



UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Consumer Advisory Council Meeting

February 23, 2023

10:00am – 12:00pm

Attendees: Dr. Mary Beth Bruder, Christine Jozef, Molly Cole, Allan Bergman, Diana LaRocco, Deborah Richards, Brian Reichow, Peter Deckers, Tom Cosker, Terrell Reichow, Adriana Fontaine, Denise Drummod, Scott Brown, Ann Smith, Darla Gundler, Nanfi Lubogo, Allyson Powell, Edwin “Win” Evarts

Introductions and Purpose of Meeting – Diana LaRocco

This meeting is going to focus on tweaking the work that Mary Beth has done so far based on the work that we did at the last CAC meeting. The agenda was reviewed by Mary Beth for this fast meeting which includes the grant structure requirements and objectives, vision and mission statement breakout groups, and work scope objectives and goals breakout groups.

Edwin “Win” Evarts (ARC of CT) and Adriana Fontaine (Connecticut Parent Advocacy Center-CPAC) were not at the last meeting. Adriana introduced herself to the group as a bilingual parent consultant and oversees two programs for families who have children with disabilities.

It was noted that the key team of Diana LaRocco, Linda Rammler, Molly Cole, Deborah Richards, Allan Bergman, and Brian Reichow have been helpful to Mary Beth.

Overview of the Grant Structure, Requirements and Objectives – Mary Beth Bruder

Today’s meeting is not to wordsmith, but it is to get the big picture concepts, items that may have been left out including any ideas, and possibly words that may be offensive for whatever reason to you. It is an opportunity to look at where we can go over the next five years.

Budget

We have a limited budget with close to \$3.75m of FTE which means not a lot of people to do this heavy lift. We are lucky that we are getting some cost share from the Dean for some faculty time which is very helpful as well as infrastructure thanks to Peter Deckers. Our budget is the first thing we must look at as well as what the DD Act and RFP requires. The RFP is very structured, very formula like. Since we are part of the DD Act, we have definitions for everything that we do, and those definitions carry over to how we collect data on the National Information Reporting System (NIRS) which is public

data which gives insight as to how do in comparison to other UCEDD our size--we are holding our own. It is also on the Association of Centers on Disability so that this is a very transparent process.

There are 16 other directors who are writing for this cohort, and we are all scrambling. These cohorts have shared their grants so that we may learn from each other. As a result of the budget constraints, the ACL has made a statement for the last five years which is "go deep as opposed to wide". For example, UMass Boston focuses on employment, they do nothing in early childhood and little in schools. We must look at where we can leverage in resources, show our past five years of history. It was noted that we are holding our own as a small UCEDD. We do not do direct service, which is an income maker, we are more aligned with Maine, Vermont, and Rhode Island.

UCEDD Core Functions – must demonstrate how we are going to meet these core functions.

- *Interdisciplinary Preservice and Continuing Education*

UCEDDs are at universities for a very strong reason, they were the first piece in developmental disabilities. National systems were put into place through the Kennedy legislation which continued with as the Mental Retardation Panel. This panel consisted of scientist who were making breakthroughs in everything from practice to bench research. These scientists were very effective in showing that we needed to move centers into universities. First and foremost, we are charged with developing and implementing preservice and continuing education defined as any type of education that allows a professional to continue in their profession (CMU or CEU or CM) or need additional education to be a member of their profession. We are fortunate that we have been funded by the Office of Special Education for our national doctoral program, two master's programs, and we are providing funding for a post bachelors but not a full masters program. The LEND Program is also part of this piece is why we focus on interdisciplinary graduate.

- *Community Services through Training and TA, Model Service, and Demonstrations*

We are charged with developing and implementing community services done through training and technical assistance. We do not do model services; these are the centers that have clinics and provide primary services. We also provide several trainings which are led by Linda Rammler that focus on adulting for those families and children getting ready to transition out of the system. They have five cohorts with a total of 58 completers. We also have a course offered through Public Health and would like to make it a mandatory course in their curriculum on disabilities and public health. Unfortunately, we are not there yet but hoping to work with some of the Public Health programs throughout Connecticut. There is also an online course through UConn Genius Program which helps parents with transition issues.

- *Research and Evaluation*

The third core function is research and evaluation. In the past 10 years, there has been an increased focus on research and evaluation. There is realization that we are not necessarily filling the gap between what research says and what practice is doing which has put out a call for more applied research. We have several small studies funded and Brian Reichow has put in two research grants. Our job is to generate research, program and community evaluations which will to allow us to do a better job with persons with disabilities across the lifespan. Our LEND students are working on very small

research projects including one student, Marco Delsanto, who has worked with our DD Council on a bill for not having IQ as a criterion for getting services within the Department of Developmental Services. There is a press conference scheduled for next week, and Marco's data will probably be shared.

- *Information Dissemination*

How do we take what we have learned and translate into practice in communities, with families and persons with disabilities lives? There is a lot that we have done, and we are looking at doing more including video clips. We have a video library for early intervention. We have over 500 video snippets showing different practices and early intervention through our Early Childhood Personnel Center (ECPC)

Under each one of these goals, we have specific objectives that meet the goals and within the objectives, we have activities. Question was asked how many activities will be done to support students in preservice and continuing education? How many activities are you doing in the community? We will really need to be able to demonstrate that.

DD Act Emphasis Areas – We have 11 emphasis areas plus 5 emerging emphasis areas with its own definition.

- EI and Schools – even though we separate our activities for EI and schools, they are one emphasis area in the DD Act. We have expertise in this area and funding that we have been able to leverage.
- Child Care - We have placed childcare into EI and schools. It is becoming a crisis for parents especially those with children with disabilities. We do a lot of work through the ACT early childhood program.
- Health Care – We will look at accessibility of health care for all persons with disabilities across the age span as well as quality outcomes of health care.
- Quality of Life – This has a very specific definition and will have to measure it through quality-of-life scales--impacting the larger vision that a family has for themselves and their child no matter how old, as well as persons with disabilities in how they define quality of life for themselves looking at the community supports and services, access participation and outcomes.

Each one of these areas is threaded throughout our four core functions, and we will have very specific outcomes that we have to measure to demonstrate every year what impact we have made, everything from finite numbers to numbers who completed to bigger chunks of some of these thing such as are we increasing screening rates through child care and primary health providers for young children with disabilities who may have diverse backgrounds such as race, language, ethnicity, culture, and what has kept these families marginalized and not getting the services they need.

Revise and Approve UCEDD Vision and Mission: Breakout Groups – Allan Bergman

Proposed Vision statement slide shared with the group. During the breakout groups, reminded this is not the time to wordsmith the document but reviewing to see what is missing and/or doesn't resonate. Proposed Mission statement slide shared with the group. The mission is what we are doing now, core functions will be part of the mission. Will be working in small groups to review both the vision and mission statements. The mission describes what the organization wants to do while the vision is what will be done in the future. Breakout groups adjourned for the next 12 minutes, one person to record outcomes and bring back to the whole group.

Breakout Group 1 – Denise Drummond, Molly Cole, Terrell Reichow

Proposed Mission – would like to remove/replace “citizen” from “Connecticut citizens with disabilities and their families”. Remove “regardless of background” -- didn't feel it was needed. Cannot use “all” and hasn't been used in the past, need to have this specific wording. Challenge was trying to define what “background” meant—needs to be clearer. Characteristics versus background. Dilemma is they would like it to be restated in the mission statement so when people look at that, they understand what that really means. On the vision, where it says “we will learn to live, work” add thrive after work.

Breakout Group 2 – Allyson Powell, Scott Brown and Brian Reichow

With the vision if we meant more than having access--is there anything about utilization of opportunity, supports and services? It would be beyond just having access. This is a point very well taken given what we know goes on not only in Connecticut but every place else. They also thought the mission statement looked good and happy to see that everything we do in 5 years could fit into one sentence. Additional note from Ann Smith regarding if they have the same access to these services as everyone else, access and engage are two different things, so in consideration of that word change perhaps give some thought to engage as an additional one.

Breakout Group 3 – Diana LaRocco, Ann Smith , Tom Cosker and Peter Deckers

The word “citizen” to change to “resident”, citizen does not resonate well because if we really are looking at addressing the needs of marginalized populations, we need to take into consideration those who may be residents in our State but who have not attained the status of citizen. We know that the population also constitutes a large percentage of those who fall into some of our other categories of marginalized populations in terms of looking at race, language, economic status, that is why the change to resident from citizen. Since this is federal money is that potentially problematic. Not felt to be a problem.

Breakout Group 4 – Win Evarts, Adrianna Fontaine, Linda Rammler

In the mission statement thought it would be possibly to remove an “and evaluation” and add a comma between the prior work and evaluation. The reason why we got to that discussion we found that the outputs were kind of bland and not very approachable for a mission statement for people to say is this a useful place for me to access services and the notion of promising practices would be that I can engage with the UCEDD and learn from the UCEDD a little bit

better and then provide a propellant in that way. The change would be “UCEDD will generate and translate interdisciplinary research, evaluation findings and promising practices.” Will need to define what “promising practices”.

Breakout Group 5 – Nanfi Lubogo, Darla Gundler and Deb Richards

Want to see the mission statement reflected in plain language--some of the terms may not be understood by those outside of the educational space. Per Mary Beth it is a requirement that our abstract is in plain language, and we can certainly do the same for the mission and vision statements. Discussed that although there are language requirements for the grant, once completed, create a very simplified one-page version of the vision statement.

Work Scope Discussion – Allan Bergman

There are five core functions and goals with objectives tied to them. Our last take is to break into groups and review objectives to see if they are clear and if there is anything missing, is there anything else that should be a part them. Again, rather than wordsmithing the objectives or the goal, think about more of implementation and where are the connections. Will reconvene in 20 minutes to brainstorm.

Breakout Group 1 – Nanfi Lubogo, Darla Gundler and Deb Richards

- Goal 1 – Objective 1.3 – want to add verbiage about “healthcare mental health services”. Noted we are not a mental health provider at UCEDD. Individuals with dual diagnosis, intellectual developmental disabilities, and the rapid growth, even before Covid of significant mental health issues that New York has very good data on this—35% of adults in in New York have a legitimate secondary DSM diagnosis for a mental health condition. This is a real issue, and it is growing.
- Objective 1.4 – expanding the training that’s provided beyond LEND to others. Training was done at the dental school and realized how much is needed.
- Objective 2.1 – Would like to know what the implementation of CSPD components means— Mary Beth explained a comprehensive system of personnel development is working with states and higher education programs to put together systems that are not just looking at one piece of personnel development but starting with recruitment and retention, looking at personnel standards, developing and influencing programs of study for those who service children birth to 5 and working with States to have evidence-based professional development being offered.
- Objective 2.4 – with IDD and ASD maybe make more general, we understand why it is specially called out here. We had included mental behavioral needs but understand that’s not really in the scope of what we do. Make it more general. We can do behavioral needs.
- Objective 4.2 – Talking about dissemination, plain language fact sheet, webinars, and podcasts for presentations.
- Objective 4.3 – The dissemination piece to also include community-based organizations, important to have a feedback loop with the people that are conducting that research.

Breakout Group - Diana LaRocco & Ann Smith

- How is UCEDD able to partner with communities that it serves. We know where the marginalized populations are but how do we bring this to them. How can we help to make these connections.
- Terms of Education –pathways to get people into the field, how do we create these, how to get folks into the preservice pipeline. We are partnering with Ann Smith for the demonstration project on access to early intervention. Mary Beth will be putting together a chart of who our partners are for what purposes and what outcomes. Network needs to be connected and make the introductions.

Breakout Group – Allyson Powell, Scott Brown and Brian Reichow

- Employment and Housing –not quite an emphasis area or have the bandwidth or expertise, is there a way to have awareness across areas.
- Need of plain language and looking at Goal 4.0. – will change the wording on this one.

Breakout Group – Denise Drummond, Molly Cole, Terrell Reichow

- Biggest change under Goal 4 – materials should be translated into other languages other than English, noted this is under activities.
- Participatory Research in the modality of teaching families and self-advocates the importance and ability to read research findings. Parents need training on this.
- Objective 2.5. would insert “children with disabilities on life course, planning for a decision, making self-determination, post-secondary transition and making referrals for assistive technology resources” –add to Adulting course.

Breakout Group – Win Evarts, Adrianna Fontaine, Linda Rammler

Translation – designing this to be consistent with the Federal language access requirements which we are required to do at some point. Do we specifically address this? – This will be under universal design making all materials accessible in multiple languages. We have partnered with the Federation for Children with Special Needs to translate materials in 17 languages.

Next Steps and Adjourn – Mary Beth Bruder

Mary Beth apologized that we had to do this so fast and reiterated that the other 16 directors are doing the same thing. Mary Beth is thankful for everyone with collaborating on this grant. The grant situation is not terrific, there are 3 times as many submissions to NIH currently. We will not be able to do everyone’s wish list.

Need a letter from Diana on behalf of the CAC by Monday. Diana added when she looked at what Mary Beth had done with what we all have given her, that it is a very good representative of the thoughts and desires of people that have participated, hearing the voices and doing your best within the constraints to make sure the voices are heard.