

2022 Virtual TA Institute

Breakout Room Notes

Session Number: 1

Breakout Room Title: Regions 5 & 8

Facilitator:

Attendees: Dana Fink, Marty Blair, Eric Moody, Kara Ayers, Brian Be, Sandy Root-Elledge, Eric Kurtz, Ryan Groeneweg, Tamar Heller, Sharon Milberger, Angela Martin, Suzanne Bancale, Matt Wappett, Marcia Moriarta, Pat Osborn, Dan Wenz

Notetaker: Dawn Rudolph

Notes:

- IL – big emphasis on racial equity, cross section of disability, race, climate disparities, refugees
- MI – health equity, addressing disparities, addressing intersectionality, social determinants of health, COVID vaccinations – collecting data on disability status (getting agreement on what the questions are and how they are asked) and DSPs
- OH-Cinn – data collection on disability status is an inequity, going to groups to advocate to get data collected and those groups are the same ones telling us to show them the data, focus on what works well in the past 2 years – not so much in DD field but in broader disability field. Disability research lab to build expertise in research among students/faculty with disabilities – add didactic efforts as students indicate need. Want to provide more training and background for students with disabilities to be hired across network.
- WY – equity and diversity and inclusion, interwoven throughout 5-year plan, telehealth work growing exponentially, manage telehealth network for state. Research network is quality state research network – community of practice research network started 3 years ago – started on community health in extremely rural state, last year or so have pivoted to focus on IDD in particular, goal is to expand this for community-engaged research on IDD with researcher with IDD contributing to every step, addressing long-standing challenges addressing rural states – able to use network to address all kinds of healthcare priorities including DSP shortages, Title X program and how to include people with IDD in family planning and sexual health, get to be very responsive to needs of state
- NM – ED&I, being more inclusive across every core function across underresourced state. Looking to hire staff level senior scientist (position just posted) to pull together ability to look in discerning way at research, collect it, applied research that is relevant to people, policy, look at how people can be meaningfully included, intersect with autism program. Be much more strategic about dissemination of information – found through COVID that our ability to share information in non-academic ways has been very powerful. Looking at



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intersection of IDD and



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mental health/behavioral issues. Our state decimated a couple years back by prior administration, need to get community based services back in place for folks.

- SD – responding to mental health crisis, momentum but also those who are chasing solutions that are outdated and not evidence based and not keeping in mind needs of people with IDD. We are uniquely positioned to bring systems together to slow process in a state where a super majority can move things forward very fast. Reaching tribal nations in state. Tribal members working on behalf of people in their communities – Oyate Circle no longer a project but is integrated in every single goal and objective across the board.
- MT – housing (affordable and accessible) creating need to develop interesting partnerships such as HUD and economic development, healthcare – pediatrics, complex, rural – engaging in ways not happened in the past. Communications – doing more in plain language – has become inclusion and equity issue for us. These concepts driving our strategic plan.
- CO – growing leadership, diversifying, equalizing power dynamics, plain language in dissemination, power of storytelling, using the arts, swimming upstream is exhausting as lions share of autism work is in children – and children become adults, community based participatory research, participating in WY research network, lead curriculum for behavioral health rotation, coordinate LEND fellows who are community stakeholders who come as family members who are also autistic. Need to be sustainable, funded, and program designers
- UT – EDI, mental health, since COVID has been partnership with Dept of Health – disparities and equity issues, co-occurring

Collaboration ideas:

- OH/WY to join on shared ECHO model for telehealth, others can join in – would be very interested in partnering with others. Project SCOPE up to 10 states, very effective
- ECHO is cost-effective tool, and so helpful in remaining nimble and responding to community concerns. Individualizing it to state, to region, timing it to meet local needs. Ready for other partnerships.
- Interest in WY is to identify funding opportunities to expand.
- Stronger research participation of people with disabilities – share successes, how helped get someone with IDD to get into co-PI position, etc. – need repository of how these successes happen. Has had to be addressed in research community of practice
- CORE, COLA, AIR-P may also be interested in getting involved.
- Advisory councils and committees need to move beyond advice and appearance, into power sharing
- Putting more emphasis on finding and hiring people with lived experience, beyond emphasizing engagement as research participants and in advisory roles
- Pre-service for PWD, finding students with disabilities who are learning about and doing research
- Multiple pathways can include advisory groups, students, internships



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- We have to include and put people in roles with power – not just research, but in every core function. The non-academic part of what we do has so much power to influence our system that can improve our system – so we need to think across all core functions. How do we make training successful? Dissemination? Etc? How do we reallocate resources? How do we work with university for them to reallocate resources, as the UCEDD can't do it alone?
- Give core functions equal weight – they work together in a cycle, a feedback loop. Grounds our work and makes it functional to the community. COVID response has really reinforced how our core functions must be working together in a practical way.
- We must translate into real world application.
- COLA members still being asked to inform researchers, though researchers don't always want to listen to what they have to say. We must find valued place at the table – in AUCD, PCORI, WITH Foundation, provide more opportunities for this growth. Building confidence for PWD cannot be overemphasized.
- As an organization, as an association, we make sure individuals with disabilities know they are welcomed in all councils, all activities – ensure clear invitation to join not just COLA but is still segregated. Our association still looks segregated. The majority of leaders are without disabilities or are family members – not people with disabilities. This needs to change too.
- PWD in Leadership Academies also.
- Including youth in CAC, or a youth CAC extension



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