Council on Research and Evaluation (CORE) Meeting
August 27, 2019
2pm

Minutes

1. Welcome and introductions
   a. Ronda Jenson (Arizona), Rodney Samaco (Texas), Karen Ward (Alaska), Ethan Dahl (Wyoming), Karen Heath (Alaska), Tony Cahill (New Mexico), Roxy Lamar (Alaska), Julie Atkinson (Alaska), Leann DeWalt (Wisconsin), Kimmie Tang (California), Sheida Raley (Kansas), Luis Valdez (AUCD)
2. Updates
   a. AUCD Central Office Update (Luis Valdez)
      i. Accessible and Inclusive Research Dissemination Initiative (Luis Valdez)
         1. AUCD is currently seeking expertise around designing infographics to promote the research from our network (as in from LENDs, UCEDDs, and IDDRCs) in an accessible and inclusive format. For additional information, please be sure to reach out to Luis Valdez (lvaldez@aucd.org).
            a. Potential tie-in to the resources developed by CORE's Data Visualization workgroup. Luis to connect with Julie A. to discuss connection points to the expertise of this group.
      ii. AUCD Conference Leading Change session – Tentatively titled: *Disability Rights, Ethics and Genetics: Generating Conversation for Policy and Practice*
         1. Ongoing collaboration among different entities in the AUCD network. This emerged from a concurrent session during the 2018 AUCD conference and will center on understanding the advancements in the field of genetics, beginning the conversation regarding the intersection of the disability rights movement and basic science and identifying the areas in which our network can be at the forefront of this issue. If you have additional questions or expertise in this area, please contact Luis Valdez (lvaldez@aucd.org) and he will connect you to the AUCD staff members leading this session's planning.
   b. Inclusive research and evaluation
      i. Alaska UCEDD update on IRB lessons learned (Karen Heath)
         1. Karen Health presented to IRB to begin conversation around incorporating individuals with disabilities as full research partners.
         2. Wanted feedback on what is necessary to move forward. Feedback received:
            a. The IRB would like to see careful descriptions of planned HSR training protocols for the IDD interviewers.
            b. The IRB would like to see some description of the cognitive capacities, perhaps expressed in approximate age of development, for the IDD interviewers.

<ol type="c" start="3">

       c. The IRB would like to see the issues of general confidentiality and mandatory reporting addressed in regards to allocation of responsibility within the research pair.

       d. The IRB is still interested in seeing resources for alternative training tools.

3. Plain language description of "what is an intellectual and developmental disability" would be helpful.
Interest in building a repository of information of how we can train PWD that is mindful of research ethics (show we have tools available).

4. Interest in forming a team to analyze how we address this as a network. Leann indicated there are folks in Wisconsin who are willing to participate. Kimmie Tang is also interested (email provided directly to Karen Heath).

5. Potential subcommittee meeting before Conference in November or block of time in Council meeting?

  c. CORE Governance: Roles and terms (Ronda Jenson)

    i. AUCD's Council on Leadership in Advocacy (COLA) is piloting a staggered election process. We are currently waiting to hear back from them on lessons learned.

  d. CORE Research Trainee Award (Luis Valdez, Ronda Jenson)

    i. We received three nominations for this award, to be given during the AUCD Conference. This award is intended to recognize the efforts of emerging researchers and is given to anyone who is a current AUCD network trainee or who completed training within the last 2 years of the award year. The Conference Awards Committee will begin review.

  e. Archived CORE minutes now available:
https://www.aucd.org/template/page.cfm?id=485

3. Discussion

  a. Survey of member feedback on proposed SMART Goal (Rodney Samaco)

    i. Will be sent again, with targeted messaging indicating a deadline for completion. Potential for incorporation into social media (amplification of the voting to twitter poll, etc.)

  b. Emerging Leaders involvement in CORE (Sheida Raley & Rodney Samaco)

    i. Cross council collaborations: Discussion among council leadership is still ongoing. Trying to get another meeting scheduled to set some deadlines. This integration of network emerging leaders into council activities is being envisioned as a funded opportunity. The cross-council group is also working to delineate the responsibility for prospective mentors from each council.

      1. **Action item**: Start thinking about trainees in your center who might be interested. Duties of what trainee does might vary. Areas of personal interest and how it coincides with what council is doing (mutual relationship) will be considered. Reach out to Sheida Raley (raley@ku.edu) for more information.

c. Agenda for CORE meeting held at the AUCD Conference (Ronda Jenson)
   i. Love to hear results of survey. Active poll?
   ii. Genetics discussion? – might be worth tying into the broader conversation to occur during the Leading Change session.
   iii. Table time to brainstorm what these activities can be to meet goals.
   iv. IRB workgroup
   v. Discussion and new learning; collaborations/partnerships – get to know who's in the room.
   vi. **Volunteers to plan agenda needed**: To include in survey?

Upcoming CORE meetings
Sunday November 17, 2019 (AUCD Conference)
9:00-11:30 am