

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

Attendees: 26 total attendees

Welcome, Introductions, etc.

Attendees: Ronda Jenson, Katey Burke, George Gotto, Tim Riesen, Tony Cahill, Randall Owen, John Tschida, Rodney Samaco, Ethan Dahl, Vanessa Hiratsuka, Curtis Smith, Eric Moody, Danielle Reed, Sheida Raley, Anne Harris, Joni Beasley, Jamie Koenig, Suzannah Iadarola, Philip ?, Conner Black, Karen Ward, Eva Weiss, Kelly Roberts, Jen De La Rosa, Katharine Hayward, Hamida

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):
 - talked about the logistics of working with Native American groups and making sure that research is approved by the local IRB groups.
- Kelly (Arizona):
 - would like to look at a collaboration on Quality of Life for people with IDD.
- Tim Riesen:
 - 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.
 - https://docs.google.com/document/d/1pkKydC0p2lzLO18HdmX6sXZ-DVa8TanxNkr7e_j7w8/edit?usp=sharing
- BREAKOUT SESSIONS were held for deeper dive into discussions

Post-breakout:

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

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