

Iowa Autism Council Meeting

June 15, 2011 meeting notes taken by Sue Baker and Beth Buehler-Sapp.

Present: Marty Ikeda, Sue Baker, Beth Buehler-Sapp, Josh Cobbs, Danielle Sharpe, Ruth Allison (for Kenda Jochimsen), Karn Johansen, Steve Muller, Susan Smith, Barbara Stineman, Chuck Wadle, and Casey (Patrick)Westhoff, Debra Waldron, Toni Merfeld, Jeff Gitchel, Rachel Heiss, Robin Sampson, and Jan Turbes.

Absent: Jeanne Prickett, Jeanne Nesbit, Jim Mumford, and Katherine Byers.

Guests: Dr. Bob Stensrud, Drake University, Dr. Mike Couvillion, Drake University;
Public Table: Jule Reynolds from Senator Harkin's office and an intern Karolyn Dvorsky from Senator Harkin's office.

INTRODUCTION: Motion to start meeting was made by Josh Cobbs and was seconded. Time was given to review April meeting minutes. Josh Cobb motioned to approve April meeting minutes and Chuck Wadle seconded the motion.

Josh described a short orientation to new members. The handouts were reviewed and the Public Comment Opportunity form will be tweaked for use with the Iowa Autism Council but if there are edits you would like, contact Josh.

FIVE MINUTE EXOFFICIO UPDATE: Becky Harker talked about the Developmental Disabilities Council and their focus on advocacy for systems change that allows people with Developmental Disabilities to live, work, learn in their communities. They are looking for a youth representative this summer. The DD council's definition of an individual with a disability is "A person with a physical or mental impairment that occurs before the age of 22 and interferes with 3 or more life skill actions." There are between 50-60,000 people with developmental disabilities but 74, 000 on IEP's but not all fit the definition as described above. The funding for this Council is spent 30% for administrative costs and 70% for activities sponsored by the Council which are provided for people with disabilities and their families to support them with learning and advocacy. The three deficits which disabled persons report experiencing are as follows:

1. Disabled individuals are not engaged in the decision making process.
2. Disabled individuals feel they don't the skills needed.
3. Disabled individuals don't have access to things.

Many disabled individuals don't understand that you can have a guardian and still have the right to vote; this was our first action step. The Council uses grants to communicate advocacy for local campaigns. We have trained 2300 people on policy advocacy, 400 families report advocacy activities, and over 800 individuals attended Advocacy/Change Day at the Capital. Also this year 2700 disabled individuals voted for the first time. InfoNet is a communication publication. The AAPD (American Association of Persons with Disabilities) encourages disabled individuals to volunteer with political campaigns and participate in caucuses. October is "Employment of People with Disabilities Month." The goal is over the next 5 years to employment transition opportunities through more businesses with "Walgreens" being the example to follow. Walgreens has made it their mission to staff up to 40% of their workforce to include persons with disabilities.

AUTISM PARENT SURVEY DISCUSSION: Bob Stensrud and Michael Couvillion from Drake University presented a review process of the data regarding the recent Iowa Autism Survey results:

- 322 persons logged into the survey
- 234 persons took the survey but this does not help tell us the number of individuals with ASD.
- 3 persons chose to log out.
- Duplicates were identified and deleted
 - 1 case where 2 separate parents attempted to take the survey with regard to the same child/individual.
 - 1 case where affected individuals were a pair of twins

Results:

Overall satisfaction with the school was high.

A question was posed to the Council: Where were they diagnosed and what degree is the reliability of the psychologist, so how do we know diagnoses are valid? Bob Stensrud's question, "If we don't have a valid diagnosis up front, then how do you select an intervention?" Chuck Wadle described entities that are qualified to diagnose: child psychiatrist, clinical psychologist, pediatricians with a specialty in developmental disabilities. There is some concern to try to get an idea of how we can validate diagnosis and assure diagnosis is made by someone who is credible.

The snowball methodology that was used is not a generalizable study and they were not randomly selected. There was a broad range of communities represented. Josh added: "This is the consensus of the population who participated in the survey." The Department of Education makes maps and a social network analysis can be made to show the reach of the Council survey, which could be reported next meeting. A review of the methodology and sampling are not sufficient to generalize satisfaction or that one town is unhappy. **This** data is qualitative.

DENSITY PLOT MAPPING: Marty: We are still not close to understanding the population. This survey has not helped answer where are the kids in Iowa. Maybe looking at the incidence from a density plot with the expected population is a next step. He says "incident results in school district's at some point would be nice. We still need to get more information in order to eventually have a density plot mapped out."

Jeff Gitchel asked if this breakout of the survey results is something that will go out automatically go to the Autism Council members or would requests for this need to be made. It will be available.

Josh stated, "This would be great to know where the kids are and what are they getting." We also want to look at whether a student is receiving the services based on the schools request or the parent's request. It should also be noted whether the student is receiving the services from the school or from a community service provider.

Other thoughts that drive the survey: It is important to know if my child receives services, that I am satisfied. Is the service beneficial or not beneficial?

REFERRAL SOURCE MAPPING: Marty theorized that a map would reflect the various referral sources in all given areas with the use of colored dots.

COMMENT SECTION AT END OF SURVEY: Bob and Mike pointed out that there were 90-100 comments on the last question. Hence, Bob Stensrud commented that he bumped into some rather assertive parents as part of this process. Transition issues were named and services for those out of public schools were questioned.

RESPONSE IMPLICATIONS: Becky Harker asked, “Was this survey only done electronically? Bob Stensrud answered, “Yes, and only in English due to time constraints.” Becky pointed out that the State of Iowa as a whole does not have high speed internet access, which is another issue related to response rate.

SURVEY FOCUS REVISITED: Marty stressed that we need to look at “To what extent are practices evidence based and that the initial research questions should be as follows:”

1. Who are the kids?
2. Where do they live?
3. What do they need?

Marty indicated he would send his other main questions to be included in the minutes and they are below:

1. To what extent are services evidence based?
2. To what extent are evidence based practices equally distributed across the state?
3. To what extent are evidence based practices offered by the school or at the recommendation of the school?
4. Are there differences in the observed report of satisfaction with evidence-based practices compared to report of satisfaction of non-evidence based practices (Chi-square type analysis)?
5. Is satisfaction distributed across the state in densities that appear representative? Is dissatisfaction distributed across the state in densities that appear representative?
6. To what extent did children receive services that were evidence based?

Josh pointed out that there were items on the survey which were not evidence based to see what was going on as a whole. Keep in mind that this is the 1st survey of several and that we know much more needs to be done.

It was noted that only one survey respondent’s child was home schooled and that there was one parent respondent whose child went to a parochial school.

QUESTION TO COUNCIL: If you see patterns of what is sticking out to you, please generate questions and share them with us at Drake.

DRAKE STAFF RESPONSE TO SURVEY: In looking at the compiled survey results Bob Stensrud and Mike Couvillion are compiling the following responses

1. What treatments are being offered?
2. Who provides these services?
3. To what extent are treatments offered, evidence-based versus non-evidence based?
Evidence Based Practices – Where, Who, Why, and Satisfaction?
4. Intervention Importance/Satisfaction?
5. Evidence Based Practices versus non-want/don’t want?
6. Responses (add comments)

Marty will send this information to Josh after receiving it from Dr. Stensrud.

SATISFACTION DISCUSSION: Satisfaction is related to expectation and how I like the people serving me. Michael Couvillion pointed out that in this survey you can cross 2 variables, i.e. respondents choice of importance versus satisfaction. Satisfaction option is often used in relation to communication.

Josh stated that he would want specifically to know “Why they’re dissatisfied?” Josh also noted that satisfaction rates typically drop (as age increases) and services dissipate when child gets older.

CONTENT FOR NEXT SURVEY: Becky Harker stated that she would like to see more about progress made, with more specific information. Josh said that the next survey will get more in-depth in gathering data. That is a much ‘mushier’ question to interpret offers Bob.

Bob Stensrud stated that ideally you’d get the same people to take the survey every 2 years.

Marty asked the Council, “Where do you want to be three years from now? We need to look at testing for results to see where kids are that need services.

Bob Stensrud observed that even though we’ve used evidence based practices in questions, you don’t know what/how it’s being reported.

Josh asks Debra Waldron what is missing. She stated that obviously we know that all children are not being served in the education system equally. We, as a Council, are not looking a holistic perspective and don’t know what parents are doing, what family supports there are, and we are not measuring these things including medication use. Therefore, she doesn’t favor making any broad recommendations, due to confounding variables. She would be curious to see what practices provide what improvements to the education process. Dr. Waldron stated that “Ideally Education, Health, etc. would be surveyed unilaterally to understand results; she knows that there is not enough money available to do this.

Bob Stensrud stated we could ask what is going on by medication, income level, etc.

Josh: We need to utilize the data appropriately with our intent to say what is going on in the educational system and then understand the ripple effect. It could then expand to family support, etc.

There are 300,000 kids in the public school system, grades K-12 receiving special education services. Robin Sampson asked, “Is there a way to drill down by regions?” The response is that 234 surveys just isn’t a large enough pool to do this with but this could be applicable at a later time with more data gathered. Josh said that data is good but that 5% (extrapolated to be ASD) is a small sub-set on the larger scale.

Jeff Gitchel stated that it’s hard to pin down what you need to get versus those diagnosed. Josh says that if you know the diagnosis, you can provide better services.

Dr. Rachel Heiss stated, “Interventions need to be evidence based. Parents can be satisfied with the efforts made but still not be satisfied with the progress their child makes.”

Marty indicated it might be a good starting data for a subset of 5%, but reminds the Council that you can provide recommendations to the Iowa Department of Education, but we don’t have to do them. Marty told everyone that in his experience it’s best to “Measure What You Treasure.” What does the Council treasure and does that align up with the survey? If you want to look at independence of the student, then push a policy agenda. How do we sustain what we want to and how do we get that data. We’re not going to improve services for kids unless we all work together.

Bob Stensrud’s philosophy was that of *onionology*, “Let’s peel layers away and get to the next layer. At 5% we’re just on layer 1 of the onion. Our recommendation could be that we want more funding to do more surveys.

Becky offered using focus groups in a certain areas to reach who we have not.

Josh stated, “We need to make sure that we know what we don’t know. Let’s focus not on what we don’t have but on what we do have.” We have to decide what we want from what results we have. How did you hear about the survey is important information to map out.

Jeff Gitchel says, “I hear it said that this will not be the last survey/data collection process we will be doing.

Robin Sampson asks the group, “Can we make the generalization that parents want a lot of services? Bob Stensrud summarizes that “Parents would like more information about the options they have. What treatments are available, and are they Evidence Based Practices, and delivered in a way I am comfortable.

Bob: If you can get information from Voc Rehab services that will assist in progress questions. Individuals with ASD (Autism Spectrum Disorders) are nationally the most un-employed or under-employed group.

CONTENT QUESTIONS AND RECOMMENDATIONS FOR FUTURE: Marty offers: What do you want to know about kids? What are the data sources? What other resources/partners are there? Your policy recommendations could be to figure out who these kids are. There are other avenues the DE could take to find out where the kids are. The Council should take time to look at the data to raise a bigger question and ask who owns the problem.

Bob Stensrud offers that every kid in the state has a unique identifier # and a social security number that could be used to track their progress (enrolled in post secondary program, if they completed it, wages they earned) over time.

Marty stated that if there are districts who want to work on transition options for students with disabilities then the department would be willing to work with them.

MISCELLANEOUS: Jeff Gitchel asked if the council is going to see the survey comments.(only overviewed)

Becky Harker stated that it takes teachers, families, & communities working together to support a disabled child.

Ruth Allison – IVRS counselors are trained with LEA staff to serve students with disabilities.

Casey Westoff observed that when planning for next year’s goals you will want to reach out to legislatures fairly soon

REVIEW OF SUB-COMMITTEE RESULTS ON ADULT SERVICES: Jeff is new to this committee. They are trying to accomplish how to start to move forward what is going well (references the TAP Program) and how to get the system to work. Laying out a blueprint is helpful to the process. Josh believes that the fall conference regarding employment options for people with disabilities is very needed. It is scheduled for October 13, 2011 before the state Autism Society of Iowa conference. Department of Education is the lead agency, partnering with businesses, and may mirror a Kansas City conference setup. They plan meetings in the fall with pilot areas to identify school districts willing to partner together with an outcome of independent or work.

Ruth talked about their system not set up for breaking down by ASD conditions, so the outcome of the work will take players more broadly defined than just those with ASD. Entities working together could be teachers, families, communities, healthcare, housing, transportation etc. DHS and Employment First will have discussions and key stakeholders at the table say Casey. We may want to consider working with individuals/entities who have a recognized presence within the field. The University of Iowa Transition group was also mentioned as a potential partner. This could be innovative capacity building project.

Ruth offers that our Council could have a voice at the employment summit on what we want to see, special things to consider, and we could be part of the agenda.

Discussion continued about some voices suggesting this as a broad constituent base rather than a separate autism focused conference.

Steve provided an example of a simple assessment of student's behaviors that can contribute to a more competitive employment opportunity rather than a sheltered work opportunity. He noted that Walgreens has established a network to hire (40% workforce) persons with disabilities.

REVIEW OF VOC REHAB'S APPLICATION FORM USED TO LET POTENTIAL ENTITIES PRESENT TO THEIR AGENCY: Josh will send a link out to the entire Council in about 2 weeks with a similar form (having used Voc Rehab's as a template) and Council members can view this form and make comments/suggestions.

IAC WEBSITE REVIEW: Council Members of this subcommittee are Josh Cobbs, Steve Muller, Katie Byers, and Sue Baker. Sue Baker revealed the format for the site, modeled after Ohio's site. This is an online resource guide not a legal or medical document. It will continue to be developed but needs review by the IAC website sub-committee, then the Council can vote and get this live on line.

REVIEW OF RECOMMENDATIONS A-I: Council reviewed the recommendations a-i (handout from last meeting). Josh reminded Council members and for new members benefit informed the group that December 12, 2011 is the deadline for the Council to turn in it's recommendations to the Governor's office. Therefore, mid October is the deadline for Josh to receive feedback from all Council members in order for him to review and implement any changes and send out to the Council members for approval.

What is the pulse to focus on now? Continue advancing what we are working on including the survey.

MH SERVICES REDESIGN: Chuck Palmer is overseeing a redesign of the system and one group served is children. This group is in discussion and makes recommendations to the legislature regarding financing of care, system of care, treatment etc, If any Council members would like to be considered or know someone who would (providing they have a relevant background), hey need to get those names submitted to Chuck Palmer. Josh can receive your e-mails and he will help your name to be submitted as a subcommittee representative. This redesign is using 8 regions. Casey Westhoff said that the Olmstead groups chair will be recommending to Chuck Palmer names of folks who might be interested in serving on sub-committees.

Josh asked that if any Autism Council members are interested in serving on a Council sub-committee that you send him an e-mail.

DHS REGIONALIZATION OF SERVICES: Listening to various entities but not to persons with disabilities or their family members is something we want to try to make sure doesn't happen. Casey stated

that discussions regarding this direction have gone on since the mid 90's. Outcomes are what matter –Does the system support the people?

There is a federal mandate for system of supports due 2014 and there could be millions going on Medicaid. This could become a huge financial issue based on if President Obama's Health Care reform Bill goes all the way through. If it passes there could be between 20,000 and 80,000 people who go on Medicaid to meet new healthcare reform requirements. Statistically this would be 1 in 6 Iowans. This would cost the individual states varying amounts of money, i.e., it cost the state of Utah \$600,000 and it costs the state of Massachusetts 2-3 Million dollars.

A note of celebration says Steve: Iowa will reinstate 2 ½ % cut for waivers that will fund child and adult services. The state is giving \$2 million into counties for increased waiver costs .

Where do we go with our priority list? Steve Muller suggested thinking about the focus that, "Whatever we do we need to do it in line with the goals of other organizations. He thinks that there is strength in numbers per say and if we align our goals/recommendation with those of other organizations we can possibly create a larger/more unified force. What if we make time at the fall Iowa Autism Council Meeting to review what other entities are supporting/recommending in correlation to those of the Iowa Autism Council.

Casey mentioned three groups with a common legislative agenda.

Becky Harker theorized that we could do the following: Ask various entities "What is your public policy agenda and then look for commonalities. Perhaps Developmental Disabilities Council could help pull entities together for a discussion. She suggested soliciting this information from:

- Iowa Department of Human Services
- Olmstead Task Force
- Mental Health Advisory
- MHDS Commission
- Brain Injury Association
- Learning Disabilities Association
- Iowa Association of Community Providers

We could then perhaps put together a synopsis to say, "Here are a list of 10 entities who jointly support these same 7 goals (list the goals).

AUTISM INSURANCE HANDOUT REVIEWED: The Insurance Policy Session is a 2 phase process, consisting of the passing of the bill and how the bill gets implemented.

Section 35.40(1) states the purpose and definition. BCBA services are clarified. People are making their way through the system and people are accessing the care. Chuck Wadle mentioned that with regard to insurance provision, it comes down to the identifications made using ICD9 codes provided by the Diagnostic and Statistical Manual. If you want to know if you're qualified/eligible, you need to contact your benefits package person. There are employers who cover certain services.

MISCELLANEOUS: Drake University is working to get a doctorate level BCBA (Board Certified Behavior Analyst) program implemented. The University of Iowa Hospitals and Clinics is working on this also. Iowa now has 32 who provide BCBA services. That web site link will be placed on the Iowa Autism Council site.

Josh asked how council members feel about the idea of “ video streaming” a meeting to anyone who wants to participate. In essence making the meeting electronically available to anyone who wishes to see it / participate. He asked Marty Ikeda if he were open to this possibility and Marty stated “This meeting is open to the public at large should anyone so choose so, therefore steaming a meeting would not pose any type of privacy violation and Marty is fine with that if the Council so decides.

Steve asked, “What are ways of making ourselves known to others, what we’re doing?” In this way we might be able to link up with joint supports. Maybe press releases would help, survey talking points to promote legislative agenda.

Deb Waldron related that the CDD and MHDS Commission are going to be reviewing Telehealth, etc. to determining how effectively and to what lengths they are beneficial to patients.

Barb Stineman encouraged folks to review the Des Moines Register’s June 8th article/interview with Danielle Sharpe.

Josh reminded Council members that next year’s IAC meetings will be on Wednesdays from 10am-3pm as they have been previously. A schedule will be determined and sent out to the entire Council, though locations may not yet be firm.

IMPORTANT NOTE: Josh stated to Council members “Please do not forward on survey results/data until the Council completes and approves this for public dissemination.”

Josh will talk with Thomas about amending the bylaws to accommodate public attending the entire meeting without commenting.

Josh Cobbs motioned to adjourn the meeting. Chuck Wadle seconded the motion.