

AJ Pappanikou Center for Excellence in Developmental Disabilities
Education, Research and Service
Consumer Advisory Council
November 21, 2014
Meeting Minutes

In attendance:

Alexia Bouckoms
Molly Cole
Linda Goodman
Diana LaRocco
Keith Mullinar
Allyson Powell
Lolli Ross
Maria Synodi
Pam DonAroma
Linda Mizzi
Mark Keenan
Regina Birdsell
Peter Deckers

UCEDD Staff In Attendance:

Mary Beth Bruder, PhD: UCEDD Director
Anne Marie Davidson, MS: UCEDD Training Coordinator
Gabriela Freye-Calish, MSW: UCEDD Diversity Coordinator
Nick Gelbar Ph.D.: UCEDD Post Doc
Annie George: UCEDD Post Grad Student
Gerri Hanna, J.D., M.Ed.: UCEDD Associate Director
Linda Rammler, PhD: ASDI-NE, UCEDD Consultant
Allison Shefcyk: UCEDD Research Assistant
Bethanne Vergean: UCEDD Early Intervention
Stanton Wolfe, DDS, MPH: UCEDD Training Director
Jeffri Brookfield, PhD: ECPC Coordinator
Jeanne Chadwick: UCEDD Post Doc
Craig Schramm, PhD: UCEDD
Jim McGaughey, : UCEDD
Orv Karan, PhD: UCEDD

The meeting opened at 9:40 am.

Introductions: The meeting began with introductions of attendees and a review of the day's agenda.

Updates:

- UCEDD staff reported on information from the AUCD national meeting. The conference focused on transition, employment and post-secondary for persons with disabilities. It was also noted that Senator Harkin is retiring so there is a push to get initiatives in place while he is still in office.
- Dr. Stanton Wolfe will retire in 2015. His last day at the UCEDD is December 10. Two retirees have been rehired to work on UCEDD projects, Jim McGaughey, former director of Protection and Advocacy, and Orv Karan, faculty at UConn Storrs.
- The UCEDD is more organized and bringing in grant funding. Two grants will be submitted in December.
- The UCEDD website has been updated and will continue to be updated through the Storrs campus.
- The UCEDD will co-sponsor an IDEA/ADA anniversary celebration in October.

DD Council Update:

The CT DD Network has a strong collaboration within the state. Molly Cole spoke to the group about the discussion going on nationally to improve how DD Networks collaborate nationally. The three directors of the three national organizations will come together to find ways to mesh policy on a national level and around the DD Network priorities of self-advocacy, engagement and better support of the self-advocacy movement.

DD Network in CT:

- Started the cross disabilities alliance
- Meets every other month
- Runs the Partners in Policymaking initiative
- Has an active council that will bring work on the next 5 year plan. The main goal of which will be no more institutions in the state of CT.
- Funding a large conference made up of the three DD Network groups and other organizations
- Funding employment and technology initiatives
- Working with parents who have cognitive limitations
- Working on on-demand, non-medical, out of normal hours transportation
- Collaborating with ARC
- Collaborating with Family Voices to renew the CT KASA youth leadership group

Areas of Emphasis:

Health:

Dr. Peter Deckers spoke to the council about the history and future of healthcare in America. The passing of Medicare created the opportunity for more people to be able to access the health system and also resulted in an increase in costs for healthcare. Also an explosion in medical technology and drugs to treat conditions.

Problems as a result of medicare: Continued barriers to access; Became bad debt for the government; Quality was variable; Cost issues resulted in discounting of bills and penalties.

Presently, Obamacare has enrolled many more individuals who were not eligible for medicare. Costs, however, will make Obamacare unsustainable without modification. High costs may create a need for a rational approach to healthcare and a possible rationing of healthcare. Future focus may be to make healthcare more about prevention and early detection.

Early Childhood:

In Connecticut, many programs exist simultaneously all with very different focuses. The challenge is that there are many programs in early childhood and the costs are enormous. Also, many programs have become 1 on 1 and have shifted into over-specialized roles. Three areas that need to be discussed:

- Combine early childhood under one office
- Training- help teachers do what they should do
- Decide where funds are going and what programs they support
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ECPC:

Jeffri Brookfield, the coordinator for the Early Childhood Personnel Center housed within the UCEDD gave an update of the project. The purpose of the ECPC project is to help states put together a program of well-trained personnel that meets their states' needs. ECPC is working with four states intensively and with seven states targeted. The ECPC conducts Leadership Institutes that bring together representatives from Part C and 619.

Guidelines:

Anne Marie Davidson updated current early learning initiatives. New CT early learning standards have been outlined in a set of new guidance documents. These documents will help people better understand early learning standards. The Office of Early Childhood has conducted six focus groups to help review the guidelines and is scheduling additional focus groups. Surveys have been sent to the focus groups. Data collected will be used to write a document for early learning standards and dual language learners.

School Age:

Nicholas Gelbar updated the group on projects surrounding school age children. Changes in the school-age system has resulted in an over-diagnosis of ADD. RTI is still in process in trying to

be implemented in schools. National reforms created one set of national standards, the common core. The common core is changing general education. It has good intentions but the focus on uniformity has changed how some things are taught. Also changed how teachers are evaluated toward working on specific learning objectives. The negative is that it negates individual learning styles like those with disabilities. Currently trying to find a balance between standardization and individualization.

Para-educators:

Paras are at the forefront and many are left to develop their own curriculum. There is a myth that para educators are skilled educators. This is creating a frustration among paras because of a focus on compliance. The UCEDD is co-sponsoring a Para-educators conference in the Spring 2015.

CAC member organization collaboration updates:

Lolli Ross- Abilis is working on dismantling our group homes, working on strategies for customized employment, sponsoring a conference on autism services with regards to safety and is collaborating with the Stamford committee on accessibility.

Pam DonAroma- need to create a standard definition of what is social enterprise. Her agency is working on community based education with state funds, creating business models and events based on these, collaborating with the UCEDD. Also working on transportation issues where the first step is clarification of the laws because the current law creates barriers.

Diana LaRocco- the University of Hartford is engaging with local universities and schools in an educational research consortium on Hartford Public Schools. This is an opportunity for the UCEDD to engage with Hartford schools. Also exploring inclusion summit possibilities as a member of DEC.

Regina Birdsell- is working with para educators on the common core. Focusing on the need for teacher education.

Linda Goodman- Agency has applied for a pre-K development grant and expects the outcome by December 10.

Next steps:

CAC members will receive a survey prior to the holidays. The survey will ask them to re-evaluate their level of participation and to clarify their role on the advisory board. The responses collected will determine how future meetings will be conducted.

The meeting adjourned at 1:00 p.m.

Respectfully submitted,

Deborah Burch
University of Connecticut Health Center
AJ Pappanikou Center for Developmental Disabilities