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

In attendance today...CAC members

Traci Brewer Elaine Brown Walt Bower **Camille Collins** Jennifer Crawford Cathy Edwards Lee Gordon Jennifer Mynear MaryLee Underwood Jay Tyner Wilson Jessica Wolfe

Guests: Megan Russell, Nellie Jones, Claire Mynear

Presenters: Harold Kleinert, Mark Samudre, and Patti Logsdon

Technical and other assistance: provided by Judy Johns

1) Welcome and Introductions Cathy Edwards

All members introduced themselves.

2) Review and Approval of June Minutes Cathy Edwards

MaryLee Underwood made a motion to approve the minutes and Jennifer Crawford seconded the motion.

3) AUCD Update – Council on Community Advocacy Jennifer Crawford

Jennifer Crawford reported that the Council on Community Advocacy (COCA) is looking to fill the position of secretary. The secretary position will require a few hours a month to take the minutes of the meeting, record the roll call of the members, distribute the agenda, and make sure people have the conference call number.

Jennifer also announced that the Administration on Intellectual and Developmental Disabilities (AIDD) and the Administration for Community Living (ACL) came to COCA to gather data on supports and advocacy. The report is in the final stages and will be uploaded to the Association of University Center of Disabilities (AUCD) website.

Update on the KY Employment Partnership in Employment Systems 4) Harold Kleinert Change grant

Harold Kleinert announced the Human Development Institute, with the KY Office of Vocational Rehabilitation, 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 was approved for a Partnership in Employment Systems Change grant to directly impact post-school outcomes for youth with intellectual and developmental disabilities in our state. It took effect on September 1st, 2016.

The grant will help students with the most significant disabilities, specifically students age 18-21, transition from school to meaningful employment or postsecondary education in their communities. The purpose will directly impact post-school outcomes for youth with intellectual and developmental disabilities in Kentucky, or more specifically, it is to increase positive postschool outcomes for students with the most significant disabilities in our state's 174 school districts by increasing integrated employment and participation in postsecondary education over the next five years.

The Partnership has four major objectives: 1) Establishing a state-level employment work group that consists of the above partners, with representation from self-advocates, family members, and our state's Regional Special Education Cooperatives, to conduct a statewide needs assessment. 2) Conducting, within each year of the grant, sustained professional development and Communities of Practice focused on implementing evidence-based transition services. 3) Disseminating information resources to families and students, as well as practitioners and employers. 4) Annually tracking outcomes data related to post-school outcomes for students with significant disabilities to ensure that state level policies promote employment outcomes.

Harold expressed appreciation to all who provided input on the HDI Advisory Council. One member asked how the grant would impact individuals who are not in school. Although not directly, the grant would improve integrated employment and participation in postsecondary education for adults not currently in school.

Harold asked for a self-advocate or family member from the HDI Consumer Advisory Council to serve on the State Employment Team. For the future community conversations, the Employment Team will meet six times for the first year (either in person or by teleconference) and then quarterly in the following project years. Parent and self-advocate State Employment Team members will receive a stipend for each meeting, as well as mileage reimbursement, and attendant expenses as needed.

5) Project Spotlight – Kentucky Peer Support Network Project Seeking CAC Input

Harold Kleinert Patti Logsdon Mark Samudre

Mark Samudre introduced the Kentucky Peer Support Network Project as a project funded by the Commonwealth Council on Developmental Disabilities. The project was adapted from the work of Dr. Erik Carter at Vanderbilt University. The project is based on the new concept of a wellrounded education, which includes the "Three R's"- rigor, relevance and relationship. Among

the three of these, Mark emphasized relationships are at the core of what really matters, and, especially friendships in schools, are at the heart of what makes school enjoyable.

Mark continued reviewing the data on the peer relationships in elementary school as well as secondary school. In elementary school, Harold pointed out that 80% of students with intellectual disability have never been invited to other children's social activities during the previous year. One CAC member commented if students with intellectual disabilities are out participating in social activities and visible participating in social activities. Another CAC members commented that incentives, such as t-shirts provided by a local bank perhaps, might encourage students with intellectual disabilities to participate in social activities.

Patti Logsdon identified and described the seven building blocks for friendships: 1) Shared Activities. 2) Common Interests. 3) Reliable Communication. 4) Valued Roles and Selfdetermination. 5) Prepared students. 6) "Just enough" Support. 7) Regular Reflection and Evaluation. Patti then described peer network and peer support arrangements as two different effective intervention approaches.

Patti emphasized one of the differences between the peer network and peer support arrangements - any school staff could work for peer networks but only a paraprofessional, special educator, or classroom teacher working with individuals with developmental disabilities could work with peer support arrangements. Patti also identified the step-by-step strategies for implementing peer networks and peer support arrangements.

Harold Kleinert shared the outcomes of the KY Peer Support Network Project for 2015-2016. The overall percentage and overall mean for each item for students with disabilities, peers, and facilitators were shared and discussed. Harold also shared representative quotes from parents as well as stories about students with developmental disabilities from the different pilot sites.

Members asked questions and provided feedback following the presentation. A member asked, "Do the peer students need to do some pre-training before they work with students with disabilities?" Another member asked this question, "What is the difference between a peer network and a peer tutor?" One member asked, "Are there any pilot schools in Eastern Kentucky?" One member commented, "An academic gap may exist among students with developmental disabilities before they pursue higher education."

Break

6) **HDI** Update Walt Bower

Walt Bower reported the HDI Graduate Certificate in Developmental Disabilities program has 14 on campus students enrolled in HDI 600 and 7 online students in the program this fall semester. HDI also has 11 research assistants working across HDI projects this semester.

In addition, HDI is offering an Undergraduate Certificate in Universal Design. The first course, HDI 350, in the Undergraduate Certificate in Universal Design will be held on Tuesday and Thursdays morning in the spring 2017 in the classroom in the Mineral Industries Building.

The HDI Fall Seminar Series was also announced. Registration for the first two fall seminars are currently available on the HDI website. Walt also reported that Dr. J. Michael Clyburn accepted the position of Director of the Kentucky Partnership for Early Childhood Services at the Human Development Institute.

7) Agency Updates (P & A, DD Council CCSHCN, DDID)

Each Agency

Protection & Advocacy - Camille Collins reported there will be a seminar titled, "Supported Decision Making: Creating a Culture of Coordinated Support" presented by Jonathan Martinis of the Burton Blatt Institute at Syracuse University on Thursday, September 29. Mr. Martinis will be discussing the concept of supported decision-making and how to use it to create a culture of coordinated supported. The location of the seminar will be at the HDI Coldstream Training Room. Camille also reported that individuals may have had issues, such as long wait times, as a result of Benefind. For some strategies to help you resolve these issues, Camille suggested contacting your state legislator. For their contact information go to www.lrc.ky.gov.

Commonwealth Council on Developmental Disabilities – MaryLee Underwood described the focus of the DD network and reported the Council finalized the goals and objectives for the new Five-Year Strategic State Plan, which will take effect from October 1, 2016 to September 30, 2021. The goals and objectives are oriented to offer support to the most pressing needs of Kentuckians with developmental disabilities and the mandates of the Developmental Disabilities Assistance and Bill of Rights Act.

Commission for Children with Special Health Care Needs – Lee Gordon announced a new support group for Latino families with children and youth with special health care needs that just started in Lexington. The support group is called "Un Abrazo Amigo" (A Friendly Embrace). Dr. Nota, a physician in Louisville with the University of Louisville Pediatrics, is collaborating with CCSHCN to start the support group in Lexington. The Lexington support group meets on the second Monday of each month at the Lexington Public Library Village Branch. Dr. Nota, through support from the CCSHCN, has had a similar support group for Latino families in Louisville at the La Casita Center for about three years now and it has been well attended.

Division of Developmental and Intellectual Disabilities – Walt Bower (for Claudia Johnson) reported that implementation of the SCL regulation is still pending SCL Waiver renewal approval by CMS, with an expected date of September, 2016. There are now, as of July 31, 2016, 184 people on the SCL emergency waiting list. The 240 slots appropriated for fall 2017 will be released when CMS approves the waiver renewal. Effective August 1, 2016, Wendy Morris was appointed as the Department for Behavioral Health Developmental and Intellectual Disabilities (DBHDID) Commissioner.

There was no new business to report.

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

All

NEXT CAC MEETING: Monday, December 12, HDI Coldstream training room, 9:00 AM -12:00 PM, followed by a working lunch.

Lee Gordon made the motion to adjourn the meeting and Jennifer Mynear seconded the motion.