

AJ Pappanikou Center for Excellence in Developmental Disabilities
Education, Research and Service
Consumer Advisory Council
June 3, 2015
Meeting Minutes

In attendance:

Diane Bilyak: The ARC of Connecticut
Regina Birdsell: Assistant Executive Director, CT Association of Schools
Alexia Bouckoms: Self-advocate
Molly Cole: The Connecticut Council on Developmental Disabilities
Linda Goodman: Director, Birth to Three System
Diana LaRocco, EdD: Faculty, University of Hartford
Robert LeGary: The Learning Clinic
Melissa Marshall:
Linda Mizzi: Office of Protection and Advocacy
Stephen Morris: Executive Director, The ARC of Farmington Valley, Inc.
Keith Mullinar: CC=A; Self-advocate
Deb Richards: Director, Capital Regional Education Council

UCEDD Staff In Attendance:

Mary Beth Bruder, PhD: UCEDD Director
Anne Marie Davidson, MS: UCEDD Training Coordinator
Nick Gelbar, PhD: UCEDD Research Director
Annie George: - UCEDD Post Grad Student
Gerri Hanna, JD, M.Ed.: UCEDD Associate Director
Betsey Howe: UCEDD Post Grad Student
Christine Jozef: UCEDD Administrative Assistant
Kelly Lupo: UCEDD Post Grad Student
Allison Shefcyk – UCEDD Research Assistant
Chris Sullivan, JD, PhD: UCEDD Training Director
Bethanne Vergean: UCEDD Early Intervention

The meeting began at 9:40 am.

Introductions:

The meeting began with introductions of attendees.

Dianna LaRocco welcomed all those participating in the meeting. She asked the members to look over the printout of the CAC member list and if there have been any changes since the last meeting to please let us know.

Christine Sullivan gave an overview of the day's agenda and went over the information that was included in the packet handout.

Update on the CT UCEDD:

- Gerri Hanna is working on completing the annual report for the UCEDD which will be ready by the end of June.
- The UCEDD will be holding Summer Symposium Series this summer on the following topics (some are tentative dates):
 - June 24th – Organizing early childhood programs to meet the needs of all children (for public school administrators). UCEDD office, Farmington
 - June 29th – How to manage the learning of all children (for teachers). UCEDD office, Farmington
 - June 30th – How to build a team (for teachers). UCEDD office, Farmington
 - July 2nd – Family Engagement (for teachers). UCEDD office, Farmington
 - July 13th & 14th – Secondary Transition at the UConn West Hartford Campus
 - July 20th & 21st – Supervision and Management of Paraeducators. UConn West Hartford Campus.
 - July 23rd - Organizing early childhood programs to meet the needs of all children (for Public School Administrators). UCEDD office, Farmington

Please contact the CT UCEDD if you would like more information about these summer trainings.

2020 Initiative Update:

Molly Cole presented a PowerPoint presentation (handouts provided) on the 2020 Campaign to close Connecticut's institutions. As of 2015, Connecticut has six state-run institutions open with over 500 residents living in them. The objective of the 2020 campaign is to push to close these institutions by the year 2020. We believe these institutions are both morally and financially wrong. The average cost per person is \$365,000 per year and as the numbers of individuals within the institutions slowly decline, the cost will go up even higher. The cost for a resident at Southbury Training School ranks at the top as one of the most costly institutions.

A committee was convened and tasked with pushing the 2020 initiative forward. The 2020 Initiative is a collaborative venture of the Developmental Disabilities Network (CT DD Council, CT UCEDD, and CT Office of Protection and Advocacy) and the CT ARC. With the approval of the CT DD Council, which authorized the primary source of funding, Alan Bergman was hired for a term of one year as a consultant to the Committee. The movement is blossoming.

There is currently a bill (Bill 1088) that was introduced by Sen. Beth Bye which is sitting in the House waiting to be passed regarding the closings.

Stephen Morris asked if there was a federal angle to this? Molly stated that they have looked at lots of angles and there are no federal repercussions on this issue.

Keith Mullinar asked where would the residents be transitioned to? Molly stated that there are many group homes that would be made available to the residents. They are hoping that Southbury would be sold and the money could be used to help the resident's transition into community living.

Linda Goodman asked if there was any feedback from the Union? Molly answered that the Union was not thrilled but that there has not been much pushback from them.

CC=A Update:

Keith Mullinar gave a brief overview of the Citizens Coalition for Equal Access (CC=A). He explained that this was a small group that came out of Farmington Commission for Aging working with New Horizons. The CC=A was developed to advocate for improving access to both the Unionville and Farmington Post Offices and are responsible for having automatic doors installed in these buildings.

They are now working on a national initiative that every post office should be required to have automatic doors. This initiative has broadened to all federal buildings (Res. 12 & Res. 37). Molly Cole suggested that the national organizations could help take this on as a national push.

The CC=A is also working with the UConn medical students and working on trainings with them for caring for people with disabilities. The medical students won an award when they presented elevator speeches to Dr. Jewel Mullen, the CT Commissioner of Public Health. They made it a point that they were going to present from the back of the UConn Health Center auditorium because if they were in a wheelchair they would not be able to come down to the stage. The medical students have stated that because of these trainings they are starting to look at things differently.

TransitNet:

Dianne Bilyak, from the ARC CT, provided information on TransitNet, a website that provides statewide transportation information and resources for people with disabilities and older adults (www.transitnet.info). Connecticut currently has three mobility managers: Southwest / Know How to Go; Eastern / ECTC; and North Central / Way to Go CT. They had also created an accessibility brochure which consists of information and phone numbers for those individuals who do not have computer access.

On the website the information has been broken down by town. Within each town page are links to important contact information for the town. Keith Mullinar requested that they add the ADA coordinator under the town contact information.

Diane explained that they were conducting a website survey and asked members to test out the website and provide feedback. A training toolkit for transportation is currently being created and Diane also asked that any information that members would like to be included in the toolkit be sent to her.

Disability Alliance Update:

Melissa Marshall, coordinator of the Connecticut Cross Disability Lifespan Alliance, provided an update on the Disability Alliance starting with an overview of the Vision, Mission and Values Statements. A handout of the activity highlights for 9/14 to 5/15 was given to each member.

A Disability Community Calendar, hosted by the CT State Independent Living Council (<http://www.calendarwiz.com/calendars/calendar.php?crd=ctdisabilityeventcalendar&>) was created and includes events going on within Connecticut.

Three position papers have been adopted and were made available. The core issues were Housing, Employment, and Transportation for people of all ages with all disabilities. The council adopted positions on the following issues: against outpatient commitment of people with mental health conditions; in favor of closing Southbury Training School and five regional centers; opposed to the cuts to Medicaid Durable Medical Equipment; and against the budget cuts that negatively impacted people with disabilities. When choosing their position on different issues they base their decision on their values, vision and mission.

In January, and during the legislative session, the Alliance began holding conference calls every Friday to keep people updated on the latest legislative issues.

In April, there was a press conference about the delivery of a petition on the DDS cuts to the Governor. They discussed how the cuts will negatively impact individuals with disabilities and presented to the legislators how deeply the cuts were being made.

Disability Policy Seminar:

Allison Shefcyk, research assistant at the CT UCEDD, presented on the Disability Policy Seminar held in Washington, DC, on April 12th – 14th. The purpose of the seminar was to discuss how to provide information needed to help educate members of Congress and to spread the word on the priorities of people with disabilities. An array of panels were held to discuss different topics. Social Security was a major issue discussed. Each organization (e.g. ARC, UCEDD, DD Council) held their own organizational briefings.

Some useful tips given included knowing your audience and customizing your approach for each representative. It is also important to tell stories of people within your community to personalize your message.

Quarterly Report Highlights:

Mary Beth Bruder, Director of the CT UCEDD, provided highlights from the UCEDD. If you would like a copy of the annual report please contact us.

- Early Childhood:
 - Parent to Parent was finished in April. This project partnered parents of children on the spectrum with parents of newly diagnosed children for support and guidance.
 - The Early Childhood Personnel Center (ECPC) held their leadership institute on May 27th – 29th. This three day institute brought together 10 states for collaboration.
- School Age:
 - The UCEDD sponsored the National Paraeducator Conference in Hartford held April 16th – 18th. The conference was titled The Power of Paraeducators: A Pathway to Excellence and had a turnout of over 250 people.
 - Working on a research grant on how to get paraprofessionals trained.
 - Transition workshops are being held which will focus on housing, school and medical needs.
 - The UCEDD is working with DSS developing trainings for physicians to help them when treating individuals with disabilities and the families. This is expected to roll out by the end of summer.
 - Working with the University of Connecticut medical students who will be caring for individuals with disabilities.

Additional Updates:

Molly Cole announced that a conference for families, self-advocates and professionals will be held October 2-3, 2015 at the Farmington Marriott. This conference is to celebrate the 25th anniversary of the ADA and the 40th anniversary of the IDEA. Registration materials will be out by the end of June.

Dianna announced that the DEC will be holding their 31st annual international conference on young children with special needs and their families. The conference will be held October 7-9, 2015 in Atlanta.

The meeting adjourned at 12:45 p.m.

Respectfully submitted,

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