

**HDI Consumer Advisory Council Minutes
Clarion Hotel
Monday, December 7, 2015**

In attendance today...CAC members

Maria Delgado
Morgan Crawford
Claudia Johnson
Cathy Edwards
MaryLee Underwood
Megan Baker
Frank Huffman
Hazel Forsythe
Allie Rhodes
Traci Brewer
Morry LaTour
Jessica Wolfe
Walt Bower
Jennifer Mynear
Camille Collins
Paula Caldwell
Lee Gordon
Jennifer Crawford
Elaine Brown

Guests: Samantha Harrison, Jaime Barger

Presenters: Jane Kleinert, Nick Gibson, Chithra Adams

Technical and other assistance: provided by Maurice Dawson

1) Welcome and Introductions Jessica Wolfe
All members introduced themselves.

2) Review and Approval of September Minutes Jessica Wolfe
The minutes were reviewed. Morry made a motion to approve and Megan seconded. Correction to the September minutes: Kentucky Connect in the September minutes was corrected to kynect.

3) AUCD Video and Update – Council on Community Advocacy Walt Bower
Walt reported attending the COCA annual meeting and showed a video providing an overview of the AUCD network. The video also included the history of AUCD as well as describing the mission of AUCD.

4) Update on TAALC Project and Feedback from CAC Jane Kleinert
Nick Gibson

The Teaching Age Appropriate Learning through Communication (TAALC) project promotes and improves communication services in the public schools. TAALC, funded through the Department of Education in Kentucky, is needed because less than half of students who need an

augmentative way for communication actually have it. The project works with teaching personnel in the school to recognize the needs and how to implement improvements for communication. There are 3 parts to the project: Tier 1 – Provides basic communication; Tier 2 – Provides advanced training and more specific coaching; Tier 3 – Provides specialized intervention working with students and teams. The family, when they are available, are included in the entire process.

TAALC completed 5 trainings in different cooperatives throughout Kentucky. The project has worked with 50 students and teams and 84% have advanced in the area of expressive communication. The project also provides continuing education trainings – including videos to show what the trainings look like and strategies to use for implementation. Upcoming goals include offering more trainings.

Perhaps due to a lack of knowledge how to use the technology or the cost of the technology, some schools are not always willing to use the communication devices. It is also important to make sure the correct professionals are targeted within the school. In addition, TAALC has 7-8 modules online that can provide training for speech language pathologists.

The CAC members discussed ideas how to encourage others to respond to the person rather than the device. Repeating the question to the person was encouraged. Making sure the communication is done with the individual with the disability rather than the other individuals present. There was a request to come back to a CAC meeting in the future to continue to receive feedback for possible next steps.

- 5) Project Spotlight – Chithra Adams
 Kentucky DD Network Needs Assessment Survey Allie Rhodes

Chithra and Allie discussed the results of the 2015 Joint Needs Assessment Survey regarding the health care needs of Kentuckians with disabilities. Participants in the survey were self-advocates, families, and service providers. 496 participants completed the survey with 74 identifying as self-advocates. The survey link was distributed electronically through various list serves and paper copies were distributed as well.

The focus of the survey was on finding the most important area of needs for individuals with disabilities. The top three needs identified were: (1) transportation, (2) employment, and (3) housing. Regarding the health care needs of individuals with disabilities, the survey found there are few trained providers and specialists, facilities that are not accessible, and a lack of appropriate care.

The members divided into 5 groups and each group reported their specific recommendations for improving the health care needs of Kentuckians with disabilities. An insightful and collaborative discussion of recommendations followed! The following is the report out of the work by each small group:

Group 1 - Change hospital trainings by providing modules on computers (including sensitivity training) and have providers gain first-hand experience. Making sure the

doctor has a good bedside manner as well as connecting new providers with previous providers (child to adult providers). In addition, making sure the provider is speaking directly with the patient. Another recommendation is to make sure the patient is prepared for the appointment and writes information down during or after the appointment.

Group 2 - Enforcement of the Americans with Disabilities Act (ADA) is typically done by complaints and we need to educate consumers about who they can make complaints to. Educating providers that accessibility can look different depending on the individual. Showing there are multiple ways to find solutions to the problem. Providing a presentation of this survey to the state legislature.

Group 3 - Raise awareness more for people who have a disability and have individuals with disabilities do their own assessment of accessibility.

Group 4 - Talking to the legislature in your state is an option. We could also look at neighboring communities so we can model what they are doing. Going to TV, news, and radio to help find solutions. Providing classes in college that teach about individuals with disabilities.

Group 5 - Making sure the providers have prior training with individuals with disabilities. Connecting training programs to resources.

Requests were made to send the PowerPoint out to further continue this discussion of needs and possible recommendations.

6) Election of New Vice-Chair and Setting 2016 Meeting Dates All

Cathy Jo Edwards will move from the Vice-Chair to the Chair next year. Hazel Forsythe nominated Jennifer Mynear and she accepted the nomination as Vice-Chair. Morry made the motion to accept and Allie seconded the motion.

The 2016 CAC meeting dates are March 7, June 6, September 12, and December 5 from 9:00 am to 12:00 pm.

7) Agency Updates Each Agency

Commission for Children with Special Health Care Needs – Lee Gordon reported continuing service work through 12 offices. They have helped offices to open Autism clinics and have opened a clinic in Corbin. There will be a parent liaison to speak with families and we are continuing to work on transition to doctors.

Protection and Advocacy – Camille Collins announced 673 individuals were provided with informational and referral activities during the last quarter. In addition, P & A provided 22 trainings and trained 332 people with disabilities. Community transitions legislation was sent to the legislature on December 2, 2015 to help individuals live in the community. P & A continues to work with other stakeholders to educate policymakers

about the ABLE Act and provide them with facts and information why individuals with disabilities would like this in KY. The PAC and PADD Advisory bodies met in November. PADD elected new officers with Ashley Layne as the new Chair, Mark Newton Vice-Chair, and Mike Smith as Secretary. New PADD Board priorities include the exploration and creation of a scholarship for post-secondary educational opportunities for individuals with developmental disabilities. The top 3 needs from the P&A survey for 2016 were: abuse and neglect, access to community, and employment. The survey included around 250 respondents with over 100 being service providers and 120 advocates/persons with disabilities. Camille suggested working with HDI to better interpret the data.

Division of Developmental and Intellectual Disabilities - Claudia Johnson reported the SCL waiver submitted in June is still in the process of being approved. The regulation is also deferred for another month. The statewide transition plan has been updated with new dates. CMS is looking at the location of the services and we have until 2019 for the state to be in full compliance. SCL now has an emergency wait list now.

Commonwealth Council on Developmental Disabilities - MaryLee Underwood reported the results of the needs assessment focused on areas of systems change. MaryLee also shared they are hiring a Communications Coordinator and there are new members on their council. There is a leadership development scholarship that they offer - persons with a disability, or family members are eligible to apply. The Kentucky legislature is meeting next month and a handout was distributed to the CAC members describing the Council's 2016 disability policy priorities. The Council's public policy agenda also includes the following emerging issues - lack of medical providers for adults with developmental disabilities, lack of appropriate services for people who are medically fragile as they age out of pediatric care, and support for medical Cannabis research and education. The 874K Coalition Annual Rally is at 1:00pm at the Capitol Rotunda on February 2, 2016. Please feel free to schedule a meeting with your legislator the day of the rally. The phone number for the bill status line is 866-849-2835.

- 8) New Business and Announcement Jessica Wolfe
 There was no new business to report.
- 9) Special Recognition Jessica Wolfe
 Certificates of recognition were presented to Megan Baker, Hazel Forsythe, Jessica Wolfe, Paula Caldwell and Morry LaTour.
- 10) Lunch and Further Discussion about CAC Members' All
 Involvement in HDI Projects

NEXT CAC MEETING: Monday, March 7, Coldstream 9:00 AM – 12:00 PM, followed by a working lunch.

Jennifer Mynear motioned to adjourn and Morry LaTour seconded the motion.