



University Center for Excellence in Developmental Disabilities

Consumer Advisory Council

Meeting Minutes

3/7/2011

Members present:

Shannon Caldwell	Norb Ryan	Karen Boudreaux	Harold Kleinert
Paula Caldwell	Jennifer Hicks	Claudia Johnson	Malkanthie McCormick
Milt Tyree	Morry LaTour	Adam Jones	Jeff Edwards
Jessie Birdwhistell	Jason Jones	Alan Wells	Jim Chesser
Fannie Stonestreet	Peter Perry	Kerri Wells	Chastity Ross

Guests and Staff: Marybeth Vallance, Ruth Caldwell, Lori Norton, Milt Tyree

Welcome and Introduction of Council Members

Malkanthie McCormick, our new Chair, welcomed the members in attendance and called the meeting to order. Members were asked to introduce themselves to the Council.

Review and Approval of December Minutes

The minutes from the December meeting were reviewed, voted on and approved with no corrections. Karen Boudreaux making the motion to approve the minutes and Paula Caldwell seconded the motion.

AUCD Update – Council on Consumer Affairs & CAC Member Interview Reports

Shannon Caldwell, CAC-COCA liaison, gave his report as COCA (Council on Community Advocacy) representative. He reported that COCA was concerned about the federal budget and its impact on services to those with disabilities. Shannon described COCA's goal as having consumer representation from each of the 67 UCEDDs. He reported that AUCD was reviewing the 2011 budget and also the President's proposed 2012 budget. He reported that COCA and AUCD were concerned regarding the following budget issues:

- Proposed budgetary emphasis on Institutional funding rather than community supportive living funding. He reported that COCA members ***were asked to write letters regarding the need for community supported living as a priority.***
- COCA was also reviewing the annual meeting's proposed speakers and needed topics. He reported that the fall AUCD meeting would be held at the Hyatt Regency near Reagan National Airport for a second year.
- COCA was also doing accessibility assessment of the facility for the upcoming meeting and conducting a needs assessment for access and accommodations.
- COCA was also working on a Business Plan and planned to stress COCA representatives participate from more UCEDDs around the country.

Harold noted that the ADD was asking for personal stories on the value of community living. Harold asked that Shannon send the members the link again re this appeal.

Jim Chesser inquired about money in the proposed budget for higher education support for those with disabilities. Harold stated that the current SHEP grant would probably be funded until September 30th, but he emphasized that without strong advocacy efforts, the post-secondary money to sustain this program is NOT in the present President's budget! He noted that the vote by the Senate & the House was to be March 18th. He explained that the present SHEP monies total only 11 million, which reflect only a tiny program in the federal budget. Malkanthie McCormick reported that she had already sent her story, but asked what parents could do to support SHEP. Shannon responded that all self-advocates and parents should contact their national Representative or Senator. Harold stressed that it will NOT be professionals who make an impact on legislators but that it is vital for self-advocates and families to send their personal story for an even stronger impact. Karen asked Shannon to resend the links and information from COCA about sending in advocacy stories to support higher education funding.

DD Network Joint Transportation Target

Adam Jones reported that they had held their 1st Joint DD Network Transportation Committee meeting. He explained this transportation issue was the target goal of all three sister agencies. He reviewed the names of the Committee and explained that the Committee goal centered on statewide rural transportation. Objectives of the Committee were to gather research around the state. Karen Boudreaux commented that the Committee needed to know emergency transportation providers vs. "leisure" providers which reflected the types of rural transportation; also how much notice providers required; if providers were private pay vs. Medicaid; and what area the providers served. Adam stated that the DD Council worked with the Martin School of Public Policy at U.K. and the Council had asked the Martin School to gather the needed data on transportation around the state. He also added that the Committee will ask a representative from the KY State Department of Transportation to sit on the Committee

HDI Transportation Provider Training Update

Marybeth Vallance reported how Norb Ryan was instrumental in Lex-Tran asking for HDI to assist with new driver training about ADA. She explained that Shannon Caldwell, Morry LaTour, Andrea Strassburg (a Graduate Certificate student), Darrell Mattingly (an HDI employee), and John Glisson from Independence Place had all participated as self-advocates who explained issues of disability needs, accommodations, and driver sensitivity. Marybeth noted that HDI had presented 2 new driver training sessions to-date with 22 drivers. She explained that training included information on ADA mandates, as well as the Training CD produced by HDI, showing both the "wrong" way to respond to specific disability needs and the "correct" way. She reported that the driver response to the vignettes was very positive and enthusiastic. After the video, members talked about disability awareness issues for persons who used wheelchairs, persons who were deaf or hard or hearing, riders who were blind, and then persons with invisible disabilities, such as seizure disorder.

Marybeth then explained that HDI is going to film additional vignettes and develop a web-based training module that could be used as an ADA training update by ALL drivers of public transit. She noted that a separate module would need to be developed for para-transit drivers. Karen Boudreaux questioned if the vignettes were broad enough so the training module could be used around the state. Marybeth confirmed that though they did reveal the vehicle company names of Lex-Tran and Wheels, it certainly conveyed applicable training to companies across the state. Harold stressed that the training modules will be web-based and inter-active. Marybeth emphasized that the idea for the vignettes and this transportation video came from our own CAC.

KY Supported Employment Training

Milt Tyree reported showed the updated Supported Employment Training Project Web page for job seekers and Employers. Milt had updated Social Security information for 2011. Though he explained that he had not yet obtained all the consents, he did have pictures representing personal job success stories which will be available on the web-site. The first example showed Mallory, who is a teacher assistant at a pre-school. Mallory uses an augmentative communication device and a page-turner. Her responsibility is to read stories to the children. Milt noted the children running up to Mallory to show her their drawings and the positive impact she has on the children through her employment.

A second video showed Daniel, a young adult with Down syndrome. He works in a physician's office doing clerical work. He does mailing and shipping and work with patient records. To increase his job hours, he now is also working for a company that produces gift cards from different retail and restaurant establishments.

Last was Alex's work transition story. Alex wanted to learn additional tasks at his job (besides cleaning), so the Employment Specialist and the employer helped change Daniel's responsibility. Alex is now doing oil changes, checking and re-filling washer fluids, and he maintains the keys for all the buses at work. He enjoys this job role!

Malkanthe requested that the web-page discuss people with disabilities getting off Social Security Disability or SSI because of their ABILITIES and NOT their disabilities!

Potential Faith Inclusion Initiative with Vanderbilt University

Milt discussed building on the program which Marybeth had coordinated with the Seminary Students at Lexington Theological Seminary and HDI Mentor Families. He noted that they had recently contacted Asbury University and hoped to extend Mentor Family matching to Asbury. Jim Chesser commented that he had enjoyed being involved as a Mentor with Seminary students. Milt added that this new initiative hoped to go further with efforts to help make faith inclusion a reality, and that he and Marybeth had discussed with Courtney Taylor and Erik Carter of Vanderbilt these additional ideas:

- Erik suggested using a Survey as an "indicator" of welcoming those with disabilities. He suggested families/self-advocates could do this survey, as well as seminary students and Clergy. He was going to send the link to this Survey.

- Courtney suggested that the Seminary students could really be considered as UCEDD “trainees” and that it would be interesting to evaluate the impact of Mentoring or any planned training on inclusion by surveying the Seminary students 1, 5, and 10 years after the Mentor experience.
- Courtney also suggested including congregation leaders along with mentor families in any panel presentation on faith inclusion.
- Erik talked of his “community conversations” through his former work in supported employment. He discussed the success of this discussion method and felt that organizing a “community conversation” with Church leaders, members of congregations and people having disabilities may be a successful way to move forward with faith inclusion actions coming out of these “conversations.”

Milt reported that Marybeth and he would move forward with contacts with LTS, Asbury College and Seminary and possibly looking at the concept of “community conversations. Milt also discussed possibly bringing in Erik Carter for an HDI-sponsored conference.

Evaluation of Annual Progress towards our Core Work Plan

Harold reported that instead of giving a detailed presentation of the status of HDI in meeting the Core Goals (as he had in years past!), we would divide into 5 groups to discuss if HDI had either met, exceeding or needed further CAC advisement to help in meeting the Core objectives. The target CORE goals for discussion were: 1) University; 2) Community Training; 3) Research & 5) Information Dissemination.

While nearly all objectives were “on target”, the CAC had several very helpful suggestions for improving our work. Harold thanked the group for its constructive and thoughtful feedback, and noted we will focus on *Goal #4 Research* at our June meeting.

Project Spotlight: Dartmouth Project-

Lori Norton, Project Director of HDI’s “Evidence Based Supported Employment for People with Mental Illness” presented this pilot project, which placed Kentucky as the 12th state to join the Dartmouth-Johnson & Johnson Project. The Division of Behavioral Health is in partnership with the Office of Vocational Rehabilitation and the grant is funded for 4 years. The program is based on the value of work in a person’s recovery. Lori reported that KY has four mental health centers around the state that are participating at this time. Each site receives initial and on-going technical assistance. Each mental health center has received \$15,000 in carry-over Mental Health Block Grants to use for start up costs for the first year of implementation, and a minimum of \$30,000 during the second year. She explained that the Job Search is based on the individual’s interests and starts soon after involvement with the individual. The OVR Employment specialists are full members of the mental health treatment team. A standardized “Fidelity Scale” is used as a quality improvement tool for reviewing agency practices and measuring employment outcomes. Other Kentucky mental health centers will be added once initial sites reach a high level of fidelity.

Agency Updates –

Norb Ryan reported for *the ADA Office* and noted the change in definition of “service animals.” He also noted that Project Safe was continuing to work on training and sexual-assault “safe” centers, which trained persons with disabilities about awareness and preventive measures, and that centers were responsive to victims with disabilities.

Jason Jones of the *Office of Vocational Rehabilitation* noted that Germaine O’Conner who previously worked with the DD Council is now working to support the State Centers for Independent Living. He reported that on March 25, the Dartmouth Project will be highlighted to OVR statewide staff. The Assistive Technology Loan Project has also loaned 6 million dollars to-date this fiscal year!

Claudia Johnson of the *Department of Behavioral Health and Developmental and Intellectual Disabilities* reported that the SCL waiver amendment will be discussed at the HB 144 Commission meeting on April 13th. The DD Council will start Public Forums on these proposed changes. The Commissioner has also set dates for hearings around the state about a proposed “I Waiver” for persons with mental illness. The Department is also looking at public comments and needed changes for the Michelle P Waiver.

Peter Perry asked to make his experienced-based comments about the process of application and approval for the Michelle P. Waiver part of the CAC minutes. He found needless delays in the process, state workers’ behavior reflecting unprofessionalism and lack of knowledge about the process, thus making the process very confusing to both parents and workers. He documented each part of the process, dates he submitted applications, names, comments and actions of workers in his own application for the Michelle P Waiver. He expressed outrage at this inconsistent and delayed process and posed the question to the CAC members of how the CAC might help with the proper administration of Michelle P. Waiver.

Jeff Edwards of *Protection and Advocacy* reported that his agency received a continual stream of complaints and was on top of the problematic areas reported by parents and consumers. Peter Perry reported that he had to call Bill Dolan at P & A several times to get people to return phone calls about his Waiver application.

Claudia reported that the Commissioner was very interested in hearing parent complaints about the application process and reported that her Office had asked Medicaid to let her Division (Division of Developmental and Intellectual Disabilities) manage Michelle P’s approval vs. the Medicaid division. She also asked that Dr. Perry submit his personal documentation to her Office and that they could use these cumulative complaints in their change initiative re Michelle P. Waiver process.

Karen Boudreaux reported on behalf of *DSACK* that all of representatives from the individual DSACK chapters around the state had met to form a *KYDSACK*. This merging into a statewide Chapter of local Down syndrome associations would help them in working collectively on statewide legislative issues.

Next Meeting - Monday June 6, 2011 – Clarion North Hotel Lexington (same place!)