



Consumer Advisory Council

Meeting Minutes

6/4/2012

Members present:

Morry LaTour	Jessie Birdwhistell	Shannon Caldwell	Jim Chesser
Lee Gordon	Claudia Johnson	Paula Caldwell	Malkanthie McCormick
Elaine Brown	Karen Boudreaux	Harold Kleinert	Jennifer Crawford

Guests and Staff: Ruth Caldwell, Marybeth Vallance, Caroline Gooden, Kim Hook

Welcome and Introduction of Board Members

Morry LaTour welcomed the members in attendance and called the meeting to order. Members were asked to introduce themselves. Harold welcomed new members, Elaine Brown and Jennifer Crawford from the Paducah area, and noted that we now had representatives on the Council from all areas of the state. Also, he explained that Jim Chesser was filling in today for Megan Baker. Harold noted that as Chasity was absent, Morry would be chairing the meeting today.

Review and Approval of April Minutes

Morry asked for members to review the Minutes from the April meeting. Jim made the motion to accept the Minutes and Malkanthie seconded the motion. The Minutes from the April meeting were reviewed, voted on and approved without changes.

AUCD Update – Council on Consumer Affairs

Shannon Caldwell, CAC-COCA liaison, first welcomed new members, Elaine Brown and Jennifer Crawford to the Consumer Advisory Committee. Shannon began by explaining for new members, the organizational structure of AUCD and COCA. He reported that COCA is The Council on Community Advocacy, which is to be comprised of a member nominated from each UCEDD's Consumer Advisory Committee. He reported that COCA has 2 Chairs and that he was serving as the Family Member Co-Chair as his wife, Paula, also has a disability.

Shannon explained that COCA was continuing to work on 4 primary areas:

- A) Transportation - He stated that COCA had a Blog and wanted individuals to submit their stories concerning their perspectives and personal problems associated with access to transportation. Shannon noted that COCA was looking at the feasibility of universal access when switching from one Para-transit system to another **without** eligibility standards being different. He stated that COCA was advocating for a Universal "I.D." card which would facilitate consumers being able to use para-transit systems in other counties and states when traveling. Shannon requested that members go to the COCA blog to post their stories or thoughts on this idea.
- B) Shannon also reported that the U.S. Congress had still not ratified the treaty for the U.S.'s participation in the treaty for the Convention for the Rights of Persons with Disabilities. This treaty would advocate legal rights of persons with disability across the world. He noted that the House passed legislation last year which would convene a Convention focused on the rights for persons with disabilities internationally. The President has given his approval and sent this Legislation to the Senate. Shannon asked CAC members to contact their Senators urging their approval of this legislation. He also reported that there was a current Petition for people to sign urging Senate approval and that people were urged to also phone, email or write their Senators. He states that this Legislation would enable persons with disabilities to be part of the United Nations in an advisory capacity, focusing on the rights of persons with disability across the world.
- C) Employment – Shannon reported that COCA had held Advocacy Summits about Employment across the country, with the goal of gaining data and facilitating some positive actions impacting employment for persons with disabilities.
- D) Legislation – In summary, Shannon stressed that all of their legislative advocacy would depend on budgetary issues and the current political environment in Congress. He stressed that positive movement for any new programs or proposed Legislation may not be resolved until after the Election.

Lee asked if Shannon would resend the Legislation link and COCA's recommendations for advocacy to members so that CAC members could send the Treaty and recommended actions to their associated colleagues and list-serves.

ADD Self-Advocacy Summit Report

Harold reported that Claudia, Megan Baker, Pat Seybold, Jeff Edwards and he had attended the national ADD Self-Advocacy Summit. He noted that Kentucky had sent 11 members but that self-advocates take the lead in the priorities and development of the each State Plan. Claudia reported that Kentucky seemed more organized and farther ahead in collaborative efforts than the other 7 states present.

Harold reported that the focus and objectives centered on

- 1) people in institutional settings getting the needed information and access to life in community;

- 2) Employment;
- 3) Students in high school learning about transition resources and options;
- 4) More publications highlighting positive success stories about persons with disabilities, such as “Exceptional Families Kentucky.”

Harold stated that Kentucky Self-Advocates for Freedom would lead the group and that there would be a follow-up meeting to continue work on and development of the State Plan.

Transportation Provider Training Update

Marybeth reported that 118 Lextran drivers took the on-line HDI-Lextran ADA and Disability Awareness Transportation Training Module and that the module did have a feedback form as part of the module. Results of the Feedback form had been analyzed by HDI and driver feedback was strongly positive about the module. HDI developed and distributed a “3 Month Follow-up Survey” for these same Lextran drivers. This 3 month follow-up survey measured long-term impact on attitudes and driver behavior toward those consumers with disabilities. Response rate, however, on the 3 month survey has not been as high as hoped, though all feedback is being currently analyzed and still shows positive impact on drivers’ attitudes and learning.

It was noted that we still have a strong relationship with Lextran. Marybeth was invited and served as a “judge” for Lextran’s June 3 “Roadeo” bus driving obstacle course at Commonwealth Stadium parking lot. Marybeth noted that the Administrator of Lextran remarked at the event about the high percentage of drivers’ positive feedback about the on-line training. Also, apparently TARC fixed transit system in Louisville was considering using the module to supplement their driver training. Marybeth had written to their Training Director but had not received any confirmation from TARC to-date.

Malkanthis and other members of the CAC advised that a description of the on-line training module be sent with an email link to the module to all fix-transit companies around the state. Dr. Kleinert and Marybeth agreed that this would be a good action plan for disseminating the availability of this program as a free program for KY or even transit program out of state.

Morry noted that Wheels had expressed some interest in exploring the option of doing a joint training project with HDI or having the on-line module adapted with some para-transit consumer experiences and disability-training issues. Marybeth also noted she was approached by Wheels at the Celebrate Disability Expo and she would work with Morry in following up on this potential project. Of course, funding may be a barrier, Marybeth noted, unless Wheels could contribute some resources. Jim Chesser reported improvements in his experience with Wheels in the last year, but he would follow-up by talking with Marybeth at a later time. Also, Marybeth noted that HDI was submitting the development and utilization of the Training project and module to AUCD as a potential program at the Dec 2012 annual Conference. HDI and consumers will continue to do face-to-face consumer training with new drivers when the Training Coordinator of Lextran has a new driver class of 7 drivers or more. Morry noted that this consumer-

driver interaction at the trainings was evidence of drivers' mutual appreciation of meeting with consumers and they verbalized learning new aspects of disability awareness.

Preparing for Joint DD Network Meeting

Dr. Kleinert announced that Council Directors for HDI, DD Council and P & A met to discuss themes for the August 31st Joint Councils' Annual Meeting. He presented a Power Point with 2 potential themes which each Council was to give their individual input on the selected theme:

1) Involvement in Community

Pet therapy
Habitat for Humanity
Community Theater
Volunteerism, etc

2) Personal Protection

Safety – freedom from abuse/neglect
Personal safety
Bullying
Pay day lending, etc

Jim mentioned adding cyber-bullying. Elaine and Jennifer confirmed that bullying children with disabilities was a major issue in Paducah schools, even starting in daycare centers and pre-school. Lee added that bullying and community involvement overlaps as children who are bullied subsequently do not participate in school activities. He noted that this can subsequently lead to depression. Shannon's mother, Ruth, noted that bullying also occurs from adults, as well as children and has gone on for years. Lee discussed that children cannot learn about the capacities of children with disabilities until the schools and classrooms are inclusive. Morry noted that attitudes of discrimination and excluding people with disabilities also occur in Churches. Lee noted that KY SPIN is doing programs around the state to help parents of children with disabilities deal with bullying.

Malkanthie and Karen discussed that barriers to inclusion through community involvement exist in some recreational programs; including some Y's and even some Park's and Rec's camps which were "special needs children" only. Elaine and Karen both agreed that many Parks and Rec programs for children with disabilities are largely staffed with teens and young adults who have no strong training in responding to children with special needs', preventing bullying or responding to a child's needs who has special health care conditions. They both have hesitated having their own children participate in Parks and Rec's programs due to these training and safety issues.

Claudia and Karen, as well as other members suggested "merging the two themes, and Claudia suggested that we add "Barriers to Community Involvement/Inclusion" in Topic # 1. Barriers should include bullying, lack of inclusion in school & churches, lack of training of staff at special camps and events, etc. Members were in consensus that Dr. Kleinert would take this suggestion back to the Joint Council Annual Meeting Planning Group.

Project Spotlight – “KEDS and KY Early Childhood Outcomes Data System”

Caroline Gooden and Kim Hooks presented the “KEDS and KY Early Childhood Outcomes Data System” using both a handout and Power Point. Caroline explained that the handout revealed the spring 2011 measurement tools used to measure children’s progress. Caroline discussed the origin of the KEDS and Early Childhood Outcomes Project by noting that in 1999, a Governor’s Task Force on Early Childcare developed a “Vision” statement which would measure school readiness, based on both social and academic success when children exited from childcare and both started and exited pre-school.

Kentucky’s Early Childhood School Readiness System developed standards and benchmarks of best practices and children’s progress from birth to 5. KY Early Childhood Data Systems Project under HDI and in affiliation with KDE, the KY Division of Childcare, HANDS, Early Intervention and KY SEED is the Assessment Organization which measures progress of these children in comparison with KY Standards, US Office of Special Education federal outcomes and Head Start outcomes. All state-funded early childhood programs are to report data to KEDS and some private day cares also participate in submitting assessment data if they are part of a state-funded pilot program.

The 3 Federal Child Outcomes are: a) positive social-emotional skills; b) acquisition and use of knowledge and skills, and c) use of appropriate behavior to meet needs. Two (2) additional federal targets were added: students who entered below age expectations in the outcome area, who substantially increase their rate of growth by exit from the program and percent of students maintaining within **age expectations** in the outcome area by exit from the program.

Caroline presented graphs showing that for pre-schoolers with IEPs, KY’s targets on social relationships, knowledge/skills, and adaptive behavior have exceeded the targets each year, from 2008 through 2010 data collected. She was asked by Karen if parents with pre-school children having IEPs are given their individual child’s “KY Preschool Standard’s Report.” Caroline replied that some programs do print this off as a guide to parents, but not all, due to the cost of printing and staff time in reviewing this with parents and then guiding parents in how to work with their child to make gains or work on weak areas.

In conclusion, Caroline noted that the partner agencies would continue looking at benchmarks and evaluating early intervention programs, childcare programs or by KDE depending on data outcomes. Kim, as Co-Principal of the KEDS Data System, will continue to review the data, organize and analyze it, and she noted that there is an individual who follows up with facilities or programs that have not sent in their data. Members applauded and thanked Caroline and Kim for the presentation!

Preparing for New Five Year Application and Status of DD Network Survey.

Dr. Kleinert noted that the HDI 5 Year Plan must be completed by February of 2013. He noted that many existing projects, such as education, transportation and employment, will

be carried over into the new 5 Year Plan, but that family members and self-advocates with disabilities around the state give their input to guide us in drafting our plan priorities. Dr. Kleinert will send out the electronic link again to CAC members for that survey (Statewide DD Network Needs Survey) and urged members to send this out to all groups and friends. The Needs Assessment Survey will be extended to July 1 and the goal is to collect input from 500 participants.

Dr. Kleinert asked if CAC members would be willing to meet from 1 – 2pm after lunch following the Joint Councils' Annual Meeting on August 24th, to review the Needs Survey and our Current State Plan.

Nominating New Members for CAC

Harold asked members if they would make a motion to extend Karen Boudreaux's term for another year. The motion was made, seconded and passed unanimously. He distributed a list of members and their term-expiration dates. He stressed that we need 2 parent nominees and 2 new self-advocate members. He reminded members that our CAC needs statewide representation and that we needed a balance of parents and self-advocates. He emphasized that we need self-advocates nominated from northern KY and eastern KY.

As the Nominating Committee consists of Shannon, Peter, Sandra and Karen, Harold asked that members email their nominations to either him or to a member on the Committee. Harold would see that the Committee received any nominee if he was emailed with a name. Any nominee willing to serve should include contact information and a short paragraph "Bio." Morry noted that former CAC members can be nominated, but must be off the CAC for at least 1 year to be so considered. Jim was to contact Harold about a self-advocate he knew from northern Kentucky and he will then give this information to Shannon.

Harold noted that a former member Meg Steinman, who is a parent, has indicated a willingness to serve again. Morry requested that the Nominating Committee make their decision with their recommendations before the August meeting, so that CAC members could vote at the August meeting.

Agency Updates

Lee Gordon from the ***Commission for Children with Special Health Care Needs*** reported that the "Family-to-Family Health Information Grant" was approved for another year. He again noted that the Kentucky Integrated Services Grant, headed by Terri Williams, was continuing its contacts to build education and collaboration concerning adolescents with disabilities transitioning from primary care to adult health care providers.

As Jason Jones from OVR was not present at this CAC meeting, Lee noted that he attended OVR's statewide conference in April. He remarked that this Conference was very well-attended and received positive feedback from attendees. He stated that one topic discussed was developing better financial assets and information about assets for

individuals and their families. Lee reported that there will be a Financial Summit in the fall to improve access to assets and access to loan programs for persons with disabilities.

Claudia Johnson of the ***Department of Behavioral Health, Developmental and Intellectual Disabilities*** reported that their new budget included 300 new slots for SCL recipients over the next 3 years. She also remarked that their Department had received new money for persons needing substance abuse treatment and monies for the new “I-Waivers” which would help fund housing and employment for those persons with mental illness.

New Business and Announcements

No one made any remarks under this agenda item.

Special Recognition

Harold presented a special framed Appreciation Certificate to Jessie Birdwhistell who has served with consistent attendance as Council’s student member for the last 3 years. He noted that Jessie is preparing for her dissertation for her PhD in School Psychology and that she has been exemplary in starting TOPS Soccer as a practicum project and has always remained passionate and involved with children with disabilities and their families. She has been working in the schools on a study focusing on social relationships and friendships of children on the autism spectrum who are in regular classrooms. She will be collecting her data on her school-system project this coming year and Jessie confirms that after completing her PhD, she will remain in Fayette County. Parents on the CAC and other members commented on Jessie’s passionate support, her continued work with TOPS Soccer and applauded her receiving this well-deserved Certificate recognizing her contributions to the CAC!

Next Meeting and Adjournment – Our DD Joint Meeting will be held **Friday August 24th** and Harold noted that it would be held at the Lexington Embassy Suites. Meeting was adjourned.