



**University of Connecticut
Center for Excellence in Developmental Disabilities
Consumer Advisory Council
December 19, 2024**

Meeting Minutes

In Attendance:

Emily Ball
Scott Brown
Helen Carney
Molly Cole
Tom Cosker
Lani Florian
Walter Glomb

Natalia Klos
Diana LaRocco
Kim Mearman
Regina Owusu
Adrianna Ramirez
Victoria Sanchez

UCEDD Faculty/Staff in Attendance:

Mary Beth Bruder
Christine Jozef
Tara Lutz
Brian Reichow

Vaishnavi Shahane
Bethanne Vergean
Toi Weatherspoon

Introduction:

Mary Beth Bruder welcomed everyone to the meeting and handed over to Emily, the chair, to discuss the agenda. Emily then provided an update on their overall work, thanking their partners for their contributions. She also mentioned that they would be sharing some of their projects and giving updates on them. Mary Beth then discussed the importance of their data set, which is used to inform Congress and the DD Council about their work. She also mentioned a recent paper they participated in about support services for people with intellectual and developmental disabilities who have Alzheimer's.

Participant updates/highlights

Budget Challenges and Partnership Opportunities

In the meeting, Mary Beth discussed the importance of maintaining level funding and the challenges faced due to the continual funding issues. She highlighted the role of Lisa, the budget analyst, in managing the budget. Mary Beth also introduced new members of the team and discussed the launch of a 13-month webinar series focused on universal design for learning. The team also discussed their ongoing work, including running support groups, workshops, and preparing for their annual one voice conference. Mary Beth also mentioned the creation of a curriculum called "Empowering Caregivers" and the potential for partnerships with other organizations. The team also discussed the recent program cuts at UConn and the merger with the University of Bridgeport. Lastly, Mary Beth and Kim discussed the need for a needs assessment for autism spectrum disorders and the potential for partnership with the State Advisory Board for autism.

Council's Funding and Community Initiatives

Mary Beth discussed the Council's funding and support for various organizations and initiatives over the past four years. She highlighted the shift from large conferences to more focused, community-based work, particularly in underserved areas. Mary Beth also mentioned the Council's work in bridging the aging and disability networks, and their efforts to address housing and healthcare issues. She emphasized the need for legislative action to improve housing stock and healthcare access, and the importance of creating a civil rights firewall in Connecticut. Mary Beth also noted the challenges of resource allocation for enforcing civil rights protections.

Disability Rights Connecticut's Systemic Work

Bethanne Vergean discussed the work of the Disability Rights Connecticut, emphasizing their focus on systemic work and individual advocacy. She highlighted their work in areas such as abuse, neglect, employment, education, and healthcare, including the creation of a series of videos on supported decision making and employment. Bethanne also mentioned their work on the Katie Beckett Waiver Work group, aiming to eliminate the waiting list. She noted that they are not allowed to lobby, but they educate and inform legislators about their work. Bethanne also mentioned their involvement in a demonstration project funded by the Office of Special Education Programs and their work on the Stars project, a tracking and referral system for children at risk for developmental disabilities.

Early Childhood Intervention Challenges

Bethanne discussed the challenges and progress of early childhood intervention in Connecticut. She highlighted the importance of early developmental screening and the need for better understanding of early intervention among families and healthcare providers. She also mentioned the difficulties in tracking and referring children to services, with 3,000 families lost between eligibility determination and referral. Bethanne also discussed the need for a data system across agencies and the importance of parent education. She mentioned the launch of a parent-to-parent program and the ongoing work with early childhood programs in Hartford, the Northwest Region, and Waterbury. Bethanne also touched on the issue of inequitable access to early intervention and early childhood special education due to various barriers.

Addressing Equity in Early Childhood

Mary Beth discussed the challenges of defining equity in early childhood special education, highlighting the lack of access and disparities in services. She emphasized the need for a more diverse and competent workforce to address these issues. Mary Beth also outlined the center's objectives, including increasing the number of higher education programs centered on equity and increasing the number of personnel. She detailed the center's partnerships with various institutions and the development of materials and interventions. Mary Beth also mentioned the center's work on state infrastructure and a national social media campaign to promote the field of early childhood special education.

Equity in Education and Workforce

Mary Beth discussed the importance of equity in education, highlighting the issue of funding being taken away from making America great again by funding social justice programs. She also mentioned the launch of a graduate certificate program in interdisciplinary disability studies in public health, which has been well-received by students. Tara Lutz then took over to discuss the outcomes of the program, including an increase in knowledge and skills among students, and their application in the workforce. Tara also mentioned ongoing work with local health departments and the expansion of the public health workforce in the state.

Addressing Concerns and Lobbying Strategies

Mary Beth led a discussion about the organization's concerns over the next four years, particularly regarding the welfare of people with disabilities. She emphasized the need for lobbying and engagement with the legislature to ensure the organization's needs are met. Mary Beth also highlighted the potential impact of federal policies on the organization, such as the reauthorization of the Medicaid program. She urged the team to be cautious and to work with the legislature to assert their authority. The team also discussed the potential impact of the new administration's policies on the organization's work. The conversation ended with a reminder to fill out evaluations and a discussion about the upcoming holiday season.

Next steps:

- Adriana to provide Mary Beth with information about the empowering caregivers curriculum and upcoming cohorts.
- Kim to reach out to OPM contact regarding partnership for autism needs assessment.
- Walt to follow up with Tom on ADA accessibility issues for people with intellectual disabilities in healthcare settings.
- Molly to implement waiting room for future Cross Disability Lifespan Alliance calls starting in January.
- Bethanne to continue work on Stars project, including launching parent-to-parent initiative in Waterbury in January.
- Tara to develop training materials for local health departments based on survey results.
- UCEDD team to monitor potential changes to IDEA reauthorization and Medicaid funding.
- All partners to engage with state legislators on protecting Medicaid and HCBS funding.

In Conclusion:

- The next CAC meeting Fall/Winter of 2025.
- Meeting adjourned at 1:00 p.m.

Respectfully submitted,

Toi J. Weatherspoon
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Uconn Health
Center for Excellence in Developmental Disabilities