

UCEDD Directors Meeting

January 27th 4-6pm ET

Breakout Room Notes

Breakout Room Topic: Engaging Diverse Communities in Research Activities

What You're Seeing:

- Not a lot of funding to figure out how to address these problems
- Hard to recruit people during COVID
 - Less able to go to organizations, engage with stakeholders, etc. Personal contact is much less possible. Can only engage with providers but people aren't engaging nearly as much with these people
 - 12 week intervention study is particularly difficult
 - Phone interviews are much easier to keep going – people like talking to people about their child
- A lot of differential attrition from virtual school-based work
- Some projects including goal-setting haven't been able to meet them because of covid.

What You're Doing:

- TN: Statewide study to better meet all Tennesseans needs. Particularly rural and racial minority.
- Observational studies have gone pretty well but interventional ones have not. Probably because time and labor intensive for certain communities.
 - Hoping that developing ways to deliver interventions remotely will help. But still obstacle of digital divide. Working to develop responsive interventions
- Mailman Center: made a decision several years ago to engage with communities and have them identify their greatest needs. Also allowing them to own the work.
 - Initial outcomes showed individual impacts but ultimately intending to look at community indicators. Both focused communities improved compared to similar adjacent areas (which actually declined)

- Missouri: multiple data collection efforts with DD councils. Always hard to get anybody not white, particularly now with covid. Looking for strategies to collect data and better engage with non-white families
- University of Texas: working with diverse families in Rio Grande valley, primarily Spanish speaking. Teaching them evidence-based practices for kids with autism. Hybrid form between in-person and virtual. Still struggled to keep families engaged. Competition with other time commitments, like family and work.
- West NY and UC Davis: working to mobilize community agendas for research, around evaluation, what resources and support they need, creating connections, etc.
- Webinars, particularly when partnering with others who have more connection already, are really helpful. Briefs for families, that have resources, also help motivate providers to recruit people
- School-based work has had to be shifted to joining in online. Thinking about how to change recruitment and engagement
- Trying to get zoom recordings to look at parent/child interaction. Making other standardized assessments online. But quality of data is questionable
- Tele-assessment. No established validity however
- Trying to do some pre- and post-covid comparisons. But with how long covid is, not sure how good of a post- comparison they'll be
- Shipping cell-enabled tablets so that they can do virtual interviews. Still some people declining because uncomfortable to receive it
 - Some have had difficulty getting tablets back but setting it up that UPS came back and picked them up fixed that
 - Also made it so that the tablets can literally only zoom with the center
- Totally separating zoom and in-person groups
 - Not sure how random the zoom sample can be given all the factors at play
 - Not sure samples will be comparable at all

What Next?

- Mailman Center: conversations with key community leaders and thinkers to choose next two communities for intervention. Looking at tribal involvement and other communities with very different culture
- Collecting participant info so to better build trust for future work/projects
- Workshop on info for how to better reach out to communities and build trust
- Conference for this year is very related to all this discussion!
- A lot of justification in annual progress reports
- Not sure that there are solutions...
- Many will probably have a covid and non-covid cohort. Will have to address that carefully in publications
- Figuring out how to quickly use No Wrong Door grant given delays in it being awarded (Just awarded but supposed to have been awarded in April)