

**Iowa Autism Council Meeting Draft Minutes**  
**November 7, 2012**  
**Meeting notes taken by Sue Baker and Beth Buehler-Sapp**

**Present:** Sue Baker, Becky Harker, Theresa Croonquist, Lin Wessels, Toni Merfeld, Joshua Cobbs, Jim Mumford, Susan Smith, Steven Muller, Dr. Rachel Heiss, Casey Westhoff, Marty Ikeda, Karn Johansen, Robin Sampson, Jan Turbes, Becky Flores (for Laura Larkin), and Beth Buehler-Sapp.

**Absent:** Danielle Sharpe, Kathy Levine, Dr. Debra Waldron, Dr. Charles Wadle.

Casey Westhoff presented an overview regarding the Olmstead letter which council members passed by a vote quorum. The Olmstead letter supports require better/more training for direct support professionals serving people with disabilities in their homes and communities. All health care workers should have a minimum of training so as to have the same basic qualifications.

There is a training program available through "The College of Direct Support" as it's entitled. Becky Harker mentioned that while this is a good program it may be seen as discriminatory to persons who have some degree of cognitive impairment and may not be able to do as well on certification testing not including accommodations.

Discussion regarding deficit in staff number of direct support professionals:

Casey asks, "Have they surveyed what the correct deficit is?"

Becky says, "I don't think this number reflects the home & community based services."

Steve says, "I could see most providers sharing that a 15-20% deficit is what we have."

Steve went on to say that he's a little uncomfortable with the minutes quoting things such as at the meeting Steve Muller said, blah, blah, blah, blah, blah, blah, blah.

Josh said, "Until the pay comes along with the training there may be a small deficit in the workforce."

It costs these direct support professionals \$25 for 6 hours of training which are the minimum qualifications required for hire by direct support professionals.

Casey voiced, "I think it's up to us to keep track of where this is going legislatively."

Becky Harker mentioned that within provider organizations there are some who require their specific training rather than generally available training as in that provided by the college of direct support.

Josh stated, "There are plenty of boards within the state to require certifications to oversee services."

A compromise is to understand that there may be requirements that fit certain selective groups which require specific services. Casey stated, This may cause a problem for some disabled individuals needing services when the requirement is often that they can only hire persons being paid by scale, for instance not to exceed \$8 per hour.

Karn stated, "It makes sense to pay more for services because the services are better if they are better paid for."

Workgroup Redesign Recommendations are required to be submitted to the Governor's office by December 14, 2012.

Action Steps agreed upon:

Action Step 1 - Support better wages & better training.

Action Step 2 - Clarify if Olmstead Letter applies to all.

Lin asked, "Does this apply to all persons or not include educational workers, para-educators, teachers aides, etc. The answer was that this does not apply to educational workers. Those persons had different training depending on their discipline.

The group discussed the Mercy Autism Center in Dubuque Proposal.

Susan asked the group, "Do you interpret this as that it would support 10 kids continually over the service period or 10 kids per year?" The answer to this was unclear.

This plan would fund \$1.7 million dollars worth of services.

The question was asked, "Do we know how the participants will be selected, i.e. socio-economic factors, IQ, etc.

This plan encompasses ideals from both ABA Training and the Star Training.

Becky stated, "if we're talking about state money then it should be applicable to all state services and not just in one county."

"What is the difference between a "Navigator" and a "Coordinator" or "Case Manager". Navigators are more of a support provider for families versus Coordinator's or Case Manger's Are usually state or county employees whose function is more to verify eligibility and oversee delivery of services.

Josh stated, "If someone is getting treatment, the provider should have their best interest in mind." "Are we assuming that families have no capability?" Family navigator fills in gaps between the system and the patient.

Lin stated, "As a parent, some of this is completely new to me."

Becky asked, "How could this be incorporated to be made available to all statewide who would need it?"

Sue said, "It's important to understand that the family navigator while helpful, has no magic to provide faster, more services, etc."

Becky stated, "The plan is to ask for the money to fund this through the legislature. A Mount Pleasant Legislator has been a strong supporter.

Steve stated, "There are not services throughout the state available regionally."

Casey stated, "This buys the state time for some things that should be done statewide."

Steve asked, "If the concept of developing an early intervention system is good then shouldn't we support this to see if it works?"

Becky said, "It can't just be for a small time for a small group of people in Dubuque, Iowa."

Susan stated, "The variable that determines the progress is not all about if the information is being provided."

Becky Flores asked, "What core services must be provided regionally?"

Becky H. said, "Sometimes, patient specific services are hard to get if they don't fit into the general population."

Josh asked, "Could this money be better spent by being spread-out more statewide?"

Toni stated, "I would be more impressed with this if it were for instance in Carroll, Iowa where there are no services available."

Susan asked, "Are other councils being asked for their recommendations?"

Steve stated, "The state can appropriate but not contract without specific authorization."

Josh said, "The catch is always going to be how do you expand the services into all of the areas where it's needed."

The council reached a consensus that resource money should benefit kids throughout the state rather than just a small # of kids in one area. Therefore, the council members collectively created this statement:

"We agree with the principles outlined in the proposal but any investment should encourage the development of a broader statewide access to services for children with Autism. The findings of this project are already well documented; What we need are the funding and resources to implement it statewide. "

Karn mentioned that she would like to see a screening protocol put in place where the baseline testing would include a CBC (complete blood count) and a ferritin level (iron level) to rule out other possibilities before assuming autism so as to discourage misdiagnosis due to overlapping symptoms.

Casey says, "Sometimes there can be a lack of partnership among pediatricians."

On November 8, 2012 (tomorrow) Josh, Steve, & Casey have a meeting scheduled with DHS Director Charles Palmer to talk about the Iowa Autism Council's existence and purpose. This is a meeting which the group has been trying to get scheduled for over a year.

Sue Baker who is the DE facilitator for this group will be retiring after 31.5 years in the children's mental health field. A Big thanks to Sue for her dedication and contributions to this work which benefits Iowa's ASD population.

Toni Merfeld mentioned there the teacher survey will be the next one initiated by the council and that she needs to pull the sample and this can then go out. She anticipates sometime in January based on her current schedule:

Who are these kids?

Who are their teachers?

There are 3 potential ways to do the survey as follows:

1. Do sample of 300. What number would we get back?
- 2.
3. Do sample of 1000. Should for sure get 600-700+ back?

Karn asked, Does this survey have a social skill goal?

Action Items:

1. Teacher Survey – Finalization of the topic list.

Robin Sampson talked about a Resource Guide created in Hardin County that was put together through the efforts of the Early Childhood Council and various community members. This has been very useful in Hardin County. It has been distributed throughout doctor's offices and other public office's as appropriate.

The group discussed the re-creation of sub-committee's to continue last year's work as follows and here is the composition of sub-committee's created:

1. Care Coordination subcommittee  
Robin Sampson - Chair  
Theresa Croonquist
2. Financing of Care sub-committee  
Josh Cobbs – Chair  
Steve Muller
3. Education sub-committee  
Toni Merfeld - chair  
Lin Wessels  
Jan Turbes
4. Adult Services sub-committee  
Susan Smith – chair  
Casey Westhoff  
Rachel Heiss

Josh will talk to Becky Harker and Becky Flores will talk to Laura Larkin to see which sub-committees they wish to participate in. All recommendations from the council are due to the Governor's office by December 14, 2012.

Positions most likely needed to be filled within the next 6 months due to members terms expiration etc. are as follows: Jeff Gitchel, Danielle Sharpe, Sue Baker, Jeanne Prickett, and Debra Waldron.

All council members are invited to pass the word the potential applicants to fill these positions based on the criteria of the vacancies. Persons can be referred to the Iowa Governors Page or go to the Iowa Department of Education webpage and select Iowa Autism Council to access the Membership Application.

Some members are interested in the option of electronically participating in upcoming meetings if they have a conflict based on weather, conflict of schedule, etc. for anyone wishing to do so they should submit their request 2 weeks prior or more to the meeting date by contacting Beth Buehler-Sapp at the Iowa Department of Education at [beth.buehler-sapp@iowa.gov](mailto:beth.buehler-sapp@iowa.gov) or 515-281-7143. Also it is felt that this could open up the participation of this group to more individuals.

Toni Merfeld asked, "If we did a survey monkey targeted toward the IHE (Institutes of Higher Education) staff, What kind of questions do you think we need to ask?" Is there a better communication method?

Casey Westhoff made a motion to approve the September 12, 2012 Meeting Minutes and Robin Sampson seconded this motion.

It is currently the mandate that there can be only 3 persons residing in an hcbs home. The group wonders if there has been a technical change done in rules or if this was done through legislation. Becky Flores agreed to check on this and report back to the group.

The group had a discussion involving IQ assessment as eligibility for services and the opinion by a group majority that functional ability should be part of this assessment and not just IQ. For individuals on the ASD waiver IQ testing is required every 5 years.

Lin Wessel talked about working with her son regarding building staying on task, focusing, and processing skills and then when her son had IQ testing and had a slight increase his eligibility was revoked for the ASD waiver. Thankfully, he was signed up for an ill and handicapped waiver as well and that went into effect or he would have been without waiver services. He is ineligible for SSI due to his parent's income.

Questions this poses the council to ask are:

1. How many individuals are being removed from services due to a slight increase in IQ score?
2. Why is this the only factor and services are being discontinued even though the person's functional ability may not have changed?
3. What happens to them after their services are terminated based on this?

The council also discussed the conundrum of services available in different states. There are families that move in-state to get services better than what they had elsewhere. And vice-versa children whose families reside in-state often have to go out of state for placement because they can't receive placement in-state. Children who are too severely affected are rejected in-state and have to go out-of-state for placement.

Rachel Heiss reminded the group that we're talking about tweaking the ID waiver and not creating a new waivers which the state has avoided doing for several good reasons. If folks want to know how many and what waivers there are they can go on the DHS website to view the 11 different waivers that exist and what each waiver covers. The term Vineland refers to a measure used to assess adaptive functioning.

Steve Muller made a motion to adjourn the meeting and Karn Johansen seconded the motion.