

**HDI Consumer Advisory Council Minutes
UK Coldstream Conference Center
Monday, December 12, 2016**

In attendance today...CAC members

Traci Brewer
Elaine Brown
Walt Bower
Camille Collins
Jennifer Crawford
Cathy Edwards
Lee Gordon
Katie Bentley (for MaryLee Underwood)
Jay Tyner Wilson
Morgan Crawford

Guests: Megan Russell, Samantha Harrison

Presenter: Stephanie Meredith

Technical and other assistance: provided by Maurice Dawson

1) Welcome and Introductions Cathy Edwards

All members introduced themselves.

2) Review and Approval of September Minutes Cathy Edwards

Traci Brewer made a motion to approve the minutes and Jennifer Crawford seconded the motion.

3) AUCD Update – Council on Community Advocacy Jennifer Crawford
and AUCD 2016 Annual Conference

Jennifer participated in the previous Council on Community Advocacy (COCA) conference call and reported they talked about more COCA member involvement within the Association of University Centers on Disabilities (AUCD) network. Jennifer also announced there was a suggestion to video conference the call instead of having a phone conversation. In addition, she reported there are scholarships available for self-advocates and parent advocates to attend the AUCD conference.

Jennifer also attended the COCA meeting held on Sunday, December 4 at the AUCD conference. She provided an HDI update at the meeting and announced that HDI had recently received a new five-year KY Employment Partnership in Employment Systems Change grant. Jennifer also announced that Kathy Sheppard-Jones became the new Executive Director at HDI. She reported that Andy Imparato spoke at the COCA meeting and talked about changes that may occur with the upcoming change in administration. There was also a suggestion that messages from AUCD should be tailored (i.e., large print, logos) to be understood by the relevant audience.

Jennifer announced that she attended the 2016 AUCD conference in Washington, D.C. and reported that the conference was attended by over 900 attendees. The opening ceremony included cards to ask questions to the speakers. On the second day of the conference, President Obama sent AUCD a letter that was read to the attendees.

4) Update on the KY Supporting Families Community of Practice Walt Bower

Walt provided an update on the KY Supporting Families Community of Practice. The goal of the KY Community of Practice is to develop support systems for families across the lifespan of their family member with intellectual and developmental disabilities. The KY Community of Practice has five Ambassadors: Katie Bentley, Donna Pottinger, Laura Butler, Stella Beard, and Walt Bower.

To introduce the KY Supporting Families Community of Practice, CAC members watched a 10 minute video segment from the National Community of Practice website featuring Sheli Reynolds introducing the LifeCourse framework and concepts. After watching the video, CAC members divided into small groups and completed the Trajectory worksheet, one of the activities in the LifeCourse toolkit.

After completing the Trajectory worksheet, CAC members shared what the good life means to them and also identified what they do not want in life. Walt invited members of the CAC or interested families they may know to join the KY Community of Practice state leader team. Katie Bentley added that family members should respond today if interested in participating in the KY Community of Practice state leader team.

5) Break

6) Project Spotlight – National Center for Prenatal and Postnatal Resources Stephanie Meredith

Stephanie introduced the National Center for Prenatal and Postnatal Down Syndrome Resources at the Human Development Institute as three medically reviewed programs that provide important materials for new and expectant parents learning about a diagnosis of Down syndrome: (1) Brighter Tomorrows, (2) Lettercase, and (3) Down Syndrome Pregnancy. These programs also offer important resources for medical professionals delivering an unexpected diagnoses.

Stephanie provided an overview of Down syndrome and introduced kids representing a wide variety of areas, as well as educational opportunities and Down syndrome resources available to people. Stephanie also explained the importance of the Kennedy-Brownback bill. Passed in Congress in 2008, the Kennedy-Brownback bill provides that any family receiving a prenatal or postnatal diagnosis of Down syndrome or any other condition will be offered accurate, balanced and up-to-date information about the nature of the condition. The legislation also ensures that families have the opportunity to connect with support services and organizations.

Stephanie reported the National Center distributed approximately 70,000 books since 2008 to obstetricians and medical professionals. In addition, the National Center provided trainings to about 85 Down syndrome organizations on medical outreach. The National Center for Prenatal and Postnatal Resources started with Down syndrome but they are now trying to expand to other conditions, including Turner syndrome and Jacobsen syndrome.

- 7) Election of New CAC Vice-Chair and Setting of 2017 Meeting Dates All

Jennifer Myneer will move from the Vice-Chair to the Chair next year. Morgan Crawford was nominated for the position of Vice-Chair and is considering accepting the position. Morgan will contact Cathy Edwards, the previous Chair, to talk about the position.

The 2017 CAC meeting dates are March 6, June 5, September 11, and December 4 from 9:00 am to 12:00 pm.

- 8) Agency Updates (P & A, CCSHCN, DDID) Each Agency

Protection & Advocacy - Camille Collins reported December 13 is the launching of the ABLE Act at the Capitol Rotunda. Kentucky State Treasurer Allison Ball and Kentucky State Senator Wil Schroder will be there for the launching of the ABLE Act. Camille announced the 2017 priorities are listed online on the P & A website. Camille also reported the 2017 General Assembly is coming soon and P & A will be tracking disability related bills. The PADD Board is sending out their members to see if publicly funded entities are accessible.

Commission for Children with Special Health Care Needs – Lee Gordon reported the Commission offices are continuing to work to provide services for Kentucky’s children with special health care needs and their families across the state.

Division of Developmental and Intellectual Disabilities – Walt Bower (for Claudia Johnson) reported that DMS allocated 300 slots for the Michelle P. waiver on September 15. The Division of Developmental and Intellectual Disabilities allocated 87 slots for the SCL waiver from September 7 to October 15. Walt also reported DDID is working with the Human Development Institute (HDI), the Kentucky Office of Vocational Rehabilitation (OVR), KY Department of Education, KY Division of Developmental and Intellectual Disabilities, KY Protection & Advocacy, KY Office for the Blind, Commonwealth Council on Developmental Disabilities, KY Office of Autism, and the KY Autism Training Center have created a Partnership in Employment Systems Change grant to improve post-school outcomes for youth with intellectual and developmental disabilities in KY. As talked about previously in the CAC meeting, the Kentucky Department of Behavioral Health, Developmental and Intellectual Disabilities is partnering with the Commonwealth Council on Developmental Disabilities and the Human Development Institute at the University of Kentucky to join in a National Community of Practice Supporting Families throughout the Lifespan facilitated by the

National Association of State Directors of Developmental Disabilities Services and the University of Missouri Kansas City Institute for Human Development (UMKC-IHD).

9) New Business and Announcements Cathy Edwards

Jennifer Crawford asked if the KY Employment Partnership in Employment Systems Change grant had selected a representative from HDI's Consumer Advisory Council for the state employment team. Traci replied that she is serving on the state employment team representing HDI's Consumer Advisory Council and is sending a letter of interest to the state team.

Jennifer reported that case managers found the new software system difficult to work with and not user-friendly. She commented that the previous system was flexible and there should be a recognition that the new system limits the options of people with disabilities. Case managers are first responders and they should be equipped to allow them to improve the lives of Kentuckians with disabilities. Jennifer added that the new system has to be used to apply for a waiver.

Camille responded that the contact for questions about the Medicaid Waiver Management Application (MWMA) is Kristy Putnam (502-564-3703). Camille suggested to have the family members call to ask questions and voice their concerns rather than the case managers. Alicia Clarke (502-564-1647 Ext 2126; alisha.clark@ky.gov) was also identified as a person to contact with questions regarding MWMA.

Jennifer also reported that at the last COCA meeting at the 2016 AUCD conference that one parent said they were lost in the acronyms. Jennifer suggested creating a welcome packet to the CAC when a person becomes a CAC member. The welcome packet could explain their role on the CAC or what a typical meeting looks like. Cathy added that it should be something that is not technically written.

10) Special Recognition Walt Bower

Walt recognized Cathy Edwards for her outstanding service as the CAC Chair in 2016 to HDI's Consumer Advisory Council and presented Cathy with a certificate of recognition at the meeting.

11) Lunch and Further Discussion about CAC Members' Involvement in HDI Projects All

Next CAC Meeting: Monday, March 6, HDI Coldstream training room, 9:00 AM – 12:00 PM, followed by a working lunch.

Jennifer Crawford made the motion to adjourn the meeting and Traci Brewer seconded the motion.