

# 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:** How to do more policy work and how to pay for it

**Notetaker:** Luis Valdez (AUCD)

**Facilitator:** Alan Cobo-Lewis

### Participants:

David Deere, Tawara Goode, Paula Rabidou, Kara Ayers, Ronda Eppelsheimer, Lori Garnes, Tony Cahill, Linda Bimbo, Liz Perkins, Olivia Raynor, Susan Fox, Carol Salas Pagan, Liz Weintraub, Denise Rozell

### Background/Intro

- Interested in hearing what others are doing (different political contexts, unique state identifications). Would be interested in hearing about the pitfalls and successes
  - What does “success” in policy even mean? We are all doing things/forming partnerships, but how do you measure it? How are you defining “policy initiatives?”
- Policy vs lobbying – Understanding the differences to lay the groundwork for this conversation
- What level of policy are we looking at here? Are we looking towards the local/organizational level, or are we looking at a higher level (state/federal)?
- Pay attention to strategies that work in red state areas with an eye towards cooperation

### Discussion and examples:

- Some UCEDDs used to do policy briefs, which were funded under old grants
  - How else where they funded? And were they effective?
  - UCEDD has their LEND trainees and communications team coordinate on this front. These briefs would help the institution understand what is going on and what the center is doing
    - Can be referenced again; and help folks learn skills
    - Can also help self-advocates understand both good and bad policy

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- Some UCEDDs are collecting data on how people are using information that is being put out
- These policy briefs aren't effective on their own, need to follow up with a multi-modal approach. One center gets bills sent to them for review (questions raised by group about how this arrangement came to be). The UCEDD is one of several organization serving on a legislation council for input on most bills
  - A another UCEDD, they get bills sent to the university, not the UCEDD
- What are some ways to gain entrée? Our state legislators only meet once every two years, and we put together white papers in the interim. What are strategies to keep "calm" as well?
- DD coalition gets priorities. This serves as a roundabout way to testify at congress (help support through data, briefs)
- Directing people to IACC supports/treatments, as there is money associated with this
- Some states are political battlegrounds and receive a lot of visits from candidates. Coordinate with DD partners to meet with as many candidates as they can
- CAC put together a legislative platform and went to legislature to ask them to consider input on people with disabilities

## Strategies:

- Red state strategies:
  - UCEDDs bring data. Use data to make the case. Assign cost to this data (in a way that's informational)
  - Make friendships/partnerships when possible. Go on visits to legislators with other University officials, depending on relationship
- Presenting data in a way that's understandable. Compare this data to other states; highlighting the real impact (knowledge translation)
  - This has to be a year-long process, not just when the legislators are in session. Must lay the groundwork soon or might be too late later. Information that is not too obviously tied to asks helps with it getting better received
- Difference between public and private institutions with regard to how their university administration accepts these legislative visits to representatives
  - Must involve good relationships with legislative affairs office
  - Different contexts depending on where the UCEDD sits. For example, old UCEDD sat in medical campus and couldn't say anything about Medicaid. New campus say they cant ask for direct appropriations, but everything else is okay (would still need to check with them first)
- Work in partnership with DD rights; serving as a pseudo bad cop/good cop routine
- Lobbying through taking leave so as to not be affiliated with the UCEDD
- Develop working relationships with more moderate political representatives

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- Always use the data to support the success/benefits on one position. Data might not be favorable in some cases, but still must report. There is a rising mistrust in science/data that must be addressed
  - Can answer skeptical questions with: “Perfectly reasonable question, but [data].”
    - This has a built-in respect for the person asking the question

## Questions:

- What are people doing?
- How do we define and measure success?
- Policy vs lobbying?
- Tension between executives?

## Follow up for TA Team: