansas children immediately following diagnosis. The Autism Waiver, when fully funded, will be the vehicle to actuate this vision. Our hope is that the Tiny K network will embrace the opportunity the waiver presents in a creative and collaborative fashion.

*Comment 3:*

*KCC: Is the assumption that tiny-k Networks and LEAs are not prepared to provide appropriate services to children with ASD?*

ATF: It is a simple statement of fact that no existing service system is providing the level of evidence-based early intervention that is now considered “Best Practice.” This is not an indictment of anyone.

*Comment 4:*

*KCC: Additionally, there are many additional systems of services that could benefit from awareness training. How does the Task Force propose to address other social services system (e.g. social workers, child care providers, Community Developmental Disability Organizations)?*

ATF: The ATF agrees that there are multiple service providers that could benefit from awareness training in screening and identifying ASDs. The ATF does also recommend training for pediatricians, family practice physicians and other primary care providers (*Early Identification: Recommendations* section page 7 first bullet). However, for the purposes of the preliminary report, the ATF concentrated on those organizations that are responsible for Child Find. In addition, other providers in the social service and/or developmental disability system (CDDOs), typically come in contact with a consumer post-diagnosis. Because of this, the ATF felt that the emphasis for early screening awareness would be most appropriate to the *tiny-k* Networks and the LEAs. However, given the probability of a later diagnosis for those individuals receiving a diagnosis of Asperger’s Syndrome and/or Pervasive Developmental Disorder, Not Otherwise Specified, the ATF takes this suggestion seriously in regards to social workers, child care providers and other community providers and will take steps to ensure that this category is included in our definition of service providers/provision.

*Comment 5:*

*KCC: How will the Task Force support referrals to service delivery programs under Part C and Part B of IDEA – those being the Infant/Toddler Networks and the Local Education Agencies?*

ATF: The Autism Task Force fully supports referrals to service delivery programs under Part B and Part C of IDEA. As a part of the final report, the ATF’s Best Practices

subcommittee will generate a final document with a *Parent Handbook* section. It is anticipated that detailed information regarding Part B and C of IDEA will be included, along with local and regional contact information (including links to their websites).

*Comment 6:*

*KCC: One of the recommendations in the Early Identification section is that a diagnostic consultation occurs within two months and a diagnostic assessment occurs within six months of when a child is suspected of having a potential diagnosis of ASD. How does the Task Force intend to reconcile this timeline differences with the timelines required under the Individuals with Disabilities Education Act (IDEA) for assessment and development of an Individual Family Services Plan (IFSP) or Individualized Education (IEP)?*

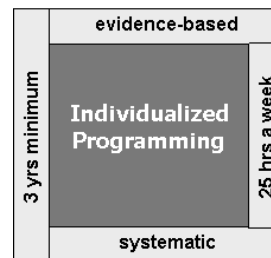
ATF: The Autism Task Force does not recognize a conflict between diagnostic timelines and those of IFSP and IEP production. The ATF believes that early identification of an ASD is a critical component in ensuring the best possible outcome for the child. The ATF does not anticipate that early identification of an ASD will conflict with the production of an IFSP or an IEP.

*Comment 7:*

*KCC: “In the vision statement of the Best Practice section, the vision is that children will receive 25 hours a week of systematic evidence-based intervention for a minimum of three years (p. 7). Many factors will affect this statement including how critical terms are defined. How will the Task Force reconcile and clarify the legal requirement of individualized planning and services as required in IDEA with statements that children will receive a certain amount or type of service on a certain level of intensity?”*

ATF: The vision statement of the Best Practice section does state that the vision is for children to receive 25 hours a week of systematic evidence-based intervention for a minimum of three years (p. 7). The ATF recognizes that many factors will affect this statement including how critical terms are defined, such as evidence-based. First, to address the definition of this term, the ATF does not imply any specific type of service (e.g. specific methodology) with this statement. We do, however, consider evidence-based interventions those interventions that have been scientifically evaluated for the benefit to those children served in the absence of harm. Given that clarification, the ATF does not recognize a conflict between IDEA requirements and evidence-based services. Conversely, IDEA states that IFSPs and IEPs should incorporate evidence-based services. Given that, the ATF recognizes that not all parents will wish their children to receive evidence-based services; the intention is to make those evidence-based interventions *available* to those parents who wish to utilize them. Our vision for the intensity of service (e.g. recommended number of hours per week) is based on the results of numerous reviews, especially the National Research Council, Educating Children with Autism. Their conclusions included a minimum of 25 hours of systematic support. This still allows for individualization, it just clearly delineates this as a minimum standard that has been documented as producing the best outcomes for children on the autism spectrum. Additional literature supporting this statement is available upon request.

The vision statement is defining best practices for children with ASDs based on scientific evidence. The ATF would like to take this opportunity to make it very clear that we understand that children with ASDs are individuals. Best Practice provides service providers with a scientifically derived, evidence-based framework within which to individually tailor the child's program. Every single child is going to require detailed and individualized programming incorporating a number of different teaching elements *within the framework* of best practice – 'systematic', '25 hours a week', 'evidence-based' and 'three years minimum'.



*Comment 8:*

*KCC: In the recommendations for the Best Practices section, the Task Force highlights the need for education leadership to maximize funding to local schools (p. 8, 10). In an age of interagency collaboration of services what does the Task Force see as the role of other state agencies (SRS, KDHE) and programs (Children's Cabinet) in maximizing funds for services to children with ASD.*

ATF: The ATF does address the need for education leadership to maximize funding to local schools, both in the *Best Practices* section (p. 8) and again, under the *Funding Issues* second (pg.10). The ATF recommendations highlight the need of an increase in funding from multiple areas; *tiny-k*, school districts, HCBS waiver, health insurance, catastrophic aid and via appropriate legislation. Secondly, the ATF fully believes that only a collaborative effort on the part of all relevant state agencies and programs will produce the best possible outcome for an individual with an ASD across their lifespan. As such, the ATF would like to take this opportunity to highlight what it considers its most recent collaborative success, and that is the implementation of the Autism Waiver by SRS. *The ATF urges all other agencies responsible for delivering services to children with ASDs to support SRS in its endeavor to access additional funding for this excellent service.*

*Comment 9:*

*KCC: On page 9 under the Funding Issues section, an identified barrier in the report references the tiny-k funding formula as based on total served. That formula also includes other factors such as birth rates. This should be corrected.*

ATF: An amendment will be made regarding the funding formula for *tiny-k* according to KCC's directions in the final ATF report. The ATF apologizes for this inaccuracy in its preliminary report.

*Comment 10:*

*KCC: In the Accountability section the Task Force recommends enforcing compliance with the “Best Practices” document (p. 11). What role does the Task Force propose for itself in the enforcement and how might that interface with other compliance systems currently in place for programs serving children with ASD?*

ATF: This is a preliminary report and the Task Force has just begun looking at this topic. However, in order to address the implementation of recommendations the ATF did discuss the possibility of establishing an oversight entity which would be a successor to the ATF.. This will need to be investigated further.

*Comment 11:*

*KCC: Also if recommendations in the Best Practice document happen to be in conflict with other law (IDEA – e.g. a specified intervention program for all children), how will the Task Force reconcile the document with other law and regulations. Under what authority would enforcement be authorized?*

ATF: As stated above in response to Comment 7, the ATF does not feel that the recommendations of evidence-based practices is in conflict with IDEA, nor does it imply that this recommendation infers any single specific intervention program for all children. In addition, “*Under what authority*” is addressed in Comment 10.

*Comment 12:*

*KCC: In the Accountability section the Task Force recommends having authority for proposing modifications in the service system. Who would these proposals be made to? Does the Task Force see this role as working through current advisory systems required under IDEA (State Interagency Coordinating Council and Special Education Advisory Committee) or is the Task Force proposing another system?*

ATF: The ATF discussed the designation of accountability within the current advisory system, as well as other possibilities for an independent oversight committee. However, as stated above in response to Comment 10, the possible need for establishment and/or allocation of oversight authority requires further investigation.

**Conclusion:**

The ATF is required to make its final report to the legislature in November, 2008. We hope to spend the remainder of our time clarifying the vision stated here and elaborating on the steps needed to achieve it.

Our current advocacy efforts include:

Expansion of the Autism Waiver to serve a total of 100 children the coming year.

SB 398 which mandates insurance policies to cover Autism.

SB 406 which provides tuition incentives to individuals seeking graduate degrees who agree to focus on autism and work in underserved areas of the state.

We would welcome your support of these efforts.

Thank you for this opportunity.