

**HDI Consumer Advisory Council
UK Coldstream Training Room
Monday March 6, 2017**

In attendance today...CAC members

Cathy Edwards
Jennifer Hicks
Jay Tyner-Wilson
Cathy Lerza (in place of Claudia Johnson)
Morgan Crawford
Kathy Sheppard-Jones
Vickey Riley
Lee Gordon
Walt Bower
Jennifer Crawford
Elaine Brown
Jennifer Mynear

Guests: Nellie Jones, Shatier Fray

Presenters: Jill Griffiths, Christina Espinosa Bard, Elaine Eisenbaum

Technical and other assistance: provided by Maurice Dawson, David Flechler, Judy Johns

1) Welcome & Introductions Jennifer Mynear

All members introduced themselves.

2) Review and Approval of December Minutes Jennifer Mynear

Elaine Brown made a motion to approve the minutes and Cathy seconded the motion.

3) AUCD Update - Supporting Families Community of Practice Jennifer Crawford

Jennifer Crawford reported that there had not been a COCA conference call since the last CAC meeting so she provided an update on Kentucky's Supporting Families Community of Practice training for statewide leaders held at HDI on January 25. The training, led by Kentucky's Community of Practice Ambassador Team, discussed community and family involvement and how it can impact an individual over the lifespan.

In the Supporting Families Community of Practice training, there was a lot of advice and techniques that could be taken home to help support families. Walt announced the national team is leading a Supporting Families Community of Practice kick-off on March 15 in Louisville. Cathy Edwards asked if the trainings are welcoming to self-advocates or if it is targeted to family advocates. Jennifer said that self-advocates are more than welcome and the information shared is transferable and not only for self-advocates but also professionals.

4) Update from HDI's Community Education Director Christina Espinosa Bard

Christina introduced herself and provided an update on her projects. Christina, Pat Kitzman, and Health Sciences are working on a Rural Clinic Accessibility Project providing assessments in rural clinics. The goal of the assessment is not to just tell the clinics how they are failing to be accessible. Instead, the goal is to build relationships and identify solutions and funding. The two pilot sites are at St. Joseph Martin and Berea.

She also discussed her role on the Mayor's Commission for Persons with Disability in Lexington. Currently, they are focused on long term parks and recreation plans, affordable/accessible housing, school systems, and transportation. She discussed how in Lexington there is a goal to make it more competitive and how Wheels has started a new notification system with reminders and text/call notifications.

Christina gave a report stating that the Community of Sharing project is based on belief that we all have contributions. The project is working on discovering skills and building social capital. In Adair County, a handful of people with developmental disabilities have been identified and they are working to facilitate good life networks, to create connections in what they are interested in doing, and finding ways for that to pay regularly. In west and east Lexington the Asset Based Community Development (ABCD) approach is being used.

The ADA Task Force exists through the Mayor Commission. Their goal is to bring awareness to Universal Design and increase people's knowledge of UD and enforce ADA standards. Christina explained that code violations should be reported to 311, however if the building is not owned by the city then it should be reported through the Human Rights Commission (HRC). A seminar to train on ADA standards will be held March 16 and 17 at HDI Coldstream.

Christina is the chair of the housing committee for Livable Lexington and they have presented to the remodelers association, proposed a tour of accessible homes for the next year, and they are working to find ways that accessible housing can be identified. The housing committee is working on developing a list of renovators, builders, and contractors who are interested in working with Livable Lexington and UD in mind. Christina explained that this is important because ADA applies to commercial buildings but not home living.

The UK Living Home Project is a multidisciplinary research collaboration with funding coming from Vocational Rehabilitation. It is transdisciplinary across the campus to come together and to come up with a better solution of housing. The goal of the project is to help people live in their own home as long as possible. Cathy asked about other states that have completed this. Christina said that this looks a little different for every region. They will be pulling in experts, but there is not anything in existence that they could cut and paste into Kentucky.

Christina continued and discussed the technical E3TC grant. Project E3 is a federally funded project designed to help state VR agencies address barriers to competitive employment for individuals with mental health diagnosis. Specifically in Kentucky, the goal is to identify barriers to employment for youth and adults with mental health diagnoses in rural and remote areas.

Christina ended by describing to the CAC the role of the center for independent living in Lexington called Independence Place. There are now working on exciting partnerships on health and wellness issues with Independence Place.

After Christina concluded her update, Elaine Brown asked about schools in Paducah; there is not playground equipment for children with disabilities. Elaine wanted to know who she would contact in her area. Christina referred to Vickey Riley. Vickey suggested going to the Western Kentucky Educational Co-op (WKEC) or HRC. Jennifer Mynear asked if Independence Place provides services just in Fayette County. Christina said that they span beyond Lexington and currently their work is being done in 17 to 18 counties around Lexington.

5) New HDI Training Director update Elaine Eisenbaum

Elaine Eisenbaum introduced herself as the new Training Director at HDI. She talked about how she became interested in this field when she started working her first job at a local pool. She met a girl with a developmental disability at the pool that she admired. Elaine started studying special education in college but saw, however, when kids were transitioning from schools they were going into nothing. Elaine continued her education and received her MA in Social Work with a focus on non-profit and transition.

She went back to school and earned her PhD in Social Work. After completing her PhD and working at the UCEDD in Texas, she moved to Lexington to start working at HDI. She explained that HDI is exactly where she wants to be as it has a great reputation and also is bigger than the previous UCEDD she was at in Texas.

Her areas of interests are inclusive research and teaching, transition, and health disparities among individuals with disabilities. She a member of unified teams in the Special Olympics. She stated relationships drive her work. Her vision is community collaboration and education for a more inclusive world. She is currently the Director of the Graduate Certificate in Developmental Disabilities. She is working on marketing the undergraduate certificate in Universal Design to students. In addition, she is involved in other training efforts and is working with Walt to expand the HDI seminars.

Morgan wanted to make Elaine aware that there is a lot of resources in Louisville for assistive technology through Vocational Rehabilitation. There were questions about the Universal Design certificate. Christina said that the certificate would include the built environment and Universal Design of Learning as well.

Before moving on to the next topic, Walt requested that the CAC reintroduce themselves for Elaine. Walt announced the last seminar in the HDI Spring Series titled, "Serving those Who Serve Us." Jennifer Mynear described the Best Buddies Program. Over the last five years the program has really increased activity. There are now more students and individuals with special needs. They have great student leaders. It is all voluntary. She would like to see more high schools involved in the future.

6) Break

7) Project Spotlight – College and Career Readiness (CCR)

Jill Griffiths

Jill Griffiths, with the College and Career Readiness project, talked about developing the career readiness measures by beefing it up for alternative assessments. Currently, the ESAR (Employability Skills Attainment Record) is being used. There is also the Career Working Experience Certification (CWEC), which includes 4 courses.

Jill presented changes in accountability in Kentucky. ESAR has put KY in the process of implementing an accountability system. The first proposal of the new accountability system came out in November, however, there is not a lot about alternative assessment and career readiness in the proposal. It appears there will be minor tweaks and changes with the current grant project, but they overall align with the new system of accountability. The biggest change will be changes in terminology. Schools are getting an additional year for the pilot program before the Readiness Program Part of Accountability.

Now Jill is looking at what is going on in regards to transition readiness in the new system. There is discussion about work based learning as well as workplace readiness skills. In February, teachers will be able to go to the website for training in alternative assessment and learn to use the ESAR. In the summer, there won't be a lot of data but there will be a lot of survey feedback from teachers. ESAR will not be benchmarked until there is sufficient data, and that will not be until 2019. Furthermore, students will not be able to get the work based learning certificate for a while as districts build the courses.

Jennifer Crawford asked about how school accountability works. She brought up a concern of having teams go to these trainings but actually to implement any change is difficult. Getting work place experience will be hard for some schools realistically. Jill said if kids are not career ready the ESAR will produce the report and the only accountability is that schools can be audited. However, Jill stated, "one thing that is positive is that most educators are excited about these changes."

Jennifer Crawford and Elaine Brown asked about ethical concerns and parents knowing their rights. Jill said that action plans in districts will have parent trainings start talking with parents now on the new standards and new assessments. She also discussed the site MSD1stop as a parent resource. This site is a one stop place where parents can go to find information and resources.

Questions arose about the KDE audit process. Jill responded saying that in the auditing process there is an issue between the letter of the law and the spirit of it. She wants to see not just compliance with standards but also quality. Jill said that when KDE receives a lot of phone calls from the same area that this is a red flag to them.

Elaine Brown stated that parents are not calling from her area because they are ill-informed and believe what the schools tell them even if it is not best practice. She stated that there is too much information for parents and teachers to know. She asked if the best way to let parents know their child's education rights is through Family-to-Family, Kentucky Spin, and teaching them through

training. In response, Jennifer Crawford suggested going through First Steps because teacher's jobs have been threatened when they tell parents about standards and setting high expectations.

Elaine brought up that often children are eligible for services in First Step, but in school that they do not receive eligibility when they should. The only option for parents is due process but the schools know that the parents cannot afford that. In addition there is a high fail rate when parents engage in the mediation process.

Jill mentioned the Taxonomy for Transition Programing. This programing has schools evaluate themselves on the issues Jennifer and Elaine brought up. In this programing there is a level of family involvement and empowerment. Christina also suggested to Elaine and Jennifer about the I Advocate app that parents could use. There is more discussion of the 40 employability standards that have been in circulation since 2013. Jill will email those out.

There was a question about if there is a document for parents that explains information that they need to know for each grade level. Jill said that there is not a specific document because they have been working towards training at this time. Right now they are getting the essential information from the school training program so that parents will want to read it. Jill stated that she is planning on receiving the assistance of the parent committee in order to help trim the essential information by grade level.

The CAC divided into small groups to answer the question, "How do we get information to parents?" The following is the report out from each small group:

Group 1 - Use radio to announcements to distribute training information in rural areas where there is low literacy, limited internet access, and people who may not read the newspaper. Other suggestions were using YouTube, social media, parent group pages, going through Protection and Advocacy, Legal Aid Services with pro bono help, parent professional conferences, and transition fairs.

Group 2 - Create a series of brief documents aimed at what parents need to know at different age and grade levels. These documents would be available online and at Family Resource Centers and Youth Service Centers. The idea is that the staff would be trained to walk through the documents with parents instead of just handing them out.

Group 3 - Hold trainings for parents in local districts, using layman pamphlets for parents, color coding information and having information in large print and Braille.

Group 4 – Use social media, YouTube, and pamphlets. An individual in the group commented, "Mostly what everyone else has said." Another comment was, "Students receive testing accommodations throughout the year as a way to reach students."

- 8) Agency Updates (DD Council, DDID, CCSHCN) Each agency

DD Council - Jennifer Hicks reported that the DD Council coordinated the 874K Rally in Frankfort and the 5,000 lunches ordered were given out. The DD Council also met with state senators and representatives during the morning prior to the rally. Jennifer announced that the 2017 Exceptional Family Kentucky magazine has been recently published. She also stated the DD Council has partnered with three organizations at HDI: (1) Peer Support Network project; (2) Health and Wellness; and (3) Community of Sharing.

Division of Developmental and Intellectual Disabilities – Cathy Lerza (for Claudia Johnson) reported that the SCL waiver has been submitted to CMS for renewal. There will be a series of trainings throughout the state in April and June for the Medicaid Waiver Management Application (MWMA). Bulletins are being sent out at least monthly to provide tips. In addition to case managers, individuals and family members of those receiving waiver services can have an account in MWMA. There are currently about 275 individuals and family members who have an account. Information about MWMA will be available at the Arc Conference in Louisville on March 16 and March 17.

Commission for Children with Special Health Care Needs – Lee Gordon reported they are in the 8th year of receiving the Family to Family grant. The Family to Family grant extends from June 1 to May 31. Debbie Gilbert and Sondra Gilbert direct the Family to Family grant.

- 9) New Business and Announcements Jennifer Mynear

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. Cathy attended the previous meeting online so she received the actual certificate today.

- 10) Lunch and Further Discussion about CAC Members' Involvement in HDI Projects All
(12:00 – 1:00)

Next CAC Meeting: Monday, June 5, HDI Coldstream training room, 9:00 AM – 12:00 PM followed by a working lunch.