



## IOWA COUNCIL FOR EARLY ACCESS

May 5th, 2023

9:30 a.m. - 3:00 p.m.

Iowa Department of Education

Grimes State Office Building, ICN Room

400 E. 14<sup>th</sup> Street

Des Moines, IA 50319

[Agenda](#)

**Iowa Council for Early ACCESS Call to Order:** Annette Hyde called the Iowa Council for Early ACCESS (ICEA) to order at 9:34 a.m., May 5th, 2023.

Due to last minute notifications today is not a quorum. This is a discussion meeting only. We can take action for a new chair for the next meeting.

Annette Hyde asks for a motion to adjourn the meeting end time. Kimberly Villotti made a motion to adjust the meeting time to approximately 1:30 pm. Julie Allison seconded.

**Council Members Present:** Julie Alison, Annette Hyde, Michael Bergan, Marcus Johnson Miller, Marguerite Macek, McKaylee Heuton, Tonya Weber

**Council Members Absent:** John Fuller, Sue Wittmack, Stephen Mandler,, Emma Bouza, Jonathan Wunderlich, Aaron Cronk, Lee Pool, Julie Jones, Jess Burger, Rozanne Warder, Karen Thompson, Eric Locke, Megan Lancaster

**Early ACCESS Staff Present:** Kate Small, Meghan Miller, Melissa Schnurr, Dee Gethmann, Tonya Krueger, Teri Mash, Kimberly Villotti

**Approval of Minutes:** We cannot approve the minutes from January but they are attached if you'd like to take a look. We can approve those at the next meeting.

**Differentiated Monitoring: Funds and Fiscal Management;** Kimberly Villotti discussed the federal allocation of the grant report that was received 24 hours ago for the Early Access budget: the state funding is just over 1,000,000 and Federal funding is 5,000,000 for Part C. The entire funding total will be about 6.7 million. She discussed how the budget functions and how funds are allocated; including staff, funding towards operation of the council, maintenance and implementation activities, direct services ( over 20 services make up 1/3 of the budget), activities by State Agencies, Optional use of IDEA Part C funds, and indirect costs.

**Family Story:** The ICEA member, McKaylee Heuton shared her family story. When she was pregnant she found out that her husband and his brother had two balanced chromosomes that could be passed onto their children. At 20 weeks along, they saw their baby had a two vessel umbilical cord instead of three. She was referred to a prenatal specialist in Des Moines. She ended up developing preeclampsia and at their next appointment they realized their baby wasn't growing as rapidly as normal and did a downs syndrome risk test that came back as high risk. She was admitted into Mercy Hospital at 36 weeks and induced. She had a C-section and her daughter was born heavier than required for the NICU. She fell out of her baby swing at four months old and brought her to the ER and there they heard a heart murmur as well as concerning oxygen levels. They were also concerned about her size and wanted to do genetic testing. They found she had Phelan McDermid syndrome which only affects 3200 people worldwide. In her case, she is missing part of the 22nd syndrome and her baby has a duplicate on the 26th chromosome. Markers of this



condition are developmental delays, intellectual challenges, and heart conditions and murmurs. They self-referred to Early Access and began the services when she was 5 months old. She found help and a community within their services. They came in and helped create a plan and how they intended to help her daughter meet these milestones. They were also a sounding board and listening ear for her. They were involved in Early Access until she was 3 years old and transitioned to preschool. She was also able to attend conferences and meet-ups with other Phelan McDermid families and doctors. She praises her service advisors for their help with insurance and Medicaid. Early Access and the AEA helped them procure hearing aids as well. Her hearing has since gotten better and she no longer needs them.

**ACHIEVE IDEA Data System:** Council member Kate Small explained the data system ACHIEVE. She showed the Early Access Family Involvement Surveys that were sent out and the data that was imported from the results. She also showcased the new technology this allows; including nudges. Staff is currently working on ACHIEVE Phase 2 (integrated monitoring and real time data), testing the Family Portal, and Early ACCESS reports.

**CAPTA referrals in ACHIEVE:** Early ACCESS State Team member, Teri Mash, and ICEA Council member, Julie Allison, shared the annual data of referrals to Early ACCESS. The referrals are increasing, showing better referral processes in place. The Council reviewed referral data from ACHIEVE relating to the status of outcomes and reasons for ending referrals. Keystone AEA could potentially pilot conduct a joint training with Department of Health and Human Services social workers and Early ACCESS providers in the region. Teri is now entering the CAPTA referrals into the ACHIEVE system, follow-up, and collaboration with DHHS and AEA Early ACCESS providers. Teri is collaborating with the families' social workers to ensure accurate data, contact information, and family circumstances. This information has helped to support referrals and follow-up of CAPTA referrals. Additional information is going to be provided to DHHS social workers regarding the Early ACCESS referral process and intent of Early ACCESS in the fall in a recorded session to share internally.

[CAPTA data](#)

**Family Guided Routines Based Intervention (FGRBI):** Early Access member Melissa Schnurr described the key components and implementation of FGRBI. One of the key components of this is integrating skills into what is already being done in the family's routine. Another component is helping to guide and teach parents the skills necessary to help them and their children succeed. Another step of this is teaching other Early Access providers to be trainers in order to teach this framework and implementation to both their families as well as their peers.

**Additional Updates and Announcements:** Council member Julie Alison stated that since March 2020, the State will have paid out nearly ½ a billion dollars in Iowa to support child welfare and stated some of the various programs that have been implemented and available.

Kimberly Villotti gave updates from the Department of Education. She brought up the Governor's Executive Order ten and the request that duplication be removed from the rules. All agency staff are going through anything related to Early Access and checking for duplication. She also updated the group that the DE has a new director; Director Chad L. Aldis. She also reminded the group that State agencies are preparing themselves for the realignment that takes place on July 1st, 2023.

Council member Marguerite (Peg) Macek updated everyone that the Director of the Child Specialty Health Clinic Thomas Scholz is going back to being a cardiologist within the university so they are searching for a new director. She also reminded the group that the nurses and doctors are trained



to be Autism screeners. University of Iowa Children's Hospital has a new position that has been filled - NICU Family Support Specialist/Liaison and it has been filled by Grant Wood AEA early access service coordinator.

Upcoming dates will be coming after review of general availability. That information will be forthcoming

**Adjourn:** Chairperson Annette Hyde adjourned the meeting at 1:24 pm.