

Minutes – Autism Council Meeting

April 29, 2009

Members Present: Sue Baker, Lana Michelson, Beth Buehler, Katherine Byers, Joshua Cobbs, Keith Gatrost, John Kohles, Steven Muller, Pamela Parker, Dr. Mary Grace Percival, Danielle Sharpe, Barbara Stineman, Dr. Charles Wadle, Patrick Westhoff, Cathy Young, Bill Gardam, Kenda Jochimsen, Becky Harker, Angela Burke-Boston (sub for Jim Mumford), Dr. Debra Waldron, Mark Wolak

Members Absent: Dennis Dykstra, Barb Rankin, Jim Mumford, Dr. Ghada Hamdan-Allen, Dr. Jeanne Prickett

Invited Guests/Public: Thomas Mayes, Konni Cawiezell, Shannon Kohles, Scott Lindgren, Pam Alger, Alissa Doobay, Jule Reynolds

Vote was taken and the By-Laws were approved.

Vote was taken and the minutes from the last meeting were approved.

There was a brief update regarding Senate file 1 and House File 1 as follows:

Senate file 1 did not pass and House File 1 did not pass the legislature but the sub-committee is still active and both bills are anticipated to be re-submitted during the next session. There are only 3 states which do not have any legislation pending.

Konni Cawiezell, Legislative Liasion from the Iowa Department of Education spoke to the group about how advocacy and the legislative process works. She used a power-point handout for the group to follow and to have post-meeting.

Leadership determines who is on a committee and the committee determines who is on a sub-committee. The current leadership is as follows:

Senate:

President of the Senate – Kibbie

Democratic Majority Leader – Senator Gronstal

Republican Minority Leader – Senator McKinley

House:

Speaker of the House – Murphy

Majority Leader McCarthy

Majority Leader Paulsen

Konni's recommendation when seeking to get a bill passed was to start by "Getting your foot in the door" rather than asking for everything you want all at once as it's easier to get this accomplished and get other things added later.

After submission of a bill is made Konni recommends that you always do a follow-up inquiry with the leadership person.

Lastly Konni recommends that you always provide a "thank you for your hard work" to them although even while you may not be successful in that particular attempt with legislation. You want to maintain a positive image with that person(s) for when you submit future attempts to get a bill heard and hopefully passed.

Thomas Mayes also spoke to the group about the process of submitting legislation. His recommendations were as follows: "Never do an e-mail when you're angry." This will always be remembered and often damage your further efforts. Later efforts may be jeopardized because of the after-effects from your previous and hostile e-mail, phone or written communication.

He encourages people to be present at lobbying sessions when possible and to remain pleasant. He further recommends that if at all possible, to attend the legislative teas on weekends, they can be very helpful. It's a smaller more intimate setting with a more relaxed atmosphere and a chance to talk directly to your intended party.

Lastly he cautions that just because you have a conversation with a legislative person and they are friendly/courteous, don't take this as an automatic sign that your bill will be passed. Many times at these sessions legislators have been given their marching orders by higher ups as to what position their affiliates wish to be supported.

Steven Muller mentioned that it's important to know the big picture when submitting legislation. Often there are politics involved behind the scene. You always want your "champion" who can go into a caucus and effectively present your case.

Thomas stated that this process can often have a Multi-Client basis where legislators have their marching orders from insurance company affiliates, etc. as to how they feel about a piece of legislation and any impact it might have on them. Therefore, he stated that due to multiple interests sometimes your message may not always get conveyed through the process and therefore directly contacting the person at the industry level who should have your information is most beneficial for your group/cause.

**Dr. Charles Wadle asked if our role is to advise or advocate?
Mark Wolak responded that as is in the by-laws for this council
it's role is to advise (not advocate).**

**Mark Wolak and Josh Cobbs stated that the action of building a coalition
with other groups to have them help get your message out would be the
appropriate practice. Various members may be part of other groups and
can represent their personal ideals through membership in other groups.**

**The purpose of the council is to submit information/policy recommendations.
The council needs to be able to explain why they did something or ruled?
This committee's role is to be advisory to the Governor and the council.
The council has done a really good job of representing ideals of a group as in
relation to being a member of this group. Thomas reiterated that John Brown
when not as a member of a group but as John Brown can say anything that he
chooses to in relation to his opinions/beliefs.**

**When speaking with legislators request to know what the issues/problems are
and offer to educate them on your cause and demand to be educated in return.
Thomas informed that group that there are many new pieces of legislation
passed all the time; i.e. in 1993 there were 3 volumes of Iowa Code, now in
2009 there are 6 volumes of Iowa code.**

**Thomas also pointed out that the personalization aspect is very important.
A handwritten or typed letter lends to a better reception and for many has
more value than an e-mail due to the aspect of additional time and attention
expended.**

**Lastly, Thomas introduced the Open Meetings/Open Records booklet to the
group which he had distributed for their benefit. It explains the definitions
of open meetings, open records, rights of parties to review records etc. and
should be helpful to those in a council, commission, board, etc.**

**Lana Michelson using a power-point presentation, presented to the council
about the Iowa Department of Education and many of the requirements it is
obligated to meet. She defined IDEA, "To insure that all children with
disabilities have available to them a free and appropriate public education
that emphasizes special education and related services designed to meet
their unique needs and prepare them for further education, employment, and
independent living."**

**She spoke about the various services available and their categories,
and the five specific bureaus within the Iowa Department of Education.**

**Early Access- Birth to 3 years of age (also known as At-Risk)
Preschool – 3 to 5 years of age
School Age – 6 to 21 years of age**

At-Risk Kids as those who encompass one of the following criteria:

**25% Delay in Developmental Growth
Exposure to Drugs/Alcohol prenatally
Are in Foster Care
Etc.**

Iowa is a non-categorical state which means that on IEP's we identify a student as being an eligible individual but do not put a label on it as a practice. If a parent requests to have a disability identified in the IEP this can be done.

The IEP Team decides if they think a student should be identified as possibly having Autism, using primary or secondary coding as an option.

Right now in Iowa there are 73,000 school-age students identified as receiving special education services.

Transition services begin at the age of 14 in Iowa and at 16 nationally.

Iowa is referred to as a Birth Mandate State because Iowa's state law mandates all services from Birth to 3 years of age for free. We are one of only 5 or 6 states that is a Birth Mandate State.

Iowa and Pennsylvania are the only 2 states that mandate intermediate units.

Data collection identifying individuals with autism is self-reported by the AEA's. However, based on the AEA's Autism Resource Teams unofficial data the current number for the state of Iowa is 2433 while the Iowa Department of Education's Information Management Systems number is 1100. Due to this significant discrepancy Sue Baker will be visiting the AEA's this year and comparing their data to the Department of Education's to access where the discrepancy exists and take corrective action.

Kimberly Byers a parent of a disabled student mentioned that for instance with her daughter's identified disability the school would not choose to provide physical therapy but that her daughter could receive physical therapy services based on an order from a doctor.

This prompted Steven Muller to ask who decides whether a student is eligible for a support related service? (such as Speech/Language, Social Worker, Occupational Therapy)

Lana stated that the IEP Team decides what services are implemented for each student based on the information available.

Steven Muller made the comment that unfortunately "The Realities of the Almighty Dollar often times have an effect on these decisions.

Lana informed the group that Sign Language Interpreter's will no longer be available as of June 30th, 2010.

Lana also stated that every school district in the state of Iowa is allowed to have a negative balance. This also means that without specific approval they can initiate an increase in property taxes in order to get more money when needed. Most states do not allow that kind of flexibility.

Iowa also has what is known as the "High-Cost Pool" which means that for any student with services provided based on a disability, and that student costs the school district more than \$32,000 the remainder of the costs for the student will be covered by funds from the state's "High-Cost Pool".

Lana talked about data available reflecting Autism students and this Data showed that none of the autism identified students were also identified graduation dropout population. Also, of the 1100 students with autism in this category none were suspended/expelled for 10 days or more during the school-year which is the maximum allowed.

Statewide assessment processes that gather the data for all students are broken down into 3 possible sources with these being ITBS, ITEDS, and IAA.

Within the category of ASD students not 1 grade level met the requirement for participation in statewide assessments (07-08) for on 95% of those students as is the requirement. This is a factor the Iowa Department of Education will be going after this data in order to address this issue. We are required to have this to turn into the federal government.

Three years ago Lana identified Iowa as one of the most restrictive states. Since then we have seen significant improvement with the standard being for most students to be in the regular classroom 40% or the time or greater.

Part C Resources

Approximately 4 million dollars for Birth to 3. Almost all of these dollars go to the CHSC (Child Health Specialty Clinics) in Iowa City.

Lana expressed the following Opportunities for Improvement:

Data Reliability

Defining Students not participating in Assessment

Learning Opportunities

ABA Teaching Strategies

Structured Teaching

Social Skills Training

Administrator Training and Resource

Lana announced that a new “Statewide Special Education Procedures Manual” would take effect on July 1st, 2009. Several council members asked if they could get one and Lana indicated that if there were enough available she would bring copies for the Autism Council Members.

Lastly, Lana spoke briefly about the Recovery Dollars that are being dispersed to the AEA’s for the 09-10 school-year as part of the economic stimulus program.

**Approximately \$122 Million Dollars Total
60% or 73.1 Million to Local School Districts
40% or 48 Million to AEA’s**

These funds will be dispersed in 5 increments or 20% per installment on approximately this schedule.

May 2009

October 2009

April 2010

October 2010

March 2011

Lana stated that this money should be used for one time expenditures rather than programming that would have to be sustained. There will be two reporting systems, one for regular dollars and one for recovery dollars.

AEA’s 13 & 14 will be merging over the next year and therefore as of July 1, 2010 we will have 9 AEA’s as follows: 1, 267, 8, 9, 10, 11, Northwest, 13/14 (whatever that is named), and Great Prairie.

The AEA’s are the mandatory sub-recipients of federal funds. Money is dispersed from the Federal Government to the AEA’s and then from the AEA’s to the School Districts.

Dr. Debra Waldron from the Iowa Department of Public Health gave a power-point presentation on Autism and some highlights were as follows:

- a. Early Identification by medical professionals:
The CHSC has provided screening services for ASD conditions since 1994 with standard screening for 18-36 months of age. Since 2007 results of early identification is typically by 2 years, 1 ¼ months of age. A UIHC Mini-Grant is supporting development of ASD training.**
- b. Appropriate early and intensive early intervention services access training models.**
- c. Integration and coordination of medical community, educators, childhood educators, etc. seamless support system.**

- d. General and Special Education Support Services.**
- e. In Home Support Services for Families-Behavioral Supports.**
- f. Training for Educators, Parents, Siblings, Family Members.**
- g. Enhancing Community Agency Responsiveness; Adults**
- h. Financing Options – Waivers, Insurance**
- i. Data Collection**

Gaps: Lack of coordination on all of these services, and have seen Services come together with Early Access and some with Mental Health, So we need collaboration to continue to go forward for ASD.

Dr. Scott Lindgren, Professor, Dept. of Pediatrics, University of Iowa Children’s Hospital did a power-point entitled “Combating Autism at the University of Iowa.

- a. UI Services for Children with Autism Spectrum Disorders**
- b. Planning for a UI Autism Center of Excellence: Core Components**
- c. Recent Initiatives at the Center for Disabilities and Development**
- d. Act Early Autism Summit**
- e. Supporting Targeted Autism Resources (STAR)**
- f. Leadership Education in Neurodevelopmental Disabilities (LEND)**

Bill Gardam and Pam Alger from the Iowa Department of Human Services Gave a power-point presentation entitled “Overview of Services for Individuals with Autism Spectrum Disorders Offered Through the Iowa Department of Human Services” April 2009

- a. DHS Services & Programs and Identified Gaps**
- b. Overview – What We Know**
- c. The Iowa Medicaid Program**
- d. The Iowa Medicaid Program**
- e. Iowa Medicaid Program State Plan Services**
- f. Iowa Medicaid Program Home and Community Based Services (HCBS) Waivers**
- g. Iowa Medicaid Program Inpatient/Residential Options**
- h.**

“Mental Health and Disability Services managed through the Counties

- a. Adult Focused, County Managed Services**
- b. Mental Health and Disability Services for Children, Adolescents and their Families**
- c. Local Systems of Care Development**
- d. The State Resource Centers**
- e. The Mental Health Institutions**
- f. The Juvenile Facilities**

“Other Services and Supports for Children with Disabilities”

a. Other Services and Supports

“Collaborations with Other State Agencies”

“Identified Gaps:” Access to specialized ASD are not statewide. Habilitations Issues, work force limitations, timely delivery, higher end care, because timely access is not there, underinsured and uninsured individuals.

“Thoughts on Moving Forward”: options for interventions, state agency coordination, best practices, identification and early identification, access to information, training and workforce development, technical assistance and consultation, adult services and funding.

There was some discussion on qualifying for “Habitation”. If a person is on a waiver or the state plan they would also be eligible for habitation.

Kenda Jochimsen stated that not all assessments relate to the model. Kenda also stated that “Waivers are categorical and that waivers should be functional rather than categorical. This leads to the problem that a student may be identified as “Too High Functioning” and therefore they don’t meet the waiver so they do not receive the services.

Subcommittee chairs will get together, discuss strategies, and share with the rest of the group for the next action items.

A motion was made by Josh Cobbs to adjourn the meeting and John Kohles seconded the motion and the meeting was adjourned.