



Consumer Advisory Council

Meeting Minutes

August 9th, 2013

Members present:

Morry LaTour	Pat Seybold	Shannon Caldwell	Malkanthie McCormick
Cathy Jo Edwards	Jessica Wolfe	Paula Caldwell	Lee Gordon
Elaine Brown	Karen Boudreaux	Harold Kleinert	Jennifer Crawford
Claudia Johnson	Jeff Edwards	Allie Rhodes	

Guest and Staff: Megan McCormick, Marybeth Vallance, David Flechler

Welcome and Introduction

Morry opened the meeting by welcoming all members present. This CAC meeting followed the Annual DD Network meeting. All of our members introduced themselves and related their role as a self-advocate, parent of a child or adolescent with a disability or agency representative. Harold introduced *Allie Rhodes* as the new student representative on the Council. Allie is both a Research Assistant with HDI and has completed the Graduate Certificate program in Developmental Disabilities.

Review and Approval of June 3, 2013 Minutes

Morry asked for members to review the Minutes from the June 3 meeting. He asked if there were corrections or discussion. Pat made a motion and Claudia seconded, with all members voting to approve the Minutes without changes.

AUCD Update – Council on Community Advocacy (COCA)

Shannon reported on the mission and purpose of both AUCD and COCA. He explained that COCA was continuing work on 2 main objectives, 1) personal stories supporting the need for a Universal I.D. card for para-transit eligibility across counties and states, and 2) lobbying efforts for ratification of the International Treaty for the Rights of Individuals with Disabilities. He reminded members that COCA still maintained a Blog for personal stories regarding the need for universal para-transit eligibility. Shannon noted that the Senate had voted against passage of the Treaty by only 5 votes and that the Treaty would recognize the rights of individuals with disabilities throughout the world. He stated that COCA supported the Treaty. Pat reported that some individuals had questions about how

this Treaty was different from the 1948 United Nations' approved "Universal Declaration of Human Rights." As confusion as to differences in the content and purpose of the Treaty and Declaration exists, Pat suggested that Shannon ask COCA members to clarify the differences and benefits of the Treaty to self-advocates.

Shannon related that COCA was also organizing a Workshop for the annual AUCD meeting, to be held November 17 – 20th, 2013. As Harold wants CAC members to contribute to any HDI projects in which they have a particular interest, Shannon will also be contacting members to see if they would like to learn more about or contribute to an existing HDI project.

Core Grant Funding and Reviewers' Comments

Harold reminded members of the Reviewers positive comments that he had formerly sent CAC members and that HDI had received renewed 5 year funding. He also distributed the Summer Newsletter and Research Brief in case any members had not already received a copy of these HDI publications. Additionally, the DD Council of Maryland's "What's Possible" was given to all members.

Results and Discussion of our CAC Self-Advocate and Family Survey on College and Career Readiness

Shannon distributed and summarized his "College and Career Readiness Report" which analyzed recent phone interviews he had with CAC members about their perspectives on this HDI Project. He reported that this was in response to Harold's suggestion that the CAC serve in an advisory capacity to this particulate HDI Grant Project. Report is attached to Minutes.

Additional Plans for Involving CAC in HDI's Work

Harold recognized members' interests, perspectives and value which could contribute to other HDI Projects. He encouraged members to look at our web-site and if they saw a Project which interested them, Harold would facilitate linking them to the Project's staff.

Nominations for New CAC Members

Harold passed out the form, "HDI Advisory Board Term Information – August 2013." He noted that we continue to need a Self-Advocate to serve on the Advisory Council and that it would best meet statewide representation if this Self-Advocate was from northern KY. **Kathy Jo Edwards**, who had a recommendation, was willing to serve on the Nominating Committee. Shannon explained that the Nominating Committee accepts nominations from Board members or others, reviews applications, and makes recommendations to the whole Board for its approval. **Paula Caldwell** also recommended a candidate, and she agreed to serve as a member on the Nominating Committee. Karen Boudreaux recommended a special education teacher in Fayette County who also had a daughter with special needs. **Morry LaTour** agreed to serve as the third member of the Nominating Committee and asked that all members with recommendations for nominees email him their candidate contact information at mlatourncis@cs.com.

Agency Updates***Protection and Advocacy***

Jeff Edwards reported on behalf of P & A that their agency had set the new year's priorities: Abuse/neglect cases; persons with intellectual disabilities living in Personal Care Homes; children at risk with disabilities; creating an Adult Abuse Registry; the SCL waiver and definitions in the waiver of "intellectual disabilities"; and following through with P and A's continued work with Frankfort State Hospital's Cemetery and its upcoming status as an Historical Site subsequent to the funds being raised for this designation. He reported that P & A was looking at case management agencies, as well as issues of health and aging, and if individuals had access to appropriate health care screenings.

Commonwealth Council on Developmental Disabilities

Pat Seybold reported that the Council was engaged in negotiations with HDI re an Education Project around peer support networks. The Council also will be releasing funding centered on transition to employment. She also described "Employment First" which is tied into incentives for private businesses and state-funded government programs which encourage them to hire qualified persons with disabilities. Pat stated that Harold will explain about the state's submission for the "Promise Grant" and the CCDD's employment grant will fold into the OVR Project. She also explained that CCDD was promoting the "Real Communities" concept and that some of their staff would be attending a Conference about this concept in Indianapolis. The Council continues to work on promoting the KY Adult Abuse Registry and is advocating for the state's implementation of the SCL waiver changes.

Harold explained that HDI had been working with the Council, KDE and OVR and other state agencies to apply for the federal "Promise Grant." This grant is to be given to 3 – 5 states and the purpose is to help children with disabilities, ages 14 – 16, who receive SSI, and their families obtain intensive case management, benefits counseling, paid work experiences for the youth and other supports to improve post-school outcomes and to reduce dependency on SSI. Though the grant targets funding for 1000 students and families to receive services, the grant also mandates setting a random control of another 1000 youth and families who do *not* receive the services. He stated that while he does not agree with the randomly-selecting control group of students and families who will *not* receive services, if KY *did* receive the funding, then the grant would enable the state's collaborating agencies to work on successful transition and work-related opportunities for 1000 youth with disabilities in KY.

Department for Behavioral Health and Developmental and Intellectual Disabilities

Claudia reported that the Cabinet is getting ready for the implications of KY's Medicaid expansion and the implications for her agency. She also shared that her Department is working on re-design of its web-site. In adding to Pat's discussion of the SCL waiver changes, Claudia noted that the roll-out deadline for SCL was still unknown. She did stress that with emphasis on supported employment in the new SCL waiver regulations, that employment and benefit-counseling are crucial. She advised any CAC members who are beginning work, to sign up for the work incentive benefits under Social Security.

Commission for Children with Special Health Care Needs

Lee reported the Family to Family program received its fifth year of funding. Debbie and Sondra Gilbert, co-directors of this parent facilitator program, continue to recruit other parents having children with special health care needs to serve in this capacity. He also shared that the Transition to Adult Health Care Grant was planning a young adult forum, with young adults ages 21 – 28, who had good communication skills and could share with others the successful tactics and the barriers to making successful transitions to work, post-secondary education, and to an adult health care provider. The Commission may develop an application process from this Forum for a “Peer to Peer” program which would match successful young adults as mentors to youth with special health care needs.

Future CAC Meeting Dates/Locations

Harold reported that the next CAC meeting will be on Monday, December 2nd at 9am at the HDI Coldstream Training Room, with lunch following the meeting. We would be offering videoconferencing to those who did not want to make the long drive.