

Iowa Autism Council Meeting
Final Minutes November 12, 2014
Meeting minutes taken by Beth Buehler-Sapp

Present: Theresa Croonquist, Rachel Heiss, James Curry, Steve Johnson, Matthew O'Brien, Sean Casey, Jan Turbes, Jim Mumford, Laura Larkin, Jeffrey Jennings, Angela Logsdon, Tara Underwood-Levin, Mary Jackson, Wendy Trotter, and Beth Buehler-Sapp.

Guests: Erika Hertel and Peggy Swails from Child Health Specialty Clinics @UIHC RAP Program

On Conference Phone: Lin Wessels. **On Polycom:** Frank Kohler, Alyson Beytien

Absent: Steve Muller, Becky Harker, Andrew Waldschmitt.

James Curry called the meeting to order and members and guests went around the room and introduced themselves. Members reviewed minutes from the 9-10-14 meeting. James Curry made a motion to finalize the minutes and Steve Johnson seconded the motion, minutes approved.

Rachel Heiss mentioned that since there has been a change in the Diagnostic DSM-5 criteria there could be a large increase in the number of persons with an intellectual disability now eligible for services.

Tara Underwood-Levin gave an update regarding the RAP program at UIHC. They have been working to fill a number of positions including several family navigator positions (a position housed at Childserve in Des Moines, a couple of positions at CHSC in Iowa City) and one or two new professionals on the expert panel.

They are also planning on hiring a social media coordinator via the new grant to focus on developing a website for resources. They hope to have an interactive website with links to other educational sites and potentially "live chat" opportunities. The website will be housed via CHSC's website.

The RAP staff are also gearing up for a National Symposium in June of 2016 at which they need to present. The 13 regional centers work in conjunction with the HRSA grant to increase awareness of free materials. Their goal is to centralize resource and program information. They also work with COMPASS which has long been a well-known resource directory database.

James Curry stated, "We still need the full picture of what's going on and what we need to do!"

Rachel Heiss asked, "What is the charge of this council?"

James responded, "To advise the Governor and Legislature on Autism and it's impact on individuals on the autism spectrum."

Frank Kohler stated, "Everybody on this council has knowledge and expertise." He has worked in this field for 25 years to identify issues and needs and new needs are evolving. There are exemplary issues and changes for families, especially for enabling parents and serving the whole family.

Alyson Beytien agreed with this and specifically in regard to Transitions into Adulthood. Her question is "Within the statewide scope, is this already being worked on or do we have a way to find out where this is within various areas of the state?"

James commented, "Information is not all in one place. One or two council members with the time could help to pursue what is where."

Steve Johnson stated, "It is hard to know if you're really having an impact." "It seems like it's hard to know where to get the data." This would be quantifiable data outside of Medicaid for whom Magellan is the provider.

Laura Larkin suggested that as a test example we could look at the state employees benefit usage data since their benefit change under 514 C28. This would give us a test group to look at.

Laura also asked, "Do you see the report trying to address in each of these areas or in just a few target areas."

James said, he's not really aware of the specifics of that but he will look into that. If there are things that the legislature endeavors to know about then this could be more focused on. Maybe he can schedule a meeting with a point person for the legislature as to what is really wanted.

Rachel commented, "The world of autism changes all the time so some things may be different." "We really want to advise the Governor and Legislature to make the lives of our autistic population better."

James pointed out that there has been a lot of grass roots leg work that went into some of the insurance changes that have been made. "What are some thoughts/reflections as to what has helped us get to this point?"

Matt O'Brien suggested conducting an informal needs collection regarding the number of adults with autism and the costs associated for the person served. We need to have data to influence a spend request.

Wendy Trotter spoke to the council about a statewide needs assessment data collection project that was recently completed and once the results are available, we could refer to the report to determine what areas of need were identified to help focus our efforts.

Matt O'Brien asked what this project looked like as far as how data was gathered. Wendy commented that this Qualitative Study included interviews from Stakeholders, Educators, Private Providers, and Parents.

Rachel Heiss said, "It's great to be talking about holes rather than the absence of anything at all, which would have been the case 25 years ago."

Frank Kohler said, "As we identify issues we can collect data, interviews, statistics, and prevalence."

Steve Johnson remembered from the November 11th meeting that the group was going to pull together specifics to gather data. Steve will look into where this is and report back at next meeting.

James Curry asked, "Is there a way to figure out what the financial cost is for a residential placement?"

Alyson Beytien said that Marilyn Althoff of Hills & Dales and DHS have worked closely on this and that Alyson can probably access this information to provide to the council. Alyson is familiar with the challenges of out-of-state to in-state relocation as she experienced it first hand with her son's transition back to Iowa as a young adult.

Alyson spoke about 4 young men who within the last 4 years went into HCBS placements. During this time they saw a 60% decrease in behavior incidents and a 40% decrease in duration of behavior incidents.

James mentioned to council members that if anyone knows of families who would be willing to share financial placement cost data with the council the council will be interested in this.

It was also suggested that we should be able to access public data regarding Glenwood and Woodward to look at the data they have available. This data will hopefully provide cost of service, # of people served daily, cost daily, and age breakdown served.

Laura Larkin offered to gather this information and send to James so he can organize and send to the council members to review. Questions: What picture are you trying to paint/research? And Is a HBCS more cost effective?

Rachel Heiss stated, "Be careful what you put out there as in past instances is has been a contributing factor to caps being put in place."

Steve Johnson says Magellan would have lots of data to review and he is going to try to organize this prior to the council's next meeting.

Sean Casey asked, "What are we calling effective/successful? There are a lot of different ways to define these."

James said, "It helps to illustrate what we're up against and identifying who or what entity we need to engage to have a successful presentation."

Matt O'Brien mentioned that the new system to train teams within the various AEA's to work with students with Challenging Behaviors has been extremely successful.

Matt O'Brien asked Wendy Trotter, "When can we expect to see the results from the needs assessment survey which was recently done?"

Wendy Trotter indicated that the summary report should be available after the first of the year (January 2015) and suggested that if council members would like to review the report and discuss results prior to the March 2015 meeting, we could do so via phone conference.

James stated "Anyone who wants to represent the Iowa Autism Council on the Expert Panel or other group is entitled to do so."

Peggy Swails from the RAP program will send the minutes from the recent expert panel meeting to Beth when they are approved and Beth will send them out to the Iowa Autism Council Members for review. Iowa Autism Council Members who are currently on the Expert Panel are Sean Casey, Wendy Trotter, Tara Underwood-Levin, Alyson Beytien, Steve Johnson, and Laura Larkin.

Steve Johnson told the group that due to a recent change, 2 year olds should now be referred to Magellan rather than IAS.

James asked the council members if they thought they should choose just one or two items to focus on for the upcoming year.

Sean Casey commented that typically workgroups (smaller) are able to accomplish more than working in the larger group.

Alyson Beytien suggested that the council get more data and choose one or two areas that the council could focus on to shape more effective change.

Jeffrey Jennings stated, "Sometimes decisions are made too much on timetables." He thinks having more time to process choices is more beneficial than having to make rushed decisions

by deadlines.

The Autism Support Program will continue funding at the current level. However, it is important to determine what might be contributing to the minimal usage of the funds to date. James suggested the council look at the income guidelines and ages limits so see if either of these criteria need to change to allow more families to access the funds.

Alyson Beytien talked about the importance of a Comprehensive Applied Behavior Analysis Program or Focused Applied Behavior Analysis Program. These are especially important for the assessment of individuals over the age of eight as they are experiencing the pre-pubescent and puberty years and many hormonal changes are occurring.

Matt O'Brien agreed with Alyson's information and stated, "Research shows that early skill acquisition programs don't have the same amount of effectiveness after the age of seven." ABA Therapy is not just early skill acquisition and the ABA behavior modification component may still be very beneficial. Reimbursement rates are higher for ABA services than any other treatments.

Rachel Heiss mentioned that since public school districts provide education services through age 21, that we may want to follow their example and expand the age for ASP.

Several council members agreed that the council may want to consider expanding the eligible age for the Autism Support Program to age 21 to be more consistent with other providers and to allow young persons with autism spectrum disorders to access needed services during some of the most difficult developmental times (puberty to young adulthood). Alyson mentioned that for this population of kids (this age range of 9-21), there are often no other funding streams available.

Council members discussed how individuals with ASD need specific training on social skills for employment, living on their own, etc. that can be done via ABA therapy if they had access to funding for these services.

Sean Casey asked Mary Jackson if her agency would have the employment data which we would want to look at as a group or subgroup. Mary said this would be available through Voc Rehab. Wendy Trotter said some of this information might be available nationally.

James will contact Josh Cobbs (former member) to see what information Josh gets while at the Autism Law Conference which he attends annually. Sean suggested talking to Josh Cobbs about the best way to proceed with legislative communication since Josh is very familiar with this by having done so for years. Sean also suggested talking to Barb Guy to gather transition data.

Rachel Heiss suggested for interested Iowa Autism Council members to go to their individual senator's and congressman's meetings so that topics/concerns are reinforced to legislators.

Lin Wessels volunteered to locate a legislative map which shows all of the legislators meetings around the state and provide this to council members so folks can decide if they can go to any of the meetings.

James will work on the 2014 Report to the Governor/Legislature and get a draft out to council members by the 1st of December.

Wendy Trotter brought up that Steve Muller (present chair) had sent her an email stating that he was stepping down as chair after completing his one year term. Wendy reminded the council that according to the by-laws, we are to elect a chair and co-chair annually. Steve Muller (via email to Wendy Trotter) nominated James Curry for chair, Lin Wessels seconded the motion.

Lin Wessels nominated Alyson Beytien as co-chair and James Curry seconded the motion.

Lin Wessels shared that it's harder to get services in rural areas than in urban areas. The cost for families is also a factor. There is a new service provider for transportation for families called TMS. This agency will pay the mileage for patients having to travel to urban areas to receive services. Reimbursement is a difficult process and sometimes folks give up because it's too much of a hassle.

Tara Underwood Levin mentioned that on a parallel note that the Pediatric Integrated Health Homes program has a benefit where if a client is enrolled the family can get their mileage reimbursed for travel costs related to their child's medical/therapeutic needs.

Jan Turbes made a motion to adjourn the meeting and Angela Logsdon seconded the motion.