



UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

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

September 26, 2023

Meeting Minutes

In Attendance:

Emily Ball
Scott Brown
Mary Beth Bruder
Karen Carney
Molly Cole
Tom Cosker
Nicole Cossette
Dr. Deckers

Denise Drummond
Win Evarts
Walter Glomb
Kim Mearman
Regina Owusu
Allyson Powell
Ann Smith
Christina Wilson

UCEDD Staff in Attendance:

Amal Alsamawi
Darla Gundler
Christine Jozef

Brian Reichow
Toi Weatherspoon

The meeting began via Zoom at 9:30am.

Introduction:

Mary Beth Bruder started out the meeting welcoming everyone and thanked everyone for their support. She indicated that we did receive the 5-year funding, along with new initiatives and funding we were also able to get.

She also explained the need of two new Co-Chairs. Asked Emily Ball if she would be interested and she accepted. However, she needs help of another Co-Chair to help with these meeting. Mary Beth will be reaching out to participants and is asking for volunteers.

Mary Beth discussed the next 5 years and the need to grow more. Two faculty positions are open. Faculty are only able to be Directors/PI's. These are Grant Funded positions. We also

looking for a Website/Communications person with negotiation experience and skills. One new Faculty person starting in October. Her name is Marnie, her Bio will go out to everyone. She went to Vanderbilt University and her background is school age Special Education.

PowerPoint on the UCEDD was shown. Explained who we are, what we do in plain language. Showcases three affiliations which are: Consumer Advisory Council (CAC), Developmental Disabilities Network (DDN), and The University of Connecticut (UConn/UCHC). References the UCEDD mission, how it supports our vision regarding our services and the areas of emphasis. This targets all residents and families and ensures they will be able to access and participate in culturally, racially, ethnically, and linguistically appropriate opportunities, supports and services that enable them to belong, learn, live, thrive, and work in inclusive communities of their choice. This power point presentation is available to everyone. If you would like to a copy, please let us know.

Participant updates/highlights:

Walt Glomb: The Counsel has about 20 projects in play at the moment. Highlights include bridging Aging and Disability networks. Next meeting October 3 at 3pm. Group meets every other week on Tuesdays at 3pm. Speakers from around the country come in to discuss other tools. Next week the arc of USA will be presenting their future planning tool. If interested in this topic and how the two might work best together, especially aging with developmental disabilities, contact Walt and he will send a link to join. Another highlight is Connecticut Age Well Collaborative in which they will be launching a campaign to disrupt ageism and ableism at the municipal level. This campaign will be launched at the annual meeting of the Connecticut Council of municipalities in November at the Mohegan Sun Casino.

Win Evarts: Advocate for services from DDS. People with intellectual and developmental disabilities and particular the medical and behaviorally complexed population. Trying to find ways to receive more resources to address these needs. In the process of doing constructive advocacy in respect to the DDS's step initiative.

Karen Carney: Her sons name is Billy who has autism spectrum disorder, with autism traits and is 22 years old. A lot of programs such as Husky, and Social Security were challenging to get assistance with being his advocate. Found Bristol Arc and he is thriving in this program. He is doing yard work and he loves it!

Molly Cole: Two years into Silk is and it is continuing to grow. Website is up and running and has a lot of information on there. Next meeting September 27, 2023, from 10-3pm in Wethersfield at Keeney Hall, Wethersfield Historical Society. Stephanie Thomas, Secretary of State will be at lunch speaking about civic engagement. If you are interested in attending, please send Molly an email and she will add you to the attendance list. Another highlight is geared towards the work of 5 centers for independent living. Working on expanding funding and working hard on improving their data system. So, we can tell their story, what is that they do and how they do it and what you can expect when you contact them. In addition to that, they are doing work with partner in policymaking alumni. Recently had a big reunion with a lot of graduates where they broke up in four groups which focused on employment, availability of sign language interpreters, transition, and inclusion.

Denise Drummond: Works with the Commission on Women, and Children as a health analyst. Denise represents the African American subdivision. She is mom of an autistic son who is a senior at the University of Connecticut. Who was invited to talk to students at Southern State College about transitioning from High School to College and what supports and services are available.

Allyson Powell: Oversees Employee Assistance to faculty and staff but also to 30 other state agencies. More employees are needing assistance with anxiety since Covid. Noticing that most kids are struggling in school and the schools are lagging since Covid and having a hard time catching up. Kids that have disability, it adds another layer of complexity.

Tom Cosker: Connecticut disability rights advocate. Finishing up Fiscal year ends on 09/30. Focus on Systemic activities, individual work, intakes, and information referral. Education clinic which helps parents and guardians to meet with advocates to understand and review IP's. Housing clinic are also alongside some of their outreach events. Where people can talk about housing specific issues. Healthcare clinics is in the beginning stages of talks. Law student interns that donate hours to help with clinic work that they do.

Ann Smith (AFCAMP): Wrapping up Fiscal year. Seeing similar trends. Increased calls on children on spectrum and getting services that they need. School with staffing issues and increase in the number of State complaints that they must file. Focusing on the following areas: 1-Early childhood. Challenges in developmental delay. 2- Develop young adult and transition.

Nicole Cossette: Part C Coordinator in CT. Lead Agency for the Early Intervention System in the Office of Early Childhood. Working on Family Survey. Grants to mention: One with the

UCEDD focused on development of leadership among part C and D preschool special education. Also have a Professional Development grant which is implementing revision to their PD system. Recently joined a family outcome technical assistance. They have updated the family survey to align with the practices in the program. Also looking at the mission and vision statement and ensure those questions are aligned and that the family outcome is going to help interpret data and make better data. Working with Bethanne Vergean with the CT Stars to establishing, tracking an integrated data system so different agencies can communicate with each other, and children and family can receive universal screening.

Regina Owusu: Transitioned from Department of Public Health to Social Services. Currently working via clinical consultation, medical consultation unit. Role is to provide medical policy to colleagues and stakeholders in the community.

Emily Ball: Youth and Student Educator. This summer she spoke to the public about what she does at the center as a CT representative. She was asked to represent the console along with other members throughout New England. It inspired professionals to want to want to develop their own advisory boards and youth groups statewide.

Christine Wilson: Professor in the School of Social Work. Also works on LEND training program, focus on Puerto Rican Latino Studies project at the UCONN School of Social Work. Part of Leadership team on Equity Center through UCEDD. Co PI with one of the Doctorial training grants, which trains PhD students across the country who will train folks that will be working with families with disabilities. They are in their last year of our OSEP funded autism and high intensity needs young children, birth to three. Training 3-3-social workers, 3-Speech, and Language and special ed together. Also, Co Directs the PhD program in school social work and are looking to recruit. If you know anyone who is interested, please sent them her way!

UCEDD Updates – Ongoing Projects and Staff News:

Early Childhood Center (Brian Reichow) - Received a call from the Special Olympics to write proposal for funding to help them evaluate their Young Athletes program. We have won the award. Specifics so far; the Young Athletes program has a home component, a school component, and a community component. It is an 8–12-week program to help caregivers, teachers, families learn how to engage their child in different physical activities. Work with them to design a way to evaluate the program. There is a new app for Young Athletes program that is available. Will likely be evaluating in a couple of states in the US but they also want us to look internationally. Mary Beth and Brian will run this program but the LEND program will also be involved. This part of the project should be finished by June 2024.

Center for Equity, National TA Cener (Darla Gundler) – Funded in collaboration with American Institute on research (AIR). Darla is funded through the Federation Special needs, which is the Parent Training Information Center in Boston and will be working in collaboration with all the parent center networks across the country to ensure that families are apart of the training. Other center is the Early Childhood intervention of personal center for equity. This was funded last year, and we are in the process of getting our website up and running. Purpose is to increase the number of personnel who have the necessary knowledge, skills, and competencies to deliver equitable scientific and evidence-based interventions to improve outcomes for infants and young children with disabilities and their families. The point of this center is to influence the way personnel in early childhood intervention are being trained so they can see the world through equity lens.

State Performance Improvement Grant (Deb Richards) – Staff shortages specifically in Special Education Administration and Special Education Leadership. The goal of this academy is to develop leaders who will provide innovative and sustained leadership to the CT Special Education system under IDEA’s four Areas and Competencies.

Expanding Public Health Project (Amal Alsamawi) – We Received small grant to investigate graduate training into enhance the knowledge and skills of the Public Health workforce in Connecticut. Public Health Students are involved in three aspects of projects:

1. Inventory of the Institution
2. Needs assessment for local health department.
3. Developing training and education materials for Public Health Students/Public Health Professional.

Molly Cole= Past year focused on our collaborative efforts. Decision making coalition that includes disability rights in CT. This includes ARC along with other entities such as DDS, State of Dept of Ed. Full summit on supported decision making on November 9th at Rocky Hill Marina. No cost to attend.

Walt Glomb – Connecticut Counsel on Developmental Disorders. Collaboration area of access to healthcare. Running series of 6 webinars. Featuring speakers on various aspects of people with Developmental Disorders. Next session is on Tuesday the 3rd at 10:00am will focus on CT context. Four other sessions, Tuesdays at 10:00, will address DEI, people of color and marginalized communities.

Next Steps:

The next CAC meeting TBD October 2023

Meeting adjourned at 11:35 a.m.

Respectfully submitted,

Toi J. Weatherspoon
University of Connecticut Health Center
Center for Excellence in Developmental Disabilities