

University Center for Excellence in Developmental Disabilities

# **Consumer Advisory Council**

Meeting Minutes Monday, June 7, 2010

#### Members present:

Morry LaTour	Jessie Birdwhistell	Shannon Caldwell	Paula Caldwell
Claudia Johnson	Jeff Edwards	Pat Seybold	Malkanthie McCormick
Kerri Lea Wells	Alan Wells	Harold Kleinert	Hazel Forsythe
Karen Boudreaux	Chastity Ross	Norb Ryan	Jason Jones
	Lee Gordon	Fannie Stonestreet	

Guests and Staff: Daniel Livingston, Marybeth Vallance, Kathy Sheppard-Jones, Ruth Caldwell, Debi Jones

# Welcome and Introduction of New Board Members

Alan Wells welcomed the members in attendance and called the meeting to order.

## Review and Approval of December Minutes

The minutes from the March CAC meeting were reviewed, voted on and approved. Lee Gordon noted on the sign-in sheet that the Commission for Children with Special Health Care Needs has a new address: 310 Whittington Parkway, Louisville, KY 40222.

AUCD Update – Council on Consumer Affairs/CAC Member Interviews Status Shannon Caldwell, CAC-COCA liaison, gave his report as COCA representative. He reported that COCA had just held their quarterly teleconference and were still working on the language for their operational rules and 5-step strategic plan, which focuses on creating more community involvement in the organization. Shannon announced that CAC members were always welcome to be a part of the COCA conference. He then reminded council members to be sure to participate in a brief survey about the effectiveness of the CAC. For more information or to take part in the survey, contact Shannon at (606) 330-1702 (home), (606) 524-6670 (cell), or email sigc14@windstream.net.

KY Supported Employment Training Workgroup – Self Advocate/Family Page
Harold Kleinert reported that HDI's Supported Employment project was in the final
stages of creating a self advocate and family page on their website. The page will have a
list of service providers, frequently asked questions, supported employment success
stories and examples of what good supported employment should be.

# Preliminary results of HDI website evaluation

Harold Kleinert announced that the preliminary results were in for the HDI website evaluation survey. Although the majority of the responses were either satisfied or highly satisfied, there were some useful suggestions for improvement, including a more balanced orientation for individuals with severe/profound disabilities, and more diversity in the imagery on the website. Survey respondents reported that the site was very accessible for individuals using screen readers and assistive devices. For suggestions regarding improvements to the HDI website (www.hdi.uky.edu), email daniel.livingston@uky.edu.

# Transportation Provider Training Update

Morry LaTour reported that a suggestion was made at the *Committee for Citizens with Disabilities* meeting for consumers to be involved with driver training for LexTran and Wheels. A committee was created to create a process to involve consumers. The next meeting will be June 23. Marybeth Vallance announced that she and Morry were invited to sit in on a consumer involvement meeting for MV Paratransit in Louisville, in which the HDI Driver Disability Training video was presented. Morry then announced that LexTran has developed a consumer advisory committee for bus and paratransit riders to offer advice and feedback on transportation services. He also noted that increased transportation needs and issues are currently being addressed in preparation for the World Equestrian Games in September in Lexington. Lee Gordon noted that, due to budget cuts, TARC in Louisville has been forced to cut routes and lay off drivers.

# MTARS site visit July 20-23: Role of our CAC

Harold Kleinert reported that the *Monitoring and Technical Assistance Review System* (MTARS) would be making a site visit from July 20-23 to ensure that the necessary services are being provided by Kentucky's UCEDD and Kentucky's developmental disability network. Kentucky is the last state to be reviewed by MTARS. There will be a public hearing during the visit (4 – 6 PM on July 20<sup>th</sup>) to allow consumers to share their experiences with HDI, KY Protection & Advocacy, and the KY Council on Developmental Disabilities. He noted that our council members were welcome to contribute as well. Harold noted that recommendations have also been made based on UK's periodic review in May and will be made available soon. Jeff Edwards from Protection & Advocacy reported that their MTARS review will include a review of 50-70 cases from 2008-present. The date and time for the public forum will be Tuesday July 20<sup>th</sup> from 4 – 6 PM.

# Postsecondary Inclusion Partnership Update

Malkanthie McCormick reported that the Postsecondary Inclusion Partnership (PIP), a 3-year grant approved by the DD council and governed by HDI, is currently serving nearly 30 students. However, budget cuts are making hard to continue the program. Dr. McCormick noted that legislators need to be educated about the benefits of the program, which has opened a lot of doors for students with disabilities, so that funding for PIP can be included in annual budgets and not just grant-based. Harold Kleinert reported that he had met with several organizations about continued funding for the project, and wants to develop plans to not only continue PIP, but expand the program and coordinate efforts

with Supported Employment. Paula Caldwell, suggested putting together talking points about the value of PIP for individuals who wish to contact legislators. Harold agreed, but noted the importance of being careful not to be seen as lobbying, but educating only. He also announced that HDI's presence at the 2010 Legislative Summit would be a great place to provide information to legislators about the importance of the PIP program.

#### HDI Graduate Certificate Update

Kathy Sheppard-Jones reported that 13 on-campus and 7 online students were enrolled in the graduate certificate program during the semester that just ended, with 8 more incoming students expected in the fall. She said that HDI was also aggressively recruiting students for the online program, and encouraged council members to refer individuals that could benefit from the 1-year certificate in developmental disabilities.

#### 2010 DD Network Survey Results

Harold Kleinert announced the results of the DD Network survey, which was completed by 543 individuals, over 50 of those respondents being an individual with a developmental disability. Over 40% of the responses were from family members, and 48% were from service providers. The survey examined all 10 areas of the Developmental Disabilities Act, and the 2010 survey showed that Education and Early Intervention was still the highest priority. Malkanthie McCormick suggested that more of an emphasis be placed on physical fitness, diet, and exercise, and Pat Seybold mentioned a gym membership program sponsored by the DD Network in which individuals with disabilities are reimbursed for gym membership fees and answer survey questions relating to gym accessibility, reaching their goals, etc. For the complete 2010 DD Network survey results, refer to *Appendix A*.

#### Project Spotlight: Core Indicators

Kathy Sheppard-Jones reported on the Core Indicators project, which has been collecting data since 1998. Over 5000 people receiving services have been interviewed, with 26 states participating in the program. For the complete presentation, refer to *Appendix B*.

After the presentation, the council broke into small groups to discuss things that stood out to them regarding the Core Indicators data. Transportation issues were mentioned by several groups, with the need for consistent, quality transportation especially important in Kentucky due to the rural nature of the state. Health and fitness were also mentioned as neglected areas, with a need for education and strategies for weight control and exercise programs, as well as safety and food sanitation programs. It was also stated that these programs should be introduced at the early intervention phase, rather than later in life. Hazel Forsythe mentioned a new program offered by Kroger which could be helpful called Nu-Value which rates the nutritional density of foods on a scale of 1-100.

The issues relating to social interactions were also discussed by the workgroups. There seems to be a need for more opportunities for social involvement for individuals with disabilities served by the Supports for Community Living Waiver, although the data could be very different if other (non-SCL) groups were examined. In any case, it will be very helpful for the different states participating in the study to collaborate as much as

possible, sharing information to understand why some things are working better in some states than others, in an effort to raise levels of satisfaction and the quality of life for individuals with disabilities.

### Agency Updates

Jason Jones from the *Office of Vocational Rehabilitation* reported that applications for services were down 15%, with those eligible for services down 36%. Part of the issue is that OVR, with state budget cuts, is now able to only serve those individuals in Categories 1 and 2 of Service Need (those with the most significant disabilities).

Lee Gordon from the *Commission for Children with Special Health Care Needs* reported that the Commission was still looking for support parents to answer questions and help other parents. For volunteer information, contact Debbie Gilbert (Louisville) at (502)595-4459 or Sondra Gilbert (Owensboro) at (270)852-2918.

Claudia Johnson, *Department of Behavioral Health, Developmental and Intellectual Disabilities*, reported that SCL waiver is up for renewal; Medicaid has not submitted anything yet, but no big changes are expected with the current submission immediately due. She also announced that a committee meeting on House Bill 144 would be taking place on June 9.

Jeff Edwards, *Protection and Advocacy*, announced that P&A was preparing for its MTARS review. He also mentioned a suit being filed within the week to prevent building of a 50 bed children's psychiatric hospital in Mount Sterling.

Pat Seybold, *KY Council on Developmental Disabilities*, announced a no-cost Aging Caregiver program being offered by ARC of KY and funded by the DD Council, to assist families in planning for the needs of their sons and daughters with developmental disabilities as families age. She encouraged people to recruit families with individuals with disabilities to think proactively about their future, and that it could apply to families with sons or daughters of all ages. She mentioned that the DD Council was also preparing for its MTARS review.

Norb Ryan, *State ADA Coordinator*, noted the considerable extent of Project SAFE training in the area of sexual abuse and disabilities, and that there would be ADA training for the Police Academy. He also noted that he would be giving a presentation at the KY Prosecutors Conference. Norb reminded our council members that this year marks the 20<sup>th</sup> anniversary of the Americans with Disabilities Act, and that there would be a rally at the State Capitol during July. He also mentioned that the Federal Communications Commission would soon be requiring all websites to be accessible.

#### New Business and Announcements

Hazel Forsythe announced that the 2010 Autism Walk (sponsored by the Autism Society of the Bluegrass) will be taking place at Keeneland on Saturday, July 10, starting at 10:00 am.

Morry LaTour announced that "Second Sunday" in Lexington will be taking place on June 13 from 2:00-5:00pm at the Bluegrass Airport. Participants will be able to run, walk, bike, etc. on the new runway at the airport and watch planes land.

Marybeth Vallance congratulated Fannie Stonestreeet on winning three medals at the Special Olympics. Great job, Fannie!

The meeting was adjourned.

#### MARK YOUR CALENDARS - UPCOMING 2010 CAC MEETING DATES:

Friday, August 20 (Joint Meeting with Protection & Advocacy and the DD Council) 9:00 AM to 2:00 PM; Embassy Suites, Lexington

Monday, December 6; Holiday Inn North, Lexington