

Iowa Autism Council Meeting

April 13, 2011 meeting notes taken by Sue Baker and Beth Buehler-Sapp.

Present: Sue Baker, Beth Buehler-Sapp, Josh Cobbs, Danielle Sharpe, Katherine Byers, Kenda Jochimsen, Karn Johansen, Laura Larkin, Linda Louko, Steve Muller, Susan Smith, Barbara Stineman, Chuck Wadle, and Casey (Patrick)Westhoff, Jim Mumford, .Debra Waldron, Toni Merfeld, and Jeff Gitchel.

Absent: Marty Ikeda , Frank Forcucci, Jeanne Prickett, Keith Gatrost, Becky Harker, and Jeanne Nesbit.

CHSC GRANT OPPORTUNITY: Dr. Debra Waldron started out presenting to the Council regarding the opportunity for a HRSA Grant which CHSC is applying for. It will address the CDD telehealth project in terms of teaching ABA to families. It will build a System of Care including Medical Home opportunities. There will be services for families and community supports with five regional autism centers; these five locations will coordinate with community supports and build a framework for a system of care for families living with autism. They are doing some editing because not enough information was written into the secondary transition services part of the application last year. The potential grants awarded has increased to 9 this year from 3 last year. CHSC would like to have support of their application from the Iowa Autism Council.

CHSC has had much recent success with improved communication regarding programming by using the social media. Steve Muller asked if sites are working with persons with developmental disabilities, family members, and providers? Deb stated they are working with persons with disabilities, family members, and community partners. She said they would work with the system of care philosophy working with families in local areas to provide capacity building support. However, as more and more virtual options assist communication there may be more than 5 centers. They are focusing on age 0-21 for MCHB services and in the 15-21 age range to shore up transition services.

If received there would be 5 pilot sites across the state as follows: Sioux City, Council Bluffs, Davenport, Spencer/Storm Lake, and Ottumwa.

This grant is due to CHSC administration by May 2nd and due to the Federal government by May 9th, 2011. Deb will get a copy of the abstract out to Josh to send out to the entire council.

Steve Muller motioned for the Autism Council to support this and Josh Cobbs seconded the motion. There was an all in favor with a show of hands, and an all opposed which was none, therefore motion carried.

PARENT SURVEY: Josh Cobbs talked about the current status of the parent survey. If IAC recommendations can move forward, we need data to determine the pattern and delivery of services.

Josh cautions that if many changes are made to the draft provided that this process would then have to start over. Also, the previous survey was very cumbersome and this discourages many people from participating in something that seems too long and time consuming.

Sue mentioned that the estimated response rate was for 330 survey results.

Therefore upon survey completion the goal is to know as follows:

1. How many persons are receiving services/which services?

2. Where are the folks geographically who are receiving these services?
3. What education services (at what grade level) are being provided?

Josh reminds everyone that the Council has used an IRB (Institutional Review Board) process and that neither Council nor the Iowa Department of Education will see any respondents' personal data. Topography will be the only information available from survey results. Josh also reiterates that a whole plethora of other questions are going to arise from the survey.

Josh refers everyone to review the draft handout which is a chart showing agencies that have agreed to help distribute the survey to potential survey takers. Dr. Debra Waldron noted that we should also have the following three entities added to this draft:

American Academy of Pediatrics	AAP	iowa_aap@yahoo.com
Association of Family Practitioners	AFP	iowa_afp@yahoo.com
Iowa Society of Nurse Practitioners	IANP	iowa_ianp@yahoo.com

Josh would like Council members to e-mail him if they know of other professional organizations whom we might consider adding if they are interested. There can be no use of sending links by social media as representation from the Council; persons on the Council who know someone eligible to take the survey could provide them with the informational link as long as the Council member is doing this as themselves (this is in accordance with the by-laws).

Debra Waldron said that due to rules enforce by HIPPA that survey availability information could be posted in a public waiting room of a provider/community agency but could not go out to the public through the UIHC communication system (eliminating CHSC sending notice through Family Navigators, etc.)

Josh can send the list to Beth to send to the council and then would have a Monday, April 18th deadline to get responses back to Josh.

A question was asked whether at the top of the survey it would say Iowa Autism Council Survey or Drake University Survey and the members present at the meeting voted by a majority that it should be both.

Because this is an internet survey, there is a place in the 2nd paragraph that says "All information is confidential and cannot be identified to a specific survey respondent." Kenda Jochimsen stated "While it would be difficult, that technology does not make it impossible to identify a survey respondent. Therefore it was decided that this statement would be removed from the survey. In that same paragraph, 'no one' should be changed to the word nobody and 'deleted' should be changed to 'destroyed'.

A question arose: if a survey respondent is between the ages of 18-21, would parents responding for an individual of that age range be acceptable? Debra Waldron stated that 18 and up is legally considered an adult. Kenda Jochimsen thought it would be acceptable but that is worth asking the question regarding culpability. Toni Merfeld related that she had asked Thomas Mayes, Legal Consultant at the Department of Education about this issue and his response was as follows: "Since the survey is specifically for parents and is not required by the IDEA, a parent could fill out a survey about their perceptions of services to their 18+ aged children." "If the survey contained personally identifiable information about the child, the child might have the right to inspect and review the survey results."

Since there was no paper version available members reviewed the electronic version to request changes. Toni Merfeld had copies made by Stoney Creek staff for folks to read as the LCD had a green screen and was very hard to folks to read around the room.

Dr. Debra Waldron suggested that within the lists of professionals provided on the survey that the options of Pediatrician and Nurse Practitioner be added. She also asked the wording in the survey question be edited to read “Does your child currently receive.....?” Also, “How is your child currently educated?” She asked if when the question reads “What is your child’s diagnosis and when and by whom was it determined?” that if the survey respondent has no answer for this (no determination having been made), Josh stated that the respondent would be kicked out of the survey at that time.

Steve Muller asked what the survey would do if a respondent answered that they were home schooled. Josh isn’t sure but thinks they might be kicked out of the survey; we will have to check into this.

Josh reminded everyone that this is survey #1 and since it’s the initial survey we will be learning as we go.

Steve Muller said that if we’re going to do a push for getting information, he would like to see us follow through with “Where are the kids?” (being home schooled)

Danielle Sharpe responded that we’d still know where they are and that they’re being home schooled.

Section 2 asks the question “How satisfied are you with your child’s school?” Dr. Deb Waldron brought up the fact that in the survey there are only 4 answers available and generally when surveys are created a likert scale is used for the respondent’s answers. A likert scale usually provides respondents with 5 answers so that they perceive to have an intermediary or middle of the road choice. When only 4 responses are available, people tend to see these as split down the middle and therefore perceive a good/bad or agree/disagree stance. Dr. Waldron feels strongly that a 4 point likert scale should be used. Josh/Danielle are going to check with Dr. Bob Stensrud/Mike Couvillion at Drake regarding changing this response options component.

Council members discussed the list of possible therapies available for persons with an ASD diagnosis. There was majority agreement that various therapies effectiveness is based on perception by participant and most are categorized as “research based” so it’s interpretative. Toni Merfeld stated that typically with this type of list, the language level is not simplified enough for comprehension/understanding by the common reader. She suggests using definers in order to help the parents understand.

Group members wanted to know if a respondent could choose multiple answers for a question if applicable. Josh/Danielle are going to double check on this with the Bob and Mike at Drake. If a respondent chooses the choice of ‘does not apply’ the survey then skips them to the next screen.

Josh stated that if the survey gets numerous answers of something not listed we need to look at this.

Susan Smith noticed that for the list of therapies there is a comment attached to ABA that says “generally provided under the age of 8”. She stated this is not necessarily the case as some treatments works for persons at various ages. Therefore, Susan asked that this be removed. The council agreed and this is one of several changes which Danielle was going to submit to the Drake folks. The request was also made to add the therapy option of Assistive Technology and this was agreed upon. Social Stories are one well known story based intervention and was also agreed upon as an addition to the therapies list.

Kenda mentioned that in completing the survey, some parents may find out about things that are available or not available and in which areas and that this is beneficial for parents.

Toni Merfeld asked, “Does the group know that there will be an AEA/LEA survey that will go out to professionals after this survey is completed?” This survey will solicit from them what training they feel comfortable in providing.

Deb Waldron asked, “Is there any way to access what services people get through medical providers rather than through educational providers?” Laura Larkin reiterated that yes many possible services may overlap through educational provider, medical provider, and/or private provider. Susan Smith asked why individuals couldn’t be given the question with the option to provide multiple answers, i.e., provider as an organization and provider as an individual.

Josh stated that this survey’s only intent is to find out what services are being provided in the schools. Deb agreed that the intent is only to find out what’s being provided in the school system, where students are located, and how satisfied individuals are with these services. Josh said that for instance, if there are 2,000 kids getting ABA from private providers, this would be good to know.

Susan Smith questioned if we could solicit to find out where ABA was being provided in the school, in the office of a provider, or in the home. Josh reiterated that for this survey’s purpose it’s important to know about school-based services only.

Josh mentioned that time is a big issue that affects a process and its results. Chuck Wadle stated that services can be provided anywhere on the range of maximal vs. in-between vs. minimal.

What is a System of Care: review by Dr. Waldron

These six concepts come up when describing a System of Care:

- screening and diagnosis
- care coordination and medical home
- family involvement
- access to services
- financing and coverage
- transition.

Literature help us understand “How well are we doing as a system?” and our state can coordinate with national tools to help determine this. For all children with special health care needs, Iowa is ranked number 1 for providing a comprehensive health care system. Yet, Dr. Waldron expressed concern over this survey finding, because we have a lot of gaps.

We may need to:

- utilize other tools, hold focus groups, etc. to determine what is actually going on
- Assess Maternal Child Health Care Program
- Provide consistent message to stakeholders

If CHSC is awarded the grant, Bridges to Care, these additional findings will help clarify our state needs

Recent Pediatric literature (3 studies) addressed Early Intensive Intervention, Medium Intervention, and Use of Secretin (Enzyme for digestive system). Deb stated that often drugs like Risperadol or Arispradol that you have to look to evaluate the risk/benefit of using them based on the possible long-term side effects. Also, the academic world’s impact on access to support is significant due to

advances such as TeleHealth. This has allowed patients not to have to travel, and has provided improved outcomes to many patients.

Susan talks of drug implications and response in adults. Karn observed that this is a difficult population to obtain a study based on the multitude of factors involved.

State Department Heads Ex-Officio IAC Updates: Deb mentioned that her opinion is that the Ex-Officios are on the IAC for the purpose of keeping members abreast of what's going on. Could this be an expectation at each meeting? Maybe five minutes of updates? Sue Baker agreed with this and thought that maybe starting with the June meeting that at the beginning of each meeting, the ex-officio's could rotate giving short presentations regarding what's currently going on. Josh adds: as a Council, we need to understand the economic and political environment that impacts our population. If there are public updates, we need to get that to the Council. Kenda's example of her input was to mention that there is a federal bill currently in the senate that would change how funds are allocated to the states.

Members should review past recommendations: Josh suggested that council members review the 2009-2010 Recommendation made by the IAC to see how the Council as a group has followed up with these recommendations. Sue Baker mentioned that the 2009-2010 IAC recommendations have been removed from the web-site and they need to be put back on the website. Beth will notify Julie Carmer at the DE of this as she does the web-site postings. View them on this site:

http://iowa.gov/educate/index.php?option=com_content&view=article&id=1642:iowa-autism-council&catid=552:state-requirements-and-reports&Itemid=2770

Agendas to be distributed previous to the meeting: The question was asked if in the future the meeting agenda could be e-mailed to the members prior to the meeting. Beth will implement doing this starting with the June 15th meeting, likely with lunch count information.

Advocacy Day on the Hill: Josh spoke briefly about Advocacy day on the Hill (125 people attended) and that the insurance bill (SF 64) did not move forward.

IAC Website: Josh said that the IAC website sub-committee for this will meet again to see what is missing (what gaps there might be on the pending web-site). All but two state departments have provided their input for the site.

Adult Services Planning Committee Update: Josh stated there is an Adult Services Planning Meeting this fall to widen stakeholders in the development of a work symposium. There may be two tracks: one for 7-11 year old issues and the second for secondary transitioning group of teens and adults in the work field.

Some goals of committee are as follows:

- To work to increase teens with disabilities in the workplace.
- Get the right people at the table at the right time for discussion.
- Mass majority of people probably won't have much without a seamless transition process (Steve Muller).
- There are some school districts and businesses willing to do some partnering.
- Get folks talking in a coordinated way to meet goals.
- Who is going to pay the staff person to deal/train the staff person with special needs.
- It really can't just be a work symposium, we need to provide them with skills.
- Need an action item to spotlight 2 or 3 pilot projects to help encourage others

Steve Muller related to the council the story of a well to do family who has offered to pay a business the money to provide the salary to be paid to their one impaired child if hired.

Jeff Gitchel made the statement that some agencies and individuals are not connected to a system of care.

Kenda Jochimsen related that recently, Senator Tom Harkin spoke to the National Chamber of Commerce about the need to provide employment for individuals with disabilities.

Josh related that some individuals like his son need more skills built in for students to be able to reach independent employment.

Kenda Jochimsen asked “Is there funding to be provided for educators to allow them to get to do this training for these students”. Toni Merfeld interjected that Marty is the Special Education Bureaus staff person who will allocate funds for various things. Also, Toni mentioned that there used to be a program called “Transition Youth to Employment” but that program went away due to lack of funding.

Outside group presenters to the IAC: Discussion by council regarding allowing outside groups to me in and present to the council as an approval process needs to be designed. Sue Baker – We would need to know what their mission and goals are; “This is not the place for someone to sell their wares.” Others ask how would people find out how to apply to come to present to the Iowa Autism Council? Jeff Gitchel suggested the use of social media for this purpose.

Steve Muller observed that there have been sales pitches made by council members on behalf of their agencies and that we want to know of things that are discovered which improve services/support our mission but that we need to be careful of who presents to the council.

Josh stated that according to the by-laws, “If an entity wants to present to the council, their content needs to feed into what’s on the council’s agenda.” The by-laws also state that presentations made cannot exceed 30 minutes in length.

Kenda Jochimsen suggested that the way to set-up this process be as follows:
Any interested entity needs to complete a form which the council will create and this form would need to be reviewed by the entire council. They would have to had time to meet and make a decision. Iowa Vocational Rehabilitation Services uses a form and process in this manner. Kenda will e-mail this form to Beth Buehler-Sapp at the DE for Council consideration.

Jeff Gitchel – How is the decision made? Kenda - Usually the chair review requests and approves or not. Josh reminded members that everyone is free to speak/correspond representing themselves as individuals but not as part of the Council.

Plans for next June meeting: Targeted Areas – Expand on previous recommendations or develop new ideas to target. Talk about areas of focus and develop appropriate sub-committees. Example: Review recommendations a-i , which ones have we done something on, completed, are working on, or have done not anything on.

Josh/Sue – IAC members don’t have to stay on a previous sub-committee for review of recommendations; if they wish to move to a different sub-committee, that is fine.

Wrap up: Danielle Sharpe will send all of the study proposed changes that we have created today to Dr. Stensrud and Mike Couvillion at Drake and she will get responses back and send onto the council members.

Reminder – For voting purposes a quorum is 8 voting members. Expect a contact regarding approving the survey and asking for additions to the distribution list disseminated. The handout which is title DRAFT is the list of providers who have agreed to disseminate the survey to appropriate contact groups once it is available.

Dr. Deb Waldron will send links to abstracts to Beth to send out to the entire council.

There are 4 council members whose terms are expiring May 1st and three of them will be leaving the Council and one has accepted a reappointment. The council wishes to extend its sincere gratitude to them for their important contributions while on this council.

Leaving are Dr. Linda Louko, Pamela Parker, and Keith Gatrost.

Danielle Sharpe has accepted a reappointment of another term.

New Members appointed by the Governor are as follows:

- Jeff Gitchel, who is a person with a disability and is taking the spot vacated by John Kohles.
- Robin Sampson who is a family member of a person with a disability and replaces Pamela Parker.
- Jan Turbes whose occupation is as an Autism/Challenging Behavior Specialist for Northwest AEA and she replaces Dr. Linda Louko (research)
- Dr. Rachel Heiss who is a licensed psychologist and replace Keith Gatrost.

Due to the fact that there will be new members attending the next meeting on June 15, 2011, Josh decided to have an orientation process with these new members and start this at 9am prior to the meeting which starts at 10am. Josh will create a welcome letter for new members and send it to Beth to send out on behalf of the Council. Documents which the Council has previously discussed Sue/Josh can have Beth get to provide to new members (legislation recommendations, Advisory vs advocacy, open meeting laws, Roberts Rules)

Josh is also planning to send departing members a Certificate of Appreciation. Beth will send him a sample to review which the Iowa Department of Education is presenting to SEAP members who are also departing due to the expiration of their terms.

Jeff Gitchel made a motion to adjourn the meeting and Josh Cobbs seconded the motion.