

**Council on Research and Evaluation (CORE) Meeting**  
Quarterly Meeting  
Thursday March 11 from 2:00-3:30pm ET

**AGENDA**

2:00 Introductions and review agenda

Ronda opened the meeting at 1:06. Shared the Agenda and provided opening comments about the agenda items.

2:10 Announcements

Introducing new Council Trainee Representative for CORE:

- Conner Black, the new CORE Trainee Representative, was introduced to the group by Kaitlyn Ahlers, the current CORE trainee.
- Connor is from University of South Carolina and is working on his Ph.D. in Psychology.

Developmental Disabilities Network Journal (DDNJ)

- CORE sponsored issue on impact of COVID- coming out in March 2021
- It will have 14 articles, 20 submitted
- Some will have the opportunity to be included in later issues

2021 AUCD Conference:

- The theme is “Learning Together: Connecting Research and Lived Experience.”
- To address involving people with disabilities in research and focusing on lived experience.
- Not sure yet whether it will be in person or virtual.
- John Tschida explained that Danny Armstrong from the Mailman Center in FL is the Chair of the conference this year.
- There will be a real emphasis on the inclusion of people with disabilities and family members.
- There will also be an emphasis on participatory research methodologies and equity overall.
- Tawara Goode pointed out that the link between the 2020 conference and the 2021 conference is equity. Including people from diverse backgrounds including disability, racial, and socio economic.
- Joni Beasley pointed out that people with disabilities and non-white people have often received maltreatment from researchers.

2:15 Discussion: 2021 AUCD Conference Theme: Learning Together: Connecting Research and Lived Experience

- Background on the theme
- Discussion
  - In what ways does your current research incorporate lived experience?
  - In what ways does your research/evaluation incorporate intersectionality?
  - What ideas do we have for collaborating with other councils around this topic?
  - What ideas do we have for speakers and programmatic content?

Discussion points:

- Call for papers need to acknowledge and address past harms
- PCORI research panel was very traditional researchers, didn't represent lived experience, AUCD could play a bigger role in promoting these changes
- OH-Nisonger- COVID-19 survey seeks input from people with intellectual disabilities about their lived experiences during the pandemic. Advocating for people to be prioritized in vaccine distribution
- AUCD- link about vaccines: <https://disabilityhealth.jhu.edu/vaccine/>
- Set of panels with people with lived experience at the conference:
  - people with lived experience doing data collection. Might be good to invite those researchers/data collectors to share their perspectives
  - Conversations about project management or planning in your research project: how are you planning and preparing for more participatory approaches? Ethical considerations included?
- "Lived experience" as though there is just one element of that, you need to consider all elements and experiences at the intersection of different identities; using engagement strategies that consider intersectionality through the entirety of the research process
- Suggestion for examples of successes from the different disciplines that are represented in the AUCD network. People could then take these lessons to their own UCEDD.
- Consider power structures and their impact on research field
  - What gets studied, who participates, what grants we go after, who writes articles, who presents research
  - This would be a big culture change for AUCD to engage with people from a variety of lived experiences in a way that shares power
- John Tschida: Biden administration is placing an emphasis on equity. We can expect to see this emphasis in upcoming grant announcements. Also, funders are starting to require equity and the demonstrated inclusion of people with disabilities in our work.
- Researchers avoid research that would involve engaging non-English speakers; need to address this bias
- Meaningfully engaging people with lived experience in setting the research agenda
  - Now becoming a part of many grant-funders
- Presenters at the conference discuss the journey they've been on to accomplish what meaningful engagement looks like; not enough to just write it in a proposal

#### 2:45 Discussion: Intersection of research with "equity, diversity, and inclusion"

*[Thank you to Tawara Goode and Janice Enriquez for joining our discussion.]*

- Update regarding the AUCD network TA on equity, diversity, and inclusion
- Update on the AUCD Board's work- defining equity for our network
- Discussion
  - What does equity, diversity, and inclusion mean in research and evaluation?
  - In what ways does your research/evaluation specifically address equity, diversity, and inclusion?
  - What ideas do we have for collaborating with other councils (i.e. Multicultural Council) and other network members (i.e. IDDRCs) around this topic?

Discussion points:

- Having CORE people, especially those focused on participatory research, in UCEDDs work around equity, diversity, and inclusion
- MCC open to ideas that CORE would find helpful to supporting CORE in understanding lived experience, especially of people at the intersection
- CA-Davis discussed development of cultural brokers who help their UCEDD reach out to communities in ways that are meaningful to them.
- Scientific circles will discuss the ED&I is important but rarely discuss the power dynamics and move towards action- a great focus for the conference
- Context within universities affects the ability and interest of researchers and evaluators in promoting equity—limitations by bureaucracy within university context
- Extra burden placed on staff and researchers who are tokenized for their identities
- Gatekeeping around resources and deciding when groups are engaged or not
- Need to discuss trust and research; past harms and abuses from research community to people with lived experiences
- Alexis from CA-CHLA: worked with black churches in a CBPR project and feels that it is a model that we should include in our work
- AUCD network consider how equity is being embedded into training around research
- Use behavior-change theories to promote change across the network to how we do research
- Navajo Nation IRB- includes questions similar to discussion questions from this meeting
  - How will the results of this research benefit the Navajo nation?
  - Periodic reports to the IRB and final report before disseminating any findings
  - PI sits physically before the IRB to present their research, which is very different than other IRB processes
- Is our research being shared in plain language
- Future CORE conversation about how we will measure our success as a network on these important issues is worth having

### 3:25 Closing information

The NIDILRR webinar with Phil Beaty is available online. Summer CORE elections are coming soon. PCORI workshop on methodological challenges is on March 15, 2021. Listed Upcoming CORE meetings.

- NIDILRR materials: <https://www.aucd.org/resources/webinars.cfm>
- PCORI event: <https://www.pcori.org/events/2021/pcori-workshop-methodologic-challenges-intellectual-and-developmental-disabilities-research>