



A.J. Pappanikou Center for Excellence in Developmental Disabilities
Education, Research and Service
Consumer Advisory Council
November 30, 2016

Meeting Minutes

In attendance:

1. Joann Barere: Connecticut Commission on Children Women and Seniors (in place of Steven Hernandez)
2. Allan Bergman: Guest Speaker, High Impact Consulting
3. Regina Birdsell: Connecticut Association of Schools
4. Karen Carney: Parent
5. Molly Cole: The Connecticut Council on Developmental Disabilities
6. Don Conklin: Special Olympics Connecticut, Inc.
7. Caitlin Daikus: Special Olympics Connecticut, Inc.
8. Pam DonAroma: Futures, Inc.
9. Ruth Eren: Center on Autism at Southern Connecticut State University
10. Lynn Fogg-Cornelio: Connecticut Department of Developmental Services
11. Mark Keenan: Connecticut Department of Public Health
12. Diana LaRocco: Social and Educational Sciences Department Chair, Goodwin College
13. Robert LeGary Jr.: The Learning Center
14. Linda Mizzi: Office of Protection and Advocacy
15. Julie Morin: Hartford Public Schools
16. Stephen Morris: The ARC of Farmington Valley, Inc.
17. Keith Mullinar: CC=A; Self-Advocate
18. Antonio Orriola: Self-Advocate
19. Deb Richards: Capital Regional Education Council
20. Isabelina Rodriguez: Connecticut Department of Education
21. Lolli Ross
22. George Sugai: University of Connecticut, Neag School of Education
23. Maria Synodi: Connecticut Department of Education Bureau of Special Education
24. George Synnott: Connecticut Association of Schools
25. Michelle Weaver: State Education Resource Center

26. Sharon Lewis: Health Management Associates
27. Audrey Brown: Goodwin College Fellow

UCEDD Staff in Attendance:

Mary Beth Bruder: UCEDD Director
Danielle Webber: UCEDD Administrative Manager
Nick Gelbar: UCEDD Research Director
Anne Marie Davidson: UCEDD Research Associate II
Linda Rammler: UCEDD Research Associate II
Bethanne Vergean: UCEDD Research Assistant II
Lindsey Lockman-Dougherty: UCEDD Research Assistant II
Ashley Moore: UCEDD Research Assistant I
Mary Stone: UCEDD S.P. Research Assistant
Annie George-Puskar: UCEDD Doctoral Fellow
Betsey Howe: UCEDD Doctoral Fellow
Chelsea Panse: UCEDD Doctoral Fellow
Tara Lutz: UCEDD Doctoral Fellow/LEND student
Allison Shefcyk: UCEDD Graduate Assistant
Erika Egan: UCEDD Executive Assistant

The meeting began at 9:35 am.

Introductions, Updates and New Initiatives from Members

Diana LaRocco welcomed all those participating in the meeting and asked each attendee to introduce themselves.

Mark Keenan has a new position at the Connecticut Department of Public Health. He is now the Director for Connecticut's Title V Children and Youth with Special Health Care Needs. He is also a supervising Nurse Consultant for the Public Health Initiatives Branch and for the Family Health Section, and he oversees the Adolescent and Child Health Unit.

Update on UCEDD Activities and Progress

Mary Beth Bruder gave an update on the CT UCEDD in which she explained the CT UCEDD's four core functions:

(A) to provide interdisciplinary pre-service preparation and continuing education of students and fellows,

which may include the preparation and continuing education of **leadership, direct service, clinical, or other personnel** to strengthen and increase the capacity of States and communities to achieve the purpose of this title;

(B) to provide community services

- (i) that provide training and technical assistance for **individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students, and other members of the community;** and
- (ii) that may provide services, supports, and assistance for the persons described in clause (i)
- (iii) through demonstration and model activities;

(C) to conduct research,

which may include **basic or applied research, evaluation, and the analysis of public policy** in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families;

(D) to disseminate information

related to activities undertaken to address the purpose of this title, especially dissemination of information **that demonstrates that the network authorized under this subtitle is a national and international resource** that includes **specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances.**

Mary Beth reiterated the four **Areas of Emphasis as determined by the CAC in CT:**

- Early Childhood Intervention
- Schools
- Health
- Leadership

She also highlighted that during the fifth year there will need to be strategic planning work done to look forward to another five years.

She noted that the objectives that were provided in the Year 4 UCEDD Report to the feds located in the meeting materials speak to the strategic planning that the CAC did four and half years ago for us.

Mary Beth gave a preview of what the UCEDD and the CAC are going to be getting started on doing so that a year from now we will have a strategic plan directed by the CAC. Through this strategic planning process, the CAC will share with us what they think the UCEDD should do for the next five years.

In the DD Act the CAC is given a considerable amount of power to guide the direction of the UCEDD. Under the DD Act there are thirteen different priority areas and the UCEDD with their CAC are to choose which of those priority areas they're going to focus on and how they will address these areas through their objectives and activities.

Mary Beth also introduced Maya Christy as the new web designer for the UCEDD. Maya displayed the newly developed UCEDD website, www.uconnucedd.org as well as the improved Early Childhood Personal Center website, www.ecpcta.org.

Anne Marie Davidson provided updates on the Connecticut State Department of Education's systematic implementation of the pyramid model in several school districts throughout CT.

Nick Gelbar provided an overview of the work the UCEDD is doing with school districts on self-determination.

Linda Rammler spoke about some of the projects she is currently working on such as:

- CT Special Olympics activities including trainings with the dental hygienist association
- Ability Beyond which focuses on relational issues with people with social emotional problems, mental health and co-occurring conditions like Autism; an entrepreneurship initiative
- Trainings on Autism on employment at the Connecticut Department of Labor American Job Center
- an article currently in publication called *"Self-Employment and people with disabilities that can work"* in the *Journal of Vocational Rehabilitation*.

Specific details of the UCEDD's projects are listed in the annual report provided in the meeting packet.

DD Network Update

Molly Cole and Linda Mizzi gave an update on the Developmental Disabilities Network. Applications are now open for the *"Connecticut Partners in Policymaking 2017: A Self-Advocacy Leadership Training Program"*

(http://www.ct.gov/ctcdd/lib/ctcdd/partners_2017_brochure_and_app_draft.pdf).

They also talked about Campaign 2020 recommending to close Southbury Training School (<http://www.ct.gov/ctcdd/cwp/view.asp?a=1997&q=574704&ctcddNav=|>) as well as the monthly Cross Disability Lifespan Alliance meeting where people with disabilities, family members, providers, and state agencies meet and cover a variety of topics. These meetings take place on the first Wednesday of every other month at Temple Bethel in West Hartford.

Molly Cole talked about the Customized Employment Conference for Providers, Families and Self-Advocates on November 14, 2016 which had a record attendance of 300 people (<http://uconnucedd.org/wp-content/uploads/sites/1340/2016/08/CONN-Employment-conference-flyer-final.2.pdf>). A new initiative related to this, is a project with the goal to give performance based certification to individuals in the areas of discovery, job development and

coaching, where the Developmental Disabilities Network will work with provider agencies to have some of their staff certified.

Federal Update

Mary Beth Bruder introduced guest speaker Allan Bergman, who was invited to give an overall overview of the *“Association of University Centers on Disabilities: University Centers for Excellence in Developmental Disabilities (UCEDDs)”* (See attached PDF)

Allan Bergman also gave a presentation on *“The Future for Connecticut’s Citizens with Developmental Disabilities: Moving from Paper Compliance to Accountability for Valued Outcomes for a Good Life: The Role of the DD Act”* (See attached PDF)

Allan pointed out that the new head of the Department of Health and Human Services is going to be Tom Price, R-GA. who wants to decimate the Affordable Care Act (ACA).

Sharon Lewis expressed that the biggest challenge with Tom Price is that he has been a major proponent of Medicaid block grant and the privatization of Medicare. She stated that in 1995, when the Medicaid block grant conversation took place it had strong support from the Governors and that it is highly unlikely that we will see that same level of support from the Governors now, including the red state Governors because in the per capita analysis the biggest losers are the red states. It will be interesting to see how the block grant conversation plays out. The challenge is that they will first do ACA and Medicare. Medicaid will most likely be the third priority. The immediate effects on Medicaid might be additional dollars for expansion, additional dollars for Community First Choice Act under Section 1915(k) of the Social Security Act which applies to Connecticut.

Allan invited everyone at the meeting to refocus on what the CAC and the UCEDD’s mission and strategy is. The main priority should be value-based outcomes and making sure that everything we recommend and everything the state is doing are in alignment.

Planning for a New Core: 2018-2023 CAC and Strategic Planning

Sharon Lewis pointed out that President-Elect Trump has an agenda that includes early childhood so there may be opportunities to work in partnership with the administration on this.

Mary Beth closed the meeting by announcing that the CAC will meet again in late spring (May or June) to lay the foundation and start the strategic planning process for 2018-2023. The UCEDD will have a lot of needs assessments and data on constituents to inform the strategic

planning process so that the CAC can appropriately guide the UCEDD as it prepares for its next five-year funding cycle.

The meeting adjourned at 12:40 p.m.

Respectfully submitted,

Erika Egan

University of Connecticut Health Center

A.J. Pappanikou Center for Developmental Disabilities