Council on Research and Evaluation (CORE) Quarterly Meeting  
September 08, 2021  
Notes

Attendees: 26 total attendees

Welcome, Introductions, etc.


New CORE Leadership Team
Rodney Samaco introduced as the new Chair of CORE
Vanessa Hiratsuka introduced as new Co-Chair of CORE
Katey Burke introduced as new Secretary of CORE

Discussion: UCEDD 5-year proposals and opportunities for collaboration

- Ronda:
  - highlighted ways in which UCEDDs have partnered across the network:
    - Special issue of DD Network Journal, PCORI application, advancing PAR activities with people with IDD, etc.
- Joni:
  - noted that PCORI added IDD to their 10-year funding priority.
  - indicated that we need to publish the results of our work because PCORI builds on what we know. They don’t invest in new ideas/research.
  - Joni talked about CORE writing an article that addresses the lack of trust that many indigenous communities have with research. They often have been harmed by research.
- John:
  - pointed out how AUCD is working to educate PCORI on the need for research in our field.
- George:
  - highlighted the Heartland Self-Advocacy Resource Network (HSRN) as an example of four UCEDDs and state self-advocacy organizations. Perhaps this can be extended to research.
- Rodney:
  - asked what the incentive is for collaboration among the UCEDDS. How are they held accountable?
  - George and John described data collection through NIRS.
- Randall:
  - talked about the ways in which he, as a new Director, is working to develop partnerships both with other UCEDDs but state-wide partners.
- Karen, Danielle, and Curtis (Alaska) gave examples of their collaborations:
• Their approach is to participate in groups like CORE and being really open to collaboration and reaching out to other UCEDDS. For example, a mental health program, and employment work.

• Karen (Alaska) and Tony (New Mexico):
  o talked about the logistics of working with Native American groups and making sure that research is approved by the local IRB groups.

• Kelly (Arizona):
  o would like to look at a collaboration on Quality of Life for people with IDD.

• Tim Riesen:
  o would like to see employment as an area for collaboration given the poor employment outcomes nationwide.

• Ronda summarized the conversation and the areas for collaboration, then everyone went into breakout rooms. Ronda also shared a Google doc to share ideas for CORE ideas re: collaboration.
  o https://docs.google.com/document/d/1pkKydC0p2lzLO18HdmX6sXZ- _DVa8TanxNKr7e_j7w8/edit?usp=sharing

• BREAKOUT SESSIONS were held for deeper dive into discussions

Post-breakout:

  o Randall talked about the fact that the Nevada UCEDD doesn’t have a whole lot of researchers so collaborating with other UCEDDs is the best way to move into research and evaluation.

  o Hamida asked if there was a way to get a list of research areas for CORE members. Ronda suggested tapping into the NIRS data to find this out.

  o George mentioned supporting people with IDD to conduct research themselves through CORE funds or some other mechanism.

  o Tim talked about “COVID money” and how we could use that to address employment barriers. People with IDD have been hit hard by the pandemic and have lost their jobs.

  o Sheida Raley suggested off-line that one suggestion for cross-UCEDD collab can be to propose/integrate participation in CORE as a work plan goal which would get people to contribute and be involved b/c they are committing to it.

AUCD Central Office announcements

  o John talked about the AUCD Conference, highlighting several of the keynote speakers. Registration is open. Concurrent sessions will be live. Poster sessions will be recorded.

  o Jamie gave a URC update. EDI meeting will be archived on the AUCD website soon. AUCD and URC are producing a podcast on EDI across the network.

  o Rodney indicated that during the IDDR Directors meeting he invited more participation in CORE from. Several IDDR directors expressed interest in participation in the group.