

# Iowa Autism Council Meeting

June 16, 2010

**Facilitator: Sue Baker, CHSC, Iowa Department of Education**

**Present:** Josh Cobbs, Danielle Sharpe, Katherine Byers, Sue Baker, Frank Forcucci, Becky Harker, Dr. Marty Ikeda, Karn Johansen, Sonia Lewis, Dr. Linda Louko, Toni Merfeld, Lana Michelson, Steven Muller, Jim Mumford, Pamela Parker, Susan Smith, Barbara Stineman, Dr. Charles Wadle, Dr. Debra Waldron,

**Absent:** Bill Gardam, Keith Gatrost, Kenda Jochimsen, Dr. Jeanne Prickett

**Speakers:** Jim Addy, Deb Samson (Department of Education), Tim Grieves, Stephanie Robinson (Northwest AEA 12), and Maria Cashman (Grantwood AEA 10)

**HRSA Autism Grant:** Dr. Waldron spoke briefly about the HRSA Grant application and Bridges to Care-Children with ASD at the Center. Overriding proposals mirrored the IAC recommendations for a seamless system of care. This is a Federal proposal. CHSC is a support system, but loses money and does not break even. CHSC is more than clinical services. Dr. Waldron reviewed Title V targeting family centered care and development of systems. She described Combating Autism Activities, reviewed I-LEND, research programs, 9 Systems of Care grants available and evaluation of this CAA which is due to the feds yearly.

Barriers are reported on the national level, and provide quarterly feedback to this council and form Iowa policy. The purpose of this grant was an infrastructure building grant and listed how it was funded for \$300,000. This grant is built off a systems plan like what IAC provided. Title V picked up the ball as the lead agency in Iowa for this grant. Systems of Care include; medical home, screening, and a transition piece. A working model of the grant proposal was shared. Goals for family, community and state level were described. ASD regional centers would be identified for five sites in Child Health Specialty Clinic system.

The grant also listed PBIS goals. Family to Family grant helps with infrastructure with someone taking on capacity building. Methodology was about information technology to build on data collection with CDD and DHS and a smaller Bridges to Care council to help with implementation. This group will do some of the work Iowa Autism Council has mentioned. Quality Improvement piece is also included. A new evaluation tool to evaluate the state system is included in the grant, Medical Home for community is established and then individual input as feedback to the system.

The three goals were named, and why these regions were chosen: Council Bluffs, Davenport, Ottumwa, Sioux City, and Spencer/Storm Lake with a known poverty level. Thanks for the IAC letter of support.

**RESPONSE:** IAC will form a recommendations review committee/panel to set up policies to review this so that the panel will have a process in place for the future. Josh will inform the entire committee.

**Overview of Data Warehouse:** Jim Addy spoke about the four Items and background on the changing infrastructure, Information Technology (IT) in education. First is statewide longitudinal data system, to collect data over time to analyze and track progress. Data System is something that is required to receive stimulus money. The Department has to report certain items (public, IT, and state) and the Department got a grant to support this project. The U.S. Department of Education is the funder with 4 years remaining on the funding.

The Department wants to connect interconnectivity with our entity working with the same data; we have a PK-20 into workforce; and unified infrastructure for all the projects. This grant funds the data warehouse. We report graduation rate for federal reporting, and expand all the data sets. We are to include some workforce data including Vocational Rehab. Electronic transcript system/student record exchange will be included. Find out about EdInsight at Iowa Department Education website site using the A-Z index.

If you want to see the press release, search for longitudinal data system. EdInsight pulls from IMS Special Education data, IPT testing data, Project Easier with student data graphics, demographic and curriculum data. The data are linked so you can use as one data system. Jim reviewed the four goals of the EdInsight (from the website). Researchers use, training with Des Moines Public Schools and AEA 267.

It will hook up to all the entities (K -12, AEA, workforce IWD, College Aid). Josh asked about who is the lead for receiving recommendations? They have a group coming together through reorganization, with Lori Tritch in the head position. We will be adding teachers, finance data, buy more assessments, adding transcript data, community college data, workforce and e-transcripts. He showed an example with individual and cohort data, APR reports.

They have used market research and will continue to use focus groups again. Also suspension and expulsion data was shared as an example. They will be adding Early Childhood assessments and teacher evaluations (question of matching student performance with teacher) to some degree. Lana asked about birth to death range for this council, so how do we access DHS, IME, and DPH etc. data? Are there student identifiers that might cross with other agencies?

They are working with DHS to expand; social security numbers we have from 40%, but others don't want to share. Josh asked about how to work around FERPA? This question, others questions, no other place to put the number, other problems exist with confidentiality issues and Memorandum of Understanding's on how to deal with agencies. There is some success with directory assistance to locate children who have moved to new locations as a start for broader connectivity.

Becky asks how to get information to call to get this information. Yes, someone will be available to call. IMS goes down to 3 years old, but don't know about Headstart etc. Nothing below preschool is being targeted. But birth to 3 is in IMS.

**DHS Draft of Five Year Strategic Plan for Mental Health Disability Services:** Ann Riley spoke briefly on why DHS is developing a five year plan. With leadership changes recently, there was no plan, so DHS wanted a living document with where to start, the governor and legislature to know, and a team committed to the plan (includes Stakeholders). CDD is University of Iowa's Center on Excellence (serving disabilities) so they received the contract to get stakeholder input.

**Target:** how do we get IAC input into this plan? This can be the first step in the Olmstead Plan. Reviewed slides from the PowerPoint. Olmstead vs. LC history to accessing community supports and is not entitlement to getting all the services you need. So Olmstead Plan was reviewed as a start for DHS and not all the state initiatives (even though they are listed in their plan). See the nine principles of what a transformed system should look like from reviewing the history of plans.

**The vision:** what works for the individual is the key. The five goals of community, access, capacity, quality, accountability were reviewed (see handout). Objectives were identified. The focus is on what they can control. Clarify Administrative Rules about insurance coverage for state employee (IAC recommendations and I-PART services) and both were saying doing functional assessments and rules should allow both groups to say who could bill. Now want to create billing with these things side by side, as IAC does not have policy and billing administrative rules to create awareness of communication. Partnerships are important.

**Next steps:** Jeanne Nesbit will want to talk with Krogmier to have discussions with legislature and the governor to determine what they can do within these objectives. DHS will select which things are moved forward first. Building capacity is important and will want your input. If the System of Care grant goes through, this is another way to define it is moving forward. Question to you: it is a short time before legislation and we need input to review the plan. 1) State plan website listed in PowerPoint presentation, (latest objectives are not always listed) and tell council members to read the document and enter comments anonymous as you want.

If DHS needs consensus, they will use legislative and committees. So, we are not asking for consensus right now. We will look at the subcommittee level and report back to the full council.

**Parent Education Connection Activities presentation:** Deb Samson told us about Rick's story (Deb's son) starting with diagnosis of cerebral palsy, access to information and to determine what is credible. It is about knowing about grief process and rebuilding dreams. Learned slowly not to be anxious about the future, not everything is about the disability, he is fine the way he is, cultivated friendships and relationships with other parents, and people with disabilities.

Deb stated that she learned more about herself, learned from tough situations, and learned that Rick's story was not hers. Medical label had little to do with providing appropriate services for Rick, IDEA First (Education of the Handicapped Act using rules) Due Process in 1979 with her sitting outside the classroom for a year as he met key people, the first time. **The Department of Education activities:** 1) Parent Educator Connection, 2) parent as presenters, 3) parent leadership summit, 4) parent and education connection annual conference, 5) indicator 8 in APR, 6) Information and training center, 7) information and resource center Parent Information Resource Center.

PEC started in 1984 with 9 AEA's currently due to reorganization. Fixed budget and headcount with 9 educators and 32 parents (budget 1.2 million dollars). Parents as Presenter held on Fri/Sat with alumni is training to tell your story to different audience places. Cross Disability, how to organize, and market your story as part of a solution. Summits in 04 and 08, 30 statewide organizations, '09 training called Fierce Conversation (tag line the conversation is the relationship).

Annual conference –does conference meet needs of parents today is their question? Provides Awareness information. Parent Training Information Center: Part D IDEA, one in each state and work with conference and parents as presenters. PIRC in education focus on parent engagement in education for all children, joint project with AEA 267, DE and School Administrators of Iowa. Info on DE parent information, see hot links of their activities. Websites referred to most often as credible (NICHY, etc.).

Josh wanted to know how do they get into training...outside of Des Moines? Parents as Presenters are only in Des Moines once a year and each household receives \$325 stipend to attend the workshop. Conference is in flux about what we are going to do. One spot to get together with others, but is that the same need now? Each PEC does tons of regional training and you build what you want and we will come to you. Maybe 10,000 training including RESPECT about good communication perspectives with 4 sessions.

Add Training Consortium with disability focus in Iowa City with national and state. Parents as presenters have an autism represented each year. Josh: says we want to get the word about all

these trainings. Karn asks about protocol or resolution at the regional level. If in conflict, then there is a strict protocol (DeeAnn Wilson then Eric Neessen are DE contacts).

**FAPE presentation:** Tim Grieves, Stephanie Robinson, and Maria Cashman from NW AEA and Grantwood AEA. Spoke about how AEAs provide services to students with Autism and address how Special Education is delivered. Tim gave an introduction to the History of AEAs. There were county superintendents and 99 mini AEA's, then to joint county superintendents and AEA (in '74 AEA's were created) along with IDEA and Public Law 94142. The state of Iowa is now down to 9 AEAs in early 2000 (study then and currently one coming up).

We are downsizing our administrators. AEA have no taxing authority and receives money from school districts and budget from local property taxes, direct state aid, various grants, and federal programs and IDEA. 30 million dollars carry over, 131 in state allowable growth, 81 in property tax. (422 million total). Josh asked about waiver under IDEA to cut Special Education by 38 million dollars.

Lana says the AEA's do not get property money, they get state aid money and can't make up a reduction in state aid. So 38 million waiver of 2 states received, this is in state funds, not federal. Same amount of money on AEA every year, can't reduce in state dollars, so we got one year waiver. We will have to spend this and 38 million next year. Present an argument for it, it would not have impact on LEA since they can (negative balance) use property tax, cash reserve levee, to continue FAPE. Only place cannot do this is the AEA's.

Everyone at the DE is employed on federal dollars not state dollars now. We knew we had 35 million dollar deficit and this was a good indicator we were in trouble with spending. It was a huge penalty if we did not apply for this waiver. Josh is concerned about districts not levying taxes, this would create a deficit. State is usually 18-20 million deficits in Special Education and use cash reserves, but they must pay/no choice that kids won't get services. Can't say there is not enough money.

The cash reserve covers unknown expenses. Lana does know who has applied for property taxes. Lana: we may have to apply for another waiver, year by year, without a limit yet. Forecast for revenue is better than expected (not good). Future is based on the state economy. Maintenance of Effort is not counted the same as AEA and LEA. Money goes to individual AEA's in different pots of money with special education being largest. 70-80% of funds are for special education.

If AEA organization went away, so would the money as it is a flow through system. AEA 11 is 100% for making sure that everyone in Des Moines receives Free Appropriate Public Education (FAPE) through contacts with each other. Katie asked if individual dollars are spent on each child. 69,000 kids are being served with services. (Most provide auxiliary and support services

not paying teacher salary). 39,000 is k-12 public schools, 5,000 non public, totally 43,000. Danielle asked about what percent for administrators. Answer: 3-4%. Reduced administrator costs, but it is also including how to add data in to system (includes Tim's administrator).

There is a problem with AEAs except Heartland and Grant Wood: all were declining in enrollment and now only 161 districts have declining enrollment, so we are looking at how to be flexible with funding and staffing. The DM newspaper article: we don't know how they were including what information. Katie asked about direct vs. indirect services: Tim does not have that information.

Tim explained about AEA support staff including Social Workers, Psychologists etc. and Tim indicated the AEA's have never really looked at their services and cost in the system; Katie says this is what parents want to know. Marie says her regional facilitators who supervise staff, majority of facilitators have about 30-50 staff they supervise, so we have reduced non direct child provider type people.

Nine mandated services were described (Services for Diverse Learning Needs).

**Iowa Core Curriculum.** 09-10: Chief Administrators are discussing this month, their priorities: the top 3 priorities were Iowa Core Curriculum, Child Find, and working with autism population. See the slide of five bullets. AEA informal survey of the joint directors. Survey to see what is going well, what can we improve on, common services that we all provide: see current common services slide.

All AEA's have an Autism team (makeup is different, some with more people than others). Josh asked about qualifications to be on team. **Answer:** AUTISM BACKGROUND, have an interest, and complete further training. Consistency from AEA asks Josh? AEAs provide Professional Development for teachers, AEA staff, parents, and school administrators. AEAs provide IEP and IFSP services to students with autism, collect data regarding students with autism. Example TEACCH training has waiting lists.

722 IMS students were identified in this system. Early ACCESS staff and Autism Resource Teams are working with 3505 individuals without medical labels. Disparities are present; why is there a difference in official and unofficial numbers? Informal data is contributing: 1) teachers are not informed of putting an AT designation in the code box on the IEP. 2) Sometimes parents of younger children who don't have a medical label interact with the teachers. Teachers may say I think maybe your child has autism, but the teachers are reticent to say that (directly tell the parent the child has a potential of a medical diagnosis), so there is often no conversation between parent and teacher and AT is not coded despite suspicion. (480,000 students in Iowa) .

CDD says ASD occurs in 1 in 150 births. Katie asked "How do you address diagnosis?" answer: IEP team visits with families and draw out their concerns: here is what we see, leads to asking when was the last time the child was sent to pediatrician and maybe he needs to get back in with the pediatrician and discuss parent and teacher concerns. Then the AEA will provide information to the pediatrician about their concerns. Steve asks: could we talk doing research, take sample data in certain pockets and see what is frequency is in a school district?

Answer: we could do this; Sue collects this data unofficially from each Autism Resource Team yearly. If we wanted to do some district data and work with the Department of Education and Sue, we could. We work with teachers to enter that code into the data collection. Lana: we still report disability labels. We could do another sample next year, that is statistically sound and improve how we record our disability category to the federal government. A member asked about sample size? Lana could get this district data. We could study how we did in the past with data submission, work with the Directors of Special Education regarding a random sample, and discuss with management staff how to move forward and more accurately put an AT disability label on the IEP in the secondary coding section.

See bars and AEA information on one slide. Characteristics of autism are more than we are gathering. AEA 9 did not report back their numbers. Unofficially found out 621 students were 09-10. So now add 621 to the total.

See slide titled Autism Supports for Schools and Families, Continuum of resources and services listing state wide resources from Sue Baker, regional resources from medical community resources (CHSC). See the slide What If Families Have Questions or Problems? on who to contact starting at the lowest level.

Josh shared an informal story about an Autism Resource Team leader, Jan. Josh got a team up for Jan, to run in the Walk for Autism and raised \$4,000.

Let's talk about systemic change, asks Katie: the way things are set up is not the best for kids with autism. Sue described Comprehensive Services Improvement efforts for staff development for the Autism Resource Teams, Administrators then public school teachers and AEA support staff. This involves a new coaching model for teachers. Maria says the IAC has the ears of everyone and is a place to start improving systemic change. There is a need to engage more parents in this conversation to get statewide change. The AEA is going to support teachers by "coaching" teachers and strategies in NWAEA.

This will give the new teacher more time to work with others, coaches to model new strategies, coach progress over time, etc. Some AEAs have a similar model to NorthWest's. Josh is concerned about accountability and consistency. Is it AEA or school district who is ultimately

responsible? It is frustrating about each of the AEAs doing it differently so we should get reasonable services from AEA to AEA.

Tim talks about what is going well (see slides) . See areas of improvement:

Networking is beneficial to know what other AEAs are doing; how time and money for training and building support are worked in; how is follow up with teachers and students provided; identification and service to younger children is also a possible network topic.

Who is pushing at the district level to get the IEP implemented? If LEAs and AEAs don't agree, or agree but not with the parent, and district is financially responsible for the IEP and we provide services. Example: parent wants speech; Is ART being used? I have not seen ART for 4 years says Danielle. No one had seen Best Practices Guidelines (AEA's problem) says Danielle.

Maria saw Best Practice Guidelines and gave to ART; she went back to them to review and needs to again and they could provide documents to others. Josh is concerned about consistency. This training to teachers is great, but is a catch up model. Can we as IAC or individuals work to increase probability to increase requirements to get licensure before they come to a job? Training at college level so we are not catching up?

Maria says with coursework, augment by talking with IAC member Linda, training becomes data and we feed the constant challenge to get the basics, how to work with students, and next new thing to get trained on appears. Linda: you need to be trained and you can adjust. University of Texas on line course work was used by Susan.

NWAEA and Chapel Hill NC contract to send our Iowa people to them to be updated in TEACCH. One person is going, and it takes a lot for each person to do that update in training.

Katie: We need to go one step further: Para Educator training is needed. Josh talks about ABA training for behavioral services and it was opposed by DE lobbying against the bill. Drake University is looking at Behavior Analysis credentialing along with Wacker and state DE person creating certification in educational delivery (Sean). Katie says she could fight for training to be outlined in IEP with more than 2 days training provided. This could mean the teacher has a sub associate with minimum wage and high turnover rate. Josh says parents have an issue: the system is fragmented. Each district gets to do their own thing regarding training and the state comes in and oversees them. Districts have different services despite same label, so how do we get those closer: AEA or district or state?

Tim will take back the issue to chief administrators. Steve warns just wait till you get to the disjointed adult system. While flaws exist in the public school system, it is good people doing good work and these frustrations continue through the lifespan.

Linda: wants to provide feedback on SLP services. She hears from parents and SLP's (she has state connections): SLPs are excellent. But she hears that speech services are great, but they are 2 sessions a week and are limited. SLP's can't recommend more because that is all I am allowed to recommend. Maria can't dispute her perception, but to provide FAPE, we provide what the student needs. Maria says we may need to do a better job of understanding the finance issues.

Tim: that is their largest department (SLP's), they know their caseload. We can't say what the child truly needs because we don't have people to provide it [sic]. Karn says medical expectations are different from school...all schools have to provide is appropriate services, not the medical expectations of a higher more intense model. School and medical recommendations don't always mix. Most families don't want long term services; they want to get it fixed now with least services.

Barb: When providing staff development, does the district ask the AEA staff to provide it or does the AEA contact them and offer it? Or is it the individual teacher requesting it? NW AEA does it all those ways. Is staff development required for all teachers? NO, it is not required but is available. Principals and teachers have trouble getting to staff development offerings, and it is not hard to get trainings filled up. Questions? This topic will go through the education subcommittee

Danielle: Heartland question. AEA Board minutes ¼ direct services are meeting the needs of the child. So if staff are not following Best Practices Guidelines, what do you do about it? There needs to be someone in charge, so who is that person? Regarding the Best Practice guidelines: how can IAC modify them and account for their enforcement?

Lana spoke on the consistency issue. AEAs are trying to implement with consistency. This is the first year of the one process procedural model. There is a commitment to implement procedures in the same way. AEAs are headed in right direction. Supervision issues: the AEA has general supervision issues. So if they found something non compliant then they have the responsibility to address it. General Supervision is with local districts (both collaboration and police officer). State has General Supervision over AEA and LEA. First call to the AEA and ask them what is going on. If there is a role to enhance it will be Marty's problem! (as the new Bureau Chief when Lana retires).

Tim explained to his staff: we are 80% service and 20% compliance. AEA wrote a letter to a school district and cited a long list of items to address; our expectations in helping that school district to be more compliant is as a shared responsibility.

**Council business:** Voting on chair and vice chair; Review Advocacy/Advisory; Share future IAC Dates; Thomas' review HPPA/FERPA with handouts from April 14<sup>th</sup>. Josh was nominated as Chairperson by Katie and it was seconded. The vote was unanimous. Danielle was nominated

as Co- chair by Katie and seconded by Chuck. The vote was unanimous. The council reviewed the charge of the Iowa Autism Council, see the written handout, which is advisory NOT an advocacy role. Thomas can be contacted in the future regarding FERPA-HPAA concerns.

IAC meeting dates were shared with the council. The next meeting is October 6, 2010, then November 17, 2010, January 12, 2011, April 13, 2011, and June 15, 2011. All meetings will begin at 10:00am and will be held at Stoney Creek Inn.

Dr. Marty Ikeda was introduced to the council. Dr. Ikeda will be the new Ex-officio for the Iowa Department of Education, Bureau of Student and Family Support Services.

Lana and Dennis are retiring, with this being their last Council meeting. Lana has taken Josh and Danielle under her wing and they appreciate her straightforward communication. We will miss you.

Jim Mumford: rules on insurance bills, through finance committee, will be meeting and report back to this committee. Who is DHS feedback? Keep at finance level.

Subcommittee chair work to be completed. October will be the preliminary draft for your area.

Send out through Sonia.

It was moved and seconded that the meeting be adjourned. Meeting Adjourned.