# Association of University Centers on Disabilities

## Council on Research and Evaluation (CORE)

## **Meeting Minutes**

## March 2, 2018

#### I. Introductions

a. Began with introductions. Approximately eight people on the call.

## II. Reports and Updates of Work Teams

- IRB workgroup (Karen Ward, lead). This group is working on the inclusion of people with IDD in research and issues related to working with university IRBs. Karen reported on the workgroup activities. The workgroups developed a survey completed by UCEDDs and is reaching out to UCEDD members who want to work on IRB issues for those with IDD. The objectives for the workgroup include: developing a position statement that can be sent to the AUCD Board for approval, developing recommended guidelines, identify best practices that can be shared, find samples of informed consent letters that have been acceptable to IRBs, developing on-line resources, and identifying positive examples from UCEDDs about including IDD folks in research.
- Data Visualization (Ronda Jensen, lead): This workgroup is focused on accessible methods of data visualization for people with disabilities. There are currently seven people on workgroup. Goals include specifically defining data visualization and the development of criteria that people can use regarding data visualization. They have a Dropbox folder and have requested that interested people submit information. John Tschida offered to publicize workgroup activities and try to enlist interested members.
- Book project on Inclusive and Participatory Research (Sally Gould-Taylor, lead). This group is moving forward. A list of interested CORE members was developed at the AUCD Annual Meeting and Sally requested the list be sent to her. They have contacted known people with an interest and want to expand the group.

## III. 2018 Conference Driving Change Session Topic Planning

- Conference Theme *We all belong here! Achieving inclusive communities.*
- Conference dates: November 10 to 13, 2018; Driving Change session is on November 10.

- The issue of a possible collaboration with IDDRCs and others around the topic of health care was discussed. The group decided that this was not a current strength of CORE.
- Ideas for the session were discussed. The group decided to use the current CORE focus on inclusion of people with IDD and other disabilities in research as the presentation topic. Sally agreed to be the moderator for the session. Karen and Ronda agreed to be presenters. Sally will develop some questions/issues for the session. This will be sent out to all CORE members to identify other potential participants. There will be an emphasis on including people with disabilities who have been involved in research or as researchers on the panel. We also want to have both qualitative and quantitative results represented at the session. The current goal is to have the session "walk through" the steps of developing a research idea to moving it to implementation. The speakers will weave their information into this.
- IV. CORE Leadership Team Election: Chair, vice-chair, and secretary positions available. Dan would like to have a slate of candidates by end of summer. The goal would be to have the new leadership in place for the 2018 AUCD Meeting. Dan will send an email seeking people willing to self-nomination.
- V. Trainee Research Award: It is time to begin the process of identifying trainee researchers for this year's award. In the past, the CORE executive committee has selected the award winner. We would like to move to establish a committee who could take on this role. In Dan's solicitation for leadership, we will seek those interested in being on this committee. If there are none interested, the CORE executive group will assume the responsibility.

#### VI. Others Matters

a. Future conference call meeting dates: June 8, 2018 at 2:00 PM EST. September 7, 2018 at 2:00 PM EST.

VII. Adjourn – 2:45 EST