

CORE Meeting, 2018 AUCD

1. Introductions: Ronda Welcome. Introduction of Rodney & George. Driving Change meeting influenced the agenda. Ronda recommends using more zoom links for our meetings. What areas of relevance would you like to talk about in CORE.
2. Updates on workgroups. Sally was in charge of the writing group/book. She is not present. Parthi says that not much has been done in the past year even though

- Popout idea. WRITING GROUP

Sent surveys out about the IRB process. Analyzing the results currently. AUCD is wanting to collect much of the same information that CORE wanted to collect. We are going to try to coordinate with AUCED on the IRB efforts. Maybe this is something we can offer to AUCD. Data visualization workgroup met 6 times. Ronda will share presentations from some of the work. Rob Carr from Oklahoma is serving as a coach for the workgroup. This role does work around accessibility as it relates to tools for sharing information. How does someone with a screen reader access information? Low text and data literacy issues. They always tried to come back to the actual content. Developed checklist for self evaluation of materials. Ronda walked through a PowerPoint that she will share with the CORE.

- Popout: Data Visualization & accessibility
- Popout: How can we share ideas that come out of CORE?

Rodney asked how we came up with the three areas. Kimberly Mills described the process. Dalun worked with the Board and we got information from CORE. Ultimately came down to energy, having a champion, and board priorities. The three we have. Kelly Roberts will check the notes. We have worked on a grant around home and community based services.

Thoughts about how to make CORE activities happen:

- We need Champions, someone who is willing to lead. If there isn't a champion things don't get done. We have many initiatives in the past that were started but it seems that when people get back to their offices it is hard to stay committed.

Members asked, "what is the purpose of CORE?"

- Parthi thinks that it gives an opportunity to bring the lessons from the UCEDDS to bear on AUCD priorities.
- It is also a way to network and share information.

- In the past we did a survey of areas of expertise and willingness to collaborate with other UCEDDs.
- In the past CORE sponsored webinars that shared information about the work of CORE members and that addressed the needs/interests of the network. Mark Innocenti indicated that in the past we did the webinars but not many people joined but ultimately it seemed that they weren't having the impact that CORE hoped they would have.

Bruce Keisling, the president of AUCD Board:

- Charged CORE with finding ways to keep the momentum going after the conference. Priorities are wide open and the board looks to CORE to understand the barriers and challenges to doing good research. There are no directives from the board it is more about out we want to focus on.
- John Tshichda says we should look at the staff, Jon and Luis, to help with information collection and partnerships with them. Pointed out that Collaboration needs to be intentional or it doesn't happen. Reiterated that he and Luis are here to make collaboration happen.
- Luis mentioned that they are developing a new planning council about how AUCD can help disseminate the work and information.

Notes from Popout groups:

Data Visualization & Accessibility:

1. offer an large picture overview of data visualization for directors and UCEDD leadership
2. offer more specific training for those in UCEDDs who would do the work - set out a training plan that would teach people how to do the work.

How can we share ideas that come out of CORE?

1. There is a need to strengthen the process for getting research presentations at the AUCD meeting. We heard one problem is getting reviewers who are in CORE.
2. Webinars: The table thought CORE should do webinars but that these should be short (15 to 20 minutes) and focus on research being conducted in the network. This would provide a great opportunity for presentations from the IDDRC and trainees could present research in which they are engaged. The presentation we had at the meeting on accessibility issues is a great example. If we did short webinars, we could potentially do at least 6/year.
3. Conducting inclusive research: We think there is a need for a guidance paper on best-practice activities for inclusive research. We thought that this paper needs to go in one of the AIDD journals for broad exposure. We discussed using the model similar to what CEC has done with evidence-based research. AUCD would need to reach out to AIDD to set the ground work. CORE could pull together a writing group that would work on this. Guaranteed publication in a prominent disability journal would help motivate the writing team.

Inclusive Research Templates and Standards:

As a group we concluded that we need to have two goals:

- 1) Collection of inclusive research templates
- 2) Develop standards for conducting inclusive research (e.g., phases, timeline, budget)

For the first step, we need to gather existing inclusive research projects and standards (for inclusive research or other related research).

Perhaps, implementing a short online survey via UCEDD network provides base knowledge on key projects and individuals.

Trainees can assist organizing and categorizing types of inclusive research and key components to develop the inclusive research standard document.

Ways of sharing CORE Resources (AUCD web site, other?):

--List of CORE Members on the AUCD web site

--THIS IS CRITICAL FOR MENTORING TRAINEES and JUNIOR FACULTY!

--this might be a place where trainees could select mentors (WE THINK THAT CORE SHOULD CREATE A FORMAL RESEARCH MENTORING PROGRAM FOR TRAINEES, AUCD LEADERSHIP SHOULD MENTOR IN AUCD CULTURE)

--Webinars are important for relationship building

--find resources for the site that are valuable to researchers (e.g. what kinds of pressures are they under and how might the resources address those pressures)