

AJ Pappanikou Center for Excellence in Developmental Disabilities
Education, Research and Service
Consumer Advisory Council
June 5, 2014
Meeting Minutes

In attendance:

Allan Bergman: Presenter and strategic planning facilitator
Alexia Bouckoms: Self-advocate
Molly Cole: The Connecticut Council on Developmental Disabilities
Ann Denué: Department of Children and Families
Linda Goodman: Director, Birth to Three System
Nordia Grant: CT Department of Public Health
Diana LaRocco, EdD: Faculty, University of Hartford
Nanfi Lubogo: Co-executive Director, PATH/Family Voices of Connecticut
Keith Mullinar: CC=A; Self-advocate
Antonio Orriola: Self-advocate
Allyson Powell: UCHC, Adoption Assistance Program
Lolli Ross: Abilis; Family member
Maria Synodi: CT Department of Education, Bureau of Special Education

UCEDD Staff In Attendance:

Mary Beth Bruder, PhD: UCEDD Director
Ching-I Chen Ph.D.: UCEDD Post Doc
Anne Marie Davidson, MS: UCEDD Training Coordinator
Gabriela Freye-Calish, MSW: UCEDD Diversity Coordinator
Nick Gelbar Ph.D.: UCEDD Post Doc
Tierney Giannotti, MPA: Data Coordinator
Annie George: - UCEDD Post Grad Student
Gerri Hanna, J.D., M.Ed.: UCEDD Associate Director
Christine Jozef: UCEDD Administrative Assistant
Linda Rammler, PhD: ASDI-NE, UCEDD Consultant
Brian Reichow, PhD, BCBA-D: UCEDD Research Director
Allison Shefcyk – UCEDD Research Assistant
Chris Sullivan, J.D.: UCEDD Post Grad, Parent
Bethanne Vergear: UCEDD Early Intervention
Phil Weinholtz – UCEDD Information Dissemination
Stanton Wolfe, DDS, MPH: 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.

Mary Beth Bruder announced that Jim McGaughey has retired as the Executive Director of the Office of Protection and Advocacy and that Gretchen Knauff will be taking over as the acting director.

Mary Beth also announced that Brian Reichow will be leaving his position at the UCEDD. He will be moving to Florida to continue his work in Early Childhood Intervention.

Molly Cole presented an update on the Developmental Disabilities Network.

- Cross Disability Alliance hoping to grow
- Molly asked to please get the word out about their interactive calendar that lets you post events because they are not getting many calls for calendar updates
- They are working on a big initiative for the 40th Anniversary of IDEA, with a focus around family support. They are planning a 2015 Family Support Conference mobilizing around family issues through the cycle of IDEA. A planning committee will be set up in the fall and they will be looking for co-sponsors and family groups to contribute

Allen Bergman announced that CT is very fortunate because it has the top 3 DD Network partners that work together collaboratively and "are all in it for the collective good".

Quarterly Report Highlights:

Mary Beth Bruder went over the UCEDD Core Values, Vision, and Mission. Mary Beth stressed that we need to always remember our vision "All individuals with disabilities in Connecticut are valued citizens with opportunities and supports that allow them to be fully included, independent, productive and contributing members of society". She also stressed that we need to help make quality of life a mission.

The UCEDD currently has two faculty appointments filled by Dr. Stanton Wolfe, Director of Training and Education, and Dr. Brian Reichow, Director of Research. Because of Brian Reichow's departure, a Research Director position has been posted.

There are some viable training activities:

- The university has been given approval for a four course online certification class on public health
- An Autism certificate program will begin next spring

The UCEDD has many partnerships:

- St. Joseph's University: support of a post doc position in research and clinical evaluation for Medicaid families

- DCF/SERC: looking at transitioning school age children to adulthood and housing
- Office of Early Childhood: working on developing materials for families using a preschool benchmark
- Special Olympics: working on a Health/Wellness/Fitness initiative with FAVARH
- University of Hartford: working on future trainings
- University of Connecticut: working within the University moving forward on an education track with different schools
- UCEDD will be hosting a paraprofessional conference in April

Updates:

Brian Reichow gave an update on the current research that is being conducted at the UCEDD.

- Parent to Parent:
 - finished enrollment (~50)
 - Began case studies
 - Finishing data collection
- ASD College/Transition
 - Systematic review published to the Journal of Autism and Developmental Disorders
 - Grant being submitted
 - Survey of adults who attend college (need more participants)
- Other Systems Review:
 - Sensory Integration for ASD
 - Parent skills training for neurodevelopmental disabilities – in data analysis phase. Results will be used to develop program
- International Website: Accepted for publication in the Research in Developmental Disabilities journal
- World Health Organization Pilot
 - Training Community Healthcare Workers, data collected
 - A July meeting is scheduled to analyze the data
- Paraeducator Survey: being prepared for submission
- Service Coordinator Update: being prepared for submission
- ECPC Reviews: Have undergone external review and will be revising and preparing for submission
- ASD Follow-up Study: received IRB approval, waiting on coordinating logistics with the University of Connecticut Health Center, Hospital for Special Care and St. Joseph's University
- Special Olympics/FAVARH: working on developing a unified fitness program

Stanton Wolfe gave an update on the current trainings that are being conducted at the UCEDD.

- Public Health Certificate program (4 courses)
- Undergraduate program at Storrs – 2 approved (Spectrum, Global), 1 in process (law)

- Transitions Training – 2 of the 3 workshops have been completed
- Learn the Signs & Act Early training – Tierney Giannotti has trained approximately 400 individuals
- Paraprofessional Training for the Avon Schools – 5 completed
- Medical Trainings continue to be the priority – CAC Health Workgroup addressing

Federal Updates:

Allan Bergman gave an update on national policy trends. He explained that people with disabilities are the largest group living in poverty. We are facing a major problem due to budget issues. It is important to focus on cheap and easy solutions to offer people with disabilities more control over their life. The Role of Assistive Technology needs to be on the forefront.

See attachment - *National Policy Trends that are Transforming Services to People with Disabilities: Policy, Advocacy & You.*

CAC Workgroup Reports:

- Early Intervention: Anne Marie Davidson provided the update on the Early Intervention workgroup.
 - We are working with the Office of Early Childhood through our MOA to develop guidance specific to children with disabilities. The guidance is based on the new Early Learning and Development Standards. We will be convening an advisory group to support us in this work, conducting focus groups with key stakeholders and soliciting feedback on the draft document. We will also design training to address this area as well.
 - Address fidelity of services for children on the autism spectrum and implementation of IFSP and IEP and related objectives.
 - We notified people that we had the capacity to conduct training on the CONNECTICUT GUIDELINES For a Clinical Diagnosis of AUTISM SPECTRUM DISORDER. Brian Reichow and Tierney Giannotti have both done trainings. Through the PIPS collaboration, Phil Strain and Ted Bovey were here providing training on peer mediated strategies for children on the autism spectrum. We are working with SDE and SERC to provide follow up to this training during the 2014-15 school year to improve the implementation of these strategies. We notified the early childhood community that we had the capacity to train early childhood providers on topics specific to young children with disabilities. Anne Marie and Bethanne provided a training on including young children with autism in early childhood programs and classrooms. This training highlighted evidenced based practices for supporting the growth and development of young children with autism. To address fidelity of assessment recommendations the UCEDD is conducting a study with the Hospital for Special Care to determine the percent of children who receive the recommended services following their diagnostic assessment.

- Looking to expand the locations for trainings to encompass different areas of Connecticut. Would like to make the Stamford campus more active for Fairfield County providers.
 - Conducted a training collaboratively with ABILIS on the UCONN Stamford Campus and we are exploring conducting a Parent Leadership Advocacy Training series there in the fall.
- A needs assessment to Early Childhood teachers will be going out. These results will be used as a guide to develop professional development options for the 2014-2015 school year.
- Developing EBP briefs for display on the Birth to Three website on the topics of routine based intervention, coaching and natural environments.
- School age: Christine Sullivan provided the update on the School Age Workgroup.
 - DCF Region 4 Pilot Training – working with SERC, DPH to pilot a regional transition training for families. Three training sessions will be held: 1-education; 2-housing/employment; and 3-medical. The first training session was May 21st and had 30 participants.
 - DCF Children’s Behavioral Health Plan – developing a website.
 - Avon Public Schools Paraprofessional Training – the 5th training has been completed. A needs assessment has been piloted.
 - Statewide survey of 2,500 paraprofessionals was conducted to better identify needs.
 - Review of student transportation issues pertaining to appropriate vehicles to transfer students. A letter from the State Department of Education will be going out to all providers to give guidance.
 - UDL trainings with HPS Social Studies Curriculum Writers. Three follow-up sessions were conducted with approximately 10 teachers and two central office personnel. The plan is to use UDL as the foundation for the curriculum.
- Health: Keith Mullinar provided the update on the Health Workgroup.
 - A goal is to work with the Health Center to train the medical students. The group will be working with Dr. Anton Alerte (UConn School of Medicine) and others to build on the recent medical student trainings on disability awareness, sensitivity and understanding. They would like to work with Dr. Alerte to build on the existing curriculum.

Next Meeting:

Please hold Thursday, September 18, 2014 from 9:30 to 12:30 for the next Consumer Advisory Council Meeting. The meeting will be held at the UCEDD Conference Room.

The meeting adjourned at 12:10 p.m.

Respectfully submitted,

Christine Jozef
University of Connecticut Health Center
AJ Pappanikou Center for Developmental Disabilities