



AJ Pappanikou Center for Excellence in Developmental Disabilities
Education, Research and Service
Consumer Advisory Council
June 22, 2017

Meeting Minutes

In attendance:

Allan Bergman: Guest Speaker

Chris Blake: Advocate

Scott Brown: Dep. of Educational Psychology, UConn Neag School

Mary Beth Bruder: CT UCEDD Director

John Dagata: Meeting Assistant for Chris Blake

Karen Carney: Goodwin College; Parent

Jackie Chiu: Educational Psychologist visiting from Hong Kong

Molly Cole: CT UCEDD Acting Training Director

Ruth Eren: Center on Autism, Southern Connecticut State University

Linda Goodman: Office of Early Childhood

Jean Herzog: Special Olympics Connecticut, Inc.

Flora Lo: Educational Psychologist visiting from Hong Kong

Nanfi Lubogo: PATH Parent to Parent; Family Voices of Connecticut, Inc.

Keith Mullinar: CC=A; Self-advocate

Regina Owusu: Connecticut Department of Public Health

Allyson Powell: UConn Health Adoption Assistance Program

Lolli Ross: Arc of Westchester

Kari Sassu: Southern Connecticut State University, School Psychologist

Wendy Simmons: SERC

UCEDD Staff In Attendance:

Nick Gelbar, PhD: UCEDD Research Director

Annie George-Puskar: UCEDD Post Grad Student

Gabriela Freyre-Calish: UCEDD Education & Development Specialist

Betsey Howe: UCEDD Post Grad Student

Christine Jozef: UCEDD Administrative Assistant II

Tara Lutz: UCEDD Post Grad Student

Jessica McKenty: UCEDD ECPC Program Coordinator

Chelsea Panse: UCEDD Post Grad Student

Linda Rammler: UCEDD Research Associate II

Bethanne Vergean: UCEDD Research Assistant

Danielle Webber: UCEDD Administrative Manager

The meeting began at 9:20 am.

Welcome and Introductions:

Mary Beth welcomed all those participating in the meeting. She announced that Dianna LaRocco (one of the CAC tri-chairs) was not able to attend the meeting because she had to attend an emergency meeting because of budget cuts at Goodwin College.

Keith Mullinar (CAC tri-chair) gave a brief overview of work that he has been doing with UConn Health. He continues to participate in panel discussions with students to teach them proper ways of accommodating individuals with disabilities. He also joined the Patient Advisory Council which will focus on accessibility for those with disabilities.

Mary Beth asked everyone in attendance to introduce themselves.

UCEDD Updates:

Nick Glebar gave an overview of the UCEDD outcomes.

- **Graduate Courses** taught: 8 Ed Psych-EC; 4 PH; 3 On-line Noncredit; LEND
- **Workshops/Training Events:** 162
- **Symposia:** Transition 6/21-22 (N=172); ECPC
- **Grants submitted:** 4 (HRSA; NIDLRR;2-OSEP)
- **Grants received:** 3 federal (1 big; 2 small)
- **Research:** 1) IEP record review for children with ASD;2) Survey of Para-educators; Special Olympics Unified Fitness; 4) Synthesis of Health Promotions for PWD
- **Dissemination:** IYC (10 articles); Web Hits= 12,532

The UCEDD website www.uconnucedd.org has had over 9,000 visitors and the average duration of each visit is 3 minutes.

Project Updates:

1. LEND (Leadership Education in Neurodevelopmental & Related Disabilities)

LEND is an interdisciplinary leadership training program aimed at improving the health of infants, children and adolescents who have, or are at risk for developing, neurodevelopmental and other related disabilities, with an emphasis on autism spectrum disorders.

LEND Outcomes:

- **More than 52 CT students, medical professionals, families and children** with disabilities participated in LEND training.
- **More than 400 pediatricians and medical professionals** participated in professional development on emerging and critical issues like Zika virus, autism, and transitions in medical care led by LEND faculty.
- **CT LEND trainees worked with over 3,000 children with disabilities and more than 2000 families** in all regions of the state, including medically underserved areas; **83% of the families** served by CT LEND trainees are from **underserved minorities**.
- **Four LEND trainees** went to Washington and met with members of our Congressional delegation; **All LEND trainees** met with legislative representatives from CT and learned how to educate for legislation and policy.
- **CT LEND trainees have received prestigious internships and fellowships** at Yale, the Rose F. Kennedy Center/ Albert Einstein College of Medicine, Westchester Institute for Human Development, and the National Association of County and City Health Officials.
- **LEND helped leverage two additional grants:**
 - a. an AUCD Diversity Partnership with Goodwin College. **Five** of the Goodwin **first generation, minority undergraduate trainees** are continuing work/studies in disability related fields; **Four are going to continue graduate school;**
 - b. MCHB LEND supplement for Pediatric Audiologists to UCONN will train **2 additional long term trainees and a pediatric audiology class at Storrs.**

2. CT Early Childhood Pyramid Model Demonstration Project

Betsey Howe gave an overview of the Pyramid Model that has been in collaboration with Maria Synodi at the State Department of Education. It is a multi-tiered system with the goal of helping early childhood special education professionals focus on promoting social and emotional competence and addressing challenging behaviors.

Pyramid Model Outcomes:

- 3 school districts in Connecticut- 1 urban and 2 suburban
- 6 teachers, 5 district coaches, and 5 administrators
- Training at three levels :
 - Teachers received training from both UCONN UCEDD staff, and a district coach.
 - Coaches received training on both the Pyramid Model, and coaching practices.
 - Leadership teams were developed to establish Pyramid practices across districts.

Wendy Simmons asked if diversity is taken into consideration when looking at the pyramid model. Mary Beth and Betsey both responded that they have not seen diversity to be a factor in any of the outcomes.

3. Early Childhood Personnel Center (ECPC)

Jessica McKenty gave an overview of the ECPC project (www.ecpcta.org)

The mission of ECPC is to facilitate the implementation of integrated and comprehensive early childhood systems of personnel development (CSPD) for all disciplines serving infants and young children with disabilities. ECPC is broken into three parts: Knowledge Development, Technical Assistance and Leadership and Coordination

a) Knowledge Development Accomplishments:

- **1** National Data Base of State Personnel Standards
- **2** National Data Reports
- **4** Literature Syntheses
- **100+** Professional Conferences across the America & Europe

Forthcoming:

- **2** step-by-step manuals for CSPD development
- **Multiple** products around **2** concurrent alignments (DEC/CEC/NAEYC & Cross-Disciplinary)
- **1** literature synthesis
- **1** National Data Report

b) Technical Assistance Accomplishments:

- Targeted: To align national and state personnel standards and/or to align preservice preparation with in-service preparation (MA, RI, UT, HI)
- Intensive: To develop CSPD framework within 12+ states:
Cohort 1: DE, IA, KS, OR – *completed!*
Cohort 2: AZ, NV, PA, VT – *in progress!*
Cohort 3: MI, MN, PR, SC – *in progress!*

(Interested States: Hawaii, California, North Carolina and Washington, D.C.)

c) Leadership and Coordination:

- **25 States** in Leadership Development
- **5** Leadership Institutes with Part C & B(619) Coordinators
- **3** Cross-Cohort Leadership Institutes
- **39 States** attended our AUCD Early Childhood Summit
- (Interested States: Alabama, Arkansas, California, Indiana, Kansas, Louisiana, Montana, New Hampshire, New Jersey, North Carolina, Oklahoma, South Dakota)

Update from Washington:

Mary Beth Bruder introduced guest speaker Allan Bergman, who was invited to speak to members on the threats and opportunities that will affect our strategic planning (*Copy of PowerPoint and handouts are available upon request*).

Allan opened his presentation reading an excerpt from [Beyond Programs: A Parable](#) by Michael McCarthy. After reading the poem about everyone being valued members of their communities, Allen explained that we need to get out of the program model and shift our thinking from programs to services and supports. The biggest resistance is that people “can’t let go”. There is a lack in value based services and supports and Connecticut has a lot of work to do!

Allan then presented on “How Does Medicaid Work & What is at Risk with the American Health Care Act”. He asked attendees to write down what they thought Medicaid pays for in the State of Connecticut (answers given: durable medical equipment, in home care, medical transportation, and medication). He then asked attendees to write down what percentage of money comes from the federal government vs. the state budget (answers given: 20%, 30% and 35%). Allen explained that 50 cents on the dollar comes from the federal government. He stressed that we need to connect the dots to how the cuts to Medicaid with greatly affect those

with disabilities. Allan gave out many handouts in regards to Medicaid and all of them can be found at <http://uconnucedd.org/cac/>. He stressed that everyone needs to contact their senators and legislators and give them your story of how these cuts will affect you. Do not underestimate the power of the people!

One handout given to attendees is titled "[CONGRESS IS TRYING TO CUT MEDICAID – ACT NOW!](#)" This is a two page template that states can use to fill out on the impact that the Medicaid cuts will have on people with disabilities in the state. He handed out a sample from [Wisconsin](#) as an example. It is imperative that people realize that once we lose the entitlement of Medicaid we will never get it back again.

Activity Updates

Molly Cole gave an update on the DD Council's search for an Executive Director. They have had 30-35 applicants and are anticipating an announcement in July. Currently Cathy Adamczyk is the Acting Executive Director.

Molly also announced that the P&A will close its doors on June 30th. They will now be known as Disability Rights Connecticut, Inc. (DRCT) and will be a new nonprofit starting July 1st. They will be temporarily housed at the CT UCEDD until there is space is available early fall. The new director is Gretchen Knauff, the Legal Director is Nancy Ahlsberg and the Intake Coordinator will be Linda Mizzi.

Attendees broke for lunch from 12:00pm to 1:00pm

Next Steps: Strategic Planning

Allen presented on "Preliminary Strategic Planning: 2018-2023". He spoke about the evolution of the DD Act and that the goals of the ADA were equality of opportunity, full participation, independent living, and economic self-sufficiency. He discussed four different generations: First Generation University Affiliated Facilities 1963-1974, Second Generation UAFs 1975-1986, Third Generation University Affiliated Programs 1987-1995, and Fourth Generation UCEDDs 1996-Present. He stated that UCEDD's need to train in best practice. When planning ahead technology needs to be discussed at every meeting. The advancements of technology can be so beneficial to individuals with disabilities.

Allan stated that the council members should revisit both its vision statement and mission statement. We need to know where we are going and the vision statement should show that. It should be short enough to fit on the back of a business card.

Current Vision Statement: “Connecticut citizens with disabilities are valued citizens with opportunities and support that allows them to be fully included, independent, productive and contributing members of society”

Allen went over the current mission statement and explained that it should be tied to 3-5 years of strategic planning. It should describe how you will get where you want to be, what do we do today, why do we do what we do, and for whom do we do it.

Current Mission Statement: “To provide interdisciplinary leadership through the core functions on evidence based practices and policies to ensure all of Connecticut’s citizens with disabilities and their families fully participate in all facets of community life.”

Allen asked the council to look over both the vision and mission statement and come back with any suggested changes at the September/October CAC meeting. He also suggested that once the vision and mission are set they should be laminated and hung up at every CAC meeting in the future.

Meeting adjourned at 2:15pm.

Respectfully submitted,

Christine Jozef

University of Connecticut Health Center

AJ Pappanikou Center for Developmental Disabilities