

Notes CORE Meeting Q2

June 8, 2021

Welcome, Introductions:

Rodney Samaco (TX), Vanessa Hiratsuka (AK), Curtis Smith (AK), Jamie Koenig (AUCD), Sarah DeMaio (AUCD), Katie Johnson (AUCD), Katey Burke (PA), Tony Cahill (NM), Connor Black (SC), Emily Hickey (WY), Ethan Dahl (WY), John Tschida (AUCD), Karen Heath (AK), Patti Bahr (IA), Party Dinora (VA), Tim Riesen (UT), Ilia Torres-Avillán (PR), Tawara Goode (DC), Joni Beasley (NH), George Gotto (MO).

Core Membership General Updates and Announcements:

- AUCD Conference. Rodney gave an update on the conference and asked if anyone would like to recommend a presentation. Time sensitive, proposals due June 11. John Tschida noted that sessions will be live this year and presenters will be able to respond to questions. No need to pre-record. Karen Heath has a team in Alaska that is submitting about using ECHO to join Disability abuse response teams. George is presenting with Maryland. Parthy submitted on a machine learning project related to employment and using Facebook live as a way to communicate research results to people with DD and their families.

CORE elections:

- Go to the landing page of AUCD's councils to learn more about the group. Elections will happen in September/October. Three positions 1) Chair, 2) Vice-Chair, and 3) Secretary. Also Council Trainee Rep. Rodney and George described their experiences on the board. Connor talked about his role as the CORE Trainee Rep. Meets with other trainee reps. Send the nominations to Ronda Jenson or Sarah DeMaio (sdemaio@aucd.org). Three year term. Self-nominations are welcome. Deadline for nominations is July 27, 2021

Equity, Diversity, Inclusion.

- Vanessa led this conversation. Directed members to the notes from the last meeting, which included a robust discussion. First, we want to continue discussing ways in which current research incorporates lived experience. There is often a power differential between the university researchers and those with lived experience. Tawara noted that many times their roles have been limited to research participants. The question is how do we honor people as valuable partners. Vanessa brought up the development of research questions and how do you include people with lived experience win this process in a meaningful way. She provided an example from her own experience and how the inclusion of people with lived experiences provided a sense of grounding and built her capacity. Joni Beasley talked about her truth and reconciliation PCORI project. Her experience in working with people with lived experience is all about building relationships and working with people where they are at. It takes a lot of discussion and meeting with people but it is one of the most rich and fulfilling parts of her time as a researcher. Joni recommends the National Research Consortium at her UCEDD. They meet once a year at Johns Hopkins if anyone is interested, they should contact her. Parthy mentioned resources and how you dedicate funding to people with Lived Experience, putting people in paid positions. This requires you to conceptualize things a bit differently. George talked about how

including people in lived experience can take time. Joni said this is true but if you work on the relationships over time it gets easier and easier. She argues that people with disabilities are not more difficult than working with anyone you wouldn't normally engage with. Vanessa pointed out that it is all about relationships and trying to build those. Rodney and John talked about the importance of Diversity, Equity, and Inclusion—funders want to see outcomes related to these issues (NICHD, NIDILRR). The timing of this conversation is great because of the importance that funders are placing on this. Tawara talked about the roles that we can play. One is making sure that large studies meaningfully include people with disabilities. This is a clear area of expertise for us to work in. We also need to try to include diversity within this area. We also what can we do to get outside our network to conduct research across multiple domains. One example is CINC awards, which only looked at specific racial and ethnic groups. Tawara encouraged them to look beyond those groups and to look at disability. Another example is how to include people in research who speak something other than English and include them in our research. Parthy talked about how we do better with some groups than others in terms of inclusion.

- Rodney shared about his efforts to recruit an NIH speaker to share funding opportunities. NICHD has been a leader is really pushing for outcomes in this space. The president's budget included funding for three new RRTCs on equity to be funded through NIDILRR. There is a need to share both what has and hasn't worked as many clinicians are still in the perspective that they want to use patient groups not partner with them – caution about “Chequity = just checking the equity box”. But most clinicians are open to learning and growing.
- For those seeking to build foundations, Joni recommends PCORI as a way to get started. They are easier to get than NIH grants.
- The RADX grant is another example of how to move forward in including people with disabilities- highlighting the role that UCEDDs can play in enhancing research in this area. UCEDDs can play the role of helping larger research initiatives with meaningful inclusion. Researchers often say they don't know how and UCEDDs can teach them. But there are still gaps in the inclusion of ALL people, a diversity of people with IDD even in the UCEDD network.
- Vanessa talked about a 10-year plan to get into the NIH work...National cohort studies are given a lot of attention but often times don't often include disabilities. This is an area where we could add something. Rodney asked, I have diversified my funding because just focusing on NIH is not the easiest way to have continuous funding, so, what are suggestions for other types of funding. Joni recommended the WITH foundation, CDC grants and local health foundations. Rodney had a great idea that he shared. Vanessa encourages us to continue this conversation in the coming months. Encouraged us to incorporate these ideas into our program evaluation efforts.

CONCLUSION

Send nominations (yourself or a colleague) for CORE leadership positions to Ronda Jenson (ronda.jenson@nau.edu) or Sarah DeMaio (sdemaio@aucd.org) by July 27.