

Iowa Autism Council
Wednesday, July 8, 2009
Facilitator: Mark Wolak/Sue Baker

Present:

Toni Merfeld, Sue Baker, Mark Wolak, Katherine Byers, Joshua Cobb, Dennis Dykstra, Bill Gardam, Keith Gatrost, Becky Harker, Kenda Jochimsen, John Kohles, Steven Muller, Jim Mumford, Pamela Parker, Dr. Jeanne Prickett, Danielle Sharpe, Barbara Stineman, Dr. Charles Wadle, Barbara Kahl(sitting in for Dr. Debra Waldron), Patrick(Casey) Westhoff, Cathy Young, Sonia Lewis

Absent: Dr. Ghada Hamdan-Allen, Lana Michelson, Grace Percival, Dr. Debra Waldron

Speakers:

Welcome/Public Comment: Josh Cobbs/Mark Wolak

Josh welcomed everyone to the meeting and asked everyone to introduce themselves. The floor was opened for public comment. *No one was present.*

WIKKI Sue Baker

Sue Baker showed the WIKI website to the council (wetpaint.com). You will click on the “sign in” link in the upper right hand corner of the webpage. She stated that each chairperson for each of the sub-committees would be inviting the committee members to join the WIKI. Each member will be able to add comments, delete, and make other changes/additions. Everyone will create their own “username” and “password.” The entry page tells how to navigate the “page.”

At the November meeting, the committee chairs will share with the council their final recommendations. On December 1st all final additions will be submitted. December 12th is the target date for completion of work all for each committee.

Report from Subcommittees: Subcommittee Chair

Cathy Young spoke for the Coordinating Care Sub-committee. This committee met by phone conference on June 29th. The committee spoke about the lack of data that the group had which is going to be real familiar (they will be watching to monitor unofficial data and the IEP official data) and looked at two things, the possibility of doing hearings around the state and some sort of repository for information at the University of Iowa.

The committee met today along with Toni Merfeld, who is replacing Barb Rankin, and Sue Baker. The committee will not recommend that the council do hearings across the state, however, we will, based on what Cathy and Danielle were hearing from other states are doing, do some type of survey by e-mail through the different Autism support groups that people have registered through (i.e. Autism Speaks, Autism Society of IA, etc).

The committee would like to gather data on how many people are out there with Autism or Aspergers, parent of a child with Autism or Aspergers, their birthdates, etc. Some of the data doesn't match with AEA and those with IEPs. The committee would like to close this gap.

Bill Gardam stated that his department (Mental Health and Disability service coordinated plan through the University of Iowa, CDD covering autism and other disabilities) will have a survey ready to go by the end of August. Bill said that his department will be gathering data and holding public meetings by December. His department is responsible for all children with disabilities, MR waivers, etc.; the purpose is not to exclude anyone, but to include everyone.

Cathy stated that the committee needs to be gathering data in a timely fashion. She stated that she would like to coordinate both the survey and the e-mail so that they are not asking the same questions because the purpose is not necessary the same. Let Bill know of any associations you want added to the list. We need an access point for kids and there is absence of care coordination to navigate that system regardless of what disability you have.

Casey Westhoff spoke for the Finance Sub-committee. The committees charge is regarding priority funding options, health insurance funding streams, insurance waivers, etc. Need to prioritize recommendations. Explore the state's current wording and accounting base funding system.

Casey: Finance subcommittee report: priority for financing options and funding, insurance, waiver, reducing waiting lists for children and adults on waiver and county services. Appropriations bill is telling us to explore whether state should have a separate waiver, working with Bill, costs, gathering data, and provide a recommendation to support separate or breaking down to include ASD. Looking at wording to take back support or modified version. Some counties are in crisis mode and IAC support with Commission etc, to raise additional dollars to support those with disabilities.

Josh Cobbs spoke for the Legislative Sub-committee. Josh had an informal discussion with Senator in Sioux City just to see how our message is being perceived of this council. Are we communicating the things that we need from the legislative side? The effectiveness of conveying a certain message. Really talking about dollar for dollar. That is a good message to take back for recommendations. In general, when making a recommendation, we really need to have sound recommendations. We may not cover every recommendation from this council.

What this council does need to do is to decide which recommendations we are going to work on (the first five or six) as our solid ones. And to keep focused and define what each sub-committee is going to work on this year.

When communicating with each other in regards to the councils work, please be sure that when you send out your minutes from each sub-committee's meetings, be sure to carbon

copy Sonia (due to the open meeting law) so she can get the minutes posted to the Iowa Autism Council Website.

Motion was made to approve the minutes from the April 29, 2009 meeting. The minutes were approved. Sue Baker stated that Lana Michelson had sent out the requested data information as a follow-up to the Department of Education presentation from the April 29th meeting.

Presentations: Jim Mumford, Iowa Insurance Division, Kenda Jochimsen, Iowa Vocational Rehabilitation Services, and Dr. Jeanne Prickett, Board of Regents

Jim Mumford did a verbal presentation on the Iowa Insurance Division. The Iowa Insurance Division is part of Commerce Division. Angela represents the division at different meetings. Susan Voss is the division commissioner and Jim is the first deputy director. The division is limited by statutory limitations as to what they can/cannot regulate and will work with agencies to solve issues. The internet address for the Iowa Insurance Division is: www.iid.iowa.gov.

Jim works with Life and Annuity Insurance and Susan works with the Health Insurance. The Insurance Division has a communications director, Tom Alger, who is knowledgeable about insurance and legislation. Tom is frequently at legislative sessions. The bureaus within the Iowa Insurance Division are; Consumers Affairs Bureau- (handles consumer complaints and questions from the public), Company Regulation Bureau (licenses insurers that conduct business in the state of Iowa), Product & Producer Regulation Bureau (responsible for the approval of policy forms that must be filed by insurance companies before being sold to Iowans and also approves rate filings by companies), Senior Health Insurance Information Program (SHIIP) can help find answers to the important questions related to Medicare and Medicare supplement insurance, long term care insurance, and other health insurance issues, Securities & Regulated Industries Bureau (administers Iowa securities law, which empowers the commissioner to regulate and investigate the sale of securities within the State of Iowa and provides for the licensing of securities sales agents and dealers, Insurance Fraud Bureau (will confront the problem of insurance fraud by prevention, investigation, and prosecution of fraudulent insurance acts in an effort to reduce the amount of premium dollars used to pay fraudulent claims).

Jeanne Prickett presentation of Board of Regent's: There are 5 basic programs through the Board of Regents. They are: Three universities: University of Iowa, Iowa State University, and University of Northern Iowa and two special schools: Iowa School for the Deaf (ISD), and Iowa Braille and Sight-Saving School (IBSSS).

The Iowa School for the Deaf on-campus program has 110 students between the ages of fifteen months to 21 years of age. This includes students with multiple disabilities. All students have IEPs and are deaf or hard-of-hearing. About half of these students may have additional needs (vision, cognitive, other disabilities). In 2008-09 six students were identified with autism and three were identified with potentially having autism.

ISD's services to deaf students with autism include; AEA/ISD shared psychologist with autism expertise, teacher/teacher assistant training provide through ISD and AEA, and all ISD students' programs are individualized. The Iowa Braille and Sight-Saving School has 400 students statewide. There are a small number on campus. Most of the students receive services from a teacher of the Visually Impaired for vision. Some receive services from Orientation and Mobility Instructors or other IBSSS consultants (e.g. Math Consultant). Some of these students have been identified with autism and may receive other special education services from their districts.

IBSSS has provided autism training for Iowa's teachers who work with students with visual impairments, provided ongoing in-service for teachers on calendars, routines and communication which will apply to students with autism, provided a Low Incidence Team to consult on vision issues for students, including those with autism and provided a consultant for students who have visual impairments and additional disabilities. Services are very different in the postsecondary K-12 years. Students are adults, evidence for eligibility is the student's responsibility, not the schools and all are handled in a case-by-case basis. Success is the primary factor in postsecondary services and accommodations. Students are ultimately responsible for their own success and work. Parents may be significantly involved with the students written permission, however, students are still expected to self-advocate, self-initiate, self-identify, and communicate with the instructors.

Accommodations and services provide access to textbooks, MP3 or other digital electronic files to download and enable students to use Braille, computer enlarged, or sound output on computers, and access to classroom lectures, sign language interpreters, and Communication Access Real-time Translation (CART).

Traditional accommodations may not be beneficial to students with Asperger's. The accommodations may need to be uniquely tailored for these students (e.g. giving a speech to the instructor in his office instead of in class). There is a wide range of need for services and accommodations and these are looked at on a case-by-case basis. See handout for further information.

Kenda Jochimsen presentation on Iowa Vocational Rehabilitation Services. There are three bureaus within Iowa Vocational Rehabilitation Services (Rehabilitation Services, Disability Determinations, and Administrative Services). Kenda's presentation was on the Rehabilitation Services Bureau. They have contracted with a Missouri organization to write the handbook from Vocational Rehabilitation sent out to Iowa Autism Council members earlier for comment.

The bureau serves ages 16 to retirement in obtaining or maintaining employment (if they are eligible for services). In the area of autism, the bureau is enhancing the community agency (there are 14 area offices throughout the state) responsiveness to living, learning and employment needs of adults with autism and provision of services. DHS are in a collaborative funding of supported employment services.

Services include: Trial Work Experiences, Counseling and Guidance, Plan Development, Physical and Mental Restoration, Training, and Employment. Counseling is not a discrete portion of the rehabilitation process, but it continues throughout the case process from initial interview to case closure. The use of medical, education, psychological, vocational and social data is used to form a realistic appraisal of present capacities, personal characteristics and work potential.

Physical and Mental restoration scope of services is to correct or reduce the effects of a physical or mental disability when the change is required to assist an individual to prepare for, enter/ maintain successful employment. This is required by the employment plan and the disability needs.

Training entails, customized training, vocational/technical training, academic training, supported employment, and other types of training (e.i. self employment).

Legislation-Senate file 134 was introduced. This bill relates to county mental health, mental retardation, and developmental disabilities services funds and levies. See handout for further information.

Wrap up:

Stakeholder discussion with Mark and Josh: What agencies or groups do we need to tackle to create a survey (with the Department of Human Services help). DHS is reaching out to as many stakeholder groups with MHC consumers, advocacy offices, ASI, Iowa Behavior Association etc. electronically or via fax to people. This is targeted for this legislative session and our priority areas. With the timing of the DHS survey, we can say data collection is in process.

Some pieces are public and others are not. Discussion about how to access people, including Juvenile Court Services for those with ASD, was held. There was discussion regarding the continuum of services and where the gap can be filled, which is what the state of the state template refers to (in the Wiki).

There appear questions about the gap of post secondary population (age 20-30) and there needs to be supports for that age group, program and services to support them developing social strategies and maturity. Therefore, a service delivery program targeted at ages 18-25 could be a recommendation.

In that recommendation, it may not include a policy to implement, but to research the gap from ages 18-25/26 years, to develop a more conceptual look at research, identify a pilot program with tangible information, adding information from home schooled populations.

Mark has completed his commitment to four meetings. He states that as the group goes alone, he has observed your development. He has appreciated your positive tone knowing that you disappoint each other. Be patient with each other and don't get frustrated with each other. Services for kids and youth will be competitive; you must partner to get your needs met. You are doing a good job of that. We will want to gather data on other

underperforming agencies, serving 18-25 year olds for example, and realize we may not get additional new funding.

Another solution is to collaborate together, from Kendra, having the right folks at the table and require compromise. How to adjust existing policies may be an answer. Asking how to get other people's needs met, using DHS as a way to help write questions. One of the rules, use partnership.

Governance and policy role is how you need to keep focused; think results, define that, and then determine what questions you need to ask. Second, you are learning from each agencies presentation. We have learned from Michel Fullen, write a small number of ambitious priorities. Lastly, allowing Josh to lead, that is a powerful gift; so will the next president, if need be. Mark will work behind the scene with Josh, Lana, and Sue, sending best wishes. A motion was made to adjoin the meeting; meeting adjourned

Next Meeting:

October 14, 2009
Stoney Creek Inn
Johnston IA