



## Consumer Advisory Council

Meeting Minutes

11/19/2012

Members present:

Morry LaTour	Peter Perry	Shannon Caldwell	Jason Jones
Lee Gordon	Jessica Wolfe	Paula Caldwell	Malkanthie McCormick
Elaine Brown	Karen Boudreaux	Harold Kleinert	Jennifer Crawford
Sandra M. Duverge	Pam Mattox	Fannie Stonestreet	Ashley Candelaria
Jeff Edwards	Chastity Ross	Hazel Forsythe	

*Guest and Staff: Chithra Adams, David Flechler, Marybeth Vallance,*

### ***Welcome and Introduction of Board Members***

Chastity opened meeting by welcoming all members present at the Coldstream Training Room and those who were attending by live, videoconferencing and teleconferencing, Elaine Brown, Jennifer Crawford, Lee Gordon, Shannon and Paula Caldwell. Members introduced themselves and Dr. Kleinert introduced Ashley Candelaria who is our new student member, replacing Jessica Birdwhistell. He noted that Ashley is a 3<sup>rd</sup> year HDI Research Assistant and recipient of the 2012 HDI “Kevin Burberry Award.” Jessica Wolfe was also introduced by Dr. Kleinert as a new member representing Eastern KY who is both a mother of a child with disabilities and a physical therapist. Dr. Kleinert applauded the Council membership which now represented all regions of the state. Chastity thanked everyone for their attendance and for those connecting through videoconferencing and teleconferencing.

### ***Review and Approval of August 2012 Minutes***

Chastity asked for members to review the Minutes from the August meeting. She asked if there were corrections or discussion. Karen made the motion to accept the Minutes with no changes and Sandra seconded the motion. Members approved the Minutes unanimously.

### ***AUCD Update – Council on Community Advocacy (COCA)***

Shannon summarized the recent activities of COCA as finalizing their agenda for the upcoming annual AUCD meeting in December. He noted that Dr. Kleinert and he were co-presenting a concurrent session discussing the role of our Consumer Advisory Council within our UCEDD, as well as activities, projects and priorities which had been developed through our CAC. Shannon remarked that HDI's CAC is recognized as being one of the most active Consumer Advisory Councils within our UCEDD network. COCA, Shannon shared, would be doing a poster session at the national conference, encouraging increased COCA membership from other self-advocates within UCEDDs across the U.S.

### ***HDI's Work with Kennedy Foundation on Insuring Accurate Information in Prenatal Down Syndrome Diagnosis***

Harold shared with members that HDI had partnered with the Kennedy Foundation in disseminating the nationally recognized booklet "Understanding a Down Syndrome Diagnosis". He further noted that HDI is creating a "National Center for Prenatal and Postnatal Down Syndrome Resources" combining three of the most recognized sources of education for physicians, other health care providers and families: 1) Brighter Tomorrows; 2) the Lettercase materials including "Understanding a Down Syndrome Diagnosis"; and 3) the Down Syndrome Pregnancy.org materials, including "Diagnosis to Delivery". He noted that 1 state, Massachusetts, had passed a law requiring that "Understanding a Down Syndrome Diagnosis" be distributed to all physicians and genetic counselors working with pregnant women.

He reported that the web-site portal for the National Center will be up in the next week. Also, he noted that all materials will be downloadable via the web, including via mobile devices. The focus is to provide non-biased, evidence-based education to medical practitioners *and* to prospective and new parents.

He noted that our UCEDD has taken the lead role with this important national issue. Sandra asked if these resources are in Spanish, and Harold confirmed that "Understanding a Down Syndrome Diagnosis" and Brighter Tomorrows are both in Spanish. She voiced a strong interest in this project, as there was a new Parent Support Group for parents having a child with Down syndrome formed within Jefferson and surrounding counties. Sandra was concerned that many myths related to having a child with Down syndrome remain in the Spanish culture.

Karen sighted appreciation for Harold's work in pursuing this national partnership, though Harold admitted that Malkanthie was the real motivator in encouraging him to pursue the original grant that started all of this (Brighter Tomorrows). Karen felt very strongly that the Down Syndrome Association should be approached regarding potential funds for wider distribution of the booklet to new parents or women who were pregnant. She also voiced that the local DSACK and CAC should advocate for similar legislation in KY. Jeff added that perhaps the DD Council could be approached re some funds for public distribution of the materials in KY. Malkanthie wanted to emphasize that the

physician training component of “Brighter Tomorrows” should be mandated and that the modules should be tracked re usage and through a pre and post-test.

***Developing the Five Year Plan – Things to Consider***

Harold noted that our Joint DD Network Survey (approx. 500 responses) had summarized the top priorities identified as being education, employment, health & wellness, and self-advocacy. Harold noted that Chithra Adams did interviews with 8 State Agencies, and that Shannon discussed, in phone conversations with CAC members, their priorities. Finally Harold presented additional data related to National Core Indicators and KY Post School Outcomes Data.

- A) ***Interview with CAC Members*** - Shannon noted that his report reflected the needs expressed by 11 out of 14 members contacted (please refer to hard copy of report). These priority needs included transition, education, employment, healthcare, advocacy and transportation. In addition to his report, he mentioned that under transition, some had suggested perhaps a transition manual be developed guiding parents, Rehab counselors, high school staff, and including assistive technology resources and programs. He noted the several CAC members noted there should be clearer information in the form of a DVD or interactive module that walks parents and consumers on how to make the waivers work or navigate through them. Understanding waivers, eligibility, and how to maximize them toward community living activities was underscored in the CAC discussion. Harold noted that the Protection & Advocacy Board was also working on a Power Point presentation about the Waiver changes. Marybeth asked if there was written information about the Waiver changes and Harold promised to send members the DD Council’s materials on this topic.
- B) ***Interview with Key Agency Directors*** - Chithra presented her Power Point (please refer to hard copy) summarizing the interviews of 8 state agency directors or managers. Chithra noted that transportation needs were expressed as an obstacle to access to appropriate childcare and continued to be linked as an obstacle to other community program accessibility through adulthood and aging. Members noted with dismay the lack of early identification and referral of children with developmental delays or disabilities to KY First Steps. Marybeth noted that the Point of Entry Coordinator from First Steps had told a recent HDI presentation to Pediatric Residents that too high percentage of their referrals came at age 2 & ½, though First Steps could only serve families from birth to three. Chastity explained another program for first time mothers or fathers, HANDS, and Malkanthie noted that she had not even been aware of that program’s existence. Malkanthie suggested that perhaps we should target education of Obstetricians and Pediatricians regarding early referral resources and the value of early referrals. Karen agreed and added that parents should have access to information about developmental milestones and early intervention in doctors’ office waiting rooms while they waited for Pediatricians visits. She also said that public service announcements could also be utilized to educate parents about what to observe in their own infants’ growth and development and how to access early

intervention programs. Shannon commented that perhaps this lack of early referrals to intervention programs could be discussed by the HDI newly-appointed “Underserved Populations Committee” of which he was a member. Chithra proceeded to discuss priorities with other state agencies, including Education, OVR, DDID, Child Care, Protection & Advocacy, and the Department of Aging and Independent Living.

- C) KY Post-School Outcomes Center – Harold distributed copies of this report (please refer to Power Point) Jennifer commented that to combat loneliness, cultivating friendships really starts in pre-school and school. Both Karen and Jessica agreed that inclusive activities and friendships with peers are problems even in elementary grades. Employment statistics also showed the need for employment to start in high school. Jennifer remarked that the access to employment in high school was even worse in rural communities. Sandra related her opinion that loneliness and lack of employment focus in schools related back to KY being a “provider-driven” state vs. focused on “person-centered” planning.

### ***Key Priorities – Small Groups to Prioritize Based on What You Heard Nominating Committee Report***

We divided our CAC into three groups, who met with “poster paper” and wrote their top 3 priorities which they felt should help guide the additions to HDI’s Five Year Work Plan. Each Group spokesperson summarized their priorities and these posters were then given to Harold after the group presentations.

Lee made a comment that there was a new model project in some schools, entitled “Operation Preparation” and that this targeted 8<sup>th</sup> to 10<sup>th</sup> graders. He reported that students with developmental disabilities would either be matched with mentors or that presentation by other adults with disabilities leading successful lives would be made to these students and their parents. This mentor/panel preparation pilot was to start parents and their teens with a vision of life in the community, including employment and how to use the resources available to move adolescents toward better involvement in person-centered IEP planning.

### ***Draft Plan***

Harold pledged to take the “story-board” priorities from members and interject them into HDI’s Five Year Plan. Malkanthie asked that these additions to the plan be highlighted and Harold will highlight them in yellow. These will be emailed and mailed to members for their final feedback.

### ***Nominating New Self-Advocate Members***

Harold distributed the “HDI Advisory Board Term Information – Nov 2012.” He noted that we needed new self-advocates to replace those members whose term was expiring. He asked permission to contact Cathy Jo Edwards who had been President of KY Self-Advocates and was also a member of the HB 144 Commission. Members agreed. Sandra offered that she will ask 2 self-advocates whom she knows from Louisville and

email Harold. He also encouraged other members to email him if they thought of other self-advocates.

### ***Elections of new Vice-Chair***

Karen nominated Paula Caldwell as the new Vice-Chairperson and Morry seconded this motion. Paula accepted the nomination. Chastity asked in 3 requests to members for any additional nominations. Motion was made and approved to close the nominations. Members voted unanimously to approve Paula in this position. Paula then accepted the position of new Vice Chair of the CAC. She will serve with Morry who replaces Chastity as the New Chair beginning at the March 2013 meeting.

### ***Meeting Dates for Next Year***

The following CAC meeting dates were established:

Monday, March 4<sup>th</sup> 2013

Monday, June 3<sup>rd</sup>, 2013

Monday, Dec 2<sup>nd</sup> 2013

\*The Joint DD Network Meeting will be on a Friday during the summer of 2013

### ***Agency Updates***

***OVR*** – Jason Jones assured members that he heard everyone’s concern about the need for OVR to be more involved and pro-active in high school transition planning and he pledged to take these concerns back to his agency. He did note that budget issues and large caseloads were part of the problem. He noted a new joint venture with OVR, Bluegrass Technology and the Physical Therapy Department at U.K. to refurbish and disseminate used medical and AT equipment to individuals who need it. The agencies involved are still planning the details of this project which will also be linked to the CATS network. HDI is doing the evaluation for this project.

***Protection and Advocacy*** – Jeff reported that the legislative subcommittee approval of the Restraint and Seclusion regulation still faced challenges. He also noted that P & A was continuing to meet with KY Department of Education staff about these needed regulations in the schools. He distributed the Restraint and Seclusion Report and another booklet produced by P & A entitled “Personal Care Homes in KY: Home or Institution.” He stated that P & A also continues to be very concerned regarding the rights and conditions of individuals living in Personal Care Homes. Jeff answered a question from Chastity, confirming that if an individual was living in a Personal Care Home and applied for a SCL emergency waiver, their application is considered a priority.

***Commission for Children with Special Health Care Needs*** – Lee reported that the Commission continues to have the “Family to Family” grant. He shared that Dr. Eugene Foster was appointed as the new Deputy Director and that he had a background in Psychology and working with foster children.

***Commission on Behavioral Health and Developmental and Intellectual Disabilities-***  
Harold reported that Claudia had emailed Harold to report to members that the SCL

regulation changes were submitted to the Legislative Review Committee last week and were to go to the Rules and Regulations Committee December 11<sup>th</sup>.

***New Business and Announcements***

Nothing added under this topic,

***Special Recognition***

Harold commended and expressed deep appreciation for members leaving the Council, who had each served 6 year terms. Framed Certificates were given to Chastity, as outgoing Chair; Peter Perry as father of a son with a disability; Pam Mattox as a mother representing a daughter with disabilities; and Fanny Stonestreet, a self-advocate. Harold expressed appreciation to Morry for taking on the duties as new Chair of the CAC.

In closing, he stressed his appreciation for retiring members' time and contributions, as well again welcomed new member, Jessica Wolfe. Marybeth and Harold noted appreciation for David Flechler in insuring all the technology was set-up and sustained during the entire morning meeting for our first video-conferenced CAC meeting!

***Lunch and Meeting Conclusion***

Karen made a motion to adjourn which Jason seconded. All members voted unanimously to adjourn to lunch which was provided.