

2016 UCEDD TA Institute Enriching Cultural Efforts: What's in Your Toolbox? March 3 - 4, 2016

Session Notes

Theme: Core Functions

Objective: Conduct research that is responsive to needs of and engages with underserved communities.

Facilitator: Valerie Williams

Part 1 of Session

General Notes/ Big Takeaways:

- Engaging diverse communities/individuals in research may require extra work, flexibility and development of new strategies
- IRBs need to be better educated about including individuals with disabilities in research as well as non-quantitative methods

Challenges and Strategies Shared/Suggested:

- With community-based participatory research (CBPR), community advisors are considered part of the research team; Collaborative IRB Training Initiative (CITI) human subjects training is required for members of a research team but it was not designed for non-researchers; it is not accessible and there are no accommodations
 - OK created an adapted version of human subjects training for community advisors and was able to incorporate this into the research protocol so their community advisors only need to take the adapted version and not the standard CITI training
 - Temple negotiated the ability to use a curriculum created by NIH for its community youth collaborators instead of the standard CITI training
- Similarly, in some CBPR, direct support staff may be assisting with the data collection; they are then considered members of the research team by the IRB and the same issues with CITI training apply. Some programs have been unable to address this barrier and so end up hiring and training graduate students instead which undermines this type of research

- Standard consent forms may not be adequate for all populations
 - WV created a more user-friendly version of their consent in booklet form that still contains all of the basic components. With adoption of this, they have seen their enrollment rates for research studies increase

- IRB members may not be familiar with the types of non-quantitative research that some of our programs are engaged in and this complicates the approval process
 - Acting WV UCEDD Director sits on IRB; suggest that programs could volunteer to send faculty with expertise in those methods to serve on IRB
 - For universities that have IRBs through schools of education or for social and behavioral sciences, it may be helpful to engage them for assistance
 - Invite IRB chair to come talk to UCEDD faculty and discuss why applications get held up
 - Share examples of published research using the methods in question with IRB

- IRB members do not always have a good understanding of how individuals with disabilities can be included in research
 - Acting WV UCEDD Director sits on IRB; IRB to also incorporate more community members

- Engaging with communities and developing relationships for CBPR takes investment of a significant amount of time from both researchers and the community; communities can become really engaged but then it may take a significant amount of time to get funded or may not get funded at all – how to maintain trust with community members in light of this can be a challenge

- Some populations are being denied the opportunity to participate in research by design
 - Children may be excluded from a research study because their parents are non-English speaking
 - Researchers don't always reach out to diverse populations for participation

- CHLA received funding to develop strategies to increase Latino community participation in biomedical autism research

- Partnered with a local Latino community organization; conducted focus groups; used community research ambassadors to talk with parents and help educate them about research; translated autism science briefs related to biomedical research into lay language
- Experienced challenges conducting CBPR with Native American communities; including differing faculty comfort levels with community members who become engaged and actively try to provide direction; resources that limit engagement to one tribal community at a time; navigating tribal politics and tribal IRBs
 - One recommendation for working with Native American populations is to make sure that the research you are proposing is part of the tribe's priorities (could be said for working with any community/population)
- LA worked to increase participation of people with disabilities in its annual need assessment by modifying the process. They first worked with their DD Network partners to identify high priority needs, then reviewed this in light of the UCEDD capacity to address and narrowed the list. They then presented this list to individuals with disabilities and used a Q-sort process to gain their input
- Strong UCEDD has a subcommittee on research as a part of their CAC and any research proposed by the UCEDD has to be reviewed by this subcommittee

Resources or Contact Persons:

- Public Responsibility in Medicine and Research (PRIM&R) www.primr.org has a number of educational offerings including annual conferences such as Social, Behavioral and Ethical Research (SBER) conference and Advancing Ethical Research (AER) conference

Recommendations/Follow-up:

- CORE should be engaged in future conversations about these issues
- AUCD could create a guide or other informational resource for IRBs to educate them around issues related to the inclusion of people with disabilities (and other diverse populations) in research as both subjects and members of the research team
- AUCD should lift up models of strong LEND/UCEDD/IDDRC collaboration and share them with the network. Would also be helpful to have a meeting of these centers.

- AUCD should use some of its unrestricted funds raised from the gala to help grapple with some of the issues mentioned in these notes that impact all network programs
- AUCD should help facilitate the creation of collaborative groups to work on a research study across UCEDDs (i.e. same protocol but would allow use of diverse populations across sites in enough numbers to make meaningful)
- Feds recently proposed changes to human subjects consent guidance that could have important implications (for instance, changes related consent for biological specimens and changes related to exempt status). AUCD should monitor this and provide information to network
- More information is desired about NIDDR grants that were awarded to minority serving institutions

Part 2 of Session

General Notes/ Big Takeaways:

Incorporating diversity into research demands reframing

Inclusive research demands navigating the tension that exists between quantitative and qualitative research, deductive and inductive research and avoiding the value judgements inherent in the systems (federal funding, publication, university culture) which prioritize one over the other. For example, we need to qualitatively define “a meaningful life in community” before we can qualitatively measure our progress toward that.

Need to be intentional about involving community members as partners from the beginning – allowing them to influence research agendas through to beyond the lifecycle of the study, i.e. researchers need to have a plan to transition interventions and not leave participants hanging. This involvement will help to transform research into a benefit to the community rather than a tax or something exploitive. Some believed that research rigor could be improved by community involvement because community members are motivated for research to benefit practice and for “significance” to have practical consequences.

Strategies Shared:

CBPR –parent and service providers are involved on the research team, and advisory group quarterly met to develop intervention including parents, self-advocates and community providers – this group brought questions around location, age, level of need, design to include social component. Identified

emerging themes around culturally diverse groups and now want findings to be applied to activities, monitor activities and show outcomes.

Revise disclosures that too often inform participants (community members) that there is “no direct benefit”. Instead describe the desired benefit to the community.

Resources or Contact Persons:

Intentionality in involvement of community members at each layer including the research teams. Shriver Center (Massachusetts) has developed a “Considering culture in autism” screening guide (kit) and now they have a grant to develop this into curriculum. For report on study see http://shriver.umassmed.edu/sites/shriver.umassmed.edu/files/newsletter/Shriver_Center_Spotlight_UCEDD_Newsletter_winter_2012.pdf

George’s conference session on logic models