

Council on Research and Evaluation (CORE) Meeting

March 5, 2020

2pm Eastern Time

All meetings will convene using Zoom.

Notes

1. Welcome and introductions
 - a. Introductions: Ronda Jenson, Luis Valdez, Alexis Davenport, Tony Cahill, Tyler Johnson, Rodney Samaco, Sheida Raley, Curtis Smith, Karen Heath, Katie Ahlers, Amy Sharp, Rene Jamison, Suzannah Iadarola, Karen Ward, George Gotto
2. CORE Trainee Introduction and Update (Rodney Samaco)
 - a. Rodney introduced the Katie Ahlers from the University of Washington. She is the new CORE trainee. Focuses her work on co-occurring conditions. Clinical psychology is Katie's area of study, and she is a current post-doctoral fellow. Interests include: Co-morbidities, dissemination and implementation science.
 - b. As the core trainee, Katie will work with the Community Education and Dissemination Council (CEDC) to come up with a lexicon that is accessible to families around genetic therapies. This will help address AUCD's efforts to create synergistic efforts between AUCD councils. She will also assist with the Texas AUCD consortium efforts and efforts around bridging the science and research world to the families in the community.
3. Review of CORE SMART Goals
 - a. Cross-communication and Cross-collaboration are two of the smart goals. George described the work of the Missouri IDDRC around best practices related to various dual diagnoses. This is a project that includes the UCEDD but multiple other state agencies.
4. Sharing and discussion: Collaboration between UCEDD, IDDRC, and others (UT-Austin Example: Rodney Samaco) [SMART Goals 3 &4].
 - a. Rodney describe the Texas AUCD consortium which includes the two UCEDDS, the Lone Star LEND, and the Texas IDDRC. He shared the agenda from their February 24 meeting. The Texas IDDRC is including this partnership in their upcoming application. It helps them fulfill the requirement to develop community engagement and communication throughout the state.
 - b. As an example of a collaborative effort between the three partner organizations, Amy Sharp from Texas described the "Tours around Texas" effort in which they travel around the state with a clinically trained geneticist.
 - c. Rodney envisions that the four organizations will have quarterly meetings and continue to look for ways to partner.
5. Discussion: Topics and format for upcoming CORE meetings
 - a. Review of November CORE meeting and topical discussion (George Gotto)
 - i. George and Luis will be in connect during the week of March 9 and will pull together the notes from each of the topic areas. Amy says there is a general perception that CORE is a group of statistical experts who are

unapproachable. We need to make sure that we invite all people to the meetings. Maybe look for cross-collaborations. Alexis discussed her experience on other workgroups and the way in which they organize their meetings. Rodney says that time is a non-renewable resource and we need to figure out how we make sure our efforts are worth the time spent. Does our work help people get funding or increase the impact of their work? He proposed that CORE or CORE workgroups meet on a monthly basis. They can bring their information to the quarterly meetings. Sheida and Amy liked this idea. Ronda suggested scheduling the next meeting for April.

- b. Ronda reviewed the results from a SWAT analysis with the Chairs and Co-chairs from the AUCD Council.
- c. Discuss opportunities and ideas for activities aligning to SMART goals.
 - i. Collaborations/topics that can be highlighted in upcoming calls: John Constantino, UCEDDs working on using NCI data, UCEDD/LEND collaborations with IDDRRC, knowledge translation, collaborations on projects/papers.
- d. Identify next steps (All): 1) George will send out the notes from this meeting. 2) George and Luis will pull together the workgroup notes from the November meeting; 3) develop the agenda for the next quarterly call; 4) figure out off line or through the listserve whether people are interested in participating in a sharing event, perhaps related to partnerships between UCEDDs, IDDRRCs, and LENDs.

6. Update: Accessible and Inclusive Research and Dissemination Network (Luis Valdez)

- a. Talked about AUCD's plan to develop infographics highlighting network research. AUCD has developed a tentative plan around the collection and aggregation of research articles on a quarterly basis, which in turn would be presented to CORE on quarterly meetings. Would like CORE assistance to decide what to include in the research infographics and which of the research options presented during the quarterly meetings to select as an infographic. Please reach out to lvaldez@aucd.org if you'd be interested in assisting with the development of criteria for which research articles should be presented to CORE, or any questions around this effort.

7. Summarize

- a. CORE would need to delineate council benefit to the network and council members. This will improve engagement.

2020 AUCD Council on Research and Evaluation (CORE) Schedule

Q2: Thursday June 4, 2020, 2pm EST

Q3: Thursday September 10, 2020 2pm EST

Q4: December (AUCD Conference)

CORE SMART Goals (2019-2020)

- 1. Pilot the project with one trainee identified at the 2019 AUCD Annual Conference for a one-year term.
- 2. Hold Webinars/Webinar series as the first step to provide information and opportunities for collaboration with other Centers and Programs
- 3. Ensure the smooth communication across interested individuals/groups that are currently working towards increasing the dialogue and shaping perspectives/narratives with respect to the

disability communities and advances in medical interventions and scientific findings by providing a means to coordinate bandwidth and potential deliverables.

4. Collaborative opportunities will primarily serve to develop the research and evaluation capacity of the AUCD network.
5. Collect information annually to inform and guide the CORE focus areas each year forward following 2019.