

2019 TA Institute

Thank you for taking notes in this session! At the beginning of the session, the facilitator will ask participants what they hope to take away from the session – this information should be written on the flip chart in the room for all to see; it can then be used to help the group get back on track if needed. The rest of the notes can be taken in any way that works for you (handwritten or typed), following the format below (no need for these notes to be on the flip chart). Your notes will be used to develop technical assistance materials on this topic, and session participants will be involved in reviewing those materials, so detail is appreciated. We hope the session is interesting for you and provides greater insight into the challenges and solutions experienced by UCEDDs.

Discussion Notes

Topic:

Achieving UCEDD Goals through Leveraging Relationships

Notetaker:

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Facilitator:

Maureen van Stone (MD)

Participants:

- Maureen van Stone (MD)
- Martin Blair (MT)
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- Sally Gould-Taylor (PA)
- Melanie Fried-Oken (OR)
- Ilka Riddle (OH)
- Sharon Milberger (MI)
- Wayne Stuberg (NE)
- Stephen Rock (NV)
- Karen Bonuck (NY)
- Amy Sharp (TX)
- Lauren Schenker (CA)
- Phil Wilson (LA)
- Daniel Wenz (NM)
- Pamela O'Brien (AIDD)

Background/Intro

Topics for discussion:

1. How people are using core funds to maximize relationships
 - a. Relationships with the community, and the community is defined as DD Act partners, but beyond that as well

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2. How to gain visibility in the state – UCEDDs are better known for their projects
3. Top 2-3 leveraged projects that the Center have had that were critical to make sustainable as part of the program
4. How to serve low-income communities – they take a lot of time and commitment (make vs. lose money on projects)
5. Balance different missions – mission driven work and negotiate connections as well
 - a. Missions and partners don't fully overlap
6. Situations where contracts can be “let go” or expire to add other relationships – allows other opportunities to grow
7. Innovative partnerships
8. Strategies to better brag about our university in a larger setting – looking for examples to promote work

Discussion and examples:

Innovative Partnerships

- Medical and legal partnership with no sustainable funding (Project HEAL – Health, Education, Advocacy, and Law – at Kennedy Krieger Institute)
 - Moved into clinical partnership for sustainable funding by providing civil and legal care they need when there is a civil legal issue requiring an attorney
 - Partnered with real-estate agencies that would contribute 5% of the closing cost back to Project HEAL
 - Partnership with local restaurants for happy hours to auction raffles, printed materials, and give back 20% to Project HEAL
 - Also helps with increasing visibility
 - The partnerships exist due to 501(c)3 that it is not through the university, but a business and education community center
 - In addition, there is the KKI Foundation, Community Education Services
 - Making sure that someone else doesn't have contact with the real estate agency or affiliated with donors
 - Includes law trainees
- Meet monthly with the DD Council
 - UCEDD can provide support for content and expertise
 - Still have conversations with PNA to determine priorities, and compare between UCEDD and the state priorities
 - Even if priorities don't overlap enough, can still ask for a letter of support on grants to make sure they are a part of the conversation

Top 2-3 projects leveraged

- Medicaid matching programs
 - Partnered with HHS in NM to contract with CMS based on available rate to expand access to Medicaid services based on classes of criteria (reach, direct coordination, referral to services, increase quality and access) and match with state partners
 - Ask them what projects they'd like to be affiliated with / “have their name on it” and do a match

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- Post-secondary program – didn't get funding for TIPS grant
 - Used core funds start up sustaining the program through a combination of parent pay tuition with the school district, money from the DD agency, some from VR
 - Becomes very visible program because undergraduate and graduate students become tutors, attract many disability field professionals, type of post-secondary benefits in many ways
 - Not getting the grant forces Center to be creative with solutions
- Partner with local businesses to provide technical assistance to employ people with disabilities
 - Other topics include how to employ, hire, etc
- Partnership between Children's Hospital Los Angeles and general pediatric with the hospitals through regional centers
 - There are 21 regional centers that provide service coordination funding for individuals who meet the criteria (CP, autism, epilepsy, and other disabilities)
 - Clients will come to the center/clinic and receive educational training
- Meet regularly with the DD Council and PNA to look for priority areas
 - Look at the DD Network and be creative – create apps for children and healthy lifestyles
- Grants that look at aging caregivers
- Experts across the state for a panel – results in white paper

Using Core Funds

- Collaborate with the DD Network and PNA and AT accessibility for the state website
 - Increases visibility because found people who are interested, hosted them to explain the standard for accessibility and general awareness
- Partnership with the state department of education related to early intervention
 - Many people weren't signing up for EI compared to the national rate or going in physician's office... but they weren't missing their appointments.
 - State department set up a program to train family member or parents with lived experience to work in the baby hospital, MDE funding, track what the barriers for accessing EI services and referrals (like parent navigators)
 - Perks is a sustainable relationship and don't need to rewrite grants
- Partnership to offer free legal seminar for young patients
 - Saw that more young adults are not ready to transition, so provided training
 - Law students wrote the lecture and delivered the training to the community, to be matched pro bono with the attorney and community education in advance on site for free
 - Get sponsors for the food and drink
 - Volunteers can help, and students donate their time
- Plan a steering call to design 8-9 sessions to address transition monthly
 - One topic per month – SSI, guardianship, IEP, etc
 - Speeches are free because agencies can't accept money
 - Schools can apply to their district
- Use core funds to contract Medical and Legal Partnership for an attorney who can help with the cross-training both medical and legal defense teams
 - End up writing grants for the community agency

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- Help the community get their grants
- Require all staff on a Board of Directors in the university or in a statewide task will help empower staff and increase visibility
 - Sponsor them to a training and figuring out the right fit for core staff
- Medical center – connect with early intervention or refer to a specialist to a site, host assessment and see results
 - EI gets paid for each referral
 - Respite staff – over half is under the UCEDD and lead person is the supervision
- Developing TA interdisciplinary team, assess, and follow up on behavioral issues in the school district
 - BCBA (board certified behavioral analyst) can help the kids earlier to figure out their needs before the problems escalate later
 - Can use Zoom or video conference and consult remotely

Hot Topics

- Sexual education and suicidality in IDD
 - Provide training on this topic
 - MD does a suicide prevention conference every year

Strategies:

- Have one-on-one conversations (can be informal!) just to start discussing and get their buy-in
- Have a donation account for sustainable funding – does not need to be designated to a specific project and can be rolled over

Questions:

- None listed

Follow up for TA Team:

- Want to start these kinds of conversations earlier *before* a project or strategy has been launched – looking for a format to facilitate this
- Parallel from research conversations: want to collaborate or write the grant because NIRS is difficult to navigate
 - Quarterly job board of: “are you interested in this topic?” “interested in this population?”