

Iowa Autism Council Meeting

November 17, 2010 meeting notes taken by Sue Baker and Beth Buehler

Present: Sue Baker, Beth Buehler-Sapp, Josh Cobbs, Danielle Sharpe, Katherine Byers, Keith Gatrost, Becky Harker, Marty Ikeda, Kenda Jochimsen, Karn Johansen, Laura Larkin, Linda Louko, Steve Muller, Jeanne Nesbit, Pamela Parker, Susan Smith, Barbara Stineman, Chuck Wadle, and Casey (Patrick)Westhoff.

Absent: Jeanne Prickett, Jim Mumford, Debra Waldron, Toni Merfeld

Susan Smith from the Woodward Resource Center will be giving a tour to any interested council members at 4:00pm today following the meeting.

Council reviewed the mission of our work and that we should all be going to the same goal. Recommendations of the Iowa Autism Council's 2011 priorities are as follows:

What action do we want?

What format do we wish to use? The new format using Principal and ACTION statements was shared. Lists of findings will also be included as well as members of the committees.

Dr. Charles Wadle commented that he was impressed with the format that was used as it is great for presentation to the legislature and has a mini RFP flavor.

Linda Louko asked what is happening in the legislature now and wants to get a sense of the next steps.

Josh stated that last year he was invited to the legislature and produced a letter of recommendation to the insurance commission; this letter also goes to the legislators and executive channels. The final recommendations document will go to Marty and will go to Governor's Council and legislative persons.

Danielle mentioned that anyone on the council can arrange to go to hearings and talk to the legislature. March 29th, 2001 is the Day on the Hill for Autism.

The Iowa Autism Council's recommendations for this year are due to Governor Culver and the legislature by December 12th. Josh needs all recommendations back from sub-committee chairs by December 1st, 2010.

Josh mentioned that while everyone is there as part of the council that a few council members have already reached out by communication to the members of the new governor's office.

Discussion was started in regards to the terms used in the new format to describe the recommendations to be submitted under priority #1. Katherine asked about the word principle and upon discussion by the group it was conclude that "principle" is somewhat subjectively defined in generality.

**For example, google would give you the following definition: 1st.*prin·ci·ple*/'prinsəpəl/Noun
A fundamental truth or proposition that serves as the foundation for a system of belief or behavior or for a chain of reasoning.**

Options to replace this word principle will be exchanged between Katie and Josh and the final represented word will be chosen and submitted with the revisions due to Josh by December 1st, 2010.

Dr. Wadle commented that for legislators issues are more illusive. Also, the perception of a definition of a term will vary in relation to who the audience is.

Steve Muller made the points that it is important to read in our document, ASD numbers are exploding, and this has a definite economic impact and creates challenges for those affected. This will probably continue to increase because based on campaign statements made during the recent gubernatorial election; Governor Elect Branstad is yes to saving money and no to expanding services. Steve suggested that the best message to send to the Governor's staff is this "If you spend money on these kids now it will save you money down the road."

PRIORITY #1 SURVEY: Marty informed the council that the Iowa Department of Education has contracted services with Drake University for their IRB (Internal Review Board) to perform a review of the survey which the Iowa Autism Council has developed. We hope to get data back by spring of 2011.

Josh reminded everyone that "We need all parts of the puzzle to understand the provision of current services."

Identifiers will marry-up with an independent review base to provide anonymity. Specifically, some of the points we are looking at are as follows:

**Frequency of identified cases of Autism Spectrum Disorders age 3-21 years old.
Frequency of the incidents among students with Autism.
Numbers of student population with ASD in relation to topography.
To understand better where the kids are and what services they're receiving.**

We need to look at all of this because the numbers which the department has received from the AEA's from IEP secondary designation don't make sense (too low). This is partly why we are implementing the parent survey because the AEA data didn't add-up to what we have recognized informally at the state level.

How close are we to the incident numbers that we think are relevant? The action is a research agenda of prevalence, with the survey being one part to better understand the population.

Marty shared that prevention should be noted in our principle and next year we can craft an evaluation agenda to say that our prevention is or is not working to build a case over time.

Linda Louko suggested that rather than using the word "Understand" to start the lead statement that the group consider changing the word understand to either Identify, Define, or Determine which each have a more substantive definition. Put the crucial information up front (example: There is currently no accurate system to count students, principle, followed by additional parameters in the study.

Katie Byers suggested that rather than using the word "Principle" that the group agree on a different term. She feels that the lead paragraph should read "Iowa does not have sufficient

access.” There is currently no accurate way to identify who the kids are and therefore services being received.

Action: to develop survey this year and implement it. Target date should be put on each recommendation – Spring 2011 in this case.

Casey Westoff stated that with regard to the Governor’s office and legislature providing a date/deadline is especially imperative.

The suggestion was made that in regards to priorities 1-4 those items appearing later show those are in progress/currently being worked on.

Becky Harker suggested that the council needs to separate out it’s objectives as follows: Research Agenda, Programmatic Agenda, Legislative Agenda. Josh suggested to table this decision until later in the day.

Kenda pointed out that when this is submitted to the Governor’s office it will initially be subject to staff review. List legislative actions first, followed by agency actions after that.

Conclusion: Priority 1 should be shifted to Priority 4 and the legislative actions should be outlined first

Priority #2: PARENT TRAINING, SIBLING TRAINING

Linda Louko asked if we could move the key sentence from last to the 1st part of the paragraph.

Josh – we want to enhance parent training and ensure access to it. Parents have the right to information. Be consistent is using ASD everywhere instead of the word autism.

Discussion regarding bullet #1 under Priority #2 led to consensus by the council to change the statement of bullet #1 to read as follows: After research of available resources, it is the council’s conclusion that there are not enough training resources available.

Marty posed the question: What type of training does an ART (Autism Resource Team) provide?

Josh stated that if we’re asking to study the reorganization of the ART then the target should be set for feedback.

Katie Byers asked how the consolidation of AEA’s last year may have influenced the ART’s (Autism Resource Teams). Marty commented that the reorganization of AEA’s didn’t really have an effect on the ART functions. Council members would like to know the following: What services are ART’s providing? All information about studying ART teams should be moved to priority 1.

The council would like to see the AEA’s ART’s offer trainings (professional and parent training) and they should be age appropriate and delivered at the AEA level. Some questions

would be do you have enough staff? and are your teams available? Council can make recommendations but cannot mandate.

Do we want to address how to provide more parent training through the role of the Autism Resource Team? Linda Louko would like to see parent training more age appropriate and individualized to the child needs.

Discussion followed about further suggestions to the subcommittee for additional revisions.

Chuck Wadle suggested this is how a statement be put: We've done our research and suggest these are areas to consider in providing parent training.

Other possibilities also include the following:

Based on what we think we know, please review these areas to confirm our conclusions.

Based on our research and findings, please study how you can reorganize your ART Team and process.

We want more access to parent trainings, AEA's aren't consistently providing parent training so please review this.

Keith Gatrost stated he likes the suggestion of the slogan/statement; "Invest now to save later".

The principle could be the people with ASD are entitled to quality services.

DHS SECTION COMMENTS: Josh asked Jeanne Nesbit from DHS what expansion of services might be anticipated and by when. Jeanne's response was "Today I have the most money I am going to have for several years." Due to the new legislation passed by President Obama for renewing affordable healthcare and the impact this is soon to have, it's hard to predict financial outcomes.

Due to the recession effect our economy is under with state unemployment, etc. and with the new Governor soon to take office and his record of reduced spending, it is unlikely that DHS can anticipate any increase in funds in the near future and could quite possibly even experience a reduction of funds depending on possible financial reorganization by the new Governor.

Response to inquiry about having one curriculum for training: The question was asked, "Who has the great curriculum?" Is there one curriculum that multiple entities can use.

Becky Harker asked the group to "Define Parent Training" and be more specific in what you're referring to. What type of skills, knowledge, etc. should be added.

Linda Louko: there is no one curriculum, no one answer for everyone.

Josh stated that it's getting dramatically better and there are more targeted approaches.

He also pointed out that sometimes, something is legislatively mandated, therefore it has to be done but may not be tied to a funding source.

Jeanne Nesbit said she would look at to see what new funds might be needed in order to add money for this mandate so as not to cut existing services.

Steve Muller mentioned that DHS should mandate remedial programs, provide ABA parent training in the home, so that family members are able to provide services needed within the home. He supports remedial training be specified in this recommendation.

Affordable Care Act – kept buckets of eligibility money and also made benchmark services are defined. It will be interesting if the state adopts medical home model for chronic health care and wrap around services with care coordination and other issues.

Under new medicare guidelines persons who aren't eligible under standard guidelines become eligible if they fall under the following criteria:

Meet 133% of Poverty Level

Fit Medical Home Model

Meet Benchmarks defined

Individual under 400% of poverty level could purchase insurance out of exchange

Regarding the process of subcommittee presenting draft recommendations to full Council: Sue Baker stated that having a small sub-committee present their draft recommendations may not be the best way to create recommendations as a council. Full council feedback is needed more when the draft is shared earlier in the calendar year. The observation is made that the subcommittee recommendations presented near the due date, many of them are not in agreement with suggestions made by the entire Council. Hence, time was wasted researching and creating recommendations that others may have updated information or suggests a different direction for recommendations. Response: There is nothing wrong with recommendations; however they need to be processed differently.

Sue observed that for a recent e-mail to members of the draft recommendations, the information was sent only to those who vote and were not submitted to the entire council. Josh indicated this was an oversight and will be corrected next time.

Healthcare facilities section: Marty Ikeda – until you define what you want a provider to do it's not certain. Others suggested that guidelines or a specific tool or group of tools should be identified in the recommendation.

Chuck suggested resources could be shared through the next IME newsletter or Iowa Plan distribution.

Laura Larkin also mentioned that the regional centers of CHSC could disseminate this information as well.

Family to Family section: Sibling training should be available. Fold Iowa Autism Council website into priority #5 might be a way to help disseminate this information.

Priority #3 Adult needs

The first item asks for flexibility to use 2010 rates since the cap on county funds in '97. Some counties would like to offer more funds and better/more services.

Discussion continued around adding eligibility criteria and how this is could be functionally defined. Discussion of Waivers continued. Laura – Administrative rules say what the criteria are. For example, in the case of a plan amendment the state sends to CMS who has 90 days to respond back to state, state has 90 days to respond back to CMS, etc. and this can go on an on, back & forth. Move the waiver section to finance section.

Steve talked about the fact that most patients in HCBS's never have a face to face (actual) interaction with a case manager or such a person. The regulatory body that oversees the quality of services has not seen patients for 8 years. In these cases paperwork is the monitoring function and one-on-one contact is not accessed in person. Steve strongly suggests that the state increase it's level of oversight of the services provided on a waiver.

Kenda suggested that the state infuse into the role of the case manager that direct client to case manager (person-to-person) contact is a requirement. (not via phone calls or e-mails)

ICFMR's (Licensed residential) have heavy oversight while HCBS's (home-based/community) have limited or non-existent oversight. Discussion continued from members about consumer choice options and the level of regulation. Josh mentioned that in the case of adults with choices/legal rights that there is a very fine line between self advocacy and controlled supervision. Usually informed choice and safety are the considerations. Kenda mentioned that it's becoming more so that the higher functioning folks are allowed to make their own choices regarding where they want to live. Steve is in favor of someone accessing a situation to determine quality appropriateness. Susan Smith says that case managers complain about HCBS situations all the time.

Second bullet about rule changes: Some want a three day notice before a change or for comment period. Josh stated that there should be a prescribed avenue of communication for changes, etc. Steve asked "Is there an external source that is accrediting these people? Steve stated that if we make it tougher to be a direct care professional, the pay will go up. He states this will drive pay up for folks doing this work.

Third bullet: this information could be put on the website. We need to watch the Olmstead plan and affordable healthcare act as parallel plans.

Fourth bullet: likely delete

Fifth bullet: currently funded program and asking for partnership to make them more accessible.

Sixth bullet: There is a difference of opinion on the subcommittee. Some want ICMFR expansion and others not agree with it.

Principle about transitioning individuals: Council talked about job fairs, work symposiums, and programs to help individuals with Autism. Kenda stated that while some of these focus on individuals with Autism, they could be used to develop similar opportunities for other disabled populations. Chuck interjected that this could be expanded and broken into facets for groups with multiple types of disabilities.

Priority #4

First bullet: OK as written but add DHS as the Department on the second line.

Second bullet: add living with ASD (medically necessary treatment)

Third bullet: correct the needed services in the last line. Meld child and finance section together.

Josh wants to address legislators to add therapies and services into the Hawkeye plans (HF21).

Priority #5: website

There was a demonstration of the mocked Iowa Autism Council website that Josh developed. It could have divisions including ages (0-2) click here to walk through the steps to find help and services. We will need input from state organizations about what is available in their state agency to support families living with ASD. The site will be located through Google and Josh has purchased the domain name for two years. It will not have personal information listed; just contact information. It will have general information and terminology with external links to other state and national organizations. Thomas has developed disclaimers that will be needed. The first half of 2011 is the target date for the website/portal.

Josh will send e-mail to Beth to send to ex-officio's that requests their agency involvement and what is being requested from their state organizations. Agencies will be given guidelines for the content to be added to the site. We will be asking for a point person to organize information from that agency and share that with the Iowa Autism Council subcommittee responsible for maintaining the website.

Sub committee for the website: Josh, Steve, Frank, Sue, Katie. This committee will be meeting soon to discuss content, guidelines, and ease of managing this site.

Wrap-Up: Josh will do a voting via e-mail rather than conference call with voting members. Voting members are to submit their final votes for each of the subpoints in the recommendations via e-mail. Beth will be the point person to send out and receive votes and then send responses to Josh.

Sub-committee chairs please have your recommendations back to Josh by Wednesday, December 1st, 2010.

Karn mentioned that under the Priorities and Strategies heading, if anyone has any changes please e-mail them to the sub-committee.

Reminder: ASI Conference is Friday, November 19th.

On December 23, 2010 there is a State Insurance Rules Meeting.

Linda Louko moved to adjourn the meeting. Charles Wadle seconded the motion.