

AUCD Council on Research and Evaluation (CORE) Meeting  
Q4.2021 CORE meeting to be held during the Annual AUCD Conference  
(2<sup>nd</sup> virtual conference)

Wednesday, November 17, 2021 from 1:30-3:00PM ET

- 1:30 Introductions of new CORE leadership and virtual attendees
- Thank you to previous CORE leadership!
  - Introduction of new leadership
    - Chair – Rodney Samaco
    - Vice Chair – Vanessa Hiratsuka
    - Secretary – Katey Burke
    - Council Trainee Rep – Conner Black
    - UCEDD TA Team – Sarah DeMaio
  - Review of AUCD 2021 registrants by organization type
    - 647 UCEDD/LEND
    - 163 UCEDD
    - 100 LEND
    - 14 IDDRRC
    - 135 Other
    - 33 Federal
    - XX AUCD
  - Thank you to past-president and board members for leadership!
- 1:45 Comments from the AUCD Board President and Executive Director
- John Tschida and Danny Armstrong
    - Critical role of research in moving forward equity
    - Importance of people with lived experience being involved at every stage of research
    - Question on integrating work across UCEDDs, LENDs, and IDDRCs and how CORE could contribute to that
      - CORE can...
        - Help bring understanding of value and importance each member organization brings to table with research and evaluation
        - Share curricula and opportunities for cross-training
        - Share research and evaluation with applications to work across various disciplines
        - *(noted)* Importance of plain language for translating research across disciplines and to/with communities
- 2:00 CORE Trainee Representative Program with Q&A
- Kaitlyn Ahlers (2020)
  - Conner Black (2021)
  - Review of application and selection process
    - Applications for next cohort will be launched in March 2022
- 2:15 Where we were, where we are, where we're going... reflections on past,

present, and future opportunities for CORE (open discussion)

- Where we were/are:
  - Institutional knowledge of CORE
    - There may have been a lack of understanding for some of what IDDRCs do.
      - Benefit of organizations understanding what each does
    - A lot of change in CORE over time
      - Emphasis on research function of UCEDDs to elevate that
      - Not a lot happening between meetings
        - How do we address that?
      - Varies based on leadership
      - Success in year-long network-wide focus on topics e.g. 1. presenting research results in an accessible manner and 2. Including people with disabilities in all aspects of research
      - Increasing collaboration across UCEDDs, LENDs, and IDDRCs
        - CORE could take the lead with doing more of that – e.g., through leadership with plain language dissemination
    - Networking, especially for smaller centers (continued interest)
    - AAIDD research agenda and goals videos from 2015 shared
      - <https://www.aaidd.org/publications/bookstore-home/new-this-year/critical-issues-in-intellectual-and-developmental-disabilities-contemporary-research-practice-and-policy>
      - <https://www.aaidd.org/news-policy/policy/national-goals-2015>
- Where we're going (see above, as well)
  - Interest in promoting involvement in research (at every stage) of people with lived experience (and families) – CORE leading that charge.
    - Ties to plain language efforts.
    - Barriers for self-advocates noted (and the need to address them).
    - Barriers for families noted (time, experience, etc.; and the need to address them – e.g., partner with state family information centers).
    - Added note: support families to empower their children to be self-advocates
  - Strategies for helping people (e.g., families) in the now (practice), alongside the research that's happening
  - Center strategies for using research to inform and drive policy
  - Share strategies for using research to improve service system
  - Share strategies for community engagement around research for

mutual benefit

- One specific interest from Anne Harris: “I’m one of the investigators on the “LEND Outcomes Study” and we are looking at the NIRS trainee outcome survey and what we are learning. Our group would be interested in working with any other groups who might want to consider revising the questions - just wanted to put this out there for the record!”
- Exploring interaction with SIGs, how to keep people involved with CORE
  - Maybe report sharing from SIGs – how we could go about developing, sharing, interfacing
- Support for adults with disabilities, not just children
- Training evaluation- need to make trainee follow up survey accessible for self advocates and trainees
- Specific interest from Valerie Wood: “As a social psychologist working in the area of system improvement, advocacy, and policy change, I would love to have an opportunity to connect in small group with those in other states that are engaged in similar work. Even just to know what issues other states are prioritizing.”
  - Bring people together with common applied and research interests
- “Focus on how to promote collaboration between centers around common research interests or to leverage resources or strengths. I think an important question for our group is to think about “what is the potential benefit of connecting with one another and as part of the AUCD Network that we do not get with our own centers, “programs”, etc. what’s the national network connection unique contribution and how to leverage it!”

2:50 Debrief and closing information

- Encourage trainees to apply for rep. position! Self-nominations are welcome.

Attendees

1. Alexis Deavenport-Saman - Assistant Director, USC UCEDD; CA-LEND Audiology Director; Public Health Research Scientist
2. Andrea Dole - NH-ME LEND, trainee, family and social work disciplines
3. Angela Harnden
4. Angelica Martinez
5. Anne Harris - WI LEND Director and UCEDD Research and Evaluation Coordinator, Waisman Center UCEDD, UWisconsin-Madison
6. Anthony Cahill – NM UCEDD
7. Bonnie McBride - LEND Family Trainee
8. Brandon Lewis - LEND trainee, Indiana, Public Health Epidemiology
9. Brian Klein - psychology fellow, Indiana LEND program
10. Cara Tilou - UVM LEND, trainee, student physical therapist
11. Casey Sowers - Data Analyst and Doctoral Student, University of Miami Mailman Center

for Child Development.

12. Chithra Adams - KY UCEDD and LEND, Evaluator
13. Curtis Smith - University of Alaska Anchorage, Center for Human Development (UCEDD), Co-Director of Research and Evaluation
14. Daniel Armstrong – Mailman Center, AUCD incoming board president
15. Danielle Reed - University of Alaska Anchorage, Center for Human Development, Director of Community Services
16. David Johnson
17. Diana Ajche
18. Ethan Dahl
19. George Gotto - Director, Missouri UCEDD
20. Heidi Fredine
21. Jacob Mason - KY UCEDD and LEND, Data Support Specialist.
22. Jen Taylor Eaton - Trainee at the Institute on Disabilities at Temple University
23. Jerusha Olthoff
24. John Tschida - AUCD
25. Jonathan Drummond – KY
26. Judy Hartmann
27. Karen Bonuck - Co-Director Rose F Kennedy UCEDD at Einstein/Montefiore n NYC- Professor at Einstein
28. Karen Heath - Alaska UCEDD Co-Director
29. Karen Ward - University of Alaska Anchorage, UCEDD and LEND
30. Kate Thompson - Program Coordinator at ACT LEND at UT-Austin
31. Kiki Oyetunji
32. Katey Burke - Institute on Disabilities (UCEDD), Senior Research Associate
33. Kiley McLean - Social Work Phd Candidate WI UCEDD Waisman Center, Former 2 year LEND trainee
34. Kristen Columbus
35. Kwot Gilo
36. Lindsey Spoon
37. Lori Garnes - North Dakota Center for Persons with Disabilities, UCEDD Director
38. Macdonald Metzger – MN UCEDD
39. Mark Shriver - Director, Nebraska UCEDD at the Munroe-Meyer Institute/University of Nebraska Medical Center
40. Paul Ganucheau - LSUHSC LEND, Trainee, Self-Advocate
41. Rachel Severs - Developmental Medicine, psychology fellow, Indiana LEND trainee
42. Rene Jamison - Kansas-LEND Director
43. Rhonda Eppelsheimer - UCEDD Co-Director, Oregon Health & Science University
44. Rodney Samaco – BCM IDDRC
45. Sara Bovat - AUCD
46. Sarah DeMaio - AUCD
47. Sarah O’Kelley - LEND and UCEDD Director in Alabama at The University of Alabama at Birmingham (UAB)
48. Shreya Paul - Institute on Disability at the University of New Hampshire, Project Director
49. Solomon Lissanu - AUCD

50. Tamara Garfield - doctoral student and research fellow at AJ Drexel Autism Institute
51. Tracy Wood
52. Valerie Wood - Center on Disability and Community Inclusion, Vermont's UCEDD,  
Research and Evaluation Core Function Coordinator
53. Wendy Parent-Johnson
54. Vanessa Hiratsuka
55. Zoey Winkler