

# UCEDD Directors’ Meeting: Roundtable Discussion Notes

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The following notes are a summary of the discussions held at the round table discussions during the UCEDD Directors Meeting at the 2019 AUCD Conference. The directors present had two 20-minute blocks of time to attend discussions on any of 10 topics identified as emerging needs by the planning committee.

## #1 Engaging in state systems change activities: leveraging UCEDD strengths and navigating challenges

- Need Information about the role of UCEDDs on policy issues
- Need information on where are best outcomes:
  - DD context? Larger disability context?
  - How to make informed decisions
  - Examples of how other UCEDDs have approached policy
  - How to make decisions and how to sort through options/activities
  - How to move out of disability context to larger world; how to integrate disability into larger community (employment for instance/CA and Future of Work – how infuse/elevate disability?)
  - How to use data to further policy
- Strategies
  - Importance of having the UCEDD Director involved in building relationships; importance of long term relationships in state; Director must make the time to build at Commissioner, Governor, high levels
  - IN – weave policy into quality assurance; collect data; weave into documents and reports
  - State plans –
    - Using NCI and other data they need for state plans go make inroads
      - NE - \$400,000 to do surveys (NCI)
      - PA -\$1.2 million to do surveys (NCI)
      - OR – benchmarking NCI data in state plan (NCI)
    - NE – Olmstead plan
    - CA – Future of Work
    - NY – Medicaid (how??)
  - DE – Every RFP from Department of Health required contractors to say how they will include people with disabilities in whatever work they are doing – UCEDD ends up being a TA provider to all people who want contracts...
  - UCEDD provides seed money to develop “something”; leads to collaboration; discussion based on the topic; build relationships; grow partnerships; continue collaboration on other issues.
  - Involvement in national leadership in organizations beyond AUCD – AAIDD, rehab, etc. to build relationships...long view
  - Convince the university/medical center to be willing to take smaller grants to start with as way to get foot in the door and build longer term relationships (and more contracts)

## #2 Knowledge Translation: What is it and what role should it be playing in a UCEDD?

### Group 1

- What is knowledge translation? It's very important, but often not used
- Lots of great work, but dissemination not always adequate. Information goes out, but how is it used?
- How do we take info and knowledge and translate it for our target audience?

### Strategies

- Explore different tasks such as storytelling to get information out and translated
- 5 minute TED Talks in community by faculty, followed by Q&A
- Connect with CDC and other centers of knowledge translation within the network
- Make messages quicker and more to the point. Go beyond dissemination
- Talk about data when appropriate (Consider using shorter, non-data-based talks)
- Bring in people skilled in research, storytelling, social media, cultural competence
- Identify objective and objectives of audience and find a way to combine the two
- Engage community in marketing and dissemination
- Network wide topic for Directors' meeting?

### Group 2

- Bridging the Know-Do Gap?
- Product to market
- Product to use
- Health info marketing
- Be mindful of audience- do they understand outcome/research?
- Audience? Translate differently for different audiences

### Strategies

- Brief series, i.e. intro, one per strategy
- Peer-reviewed publication
- Work with advisory board
- Other media such as magazines
- Radio, TV shows
- Various mediums
- Core staff, leverage university resources dedicated to this
- National non-disability hashtags- connect with bigger messengers

#3. Administrative and organizational tools that facilitate smooth operations – no notes

#4. Models for implementing Equity, Diversity, and Inclusion in your UCEDD – no notes

## #5. TA Tool: Increasing network visibility

### Discussion and examples:

- Westchester Institute for Human Development (WIHD) hired a public relations (PR) firm who puts press releases out in the paper so that every little accomplishment goes out. The local news media staff knows the PR firm. They don't send out announcements on publications, as that is not of much interest to the general public. The UCEDD staff have a different view of the types of things that are worth promoting, and don't do enough to promote themselves; PR firm take care of this for them. The PR firm also keeps an eye out for awards given by numerous community entities, and applies for those awards on behalf of WIHD staff – they have seen a notable increase in receiving awards. Cost is \$5k monthly retainer.
- Outcome from having PR firm:
  - Increased visibility, increased fundraising, increased access to Board members who have good connections to deep pockets for more fundraising. Note that WIHD is an independent non-profit entity so fundraising is a critical role for Executive Director.
  - Decreased likelihood of funding cuts from state or local entities who also fund UCEDD activities, due to community awareness and support
  - Build knowledge in the community about what the UCEDD does
  - Community agencies have greater awareness of UCEDD and reach out to partner on funded projects; UCEDD now often partners to provide evaluation of community projects

### Strategies:

- PR firm for \$5k/month is cheaper than hiring staff when considering salary + fringe costs
- Even if a PR firm isn't hired, consider hiring someone who can write well and knows how to get stories into newspapers and on TV and other media sources
- Another strategy for increasing visibility is to go to every meeting that might have anything to do with disabilities, to ensure disability is represented at the table. This is helpful in getting to know and meet lots of colleagues from many other organizations that have traditionally not been partners – including health coalitions, anti-poverty coalitions, many other good causes in the community
- UCEDD staff can sit on Boards of other community organizations – to raise visibility of UCEDD, and also raise visibility of disability considerations
- Join diversity coalitions to bring disability to the table
- Send articles to university communications office, which they send to news agencies.

### Next Steps:

- AUCD to improve marketing and communications of network members' and trainees' accomplishments with refreshed approach to communications starting in 2020.

## #6. Navigating the internal politics of your institution

### Group 1

- Grants office can't track every in-kind
- Change of any administration takes huge time
- Fiscal climate of university impacts UCEDD, partnerships
- No one-size-fits-all policy
- University is more bureaucratic
- No access to foundations unless you have your own endowments
- Physical location on/off campus influences a lot
- Site DD Regs in MOU to support your work
- Be clear about what is grant work
- Use programmatic language not administration language
- Get your own development officer to build endowment
- Go for government relations and other topics to build good will
- Be in key leadership roles in other parts of the university
- Create moves within 5 year applications
- UCEDD 101 to educate university leaders
- Guidance of impact audit; standard flexibility/project officer
- Need guide for moving within university divisions
- Share pros and cons list of different settings

### Group 2

- Need help understanding guidance
- Get grants via system
- Split of medical center and university cost needs- negotiated solutions
- University hiring takes too long
- Multiple centers focused on disability; UCEDDs may be seen as less than others
- Travel is taxable income
- Turnovers create major challenges
- We need each other, but UCEDD is different from other academic departments
- HR policy against inclusion
- Have your own fiscal liaison to deal with offices
- Keep tuition for courses in UCEDD for dollars
- Get % of indirect or grant to support (need MOU with dean)
- Create position/use magic word titles
- I/A/ request to deal with guidance challenges
- AUCD could collect examples of all templates for MOU to push change
- Director networking power
- Understand various roles of Associate Directors
- AUCD attend Land Grant and similar meetings to educate about UCEDD University Presidents

## #7: Creative approaches to funding: Building innovative projects that leverage UCEDD strengths

### Group 1

RI: Problem: Integrating service delivery outside of medical school

VA: How to engage with foundations?

PA: Working with Act funds

IL: Tried to hire a consultant to identify fundraising

KY: 50<sup>th</sup> Anniversary Gala: silent auction

- Need more examples of effective ongoing fundraising

NE: Works with Munroe-Meyer Institute fundraising director

AUCD can help open doors with managed care

WI: Waisman has "Friends of Weisman" group

MI: have connected with foundations because of limited resources

- Storytelling works
- Educating top administrators is tough

Temple: Through fundraising app, crowdsourcing raised 10k

List cultivation (potential donors)

- SD 2000 people
- NE 4k
- Develop themes

Identify community leaders with disability

Corporate donors- AUCD can help connect with those who support our events

### Group 2

Fundraiser: galas, open houses have been successful

IL: Foundation support, university politics prevented more

- Work with university advancement office. Can be tough to engage though. Personal connections are needed, people give money to those they know.
- MN: Aligning with med school
- OH: Annual Fund \$60k-90k
  - Employees can donate

TA Help needed on the subject- UCEDD Directors' meeting?

Speaker/consultant on creative fundraising?

## #8 Cultivating a network for new leaders from non-traditional backgrounds

- What do we mean by nontraditional leaders?
- Challenges the systems hiring those with needed lived or other experiences relevant to projects
- Difficulties within university systems
- Two populations: diversity in lower level positions (living wage)
- Cultivating new leaders- educational institutions
- Strategy: work with HR
  - Build up institution to be more inclusive
  - Build individual capacity to negotiate these unsupportive systems, help retain
  - Hiring disability/diversity fellows (pipeline)
- Building relationships with those within your institution who might be barriers to nontraditional hiring
- Getting data externally to support salaries, etc.

## #9: Engaging with culturally distinct and historically underrepresented communities

### Group 1

- What does this look like in systems-level work, like Think College? (ICI Boston)
- Are you engaging in research with national coordinating centers?
- Some centers don't have national-level activities, more are on local-level engagement
- Need more diverse representation on staff
- ICI: Critical issues in systems change and research
- On the local level: need to identify change agents within communities and partner with organizations that have credibility within that community
- Projects of National Significance examples show that you have a better chance of engaging when you have a more diverse staff
- What are the questions that we need to be asking?
- Within states with large Native American populations, you can't make inroads without taking the time to build relationships first. There has to be trust.
- What about large metropolitan areas? What are good strategies for reaching out to immigrant populations?
- They will look to the ethnic makeup to your staff, and if you have a diverse staff, you'll have an easier time reaching out
- In Iowa City- large Sudanese and Congolese communities, same approach, build relationships, establish trust

### Group 2

- 9% of South Dakota is Native American, lots of need and opportunities for intervention, especially around mental health
- One of the biggest issues is geographic size
- They've experienced a lot of experts talking at them about health disparities, rather than listening
- You need allies in the community
- Diversity Fellowship helped! Created contacts within tribal college

- Need to be present without an agenda
- Work with communities to build capacity and provide support
- Have clinics within communities
- “We want our own people trained-“ need to bring students from tribal colleges to be trained
- Create coursework for student and faculty

#### #10: Mentorship and collegial consultation: Finding peers and making connections

UT and TX: feel well connected and supported by colleagues inside and outside the network. Both willing to mentor others. Through collaborative work you get to know others’ strengths and build relationships that you can return to with future opportunities.

AUCD: seeking models to support new directors with building collegial networks

UT recommends a competitive application process to access a suite of resources (UCEDD directors are competitive), need to improve marketing of TA “opportunities”, be clear about funding that is attached. Some UCEDDs might think that there is a cost, but AUCD should be clear that these are funded opportunities.