



TA Institute Discussion Notes

Topic: Leveraging the Strength of the Universities and UCEDD for Improved Partnerships

Notetaker: Siddarth Nagaraj

Facilitator: Kara Ayers, Associate Director, University of Cincinnati Center for Excellence in Developmental Disabilities, Cincinnati Children's Hospital Medical Center, OH

Participants:

Melanie Fried-Oken, Co-Director, Oregon Health & Science University UCEDD

Marcia Moriarta, Director, University of New Mexico Center for Development and Disability

Kimberly Mills, Director, Virgin Islands University Center for Excellence in Developmental Disabilities

Amy Hewitt, Director, University of Minnesota Institute on Community Integration

Brian Freedman, Associate Director, University of Delaware Center for Disabilities Studies

Sally Gould-Taylor, Associate Director, Temple University Institute on Disabilities

Amy Sharp, Director, University of Texas at Austin – Texas Center for Disability Studies

Discussion and Examples:

- **Dr. Fried-Oken:** One of the biggest strengths that UCEDD possess is simply being in a university setting. This inherently provides partnerships and resource-sharing access with medical schools, dental schools, etc. and eases cross-collaboration in a manner that isn't an open to community-based organizations or even public agencies.
- However, it is difficult to initiate (let alone sustain) those relationships without the money to back it up.
 - Not everyone has NIH funding.
- NIH funding is an immensely powerful resource for partnership-building within and with other universities, but it is not sufficient or available to enough UCEDD or universities generally.
- **Dr. Moriarta:** Universities have strong state partnerships, but may not have the same access to federal resources and relationships.
- Universities are in a strong position to look ahead to the next five years.
- There's a balance that needs to be struck between the strength of a university and the strength of a UCEDD. UCEDD have a goal to keep strengthening the synergy between both parties.



- It is critical to articulate why what we do is important to a broader audience (e.g. the people of your state rather than just the disability community).
- **Dr. Mills:** UCEDD bring many specialized strengths to universities, including special grants and unique technical assistance that university leadership cannot draw on from elsewhere.

Strategies or Resources:

1. How AUCD can help – Advocacy

- **Dr. Moriarta:** One of AUCD’s greatest areas of support to UCEDD is advocacy, especially guidance on how to navigate politics.
- The politics surrounding disability issues and policymaking (at all levels) often doesn’t align with higher education operations. AUCD’s clarification and provision of information to UCEDD is extremely important.
- A huge part of a TA director’s role is navigating this politics and drawing upon mutual support for key priorities – guidance on policy advocacy matters.
- We should continue to explore how AUCD can continue to cultivate TA, especially in current times with massive turnover and upheaval among directors.
- The network itself could put a group of folks together to look into this and lead.

2. How AUCD can help – TA

- **Dr. Mills:** The TA that AUCD provides is invaluable, especially since it operates at a unique federal role
- It provides unique access to federal funders and partners and also has excellent coordinating capacity

3. How the network can help – Collaboration and Presence

- The UCEDD are a national network – that is truly powerful, for both substance of intellectual knowledge/resources and image purposes.
- UCEDD need to leverage this more to elevate our own collective reputation.
- UCEDD often write letters of support for recruitment and note they are part of a national network – being able to rely on the strength of the network is a huge advantage.

Outstanding questions for follow up:

What are ways in which UCEDD can collaborate more closely to elevate the network’s profile?



UCEDD have varying relationships with their universities' communications departments, but those that have good ones have been able to leverage them to great success. UCEDD could use collective help with this.

Greater synergy with university communications teams would also raise the profile of UCEDD and the AUCD network, as well as increase the ability to engage in high-level advocacy and attract attention from important stakeholders.

Follow up for TA team:

No specific questions – high praise for the TA team.



Discussion Notes

Topic: Reaching community audiences with relevant research knowledge

Notetaker: Luis Valdez

Facilitator: Suzannah Iadarola

Participants: Tawara Goode, Mark Crenshaw, Chris Knowles, Marty Blair, Karen Bonuck, Patricia Patrick, Elizabeth Perkins, Robin Greenfield

Discussion and Examples:

Marty Blair: We are in the process of finding innovative methods (video, social media, etc.). Have begun looking into radio for reaching rural parts of the state.

- **Tawara Goode:** radio can be relevant to URM in non-rural settings as well; backed in the literature as a preferred method of communication.
- **Suzannah Iadarola:** We utilize the radio station for event promotion.

Marty Blair: Sharing events and activities is useful, but we are interested in sharing research results and outcomes (next steps in research).

- **Elizabeth Perkins:** Social media campaign is helpful. Looking into the creation of mini-podcasts on a variety of topics (sound bites) and coordinate for radio release – would be interested in creating these for the next five-year plan.
- **Suzannah Iadarola:** We have created our “street team” to facilitate and develop relationships with local public radio.

Tawara Goode: Participating on a PCORI grant looking at populations that are consistently left out of research. Partnered with UNH and USF and using a truth and reconciliation model to bring together DD and mental health service systems to help and share what the issues are regarding inclusion in research. This is in the second year and is engaging people who are most impacted by the research. It has been important to hire people as a part of the project team in order to break barriers (especially regarding ethnicity and language) and engage in community-engaged research with regard to DD populations.

Marty Blair: Have a contract with www.publicnewsservice.org (have to buy into this) where this service can write up to 8 stories a year on research by a professional journalist, as opposed to doing this in-house in the UCEDD where the cost may be larger. The service would only run around \$5-6K compared to having to hire someone full time for this duty.

Tawara Goode: Important to adopt a truth and reconciliation model – people have been harmed by the research in the past and as a result, lots of communities are hesitant around what “research” means. Important to acknowledge historical wrongs and provide plain language protections in place for success. Need to highlight why research is important in a way that is relevant to the community, and have an openness to share all results obtained, even if not positive.



Suzannah Iadarola: Have any centers explored the use of needs assessments to determine what matters to community members regarding research?

- **Tawara Goode:** It's important to have community engagement from the beginning, so as to have the research questions formulated and reflecting community participation from the start.

Karen Bonuck: Important to conduct some research that is clearly translational from the start, in settings with people/practitioners who will then do the follow up care. This offers so many different perspectives.

Strategies or Resources:

- www.publicnewsservice.org – Hire journalists to write about research.

Outstanding questions for follow up:

Has your UCEDD explicitly developed (and promoted publicly) guiding values for engaging diverse communities in research?

- What is your UCEDD committed to? (for conducting research in communities)

Some examples of this:

- Marty Blair: Yes, with and by native communities.
- Tawara Goode: Yes, and willing to send some to the group.

Follow up for TA team:

AUCD can gather and collect examples of these guiding values for engaging diverse communities in research activities.



TA Institute Discussion Notes

Topic: Providing and Participating in ongoing staff/faculty training

Notetaker: Denise Rozell

Facilitator: Lori Garnes, Associate Director, North Dakota Center for Persons with Disabilities, Minot State University

Participants:

Derek Nord, Fred Biasini, Matt Wappett, Lori Garnes, Denise Rozell

Discussion and Examples:

Derek -- Challenge – diverse staff. Increased research staff recently and end up getting an academic career ladder (not accessible to everyone). Has requirements for being known, promotion, escalate work, etc. – how do others support further development of research faculty. What support and development can we provide?

Fred: Response to Derek – just promoted but should have happened years ago. Took an interim director who saw it and worked on it. How to educate your university a to who you are and how we do training vs how others do training in other university settings.

Strategies or Resources:

Lori – same issue at Minot even though not a research emphasis at university; Minot not consider grant writing a scholarly activity. Had to go through a process to show it actually is. Directors from Day 1 make a plan for promotion for all staff. Actually, in plan for the year, how many scholarly activities are you participating in this year and where, how get to conference so can do peer presentation, how hook you into publishing, etc.

Application template for what is required and then use that to look at basic outline

Lori -- One Director helping another Director on promotion committees, find a mentor in the network to support (particularly if publishing a lot, you can get on as second author or some other idea.



Matt – are UCEDDs in separate academic unit? Answer – depends... each has different examples. Minot at same level as an academic unit; Fred says theirs are all over (depends on where faculty is), Utah – must have academic home outside the UCEDD for academic faculty.

Fred Q – 20 to 25 folks need CE to renew license and UCEDD can't always support or pay for that. How do others address it? Since moved into peds, center running at a deficit, but university has decided not to support as a money saving issue

Derek = not an issue;

Matt – very few who need to maintain license but for others have discretionary funds can draw on. Use ECHO training? Participate for free but also get credits so that may help for some

Lori – Double dip as often as can – conference where UCEDD pays for registration or exhibits, but attendees can also get CEUs if they are also offered

Matt – invest in professional development for all staff and get commitment across projects but getting pushback on whether all the projects are willing to opt in. e.g. accessible documents is important for everyone but how get them all to buy in?

Lori – mandatory training for everyone. Appears on performance appraisal if they didn't do it. And salary is based on performance appraisal. Pick your battles.

Matt – tried a variety of things – mandatory for all staff, staff turnover means additional stuff, online training put together for new staff, still pushback...

Minot – person who oversees onboarding makes sure that everyone completes their training before they can go on to their other/permanent job. That way you must do it before you move on.



TA Institute Discussion Notes

Topic: Developing strategic partnerships outside your university

Notetaker: Dorothy Garcia

Facilitator: Derrick Willis

Participants: Maureen Van Stone, Evan Dean, Susan Hetherington, Tanisha Clarke, Jordan Kerr

Background/Intro/Goals for discussion:

- SH: UCEDDs need to be more involved in partnering outside of the organization, in order to better serve their communities
- MVS: Has been cultivating unique partnerships outside of the university, but is always thinking strategically about untapped resources and collaborators
- ED: Partners with self-advocates and parent groups; how can we leverage existing relationships to expand research capacity and be a driver of innovation within our state?
- DW: Number of goals: Identify agencies and partners that touch lives of people with disabilities. Iowa UCEDD has had good relationships (Iowa Dept of Public Health, Vocational Rehab Services, other agencies), but not many contractual relationships.
 - o Look at what's happening across your state, demographic trends. Ex: 30% of Iowa's population is 65% and over. There are opportunities for collaboration with other groups. How does UCEDD build capacity to serve, align with other partners to create opportunities for PWDs?
 - o Other partners: Iowa Department for the Blind, Iowa Department of Human Rights. Who has a responsibility to provide services? How can UCEDDs leverage their existing services to work with other organizations?



Discussion and Examples:

ED: We have more grassroots partnerships, but less state-level ones. Trying to make inroads and opportunities for contractual services.

- Research, service provision
- Supported decision-making

SH: More grassroots-oriented in the past but changed drastically in the last few years. Currently have multiple contracts with the NY State Dept of Health. Former colleague is now the commissioner of DD agency. We've worked really hard to expand our CAC (numbers and geographically), resulted in more recognition of the UCEDD and its work. Doing much more participatory research, which results in community agencies and advocates being involved. Hired more self-advocates, which makes a huge difference- they are extremely effective at speaking with community groups, business groups, etc. Project SEARCH engages voluntary agencies around employment, vocational rehab and DD state partners. Has held an employment-focused summit attended by Sen. Harkin and engaged with business leaders in Rochester. Having known areas of expertise helps with increasing name recognition.



Discussion Notes

Topic: Diversifying Funding with Creative Strategies

Notetaker: Natalie Martinez

Facilitator: Deborah Spitalnik

Participants: Pat Morrissey, Eric Kurtz, Karan Burnette, Deborah Spitalnik, John Spitalnik, John Tschida, Angela Martin, Chris Murray

Discussion and Examples: Successfully had legislation introduced to the state to get infostructure for children with disabilities in high school- Pat
Figure out ways to diversify the portfolio- they relied heavily on the core funds. She loves the idea of the TA model that Pat uses. They want to be more engaged with their state partners and make sure their network gets the highest services. Rhonda is interested to hear about UCEDD that have increased their funding opportunities with these types of activities. They worked with their community partners- assistive technology lab- they helped them apply for a grant and was successfully funded-Rhonda

They are trying to increase some of their unrestricted funds and increase their contract work. They need that to help sustain themselves and provides them demo opportunities. They can use the data from the demo on a much larger scale. We have core funding and LEND fund and 2 year grant from Blue Cross fund. They have contract work that varies from year to year. They do not have very solid partnerships with other departments in state agencies. The chaos of state agencies. They have a relationship with DBHMD in MI. The agency that is new to them is Aging- both for their shared common interests and a willing agency director- Angela. Has any UCEDDs built anything on Aging or Direct Support-Angela

Successfully utilized DD Council funding but had trouble sustaining that beyond a pilot- Deb Even though they are doing a lot of work in direct support they is a demand in increase in salaries but not competencies. It perpetuates the inequity and challenge. They started their UCEDD in partnership with their DD agency. They found moving to co-op agreements rather than a project contract creates more flexibility. It creates a more meaningful partnership and a longer partnership. Keep track of the start and end date falls with the change of governors.

They have a strong relationship with their DD, Medicaid and Young Children agency. They have been working with their DD agency since 2011- they helped them work on a waiver. They are involved in childcare and early child ed department. They have almost shifted their funding to where the bulk of their funding comes from those agencies. They still have 6 large ICF and managed care is taking over community services. Has anyone gotten themselves in that position? Karan Burnette. Angela had a similar situation- with a home and community based project. They tried to push back on some of the plans with statewide advocacy partners-they tried to doing some supports for the agency but they were



admonish for the support. The DD Act drives how they do business. They helped with HCBS. It is a bit of a challenge sometimes. They have 6 agreed upon topics that they work on. They make sure the 3 of them are in agreement before 1 of them advocates something.

Rhonda resonates with Angela with walking the line. Bringing a strong message but they are mission driven as well. There DD network partners are young and new. That layer of support they don't have as of yet. They are re-forming. They need to be mindful when doing work in your state but it can also be a wonderful opportunity to have an in to present your information and outcomes. - Rhonda

No matter how strong the relationship is we need to thread the line- Deborah



TA Institute Discussion Notes

Topic: Successful Leadership Transitions

Notetaker: Dawn Rudolph

Facilitator: Sue Fox

Participants: Dana Yarborough, Carol Curtin, Mark Shriver, Danny Armstrong, Karen Ward, Deanna Buck, Stephen Rock, Dan Crimmins, Cari Murphy, Olivia Raynor, Beth Mineo, Aubyn Stahmer, Emily Graybill, Brent Askvig

Background/Intro/Goals for discussion:

Sue came into her role after a much-loved director. Had 90-day transition plan with every person she needed to meet, every document needing review, agency policies, info on Board of Directors, financial budgets, where things were located, this was all extremely helpful. Predecessor helped introduce her to outside people at university, state, DD Council – this was most helpful thing. Query – can this be shared?

Talked with about 100 people in and out of the organization, approached like qualitative research project to identify priority goals of the first year to 18 months.

Following a legacy director is hard. Culture eats vision for breakfast. Build new allegiances, new leadership teams, very difficult to develop new culture.

Discussion and Examples:

VA – transitioning in several projects and roles, opportunity to look at agency approach to leadership transitions. Prior director had limitations on who could serve as PI, current director has broadened this. Big gap between new professionals in the field and folks who have been there a long time, associate director positions (2) are open and not filled.

Many long-time directors retiring, taking long time to recruit replacements. Not a deep bench in many UCEDDs. Different feelings about people coming into those positions from outside their UCEDDs.

Critical need to develop people internally. On first day of the job, prepare for the last day of the job. UCEDD Directors have responsibility to organization. ND made an ICE (In Case of Emergency) plan, which needed to be implemented last year, and was able to see who could step up and meet the needs on interim basis.

FL – came in after interim director for 4 years, when he started, was told he had 3 grants that don't cover everything, there is a \$20k pot of money – hide it because you might need to cover your salary.



Made decision early on that a need for deep succession plan put in place. Strong Associate Directors who can easily step into role. Built leaders into professional collaboratives. Associate Directors join Director at multiple critical tables – learning by doing rather than by talking, building relationships. Takes more than a plan – takes training, developing leadership skills, understanding how to negotiate systems, embrace the Center rather than the grant.

Training people, bringing them to the table, is critical. 90% of what we do is build on relationships, and this is not transitioned on a piece of paper.

Share with people how decisions get made – not what the decision is, but how it was made and the considerations involved. Understanding the thought process – weighing value of UCEDD with considerations on how to respond to emerging needs.

NV - Sponsored projects, relationships in community, another issue is that sometimes Director is the only one with an academic appointment. Lack of understanding about the balance of community outreach and the traditional academic structure – this is critical piece also. Strength and challenge of UCEDDs across the country – degree programs are in other academic units. Hard to find the right person to bridge community and academic requirements.

Directors need to bring in people they report to. DE has reported to 6 or 7 Deans in her time as UCEDD Director. We can position ourselves effectively there as well. Prior Dean decided that UCEDD was going to undergo academic program review – it was a stunning ton of work – time so incredibly well spent. External team came in, had to prepare extensive document that was handed to new dean a couple months ago, recently handed it to another. Captured history, finances, documents – investment that brings dividends over and over.

CA – Institute in which the UCEDD sits is going through transition – need to educate on the academic process and the UCEDD. Navigating this change at the same time that are navigating own succession plan is challenging.

One recommendation that came out of a previous search is that Directors should perform a job audit — what are all the tasks or decisions that default to the director that are not in any formal job description.

Strategies or Resources:

NY WIHD succession plan policy:

https://www.aucd.org/docs/urc/Succession_Plan_Policy_Procedures_WIHD.pdf

URC resources on succession planning:

<https://www.aucd.org/urc/Succession-Planning/Resources-for-Planning>



Outstanding questions for follow up:

Prepare people for directorships – need focused training to prepare folks to succeed in these roles.

Follow up for TA team:

TA on clarifying the qualifications needed for the UCEDD Director role, and providing training and experiences to help UCEDD faculty meet those qualifications to build capacity to succeed in director searches.



TA Institute Discussion Notes

Topic: Designing sustainable programs

Notetaker: Maureen Johnson

Facilitator: Cindy Thomas, Director, Institute for Community Inclusion, University of Massachusetts-Boston

Participants: Leann DaWalt - Waisman Center University of Wisconsin

Background/Intro/Goals for discussion:

LW - Geography is important when considering sustainability

CT - Need to build capacity and suggesting model programs that would be sustainable elsewhere

LW - Responsibility to ensure that work has staying power

CT - Work should be relevant and applicable to communities

Discussion and Examples:

CT - Projects in schools with high turnover can be a threat to sustainability. How can we do things that take sustainability in mind at the beginning especially if the "champion" of the project leaves?

LW - Require supervisors of individuals involved in community practice to attend first full-day session to make sure that supervisor had a broad level of understanding of the concepts.

CT - Strongly encourage teams so that multiple people within the same organization are learning and hearing the same things so that there is still some integrity to the knowledge. This particularly applies to training.

LW - Training direct support individuals – getting team members on board with a financial incentive. Goal is to get buy-in at multiple levels if the sustainable isn't going to happen at the direct service level. Good to involve individuals on multiple levels especially at administration level.

CT - How can you embed short-term projects into work you are doing. Example: website creation project was embedded into another project which was attached to long-term support. Think about how project can align with long-term projects.

CT Public Housing Project – example of how not to do sustainability

- needed a stronger partnership



- more emphasis should have been placed on ICI's role as a navigator to help build the org's capacity to support their population instead of focusing solely on ICI's role as a direct service provider

LW - Consider critical partnerships and think about how projects will be sustainable to them with their resources.

CT - For example – worked with a group in Boston that supported Haitians. The organization was grassroots and had limited access to resources

Strategies or Resources:

LW - Approach new projects with a sustainability lens and breaking down how each piece contributes to that goal

CT - Develop service models in the context of current mechanisms in place and how it aligns with the support structure currently in place. How is the program designed so that sustainability can happen?

CT - Start with sustainability in mind.

Think about partnerships resources and what is sustainable for them as well.

LW - Knowledge translation – especially in research how are looking to get what we learn out into the field as fast as possible

Charting your course tools: https://www.aucd.org/docs/2020_Charting_Your_Course_FINAL.pdf



TA Institute Discussion Notes

Topic: 5 year planning to leverage funds

Notetaker: Sarah DeMaio

Facilitator: George Gotto

Participants: Karen Heath(AK), Ilka, Wendy, Sandy (WY), Larry (CA), Phil Wilson, Sharon Milberger, Joe Piven

Background/Intro/Goals for discussion:

George is trying to write next set of goals strategically.

of grants UCEDDs get relative to the # of grants that they write.

Setting realistic goals

How to best leverage core funds.

Discussion and Examples:

AK – struggles with mission drift in chasing the money. Try to fit funding into mission instead of reverse

OH – last plan – goals were around the core functions. Objectives cross align. They were strategic about funding proposals that did not fit mission or expertise. E.g., Employment is not center strength, try to partner with others on those topics

Staff knows own individual and center strengths. Helps people be prepared to mobilize when opportunities do come up in areas that align.

MO – Discussion with staff about where are our strengths (also not strong in employment)

Work closely with partners across the state to ID where are their interests and align skills and expertise to support others who have strength in employment other weak areas

Larry – employment also not a strength, brought project search into hospitals to have

Goes after foundation and state grants, more success

Batting average need qualification (state, foundation, NIH, etc.)



More success with contracts to allow for reporting on data and services

Michigan also aligns goals with core functions, challenge that people expect a lot for free. How much is in workplan to do free services vs. grant writing with core funds

MO – two key core fund investments partner with DD council on self-advocacy group and peer group (family to family network) , other “free” requests just aren’t in the budget

Also finding success in contracts and smaller foundation grants in partnership with community orgs.

AZ – when in SD, wrote 5 year, and planning for AZ 5 year next year. Have people been able to use core funds for capacity building? Limitations on staff capacity and expertise.

OH – Similar to AZ, struggling with this, how to change the culture of expecting Ilka and Kara to do all the writing. Have had TA on this, but still looking for strategies. Have tried partnering with others who are leads. Training and outreach are where the staff see their own strength and interest.

MO – wrote in a full time position for grant writer. Support 2 staff at .75-.8 FTE as grantwriters. The outstanding question is what are the realistic goals for them? Figure out what to chase. They have resulted in a 19% increase in this fiscal year to date.

Where are they from? What are their expertise? – Grant writing expertise, they leverage the content expertise of others. One is a former English teacher, got a MPA with grantwriting expertise. Other is an excellent writer, she works on all the backgrounds and lit reviews. The others with content expertise can focus on the research design etc. One was responding to an advertised position, the other had been on staff and George identified this as an area of expertise.

Do they ID as UCEDD Staff? Yes, they see themselves as staff, they work on projects. Have own areas of interest and connection to community, field and mission.

Did they already have a resume / record of successful grant applications? The program development director did (hired externally), the internal hire did not but had demonstrated the skills

Dev. Director has helped MO to focus on areas of expertise for grants and strengths to market to state and partners.

George to share position description.

CA – leverage smaller grants to get seed data for larger applications. Market access to populations.

All agreement that University is pushing for grants with larger F&A

AK – intentional about who to hire and all are done as a team, actually loan out grantwriters

University-based grantwriting staff have been hit or miss.