



Consumer Advisory Council

Meeting Minutes
8/24/2012

Members present:

Morry LaTour	Peter Perry	Shannon Caldwell	Jason Jones
Lee Gordon	Claudia Johnson	Paula Caldwell	Megan McCormick representing her mother, Malkanthie
Elaine Brown	Karen Boudreaux	Harold Kleinert	Jennifer Crawford
Pat Seybold	Sandra M. Duverge	Fannie Stonestreet	Megan Baker

Jeff Edwards

Guests and Staff: Ruth Caldwell, Marybeth Vallance, D’Arcy Robb

Welcome and Introduction of Board Members

Morry LaTour, as Vice Chair and in the absence of Chasity Ross, welcomed the members and called the afternoon meeting to order. Members were asked to introduce themselves. Harold noted that as Chastity had to leave after the morning session, Morry would be chairing the meeting today.

Review and Approval of June Minutes

Morry asked for members to review the Minutes from the June meeting. Claudia asked for a correction to be made to her Agency Report changing the sentence that her department’s “...budget included 300 new slots for SCL recipients over the next 2 years (instead of “3” years).” Peter made the motion to accept the Minutes with this change and Jennifer seconded the motion. Members approved the Minutes unanimously with this change.

AUCD Update – Council on Community Advocacy

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 appointed from each UCEDD’s Consumer Advisory Committee and who is a voting member for his or her respective UCEDD.

Shannon noted that the Annual AUCD and COCA meetings will be held during the first week of December 2012. He explained that this was the reason that HDI's Consumer Advisory Council was moved to November 19th. Harold noted that this will be our first CAC meeting where people can attend either at HDI's Coldstream Office or via video-conference. Jennifer and Elaine will plan to attend via video-conferencing.

Shannon summarized the COCA areas of discussion and action items. He reported that COCA members were discussing how COCA and Consumer Advisory Councils can be more active in their advisory capacity for AUCD and individual UCEDDs. He also discussed the status of the United States Senate's ratification of the Conference on Rights for Persons with Disabilities International Treaty. Shannon reported that COCA also has formed a Sub-Committee reviewing the employment disparity of individuals having disabilities.

Nominating Committee Report

Shannon reported that the Committee "met" through emails and phone calls and did obtain information on a potential nomination for a new member. Jessica Wolfe is a parent who works as a Physical Therapist in a school system in Eastern KY. Shannon will confirm her continued interest.

Harold emphasized that this upcoming December will represent the largest number of persons rotating off the Board: Peter Perry, Pam Mattox, Sandra Duverge and Fannie Stonestreet. He reported that as we now need 1 new parent/family member position from eastern KY, Jessica may be able to serve in this position. He stressed that we need 2 self-advocate members, with representation needed from Northern and Eastern Kentucky.

Jennifer volunteered to contact Barb Green from KY Partnership for Families and Children and email any potential candidates from Eastern Kentucky to Shannon.

DD Network Needs Survey Results

Harold presented a Power Point of the Survey results and explained that the Survey did have a lower response rate than in 2009-2010. The Survey had a two-fold purpose of determining the primary issues affecting the lives of individuals with disabilities and their families, and identifying priorities upon which all three Councils will focus their strategic plans. Harold noted that responses from individuals with disabilities were lower than hoped. While the DD Council did do face-to-face interviews from some self-advocates, Arthur Campbell of Protection & Advocacy's Advisory Board noted that we should work with KY Self-Advocates for Freedom and other self-advocacy groups to obtain more face-to-face surveys in the future.

Harold noted that the overall rankings of life areas of emphasis were fairly consistent with the rankings of the last two survey administrations (2007 and 2009-2010). In the area of "Education and Early Intervention," Harold commented that HDI is starting to work with child care centers to screen and identify children with delays, which could then prompt earlier intervention services. Concerning "Self-Advocacy and Choice,"

Harold reported that the Advisory Board (PADD) of Protection and Advocacy was doing a very good job of teaching self-advocates greater empowerment and advocacy skills, and that we could learn from PADD. Harold noted in the "Employment" arena, the post-school outcome data showed that 1 year out of High School, only 9% of former students with autism had jobs, so this supported a significant priority need.

Under "Transportation," which had been a joint priority of all 3 Councils, Harold reported that the DD Council had commissioned the Martin School of Public Policy to compile a list by county of all public and para-transit services across KY with eligibility information, hours of operation, etc., and that this report was posted on HDI's website. Marybeth noted that Oyo Fummilayo had chaired a Committee which compiled state and national resources, such as Project Action and that these KY and national resources should also be posted on the HDI, DD Council and P & A websites to provide helpful information for consumers in rural areas who want to form action groups around the issue of improving transportation access in their area.

After the Power Point review and discussion, Harold asked members their initial thoughts on the problem areas or priorities we need to place in H.D.I.'s 5 Year Plan.

- Lee noted that there should be a review of the impact of the Health Care Reform Act on improving health care access for all persons with disabilities and that this should be reviewed as part of the 5 Year Plan. Shannon offered to send the CAC list-serve AUCD's summary of how the Affordable Care Act would affect consumers.
- Sandra and Karen both remarked on the dis-connect in transition planning through the educational system starting with elementary to middle school through high school and to supported employment. Jennifer concurred and remarked that she felt students in special education were still not included in all areas of school and classroom activities. Harold noted that the HDI post-secondary data showed that for the approximately 5,000 former students who had IEPs, the greatest predictor of post-school employment was if they had paid jobs while in high school. Marybeth commented that many of her HDI Mentor Families had noted that there was little feedback and planning after the initial contact with OVR. Elaine and other CAC members agreed that OVR participation with job placement and job-skill training was a problem and a missing piece.

Lee, who serves on the OVR Statewide Advisory Council, discussed that while policy emphasizes early OVR involvement with high school students with disabilities, the Office of Vocational Rehab also had to insure that funds would be available to support individuals in job placement *after* they left high school. Finally, Morry noted that the strengths of individuals with disabilities are not always assessed for job placement.

The members concluded that an action item on this topic should include Lee presenting our CAC concerns to the state OVR State Advisory Committee. Karen and Sandra asked for HDI to prioritize transition as a focus area, and Karen proposed that a TEMPLATE be created and communicated, via webinar for parents, teachers, school counselors, and OVR transition staff, so that all parties understand every agency's role and timing of services in transition to employment and/or college for students with disabilities.

Harold shared that KY had applied for a national grant involving each of KY's major state disability agencies, and all 8 KY Special Education Cooperatives, to increase employment for transition age youth with significant disabilities. He noted that only 2 states will be awarded this grant, but that if KY does receive it, we would have additional inter-agency resources to facilitate transition to college and employment.

- Shannon suggested that HDI also focus on sub-wages and the disparity in supported employment for persons with disabilities.

Next Steps in Planning: Scheduling Individual Interviews with CAC Members:

Harold offered to write up the targeted areas proposed for the 5 Year Work Scope and send these out to members for review and comments. He noted that Shannon will be contacting members by email and then by phone to get their ideas, as it was recognized that not everyone was comfortable expressing their ideas in public. Harold encouraged members to talk with Shannon and share their thoughts on the areas of emphasis for HDI. Also, he explained that the November 19th CAC meeting Agenda would be focused on our priority areas for the new Five Year Plan.

Agency Updates

Pat Seybold from the ***DD Council*** informed members that the Aging Caregiver Project was continuing throughout the state. The DD Council is also working with Protection & Advocacy on a proposed seclusion and restraint regulation for schools in KY and working with legislators to pass the Provider Abuse Registry. Pat elaborated that the DD Council and P & A were asking for parent input if their child had ever been in restraints or seclusion while in school or a classroom. She noted that this parent input was necessary as the School Board Association responded that P & A did not have meaningful and substantiated data on abuse within KY school systems.

Jeff Edwards from ***Protection & Advocacy*** reported that they continue to work on a project involving staff and PADD board members going to sheltered workshops to interview individuals with disabilities who work there. This information will provide consumer input as the waiver programs provide greater emphasis on supported employment. Jeff also noted that P & A sponsored the Frankfort State Hospital Cemetery Memorial Project, which had many volunteers involved in a clean-up day for

the many unmarked cemetery markers and plots. P & A continues to work on the proposed restraints and seclusion regulation.

Lee Gordon from the ***Commission for Children with Special Health Care Needs*** reported that they had gone through a Block Grant review by Maternal & Child Health funding authorities and were pleased with their feedback. He reminded members that the “Family-to-Family Health Information Grant” was approved for another year. He discussed that the Kentucky Integrated Services Grant, which was headed by Terri Williams, focuses on health care transitions for older adolescents/young adults. Teri will hold workshops around the state focusing on parents and youth concerning this important topic. Lee noted the “Bridges” program, which employs an RN to assist in the transition project, has discussed using HDI’s health care training modules.

Lee reported about an upcoming OVR event on the topic of “Asset Development and Financial Independence” obstacles for consumers. He reported that OVR was bringing in bankers and investors to lend their financial expertise toward the goal of helping persons with disabilities gain financial independence and in securing loans for homes. Additionally, he mentioned the Youth Transitions Conference (“YES Conference”) for youth, ages 14 – 23 which will be held on September 14th.

Claudia Johnson of the ***Department of Behavioral Health, Developmental and Intellectual Disabilities*** reported that September 21st would be the Public Forum on the new regulations for the SCL Waiver. She informed members that changes would also eventually impact the Michelle P Waiver and that case managers were currently being trained on the changes.

New Business and Announcements

Shannon reported that the Joint OVR and State Independent Living Council state meeting was coming up. Paula also reported that the Assistive Technology Conference would be held at the Galt House. Shannon will send out these notices to CAC members.

Marybeth reminded members of the HDI Fall Seminar Series and promised to send the registration links to the first 2 Seminars to members via email again. She reported that they have about 15 statewide sites which would be participating in the first Seminar via live, video-conferencing. Morry remarked that October 15th is “White Cane Day.”

Next Meeting and Adjournment – Harold reminded members that the final 2012 CAC meeting would be on November 19th and the agenda would be to work on the targeted goals and priorities in the 5 Year Plan. Members were encouraged to come to the HDI Coldstream Training Room but could contact him to arrange to attend the meeting from their communities through live, interactive videoconferencing. Meeting was adjourned.