



UNIVERSITY CENTER FOR  
EXCELLENCE IN  
DEVELOPMENTAL  
DISABILITIES

**University of Connecticut  
Center for Excellence in Developmental Disabilities  
Consumer Advisory Council**

June 13, 2019

Meeting Minutes

**In Attendance:**

Emily Ball: Advocate	Diana LaRocco: Goodwin College
Julie Ball: Parent	Nanfi Lubogo – PATH, Parent to Parent
Allan Bergman: Facilitator, Consultant	Linda Mizzi: Disability Rights Connecticut
Chris Blake: Advocate	Stephen Morris – The ARC of Farmington Valley
Mary Beth Bruder: CT UCEDD Director	Keith Mullinar: Advocate
Karen Carney – Goodwin College	Regina Owusu: CT Department of Public Health
Molly Cole: CT UCEDD Acting Training Director	Allyson Powell – UConn Health Adoption Assistance Program
Win Evarts: The ARC of Connecticut	Deb Richards: CREC
Walter Glomb – CT Council on Dev. Disabilities	Lolli Ross – Arc of Westchester
Steven Hernandez – CT Commission on Women, Children & Seniors	Joshua Rucker – UConn Office of Institutional Equity
Jean Herzog: Special Olympics of CT	

**UCEDD Staff In Attendance:**

Kelly Ferriera	Tara Lutz
Darla Gundler	Heather Petit
Betsey Howe	Linda Rammler
Woodlyn Joachim	Katie Straka
Christine Jozef	Bethanne Vergean

The meeting began at 9:35 am.

**1. Introductions and Overview of the Day:**

- Mary Beth Bruder welcomed all those participating in the meeting and had all in attendance introduce themselves.
- Mary Beth reviewed the agenda and explained to the council that staff members from the UCEDD will be giving updates on the different projects that the UCEDD has been working on. The packet provided contained a large number of handouts from

Allan Bergman (if any council member would like a copy of the larger handouts please let Christine know ([jozef@uchc.edu](mailto:jozef@uchc.edu)) and she can send them to you via e-mail).

- An announcement was made that Linda Mizzi will be retiring. Kathy Kushman will be taking over her position on the CAC Council.

## 2. Review of the Past 6 Months: Progress and Changes

Mary Beth informed the council that two individuals who made a great impact on improving the lives of individuals with disabilities had passed away. Ray Elling died on November 23, 2018. He was a Co-Treasurer of the Connecticut Coalition for Equal Access (CC=A) and a fierce advocate for social justice. Therese Nadeau died on June 5, 2018 and she was a past UCEDD staff member. After working at the UCEDD, Therese went on to work at Connecticut Community Care working on Emergency Preparations for individuals with disabilities.

Mary Beth announced that there would be some staff changes at the UCEDD. Nick Gelbar who has been the Research Director is leaving at the end of June to go into private practice. Cristina Mogo-Wilson who currently works at the School of Social Work will be working part time (30%) as the new Research Director. Tara Lutz has been hired to be the new Training Director for the UCEDD.

There is no budget to report on because as of the date of the meeting the UCEDD has not received notification that it has been fully funded. One issue that has come up is that all UCEDD union employees will be getting a raise and step increase in July. The money has to come out of grant money, so some cuts may have to happen if there is not enough money to fund these positions. The UCEDD currently has 30 full and part time staff with a majority of the staff members at part time.

### Early Childhood Updates:

**Act Early** - Bethanne Vergean gave an update on the newly awarded Act Early Grant. Bethanne explained that the CDC's Act Early Initiative promotes collaboration among early childhood programs in states and territories so children with autism or other developmental delays and disabilities can be identified early and referred to appropriate services and supports. The Act Early Ambassador Program is a collaborative effort of CDC's National Center on Birth Defects and Developmental Disabilities, HRSA's Maternal and Child Health Bureau, and AUCD.

The focus of our work:

1. Health Education - To help families “learn the signs” of healthy development and understand when and how to “act early”
2. Act Early Initiative - To improve developmental monitoring in programs and across systems at the state and community level
3. Evaluation - To refine our efforts and identify promising practices for improving early identification

The work plan for the next year is:

GOAL 1: Collaborate with Connecticut Department of Children and Families to establish Learn the Signs Act Early (LTSAE) training and dissemination of LTSAE materials in their Academy for Workforce Development.

GOAL 2: To collaborate with Early Childhood Collaboratives throughout Connecticut that support Early Childhood Programs ( Head Start, Early Head Start, School Readiness and child care programs) to develop a system to improve developmental monitoring by training and LTSAE materials that including the CDC Milestone Tracker app, for use in the classroom and with families

GOAL 3: Collaborate with Early Childhood partners (CT Department of Public Health, Healthy from Day One, Office of Early Childhood, Wheeler Clinic, Help Me Grow, CT Academy of Pediatrics and the CT 2-1-1 Child Development Infoline) to develop a webinar and guidance document for early childhood providers, medical providers and medical students on the importance of periodic screening and developmental milestones.

**Early Childhood Personnel Center (ECPC)** – Darla Gundler provided an overview of the ECPC project and shared the website (<http://www.ecpcta.org>) with the council. She explained that the website is currently being redesigned and the new and improved website should be up and running soon. ECPC is a project funded by the US Department of Education, Office of Special Education Programs (OSEP) and we are currently in our second year of the five year grant. The mission of ECPC is to assist states to develop, implement, and evaluate integrated and comprehensive systems of personnel development (CSPD) for the early childhood workforce so that young children with disabilities and their families receive effective early childhood intervention. We are working with states across the country consisting of teams of 5 people per state to address challenges and build a more efficient and sustainable state system that can support a competent early childhood workforce within their state. The teams consist of Part C and Part B/619 coordinators, UCEDD or higher education representative, a family member and an early childhood partner.

## Schools:

**Community College:** Betsey Howe explained that the UCEDD has a personnel preparation grant from OSEP to work with CT Community College Early Childhood Associate Degree programs to redesign and enhance their courses to include a focus on young children with disabilities and their families. This is a five year grant, with the first year centering on the development of tools to assess course syllabi, activities and practicum, followed by updating syllabi to include the focus on young children with disabilities and their families. In addition to providing support to community college faculty to enhance and redesign their curriculum, UCEDD staff will train faculty so that they understand the new content and how to teach their preservice students the use of evidence based and recommended practices to support young children with disabilities in early childhood classrooms. The project is underway, with strategic planning conducted in April which led to the development of three workgroups to support enhancing and redesigning syllabi and practicum.

**Customized Employment and Think College-** Linda Rammler gave an update on these projects. Linda explained that we have been training parents of transition age students in LifeCourse planning to prepare them for supporting a seamless transition from IDEA-mandated services through the public school systems to the eligibility based, poorly funded adult services system. The core of this training uses the UMKC LifeCourse materials that have been enhanced by interweaving the State Department of Education's Core Transition Skills and evidence-based person-centered practices to build social capital and support networks outside of the traditional human services systems. Dr. Craig Schramm provided training to participants on transitioning from pediatric to adult health care. Participants also become aware of Customized Employment and Think College opportunities so they think positively and creatively about their sons' and daughters' futures. Two cohorts participated in this program (one will complete initial training June 29th) and both will be brought back together in the fall as follow up. We plan to continue this training in the future.

A white paper on "Why Not Punishment" has just been completed. This started specifically to address restraint and seclusion time out in public schools but expanded to punitive practices in general based on this literature on both positive behavior supports and team-informed strategies.

The Think College project funded by the TC National Coordinating Center from 12/15/17 through 9/30/18 was completed and both the final report and Strategic Plan will be posted on the UCEDD website in the near future. The DD Council has been implementing portions

of the plan in the interim and the UCEDD will become reinvolved as a result of the availability of DD Council funding July 1st. There are six focus areas:

1. Family involvement
2. Self-advocate involvement
3. Institutions of higher education
4. Public school roles including curriculum
5. Employment
6. Leadership and Sustainability.

The last third of 3 cohorts has just completed 3 consecutive day trainings in Customized Employment by Marc Gold & Associates. This training focuses on the three components of customized employment: 1. Discovery (i.e. really learning about the strengths, skills, interests, and preferences of a person who was previously thought unemployable), 2. Job Development (i.e. avoiding traditional approaches to job seeking by creating competitive integrated employment opportunities for specific individuals to meet an individual employer's unmet needs), and 3. Systematic Instruction that assure the person can fulfill their job responsibilities and sustain employment. There are 13 staff in CT to date who have obtained certification in one or more of these areas by completing an additional 20 to 40 hours of applied work supervised by MG&A staff. Others have received ACRE Certificates. Customized Employment is important because it is one tool in the toolbox of reaching Employment First for all.

#### Health Promotion:

Tara Lutz gave highlights from this year under Health Promotion which included updates about the Certificate and research project updates.

UConn approved the name change for the Certificate which is now entitled "Certificate of Interdisciplinary Disability Studies in Public Health." Since started in Spring 2014, this online, 4-course, graduate Certificate has been conferred to 10 students, 3 students are currently enrolled, and 1 has been newly admitted for the fall. One hundred and seventy-nine students from 17 disciplines have taken at least one course. Tara has provided TA to 3 universities/programs to date regarding course development in the area of disability and public health.

Four research studies are in various states of the project under health promotion. The outcome evaluation of certificate course students is currently under the second round of revisions with a peer-reviewed journal. Findings indicated that students are applying the

knowledge gained in other classes and at work. A needs assessment of certified health teachers in CT is ready to be sent for peer review. Results indicated that while teachers take courses in their pre-service training and have in-service professional development opportunities related to adapting general curriculum, they did not receive pre-service or in-service for adapting health education curriculum in particular. A survey of adult primary care physicians regarding their provision of health care to patients with disabilities has just been conducted. Data is currently being analyzed. Physicians reported that lack of time and lack of knowledge of community resources are the biggest challenges to providing quality care. An environmental scan of emergency department staff was also conducted and in the process of being analyzed. Participants indicated that they are not knowledgeable of the co-occurring conditions that people with IDD may experience and also are not knowledgeable of community resources available. Results of these studies will inform future directions and training opportunities in the future.

### **Leadership and Sustainability:**

Molly Cole gave an update on Partners in Policymaking. She explained that we have been doing this training since 1989 and this year it consists of half families and half providers. This year they have integrated service providers into the training because if we only train families and advocates and we do not train service providers then we really miss out on the full scope of training. There are about 340 graduates from Partners and we are currently recruiting Partners graduates to work on our LEND training. Past graduates that have also worked on LEND are CAC members Keith, Chris, and Emily.

Kelly Ferreira gave an update on our Leadership Education in Neurodevelopmental and related Disabilities (LEND) grant. She explained that there were 46 total LEND fellows for the 2018-2019 academic year (13 Long-Term trainees, 10 Medium-Term trainees, 16 Short-Term trainees, and 7 Family/Advocate trainees). The program had students from multiple disciplines, including audiology, developmental behavioral pediatrics, nursing, physical therapy, public health, school psychology, social work, special education, and speech, language, and hearing sciences. Overall, all trainees showed a significant increase in knowledge regarding working with individuals with disabilities from the beginning of the academic year to the end. Additionally, trainees reported increased strength in MCH competencies over the course of the year. Finally, to complement the work done in seminar, trainees completed practica at 10 unique sites, seven trainees went to Washington and met with members of our Congressional delegation, all trainees met with legislative representatives from CT and learned how to educate for legislation and policy, and all long-

term and family/advocate trainees completed individual research projects, four of which were submitted as posters to the AUCD annual conference.

Heather Petit explained that as part of a LEND project, a few students presented our existing Emergency Preparedness flip book ([https://uconnucedd.org/wp-content/uploads/sites/1340/2015/06/Emergency\\_Flipbook.pdf](https://uconnucedd.org/wp-content/uploads/sites/1340/2015/06/Emergency_Flipbook.pdf)) to Connecticut state legislators. CT State Representative Liz Linehan brought to flipbook to the CT General Assembly to advocate for a bill to enhance communication between emergency responders and children and adult with disabilities in times of crisis. The bill unanimously passed and directs the CT UCEDD to expand and revise the communication toolkit.

### **3. Partners Updates**

Developmental Disabilities Network – Walt Glomb, Executive Director of the CT Council on Developmental Disabilities presented an update on the DDN.

- CT Cross Disability Lifespan Alliance has been very active holding legislative advocacy meetings. The committee meets by phone every Friday to discuss current legislation, identify individuals who can testify on particular legislation, mobilize others to attend hearings and assist individuals in preparing testimony.
- The 2019 People First of Connecticut Embracing the Community Conference will be held on Saturday, June 22<sup>nd</sup> in Rocky Hill, CT.
- CT KASA has been working together to help educate healthcare workers who are treating patients with disabilities.
- The All-Abilities Alliance is a student let group working to foster community goals to minimize bullying of individuals with disabilities.
- Building a Great Life Conference – The planning for the next conference is underway for April 2020. A date and location has not been set.
- Customized Employment – working to provide training to private providers in CT to provide employment for individuals with disabilities.
- Transportation – Walt explained that getting better transportation has been the toughest project. They are focusing on improving transportation for individuals with disabilities and looking for solutions on how to help everyone in the Connecticut landscape have timely and affordable transportation. Walt suggested to the council that if any members had ideas about how to improve transportation, to please share their ideas with him.

Disability Rights Connecticut – Gretchen Knauff, Executive Director, presented an update.

- Disability Rights Connecticut, Inc. (“DRCT”), a new independent, nonprofit organization established to be the successor entity to Connecticut’s Office of Protection and Advocacy for Persons with Disabilities which was abolished by Connecticut law as of June 30, 2017.
- The following are DRCT’s programs and activities
  - Information and Referral (I & R)
  - Client Assistance Program (CAP)
  - Protection and Advocacy for Assistive Technology (PAAT)
  - Protection and Advocacy for Persons with Developmental Disabilities (PADD)
  - Protection and Advocacy for Individuals with Mental Illness (PAIMI)
  - Protection and Advocacy for Individuals Rights (PAIR)
  - Protection and Advocacy for Persons with Traumatic Brain Injury (PATBI)
  - Protection and Advocacy for Voting Access (PAVA)
  - Protection and Advocacy for Beneficiaries of Social Security (PABSS)
  - Protection and Advocacy for Beneficiaries of Representative Payees (PABRP)

Favarh: New Healthy Eating Initiative – Stephen Morris Executive Director, presented an update and announced that Favarh is in the process of building two innovative specialty housing complexes that will give tenants with intellectual and developmental disabilities (IDD) increased independence and autonomy in an integrated and safe environment. The complexes will be located in Canton and Bloomfield. The innovative nature of the projects will be the incorporation of ADA+ features along with a cutting-edge smart-home management system to help tenants with IDD safely thrive in a fully integrated community setting. Stephen discussed with the council that the hardest part will be to provide healthy food deliver to the residents. They are partnering with Healing Meals who is a service that provides organic meals for individuals and families who have serious illnesses. They will be doing a pilot this fall of the food delivery option.

#### **4. Update on Federal Policy and Initiatives**

Allan Bergman presented a PowerPoint presentation to the Council entitled “Federal Update: Challenges and Opportunities; Keeping Your Compass on “True North”. A copy of Allan’s PowerPoints can be found at: <https://uconnucedd.org/wp-content/uploads/sites/1340/2019/07/Bergman-CAC-6-13-2019.pdf>



## 5. Workgroups

The large group met during a working lunch to discuss state and federal policies as they relate to UConn UCEDD Priorities.

- Deb Richards addressed that there does not seem to be any support for training in the state. She shared that the way the system is funded right now, it doesn't provide any support for what really is best practice. It is reverting to a medical model where whatever can be reimbursed through Medicaid or insurance is what is driving the system. Alan suggested that anything the UCEDD could do to monitor what is going on and to implement the best practice training would be beneficial.
- Chris Blake suggested that there should be a law that states that if there is a project about any group that it needs to be mentored and have all the stakeholders at the table for it to be even make into a project – “nothing about us, without us.” Allan asked if that is something that could be proposed to the Governor. Molly stated that there is a time for that conversation, but since it is post budget now maybe wait until the fall alliance meeting. Win agreed that Chris's suggestion makes sense because if you have stakeholders at the table then they will work for the best solution since they are the beneficiaries. Molly agreed and recounted that at last year's Partners in Policymaking sessions with the legislators, they commented that this was the best way for them to learn about issues from the actual people that are affected.
- Beth Bye is the Connecticut Office of Early Childhood Commissioner. Allan said he thinks that she is an ideal person to have the conversation with in terms of changing the paradigm and also bringing all stakeholders to the table. Win said that with Beth Bye there is a lot of opportunity to change the dialog from procedure to outcomes.
- Molly suggested that the key part of the initiatives is leadership and the critical component of leadership is core values. Diana agreed and also said that the other things that transcends each of the key areas in addition to leadership is the notion of outcomes and people understanding what it means to advocate.
- Mary Beth said that the good thing about values and outcomes is that you do not get grants unless your values have shown through your outcomes and is the grant world that we live in. Mary Beth was on a call with OSEP and that a quote from the project director is that we have no idea how bad things are right now. It is not a good place right now but we will have to figure out how to work

around it. Mary Beth said that our next steps will be calling on the council members in their areas of expertise to push through our agenda.

Meeting adjourned at 2:05pm.

Respectfully submitted,

*Christine Jozef*

*University of Connecticut*

*Center for Excellence in Developmental Disabilities*