

Iowa Autism Council Meeting Draft Minutes
September 12, 2012
Meeting notes taken by Sue Baker and Beth Buehler-Sapp

Present: Sue Baker, Dr. Charles Wadle, Theresa Croonquist, Lin Wessels, Toni Merfeld, Joshua Cobbs, Kathy Levine, Susan Smith, Steven Muller, Laura Larkin, Dr. Rachel Heiss, Casey Westhoff, Marty Ikeda, Karn Johansen, Robin Sampson, Jan Turbes, and Beth Buehler-Sapp.

Absent: Danielle Sharpe, Becky Harker, Jim Mumford, Dr. Debra Waldron.

Josh called the meeting to order at 10:03am. Josh stated that we need to approve the June 13th, 2012 meeting minutes as the 1st agenda item. Chuck Wadle made a motion to approve the June 13th minutes and Casey Westhoff seconded the motion.

The Council reviewed the voting to pass the council's support of the Medicaid letter to the Governor. Sue Baker asked if the letter should be posted on the Iowa Autism Council's website and the Council members present agreed that this letter should be posted on the website.

Governor's List of topics: Autism Insurance Legislation:

In review: this bill passed 43-7 in the Senate but died in the House. There was discussion if this legislation is restrictive to ABA or includes other treatments; the legislation serves to broaden ABA coverage. It was voiced that insurance companies will pay only ABA and not other treatments. Rachel Heiss stated that the ABA services available from many psychologists are not covered by many of the insurance plans which patients have. She plans to call Dr. Greg Forbraro, chair of the State Psychological Society, for their update and to voice her support of ABA as a covered service option.

Josh will send out codes to the group regarding claims made in 2011 for ASD related Services, which include many services including ABA.

Steve Muller asked, "What is a fair amount for an insurance company to take of a premium to keep to pay for service/overhead of the insurance company?"

Chuck Wadle stated that under the Iowa Plan, IME (Medicaid/Medicare), etc. this figure is 12%. Rachel Heiss stated that in her son's case the figure was 20%. Steve Muller encourages folks to think about what is enough and to get involved with the rising cost of health insurance issue. Josh will talk to Angela Burkett Boschett, who is an Insurance Industry Representative Liaison, and ask about rising cost based on Iowa's usage and send her responses to the Council or invite her to talk with Council members.

Steve Muller voiced that he is strongly in favor of making this topic a priority in our recommendations.

Steve Muller attended an Autism Speaks law summit and shared a story about recent insurance practice that had a devastating effect as follows: For veteran's injured in the line of duty who were receiving ASD services for their children if their injuries lead to discharge from the military then their children are no longer able to have covered services. This is a bad situation for which it would be beneficial for many military service persons if this were changed.

Steve pointed out the following example that exists in South Carolina.

20% of population is medicare covered

10% of population is medicaid covered

11% of population are insured

10% of population are state employees.

This totals 51% of South Carolina's population on some type of government funded insurance coverage.

Chuck Wadle said that with most states the government supported average totals 50-60%.

Also some folks are covered by self-funded plans. These folks purchase supplemental plans through a known company but are not actually covered by that company. Autism Speaks is supportive of in-for-profit company coverages.

Lin Wessels brought up feelings of bitterness and anger that their needs are not being met. A plan may for instance say it covers speech services but this is definitive. For example, this will cover speech services that are related to a speech problem due to a birth defect, brain injury, or neurological disorder, etc. Conversely, they would not cover speech deficiencies due to an ASD or other type of disorder.

Josh responds there have been Autism Speaks tours around the state talking about benefits and barriers and it is often an individualized case that makes it through the system. We could stress that with this bill speech and OT services may not be taken away, but ABA will be added.

Toni Merfeld suggested for concerns that if speech is not determined medically necessary it may not be paid for and in these cases, to call the Department of Insurance or write to the Governor's office.

Rachel Heiss stated that within the insurance spectrum the general guidelines expect to cover 32.7% of services, so we need to be willing to participate in the appeals process. So information about this bill in the form of Frequently Asked Questions could be added.

Governor's List of topics: Redesign website: Susan Smith asked for the link to the report results:
<http://dhs.state.ia.us/Partners/MHDSredesign.html>

Governor's List of topics: Adult Services Study: Susan Smith asked about a study to address who is funding Adult Services? What are other states doing and where are the gaps? She shared that Alyson Beytien, 3-4 years ago with one of her colleagues, did a large survey regarding this and suggested that this information could be reviewed and expanded upon. It's doable but, "What would we do with this information once we have it?" What are we looking to do to address employment outcomes improvement? Increase specialty providers or identify the gaps?

A discussion on students eligible for PMIC services, Psychiatric Medical Institutions for Children, including those in foster care who may have to be served out of state: Medicaid funding served in 2011 84 kids and 14% had autistic disorder (not listed in both primary and secondary handicapping disabilities) with 11% with that diagnosis the year before. This includes children up to age 18. Placement costs are also a difficult figure to analyze. Within the State of Iowa, 3 residential facilities have really stepped up to overcome service restrictions in order to prevent kids from having to go to out of state placements. The duration of out of state services is also difficult to describe, but the average duration

for a child's placement in Iowa is 9 months. It is unknown if Iowa's out of state placement is larger number than other states and bordering state services make it difficult to determine.

Laura Larkin said that prices, child welfare, etc. are factors in child placement. Casey Westhoff said that the cost factor, continuity of family, etc. influence placement. Sometimes kids get rejected by all in-state facilities. Iowa was two state run ICF's which are the Woodward and Glenwood Resource Centers. These facilities have IQ requirements (must be less than 70) which are part of the eligibility requirements.

It was decided that this would not be a recommendation but instead it could be activities a subcommittee of the Iowa Autism Council could do.

Governor's List of topics: Increasing Employment for Adults: Steve Muller vocalized that he would like to see Jeff Gitchel's position on the Council filled to gather that perspective on employment needs. It's very helpful to have a highly functioning person with a disability on the Council. Is there anyone involved with the REACH program that could fill this position? Not that Sue knows, but there is a person in the GRASP group who might be a candidate for the vacancy. Marty stated that interested persons will need to apply through the Governor's office and when a selection has been made, the Council will be notified.

Becky Harker's page Iowa Coalition for Integrated Employment was mentioned with no action at this time.

Kathy Levine talked about Voc Rehab's employment services/training available to disabled adults. Last year 2100 individuals were employed with \$44.7 million in wages paid out to disabled individuals.

Lin Wessels and Steve Muller asked questions about separating out data for ASD and details of reopening cases. Linda stated that on her data shared with the Council that if a case was labeled "not successfully competitively employed" that Voc Rehab does not categorize this as a successful closure. A successful placement is categorized as when an individual becomes employed at 20 or more hours per week at minimum wage or better for

Josh wanted to know which industries have the highest placement rates? Kathy said that the service industry maintains the highest placement rates.

There appeared a big gap between 24 adults with ASD who were successfully placed in one year and how many are unemployed with ASD. Kathy's data showed that last year there were 181 cases opened with 24 successfully closed. There are also 100+ cases still open so this leaves less than 57 or 32% closed unsuccessfully. How can this service be expanded to help those adults at home without jobs? Is Voc Rehab capable of receiving more referrals? An individual who needs multiple services is eligible immediately rather than being on a waiting list.

Referrals for persons needing services can come from a variety of sources: Schools, parents, community agencies, doctors, lawyers, workers compensation, and referral agencies. What is the most common reason people don't achieve successful completion? Lack of Social Skills was suggested. So how do we predict who will be successful?

Discussion continued about supported employment and eligibility for Voc Rehab. Casey Westhoff mentioned that there is another program called supported employment. However, Vocational

Rehabilitation Services has to turn away a person before they can be eligible for the supported employment program. Supported employment is low; only approximately 2% of disabled individuals receiving services are getting supported employment.

Governor's List of topics: Institutes of Higher Ed Study: What is the curriculum and how IHE curriculum relates to the results of our educational study? Marty talked briefly about the IHE (Institutes of Higher Education) Study. Big Question: How are teachers prepared to serve this population? Marty indicated this would not take much to do and we do plan to address it this year. Marty will investigate contracting out with others (Drake University) to see about conducting a survey. We are talking with AEA members about evidence based practices and what is being done about that. We can identify a plan to find out how well teachers are trained, by the end of this school year.

Achievement Gap: Most kids on IEPs are not making much growth, but a lot of kids did not make a lot of growth, so this is a statewide problem. Marty talked about the education system and the need for IHE involvement. Reasons we have determined this are as follows: We only test in the 3rd-8th grade range and then again in the 11th grade rather than testing kids yearly. We should have an overall proficiency rate amongst all kids at 80% but actually only have a 55% proficiency rate.

Marty added that we have to have something to give to teachers to tell them what to do, asking RTI teams for input, Administrators, teachers, parents. A module will have to be planned to take out to everybody. How do we look at evidence based practice to do enough to make a difference?

Susan Smith stated that she feels classroom effect is a much overlooked piece that affects student achievement. Examples exist in positive relationships, character counts, etc., but understanding reinforcement and consequences is difficult. Staff Interaction to student has a huge influence.

Marty mentioned that we endorse PBIS but that while we have 170 schools across the state doing this, only a handful of buildings can we verify that it is being implemented well (that includes classroom level, too). If Institutes of Higher Education could add reinforcement and consequence training in their teacher education background, that could make a difference. Discussion continued about discipline interfering with academic growth. Marty mentioned about 24% of the buildings are providing the necessary structure for PBIS implementation. Others mentioned that we need to know how RTI, reinforcement, consequences can be applied across students and settings and all work together.

Governor's List of topics: follow-up on out of state placements issue (page 2) by Marty: Marty shared a recent data pull of out of state totals, private school, program, resident, self-contained special schools, and senior plus data. A total of 1645 records were pulled with 96% noting residence as the location for school attendance and 4 (0%) out of state, and 2% receiving education in a self-contained special school. It is possible that the 84 kids noted from earlier out of state data, they could be the same kids with autistic disorder as a primary condition leaving 11 of those on the autism spectrum, though we don't know duplicates for sure. Children in foster care and not in their resident district makes comparisons from state to state difficult given different vocabulary used in the different systems of data (DHS and DE), but the number is suspected to be low.

Update on DE study of IEP data: The study is being proofed, with errors found in a table, but it does not change the data by much. The study used the National Autism Council evidence based practice report as a reference and a new Missouri report has been recently released: Autism Spectrum Disorders: Guide to Evidence-based Interventions A 2012 consensus Publication Missouri Autism Guidelines Initiative www.autismguidelines.dmh.mo.gov . If our sample was coded by Missouri guidelines, most of our sample would be getting researched based practices. So how do we amend or change our report? If

there is an education group from the Iowa Autism Council wanting to look at that, let me know, says Marty.

Governor's List of topics that has become an Iowa Autism Council activity not a recommendation:
Gather other state autism tool kits for distribution. Autism Resource Tool Kits were mentioned as a potential resource for providers of services. There are various ASD tool kits available as well as other tool kits but the group would need to study these more closely to know about all that are available and which ones might help the most.

Governor's List of topics that has become an Iowa Autism Council activity not a recommendation:
gather police and EMT training in autism for more consistent distribution. Susan Smith said that the Resource Centers have a tool kit on interacting with mentally challenged individuals which they send to law enforcement and EMT departments at the state level and many of these agencies have expressed positive feedback regarding the effectiveness of these tool kits as a training tool for their staff members. Casey Westhoff also stated that the ARC has a website which also makes people/agencies aware of resources that are available to broaden people's awareness and knowledge base.

Casey asked if we needed a stand-alone website for this kind of information. "Is there a better way to get our information out there for families and professionals?" Do we need a better awareness, distribution of the resources we already have?

Rachel Heiss suggested a possible action step would be to contact law enforcement academy and police departments to see if the Council could send them out information that we gathered as resources. Laura Larkin mentioned that for all state employees working in a mental health environment there is a minimum requirement of 12 hours of mental health training. Susan Smith stated that the Iowa Sheriff's Association gets training annually through I-PART.

Governor's List of topics that has become an Iowa Autism Council activity not a recommendation:
DSM5 impact on Iowa school services. Sue Baker stated that we could communicate information as to why this medical diagnosis change will not change the education eligibility system. For folks who are adults and don't meet the new DSM5 criteria, they may potentially fall off of the covered spectrum. Diagnosis is needed in order to receive services as an adult. First, they look at if a person is Medicaid eligible and then second, they look at if a person has a chronic medical condition. Consideration for distribution through websites, and Autism Society of Iowa electronic newsletters were options.

Governor's List of topics that has become an Iowa Autism Council activity not a recommendation:
target insurance legislation for ASD. Robin Sampson stated "It's difficult to know what's out there." Steve Muller suggested that he would like to form a group to get together with the key legislators and have some round table conversations. Now is a time when many new legislators are coming into office and this might be a valuable thing to do. It was asked for instance if Josh and Steve should be doing this as an action representing the Iowa Autism Council or themselves as individuals.

The group was reminded that the council is advisory and not allowed to function as an advocacy group so all persons whether networking as themselves or in a small group must be representing themselves and not the Council. This would be informational not lobbying.

It was mentioned that Senator Matt McCoy suggested waiting until after the election and then to do something regionally. This could be one hour with key legislators with some parents telling their

insurance stories. Robin Sampson stated, “You have to do the process right and connect the right folks up with each other.” Rachel Heiss suggested that people go to regional meetings that are within a legislator’s area so that they have an ability to influence the legislators thoughts as they are more open to the input of their constituents.

Governor’s List of topics that has become an Iowa Autism Council activity not a recommendation:

Children’s Mental Health Redesign: Casey Westhoff mentioned the Senate file 2315 service delivery systems issue and a citizen he spoke to recently. A man in Waterloo was concerned that the redesign is not focusing enough on autism and not helping enough for folks with Autism. Per discussion regarding File 2315, Section 22, developmental disabilities data is being collected and will be due to the legislature in November. Would this Council group ask DHS to address ASD specifically in the redesign?

Laura Larkin stated, “When a redesign happens and people lose services simultaneously they are sure that the redesign process is responsible for this.” Chuck Wadle stated, “There are multiple factors that affect services/eligibility such as waivers, CAPs, and the struggles that ensue.

Governor’s List of topics that has become an Iowa Autism Council activity not a recommendation:

autism specific waiver. Lin Wessels stated, “Without an Autism waiver a child has to qualify underneath another umbrella to get services. Laura Larkin asked if the council has requested a meeting with Director Palmer as was suggested at a previous meeting. It was thought that this was done and no response received.

Continued Governor’s List of topics that has become an Iowa Autism Council activity not a

recommendation: Children’s Mental Health Redesign. Casey Westhoff made a motion to request another meeting with Director Palmer and Administrator Schultz of MHDS to convene a workgroup regarding Autism and the redesign process. Karn Johansen seconded this motion. Based on this motion the Council’s outcome is to evaluate the expansion funding to include people with ASD and eligibility for services of persons with developmental disabilities. This passed by voicing “ayes” (quorum) with none opposed.

Action Plans before September 7th: Josh will put together an e-mail for Council members to vote on action steps 1 and 2 below and other recommendations and action plans above. November 7th is discussing who and how will we accomplish these items.

Action Step 1: Karn Johansen suggests adding staff development/ educating healthcare providers (medical school, nursing schools) about autism for treatment purposes and making referrals to supporting agencies. This could include early identification (connecting BCBA providers with pediatricians to decrease use of medications). Chuck Wadle – Most persons don’t want to see it because they don’t know what to do with the information.

Action Step 2: Dissemination of information to medical providers within the state and address continuing education if needed.

A Council member motioned to adjourn the meeting (2:15) and it was seconded ; it passed by a quorum, with none opposed.