

AJ Pappanikou Center for Excellence in Developmental Disabilities
Education, Research and Service
Consumer Advisory Council
November 4, 2013
Meeting Minutes

In attendance:

Allan Bergman: guest presenter (via skype)
Molly Cole: Developmental Disabilities Council
Roberta Daversa: CT FEAT
Ann Denué: Education Specialist, Department of Children and Families, Region 4
Pam DonAroma: Futures Inc
Linda Goodman: Director, Birth to Three System
Bob Greenstein: UCEDD Founder
Diana LaRocco, EdD: Faculty, University of Hartford
Linda Mizzi: Assistant Program Director, Office of Protection & Advocacy
Keith Mullinar: CC=A; Self-advocate (via phone)
Allyson Powell: UCHC Adoption Program
Lolli Ross: Abilis
Lisa Seminara: Family Member
Karen Steinberg: Nurturing Families
Deirdre Summa: Cornelia DeLange Foundation
Maria Synodi: Connecticut Department of Education

UCEDD Staff In Attendance:

Mary Beth Bruder, PhD: UCEDD Director
Deborah Burch: UCEDD Executive Assistant
Anne Marie Davidson, MS: UCEDD Training Coordinator
Nick Gelbar, PhD: Post Doc
Tierney Giannotti, MPA: UCEDD Associate Director
Gabriela Freye-Calish, MSW: UCEDD Information Coordinator
Peter Love, PhD: UCEDD Consultant
Linda Rammner, PhD: ASDI-NE, UCEDD Consultant
Brian Reichow, PhD, BCBA-D: UCEDD Research Director
Isaac Smith: Research Assistant
Allison Shefcyk: Research Assistant
Stanton Wolfe: UCEDD Training Director

The meeting opened at 9:40 am.

Introductions

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

Federal Update

Allan Bergman gave an overview of the state of federal legislation and funding for disability. See attachment, *Challenges and Opportunities; Keeping Your Compass on "True North"*

The presentation focused on budget, and the lack of dissemination of information in policy and practice.

Updates

The UCEDD just hired a dissemination specialist, Bethanne Vergean

Early Childhood Personnel Center (ECPC) - finished knowledge development and information is now on the ECPC website, www.ecpcta.org

Ready to roll out technical assistance to states across four regional centers

Will identify what states the center can work with

Working on bringing in more grant funds

Parent to Parent is ongoing

Stanton Wolfe highlighted two new curriculum programs in disability that are approved and offered through the Department of Community Medicine. The first is a post baccalaurate and the second is an undergrad pre-baccalaurate concentration in disabilities.

Brian Reichow gave an update on research projects.

- His team is working on evaluating web-based information on autism so that parents and others will know where to get faster, higher quality information when searching online.
- The research team is working on creating a transition tool for high school students with autism who want to go to college. They are looking for NIH funding for this project.

Molly Cole gave an update on the DD Network:

- Network agencies meet regularly
- Concerted effort among the three to plan priorities and collaboration
- Network arms share responsibility in conducting events
- Partner in Policy Making (PIPS), one of DD Network's large initiatives, just graduated a class

The Family Alliance is growing. Collaboration among the three network arms is the way to go in terms of time and division of resources.

The CAC divided into three workgroups according to the focus area that members selected to collaborate on. Each workgroup's mission was to identify priorities for its work within UCEDD objectives and to identify opportunities to collaborate.

Early Intervention:

- New learning and development standards in Birth to 5 is done and should be incorporated into objectives
- Fidelity as a goal for children on autism spectrum and implementation of IFSP and IEP and related objectives

- Geographic considerations of who can attend workshops. Make Stamford campus more active for Fairfield County providers.
- Transition from NICU to Birth to 3; honing this area.

Mental Health:

The mental health workgroup agreed on the following objectives:

- Determine dates, times, locations for appropriate regional major medical meetings during 2014 and 2015; determine process for inclusion of disability training workshops during selected meetings.
- Complete Training Plan for: planning, development, evaluation, implementation and sequencing of training(s) in disabilities for medical providers.
- Meet with DPH to explore process for inclusion of disabilities as a content area for medical providers' CME licensure mandate.
- Complete draft of medical providers' trainings re: number of trainings, topic areas, intended trainees, learning objectives, course content, evaluation plan, and format and locations (Online? Webinar? Teleconference? Face-to-face?), etc.
- Identify trainers, secure training location/dates/times, and finalize related logistics for conducting trainings.

School Age:

The school-age workgroup agreed on the following priorities and actions:

- Recently attended Connecticut Core Transitions Skills—focus was on the skills that students need
 - Training done by SERC
 - Is there a way to a way to have other experience this training (e.g., families, public school personnel, the UCEDD staff)?
- Ability Beyond Discover Learn Work modules for students
 - Developing a related curriculum for families
- **DMV/SDE—Transportation requirements for students continue to be a problem**
 - UCEDD staff will take initiative to gather the information from CAC members
 - UCEDD staff will summarize information, creating fact sheet to be used as talking points to meet with legislators
 - School workgroup members will work with UCEDD staff to schedule meetings with key legislators (e.g., Beth Bye) to discuss possible legislative remedies
- **Transitions to postsecondary opportunities (2.5.4)—Workshops**
 - What's the biggest challenge with transitioning?
 - Linda P&A—Looking at the transition of students to BRS
 - There is a need to educate transition coordinators, family members, and others about the role of BRS and vice versa
 - UCEDD staff will coordinate with Linda R. and Linda M. to develop a proposal to educate BRS/DDS/DMHAS, School based Transition Coordinators, and families around transitions, and various roles
 - Common Core Skills will be part of the education

Next Steps:

- The CAC decided to continue to meet twice a year on Mondays works well for members
- A survey monkey will be sent out to members asking what time of day is best to meet
- Each workgroup will determine for itself the method to keep in collaboration via phone or in person. The UCEDD will facilitate meeting space or conference call service for these meetings.
- UCEDD staff assigned to each group will coordinate bringing the group together
- The UCEDD welcomes CAC members' involvement in UCEDD projects. Members may contact Mary Beth to discuss.

The meeting adjourned at 1:15pm.

Respectfully submitted,

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