

# Iowa Autism Council Meeting

Minutes – March 8, 2017

Meeting minutes taken by **Beth Buehler-Sapp**

**Present:** James Curry, Erika Hertel, Angela Burke-Boston, Theresa Croonquist, Andrea Keith, Brandon Reese Arkland, Rachel Heiss, Jan Turbes, Wendy Trotter, Angela Logsdon, and Beth Buehler-Sapp.

**Absent:** Steve Muller, Jeffrey Jennings, Susan Etscheidt, Rik Shannon, and Sean Casey.

**Zoom:** Matthew O'Brien, Jenny Phan, Connie Fanselow.

James Curry called the meeting to order at 10:10 am. Council members reviewed the minutes from the November 9, 2016 meeting. Two edits were suggested. Andrea Keith addressed a few questions that came up in the November meeting regarding what, if any, training do Vocational Rehabilitation (VR) counselors receive related to ASD. She reported VR counselors do not receive any ASD specific training. James Curry motioned to approve the minutes as corrected and Jenny Phan seconded the motion. Minutes approved.

## Introductions/membership updates:

Participants introduced themselves. Rachel Heiss reported this was her last meeting (her term is ending) and she is retiring and moving to Wisconsin.

Other terms ending on May 1<sup>st</sup>, 2017 include: Angela Logsdon, Jan Turbes, and Jeffrey Jennings. Angela Logsdon has reapplied for another term and received confirmation. Jan Turbes is stepping down upon completion of her term. Jeffrey Jennings was absent from the meeting so we do not know his intentions.

## 2017-18 IAC election of co-chairs:

Wendy Trotter initiated electing next year's chairs. Matt O'Brien expressed interest in continuing his current position as co-chair. Brandon Arkland also expressed interest in co-chairing the council. Council Members voted and approved Matt and Brandon as co-chairs for the 2017-18 term.

## Legislative Updates (SSB 1043/HSB 41):

Jenny Phan reported that the House bill had unanimously passed and was now circulating the senate. She stated that a Facebook group dedicated to insurance reform in Iowa has been emailing legislators and gathering names of those supporting the bill. They have had limited responses thus far. However, they have noted some senators who had not supported the bill in years past shifting to supporting the bill this time around.

Brandon commented that he has heard some legislators express concern that if they say "yes" to insurance coverage for ASD that they will have to say "yes" to other types of "special treatment" – but this is a misinformed assumption.

Angela Logsdon reported that Autism Speaks has been very helpful in moving this legislation forward. She stated that there are still some concerns regarding specific language in the current bill (i.e. age and cost limitations, limiting the number of visits per year, etc.). The House bill passed the sub-committee quickly, but some concerning language was included in that version. In the Senate bill, modifications to some of the concerning language were made prior to voting.

Jenny stated that the Senate bill is similar to the House bill which is similar to laws in other states. It is a compromise, but at least we are getting a foot in the door.

A question was asked if there would be administrative rules that would have to be drafted if the bill passed. Angela Burke-Boston stated that if the bill is written very clearly they may not need administrative rules.

In summary, bills have made it through the first funnel and supporters are optimistic that they may pass through the second funnel as well. Matt O'Brien shared that both bills were introduced by Republicans this year, so supporters are hopeful they will receive more support than in previous years.

#### Strategic Plan Update:

#### **Focus Area B** (Have Access to and Obtain Needed Services) -

##### **Strategy 3** (*Increase access to high quality services throughout the lifespan*):

- Wendy Trotter updated the Council on work happening related to statewide educational services and supports. A small task team has been working on developing a tiered system for supporting and training school personnel to support students with ASD and their families. The task team met in January and again in February. Work is still in the preliminary stage, but Wendy will continue to update the Council as they progress.

##### **Strategy 3 & 4** (*3 – Increase access to high quality services.../ 4 – Ensure equal access to high quality and timely services across the state regardless of geographic location*):

- Brandon spoke to Maria Valdovinos from Drake University about the status of their BCBA program. Drake will be offering programs next fall.
- Jan Turbes stated, Briar Cliff is continuing the undergraduate program in behavior analysis but the graduate program is not accepting new applicants due to the discontinuation of the program.
- University of Iowa does not yet have an approved program, but they are looking to partner with Drake to offer satellite classrooms.

#### **Focus Area A** (Get a Good Start) –

##### **Strategy 1** (*Expand and intensify public awareness of the early signs of ASD and educate the public on the benefits of early identification*):

Peggy Swails, who was unable to attend the meeting, reported the following updates via email sent to Wendy Trotter:

##### Iowa Act Early –

- Developed New Logo
- In the process of developing a brochure insert/stand-alone flyer to increase awareness on Iowa Act Early/CDC LTSAE program and free materials

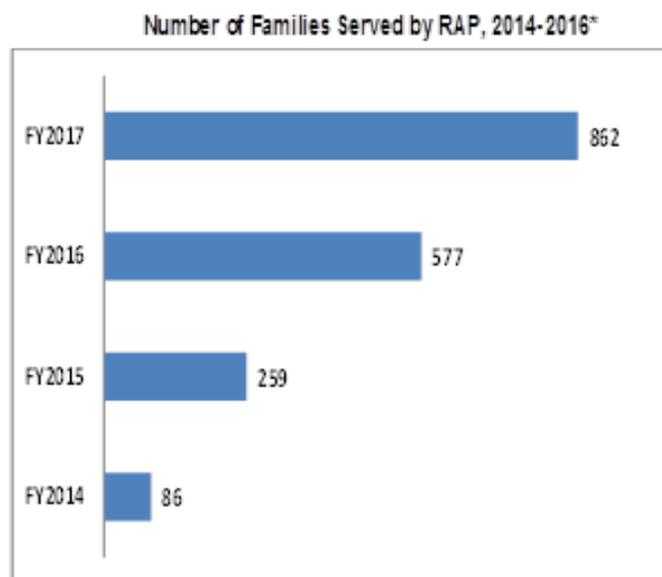
- Developed Iowa Act Early website:  
<http://www.iowachildhealthconnections.com/iowa-act-early>  
(being moved to: <https://chsciowa.org/programs/iowa-act-early>)
- New email being created: [iowa-act-early@uiowa.edu](mailto:iowa-act-early@uiowa.edu) – should be “live” next week.
- New Phone # being created as well
- Peggy and Rachell have met with Tom Rendon with Early Head Start/Head Start. Discussions held on developing a one-day training on early signs and symptoms of ASD, referral sources, family-to-family support. Will use materials from the CDC’s LTSAE program, Autism Navigator, Iowa Child Health Connections website, etc. These discussions have broadened to offering this training on a regional/multi-state level, in collaborations with the Act Early Ambassadors from NE, MO, and KS.

**Strategy 2** (*Ensure that Iowans are receiving timely screenings and comprehensive diagnostic evaluations at the first suspected signs of ASD*):

- Kelly Pelzel has been trained on the STAT. She can offer TA to our ARNPs and RNs who have been trained.
- Two RNs have now been trained. These are regional centers where there is not an ARNP (Carroll and Spencer).

Regional Autism Assistance Program (RAP) Update: (*as reported by Erika Hertel and email from Peggy Swails sent to Wendy Trotter*)

- Tara Underwood Levin is no longer with Child Health Specialty Clinics – she has moved to private practice.
- RAP continues to grow since launching the statewide program in 2014. Below is a chart prepared for the bi-annual report to IDPH in January 2017. This information was also shared with legislators during Autism Day on the Hill on February 1.



\* These numbers represent families being served by RAP - both new and ongoing

- Developing New Processes to Increase Access to Family-to-Family Support. A Family Navigator (FN) Consult was developed with coordination between RAP and the DCCH Family Navigator Network. This FN consult has been added to the UI Hospital and Clinic's (UIHC) electronic medical record system, simplifying the referral process and increasing families' access to the statewide family-to-family support.
- A new guide will soon be available to families. *Navigating Iowa's System of Care: A Caregiver's Guide to Autism Spectrum Disorder, First steps after Diagnosis.* This new guide was developed with HRSA funding and was a collaborative effort with several providers, including the University of Iowa Stead Family Children's Hospital – Autism Center & Child Psychiatry. One of this year's ILEND trainees, Jessica Gallegos – MSW student, led this project. The guide will be available for distribution in April.
- HRSA project funding ends 3/31/2017. Final, comprehensive report due 6/30/2017.
- IDPH state funding for RAP was decreased by 3.86% (\$15,447) effective for the remainder of State FY2017. As of right now, this decreased amount will be the appropriated amount for the FY18 budget.

#### Autism Support Program (ASP) Update:

Connie Fanselow reported that every December DHS files a report with the legislature on ASP. Here is a link to the Autism Support Program annual report:

[http://dhs.iowa.gov/sites/default/files/Autism\\_Support\\_Program\\_Fund\\_2016\\_Report.pdf](http://dhs.iowa.gov/sites/default/files/Autism_Support_Program_Fund_2016_Report.pdf)

Below is a summary of data for State Fiscal Year 2016 (SFY 16): **July 2015 – June 2016**

1. The total number of applications received under the program for the immediately preceding fiscal year.
  - MHDS received 31 applications during SFY16.
2. The number of applications approved and the total amount of funding expended for reimbursements under the program in the immediately preceding fiscal year.
  - MHDS approved 15 of the applications received during SFY16. The remaining 16 applications were denied for the following reasons:
    - 10 were over income guidelines
    - 4 did not supply a diagnosis meeting the program eligibility requirements
    - 1 did not supply evidence of denial by third-party insurance
    - 1 was found to be Medicaid eligible

Three of the ten applicants that were denied as over income prior to July 1, reapplied and were enrolled in ASP after the income eligibility ceiling was raised to 500% FPL.
  - A total of \$356,440.55 was expended during SFY16 for reimbursement to ABA service providers. This represents an increase of 295% from \$120,875.88 expended during SFY15.
3. The number of eligible individuals on a waiting list, if any, and amount of funding necessary to reduce the existing waiting list.
  - No individuals have been placed on a waiting list due to funding. Individuals who have been found eligible for ASP funding are sometimes placed on waiting lists

with provider agencies due to lack of provider capacity. ASP funding has been sufficient to serve all eligible individuals to date.

**Additional Information:**

- 33 children have received ABA services through the program
- 2 children have completed their full 24 months of eligibility
- 20 children are actively enrolled
- 10% of applicants are female and 90% are male
- the average age of ASP applicants is 4.7 years
- the average income of ASP applicant families is 364% FPL
- the average monthly service cost paid from the ASP fund per participant (after the family cost share is applied) is \$2592

As of March 2017 – ASP has expended approximately \$330,000, and projects they will spend \$450,000-\$500,000 for the 2016-17 fiscal year. Appropriations for ASP have been reduced from \$2 million down to \$900,000, but given expenditure trends, this should still cover approved services. Unspent funds from this year have been repurposed to cover budget short comings.

Since December 2016, they have had 57 applications; 8 last month. Still seeing denials due to income being too high, but they are seeing an increase in applications since the income eligibility ceiling was raised to 500% FPL.

James Curry asked if we have a sense of what the income tends to be – would there be a logical new cutoff that could be proposed? Connie responded there doesn't appear to be a percentage trend that stands out; but if they did make any adjustments, they would also need to increase the cost share percentage to include higher income levels.

In December 2016 there were 21 individuals receiving services. In January 2017 there were also 21 individuals receiving services. Connie stated that they seem to be enrolling and un-enrolling fairly frequently. Reasons vary, but mostly if families leave the program it's because they have had a change in eligibility due to now receiving coverage via other means, i.e. Medicaid waiver slot, Medicaid coverage, insurance change, etc. However, they will allow families to enroll in ASP even if they have been notified of receiving a waiver slot because it can take 4-6 months to get services initiated via the waiver program. So ASP is often covering the interim period between coverage options for families.

Connie also reported that they have had 3-4 families request the co-pay to be waived and all of those requests have been granted thus far.

James Curry asked, "Are there any RAP served families also receiving ASP services?" Connie reported that so far for 2017, 100% of families receiving ASP services were also receiving RAP family navigator support.

BCBA Education Grant Update:

Wendy reported that there is a new contact now for inquiries related to the BCBA education grant. Her name is Megan Hartwig.

Matt reported that he believes 11 people were awarded the grant for this year.

James asked if \$250,000 was being allocated again this year from ASP to this grant fund. The answer was not known.

### Review of IAC goals:

James reviewed progress on the following goals that were identified by the Council for 2017.

1. Insurance Reform – as reported earlier, this is progressing. If you feel strongly about this, as an individual constituent you can reach out to your individual legislators to indicate your support.
2. ASP – it was reported that ASP will continue to be funded, but appropriations were cut to \$900,000.
3. Statewide Transition Plan for Compliance with federal home and community-based services (HCBS) – do not know the status; will defer to next meeting.
4. Iowa Strategic Plan – Wendy discussed bringing in various groups and organizations that may be addressing some of the focus areas identified in the plan to council meetings so that the Council can begin to foster collaboration among these providers.
5. Minimum wage vs. reimbursement rate floor – James suggested we re-extend an invitation to the MCO representatives to attend our meetings. This would help us to engage in conversations around this issue and to know the status.
6. Reduction of wait times associated with HCBS Waiver Program – Angela Burke-Boston reported that there is a new DHS quarterly report that addresses this issue: <https://dhs.iowa.gov/sites/default/files/Q2SFY17report02202017FINALv1.pdf>

### ABLE Act:

Rachel Heiss asked if anyone knew the status of the ABLE Act?

Andrea K stated she thought they were opening them now in Iowa.

Angela B stated that it is a consortium between several states.

Angela Logsdon stated the treasurer's office launched the program last month and are now accepting money. You can learn more at [www.iable.gov](http://www.iable.gov).

Rachel asked if it had to be done in the state in which the person lives?

- Andrea – doesn't think it matters.
- Angela L – look at the rules on line – there may be something about age limits
- Andrea – individuals need to have been declared disabled before age of 26. Also, if the person passes, that money then goes to state Medicaid, so be aware of that.
- Angela L – the fund is tax deductible (state) up to a certain amount.

### Agenda items for the June meeting:

- Initiative updates
- Statewide transition plan for HCBS
- Minimum wage discussion
- Voc Rehab update – services available, how to access
- Set schedule for meeting dates for next fiscal year

James Curry made a motion to adjourn the meeting. Jan Turbes seconded the motion. Meeting adjourned 2:45pm.