

Iowa Autism Council

Oct. 14, 2009 meeting notes taken by Sue Baker and edited by Beth Buehler who was a sub for Sonia Lewis. Absent is Bill Gardam, Jean Prickett, Keith Gatrost, Dr. Ghada Hamdan-Allen, Sonia Lewis and Charlie Levine is replacement for Kenda Jochimson.

Public table is Scott Lindgren from CDD, Tory Christensen from ILEND, U of IA grad. Student.

Sue: Beginning teacher and advanced competencies: did not take notes as was speaking. IAC comments: Specialists/advanced level: needs to be accessible to those outside of the Autism Resource team; needs to be available to anyone including resource teachers. Not to address the ratio of ART to district services provision; ART is a team approach to perform the Advanced level.

Future recommendations from this council could ask Education to examine and come up with a plan how to implement. IAC has the responsibilities: if you feel it's important, recommend that Education examine them and how they fit into the system. No one answer is available at this time. The field is happy for this blue print as a guiding document to help states figure out where to go.

Katie: Note importance of having teachers who have graduated get this information along with new teachers getting a degree. General Education teachers don't have autism training and no one anywhere near them geographically who has knowledge of autism. Principals must be bought into supporting training teachers. Also look at funding needs for this area (parent provides \$500 to school to send teachers to training and have people moving in to the school because of that training.) Both public and private schools need access to these competencies.

Today: committees will present recommendations, why they are making certain recommendations, what data is needed to support recommendations, etc. There will be a form sent out from Josh to say what issues you have, what would you like to change and this will be due Oct. 30th. The November 16th meeting will be final presentations and vote on the recommendations.

Pam: Vocational Rehab Guide and state planning for the system and follow-up with the Medicaid piece. What is the DHS world? It has many departments and collapsed into child welfare and not a lot of change in representing disabilities. This is work to move forward with state plans, Developmental Disability plan with DD group, mental health plan, Olmstead plan, etc., keeping in LRE choice, and they want one plan for all Mental Health and disabilities regarding how to move forward to identify gaps in service system.

What can be built into county system, Medicaid for kid? They were gathering legislative changes in the system, different planning groups that have good recommendations which are not enacted yet. Iowa Code says or dictates some things and population groups they should serve (SED, MR Intellectual. Disabilities, DD, brain injury planning, and ASD).

See the handout Transforming Iowa's Mental Health and Disability Services system: A Community Discussion. We/DHS want your input in this area about this planning. Survey is a piece of this and ready for input from the committee. What is a process: build into this, use the survey, make recommendations you are putting together or whatever you want to do in this area.

Josh will post electronic version of the survey on the Wetpaint/WIKI and people can see it (and feedback is needed by Oct 30th). It will be its own page and we can provide feedback on the WIKI. Think about what data we want to collect. Individual feedback statements will be molded into an overall document. Grace: if this survey could be part of our recommendations for IAC this could be helpful and part of Seamless Care Committee. (Sue will provide an introduction to frame feedback on this survey)

Back on the Powerpoint handout: (slide 5) our rate was high in settings, but not individual settings. High use of settings of 6 or fewer, but does not say 7 or greater, but not showing that data. Second in nation for out of home placements of children.

Lana questions about page 4: These are national stats for first bullet not state. Question: Casey: is the 10% decrease for all state departments? Does this affect Medicaid and/or providers? Yes and no was reported. No one can answer that right now says Becky. Steve: One problem is federal match and providers would lose money if there were such cuts which would impact community service providers.

January 1, 2011 when the state has to cut \$123 million is the important date. The Medicaid shortfall will be off by a lot at that time. Pam: DHS is working on where cuts are going to come from. We have to come up with 10% cut. Options could include the Governor coming back to legislature to restore some funding to certain organizations.

Lana: Everybody is as concerned as you, you must have state dollar first and then the federal match, so make sure state dollars are in the right places. Advocacy now is important. Restructuring is going on and everything is open for speculation. Recommendations need a lot of thought. One consideration is that all boards or councils go away. Put recommendations in priority order, the most critical pieces are up front. Grace: we can get into too much detail, so we need to distill down to what is primary in our recommendations. Subcommittees have made important recommendations. We need to recommend that the Governor's Council review these survey results.

Vocational Rehab training by Danielle: A presentation was put on Wilgreens Distribution Center in NC and set up for individuals with disabilities. Few people knew a lot about autism there. Schools have to recommend Vocational Rehab and have to be invited to participate, and they just choose not to come. This might be the first time meeting with Vocational Rehab and the person with a disability.

Preparing the student to be part of that meeting is needed. Environment is not set up for a person with autism during the interview process. Concern that if a bad interview was the first impression and decisions made on employability, they would not be positive; but that decision is not made on one first impression.

Minimal social skills and self advocacy skills were mentioned as a concern. Those with autism are losing their jobs. It is not an area where students are well prepared. Matching jobs to strengths and interests of the job is important, not just placing them in any job that can be found. Kenda's replacement talked about what training they have and their job entails a lot including resources for counselors to get that information.

Becky: you will know your son better than anyone else, so being part of the team is really important. Motivation is an issue, paycheck has no value. Charlie: You need to identify if an individual can benefit from services. Accommodations of using a schedule, visual time timer, were discussed. Independence with general education, and self advocacy, minimal reasonable accommodations are required at a college level. It is important to develop a portfolio for your child for college professors, etc.

Becky: next week is a meeting about the concept to view employment for people with disabilities. Employment First practices have a focus group meeting in policy and practice in Ames. Let Becky know your interest in participating. This is all about expectations that people with disabilities should be working. Katie: in special and AEA world, whose job responsibility is it to teach social skills? Guidance counselor, etc. Is there something in the system to designate a professional?

Sue responds that it is an IEP team decision for social skills to be targeted but not just one provider but a host of teachers, SWs, psychologists, etc. to provide social skills in a school setting. Pamela spoke about circle of peers to support social skills around individuals. Casey stated we don't connect what school is doing with providers to address socialization through Medicaid service providers. Toni: social skills are not a setting, these should start when the individual wakes up and help them embody those skills to use constantly. Para teachers need access to teaching social skills ongoing throughout the day, which is a gap at school given emphasis on academics.

Early Identification subcommittee: Iowa needs a statewide coordinated early identification system which requires training and resources with result being a standard system. When developed through state, a network of professionals who network and mentor will address evaluation. Committee Survey was reported by John: contact made with 20 people, 10 with ASD others are parents. All wanted an early identification system.

They agreed it is important for the future for their child. Finding the right specialist is most important. Child should look up to parents then to the specialists. Pamela summarized findings under number 1. Sue did number 2 with Deb mentioning we want to rework the CHSC portion statements under number 2. (Deb clarified bullet 5 sentence 3 do not meet definition of a comprehensive system, so we should define a comprehensive

system). There is a system that exists and it could be better defined. We need representation with what we are occurring for what to be built upon. Deb did number 3; adequate resources, coordinated network, need to recognize different bodies have expertise to be included in process.

Quality improvement cycle and looking at our processes and procedure. Iowa Autism Council will provide advice and guidance to Iowa Early Identification system. Recommendations need a system of early identification that is statewide, early, that is coordinated to do that we need, plan to provide training and support the plan with adequate culturally competent resources. **Add: reference the entire document shaping the Future for Iowa's Children Sept 2008.** Will there be a bibliographic reference? **We will need to make this bibliography available.**

*** Add birth to 21 on the 4,500 versus what is being tracked. Don't know why it comes up different with ART versus IEP system.**

Coordination of Seamless System of Care: Danielle Read Executive Summary. We need this council so I can know about Vocational Rehab, misdiagnosed, etc. Read the recommendations. Deb: when we do recommendations: use bullet points with the broader points and recommendations.

Comments sent off line to be clearer on how to formulate to be part of the recommendations. Becky: number 3 policy or regulatory organization function was stated so discussion needs to refine or retool the language away from this regulatory function for Iowa Autism Council. That is beyond our defined role in the By Laws. Josh said it is a good start. Lana; strengthen is trying it build upon a system that exists, not build a new system. Looking at Child Health Specialty Clinics and that might work.

Cathy: knowing economic climate for today, is it possible, by going with CHSC will there be cost savings? Not able to calculate. If it is a right recommendation today, it is right today, and then the processes should go forward for the future. Deb, agree with coordinated system appointment, believe in interagency agreement with big parties Like Early ACCESS, named the organizations to plan and implement what needs to be, groups with familiarity with the system, it would be a good thing.

Regionalized centers of care will really work, and needs to be community based. Data collection, partner with statistical analysis that needs to be done, and we need best that is available; UNI, IA State, Drake, but need an academic program. Continue IAC oversee role, similar with Early ACCESS Council. See her list of recommendations. Charlie: If it's being purchased by the State then an RFP (Request for Proposal) process had better be followed.

Feedback on Seamless Care recommendations: look at verbiage from Deb's final wording to update what was presented today. Look at language to serve as overseers over the coordinated system of care and use Deb's language. Identify data on how many as well outcome data to reflect Best Practices changes that need to be made.

The role of the Council is to look at the results and determine if it is good, and make further recommendations to the entity, interagency component. We are not looking to design a new system but to build on a system that already exists. Autism is the fastest growing developmental disability in the United States.

Number 2: about U of I: define what outcome we want. Data on the prevalence of autism. Is it CDD? It is not needed to specify an agency but a Request for Proposal to be offered for an organization at U of Iowa. What is the mandated role of the council and some of the assumptions underlying it means we don't want to be oversight but advisory versus a regulatory agency.

Cathy: go with ASD specific recommendations, should we take the lead to say we will be willing to work with 38 MH and DD services, and to reference coordinated care, that we are willing to work with other Advisory Councils. Josh says to make ASD specific recommendations and others with DD can benefit from them and let other councils know what we are recommending.

Grace: once we get subcommittee work in order, we could talk about introduction or summary statements (i.e. care coordination is imperative, across disabilities). Becky adds: Regarding developmental disabilities, then you need a public policy agenda, who else thinks like we do, willing to join us, who does not think like we do, who are those with resources, group; then a planful agenda will be moving forward. She has learned from failures among advocates, defining one or two issues, stay focused.

One of the failures of current system is it advocates to be all things to all people. Streamline processes to help specific items and not lose focus. Pick your priority and coalition around that issue, not disability community. Josh: if we have seamless global home to start conversations with other parents of children with disabilities. Specific recommendations for autism, but allies are needed with other disabilities; what we want is needed in the entire state.

For example; Early Identification goes across diagnostic labels. Capitalize on using one voice and other groups will be willing to join us. More than one problem is needed to be addressed in ASD (depression). Think of functional needs not diagnosis. Looking at the bigger picture of ASD about other task force groups and their mission is needed.

Josh: global statement, we all want this seamless coordination. Becky wants to emphasize grass roots. Steve: started here with agency reports, but also identify where people fall through the cracks, how he gets access to job, transportation is living in the correct county and other locations are not providing the same supports. Three tracks of rule makers, funding, and community based services have different trajectories rather than working together.

Expectations in 99 counties should have a more cohesive system so living in County A does not provide services for which you were or would be eligible for in County B. Look at subcommittee work to define essence of the work, systematic, and statewide services.

Ask Governor for family member of adults that have not come to the IAC table. Josh: Finish with Finance committee; we will make additions and get final report back to subcommittee chairs. Chairs send finalized versions with supporting articles, as a pared down list.

Finance committee: Casey

With two members having made the recommendations, others will be surprised. Read executive summary. Read insurance recommendations about the same recommendations from SF1 and HR1. Last year, good education for legislators, why asking for mandate in this area, it is going to be tough regarding mandates being made. More allies now but still tell us it will be a tough sell despite 4 states having passed a mandate. We need regional care coordination centers needed to be added to the bill.

Talking about Medicaid handout by Casey: see the number of states, 11 states, with autism specific waivers with 10 of that child focused and Pennsylvania focused on adults. Findings list most needed services; hoping to get numbers of kids and adults from Medicaid and not easy to attend (DHS is hoping to have some numbers, but they are likely low numbers given the focus on claim, losing the ASD diagnosis (underrepresented).

Iowa is 49/50 states and Minnesota is number 1. Last page Medicaid recommendations were read. Discussion: EPSDT theoretical use of Medicaid payment could access additional ASD services. Pam: submitted a plan to allow ABA and a back and forth questioning, before IME: Within Iowa, housed in DHS. State plan amendment is being drafted to apply the rules for ABA. Means the service system plan anyone eligible for Medicaid you can access (opposed to waiver based on population and state plan).

Uses remedial structure on waiver and Medicaid or on Medicaid w/o waiver. ABA cautions were shared that this would be paid, describing who is able to do it, etc. (using shock) so cautions about using ABA language with good descriptions. Chuck: The question that has long been asked is how do we get the money to follow the child? Casey: We need to have a simplification of Waivers to cover multiple services. Becky: It would seem desirable to have a family member of an adult with Autism appointed to this council when appointments by the Governor are next made. Let's make sure this recommendation reaches the Governor's office.

Casey: there are limited funding options for those not getting Medicaid, adults are those who fall between the cracks and need to be identified to expand some of their services. The Finance committee and DHS need to work more together so the finance committee has a better understanding of the language. If we want services, put them in a waiver to broaden the base of the waiver.

Amend the eligibility of the waiver and identify the waiver you choose to amend. We do not want it to be cheaper to be in an ICFMR than to be in the community. If you're eligible for state plan services this doesn't make you eligible for waiver services. However, if you're on a waiver this includes your eligibility for state plan services.

Discussion about family payment for all waivers existed. If recommend to modify whichever waiver, does the benefit package benefit the population. We need a list of what services are covered by what waiver. (Pam will provide to the insurance committee) Put in waiver rather than state plan, but we are missing the adult population. EPSDT descriptions and what services are in waiver will be posted on the WIKI. For example ID (MR) waiver serves adults. The committee needs to work with DHS and maybe pursue both waivers and state plan.

Difficulty of those getting SSI and Aspergers covered is problematic due to IQ eligibility. Regarding recommendations, how do we develop incentives for providers outside DM to provide services, and modify existing providers to get into this, even to break even. Provide it and they will come is the short response. Modifying waivers and what services are provided is the issue. Lana: Let's talk about Hawk-I insurance. If we can't get it in all insurance, seems that we must get it into Hawk-I, just because it is the proud factor for Iowa and targets kids. Benefit plan can be parallel to Medicaid plan.

Josh will send e-mails to all members to provide feedback on Proposed Strategies for Autism Survey Data collection by October 30th. Participate in the meeting that you are invited to attend and support committee chairs. The next meeting is November 16, 2009.