

UCEDD Directors Meeting

February 17th, 2022, 3-5pm ET

Breakout Room Notes

Breakout Room Title: Authentic Community Engagement and Partnerships

Facilitator: Cindy Thomas

Notetaker: Jeanette Córdova

Attendees: Daniel Armstrong, Director of Mailman Center for Child Development, UM, AUCD President this year; Susan Russell, Associate Director at the Center of Community Inclusion and Disability Studies, Maine UCEDD; Deborah Spitalnik, UCEED and LEND Director at the Boggs Center, New Jersey; Jerry Alliston, Associate Director at the Institute for Disability Studies, Mississippi UCEDD; Josephine Cruz, Association Director at University of Guam, Guam CEDDERS; Cindy Smith, Director, AUCD Public Policy

Notes:

- Why did you pick this session and anything in particular you want to get out of the breakout?
 - Josephine Cruz – There is a distinct difference when engaging families and community engagement. Surveys or invitations to session are just surface activities for engagement. True engagement is them being involved from the beginning to end. How does one sustain this, is the real question?
 - Susan Russell – In Maine, we have several communities that we are working really hard in engaging, Tribal and Somali communities. We have found that in order to really engage them authentically we have to build relationships. The relationship building piece can be time consuming and slow, but it is critical. If you don't have it, you don't seem to move forward at all. The ultimate goal is around disability but had to come at it through a broader approach and how to keep it going to get into our diverse communities.
 - Jerry Alliston – I was taking this from a different perspective because I have worked so much on youth services and young adult in the last 15 years. In Mississippi, we don't have a lot to engage these folks, that aren't just day centers. Now they are in their 30's and focusing on how to actively be working in the communities.
- Cindy Smith – how are you engaging those diverse communities? Engagement is something we are interested in learning for our policy work. Thanks for letting me listen in.
 - Daniel Armstrong – Six years ago Mailman Center decided to prioritize the intersection of disability and diversity as a primary focus. We designed a community engagement process that was a little bit different at the time. We reached out to two



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- communities, each with a population of 100,000 people, one was 95% Hispanic with a median income of \$32,000 and the other was about 70% black/African American and 20% Hispanic, with a median income was \$22,000. We reached out to some of the key community-based organizations in those groups that had made connections and asked them to help build a relationship. We asked what you need to build capacity. Began working with them. It was a stretch because we helped them obtain an independent grant, which was accomplished. If we work with groups within the communities, could we change things on a population level. Children’s Trust actually collects street level data all children under 18, that live in those communities. We were able to pull out five different markers; high school graduation rates, kindergarten readiness, involvement with juvenile justice system, did they have access to a medical home and really high initiatives. We brought the groups together, along with mental behavioral services, we had 15 different agencies, who had big holes in their ability to meet community needs. We worked with them to determine what training do you need and we let them take the lead. We have members of Mailman in the councils of these agencies. We published a paper in MCH last month. We were able to show in the two communities we worked with and in an adjacent community that was economically similar we didn’t work with, we saw in each of our target communities over a 5-year period we saw significant increase higher graduation rates and kindergarten readiness. During the same time in the adjacent community their numbers rocked significantly. It is powerful finding that we have that by asking the community what they need and empower them to do it themselves. This community work does impact on a population level. We are now engaging with the Haitian and tribal communities.
- Deborah Spitalnik -We are trying to figure out with what New Jersey is calling the Office of New Americans, how to connect with the refugee and immigrants, especially from Afghanistan. There are good examples out of NY for developmental screenings. One of the concerns we are always having If we are involved with screenings, what happens to people after screening and where and how they will be resettled. We are also working with South Asian Total Health Initiative that started out of our medical school. I feel a bit overwhelmed on how to connect and do the work in meaningful ways. We have had good relationships but need to do more. COVID has impacted people with focusing on more basic needs and getting vaccines to these communities. Deborah – the number of languages and dialects is a challenge. How to support that? How to make everything assessable to communities? Cultural beliefs affect services as well.
- Josephine – We partnered with the Guam OSEP grant, with his NASDE (National Association of State Directors of Special Education. We are doing more deliberate convenings. [Learning by Convening Blueprint for Engagement by NASDE](#). We look at who isn’t at the table and invite them to the table to be heard. Premise is a learner and leader. The grant is about family and professional learning, which in the past has been



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- done to people vs people leading. We are really excited and doing three learning by convening meetings. It is fairly new and the three tenants are coming together about concerns, ensuring relevant participation, and doing the work together.
<https://osepideasthatwork.org/leading-convening-blueprint-authentic-engagement>
- More concrete ideas to growing relationships:
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 - Susan – When we first started engaging, we worked with the New Mainers Community Public Health initiative. We had a conversation about what they thought was needed in the community and what we might be able to provide. One of the things that came up was parent's information about what happens arounds schools, assessments, etc. We started doing some training around what they needed. As we moved it to our UCEDD, they took a step back and brought in a group of parents, Somali mothers who had kids with a diagnosis of autism. They asked them what they needed. Their needs aligned in some ways and in other ways it didn't. They would develop an agenda for the training. They worked together, created a trusted relationship by the lead of the project. Our EI is called Child Development Services, they thought it was Child Protective Services and same with the school, we have to start with very basic and continentally meet them where they were. The work had to be flexible when they went in and throughout the process.
 - Jerry – It is similar with what others are doing. We created a youth advisory council (14-30) that gave information. It was people that worked with youth and now it is separate for youth and parents have their own component. We hired younger advocacy coordinators to coordinate and work with them. I don't see a lot of UCEDD's doing a youth advisory council.
- How do you partner with the community agencies and what some of those agencies may be?
 - Daniel – Our work is actually with community organizations. I do want to mention one of our experiences with vaccine hesitancy. When we tried to shift to telehealth and zoom, the conventional wisdom was that the low-income minority communities weren't as digitally capable and this wasn't going to work. Many said this is over our head, we can't use it. One of the community partners said they all use Facebook. So, within two and a half weeks, we had everything on Facebook.



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- Key strategies to ensure authenticity and integrity of translations, etc.:
 - Josephine - Before putting out a brochure have someone from the community/parent from that community help to ensure the information is understandable and meaningful. This will ensure that language is more inclusive and engaging.
 - Someone said this is critical on all levels of materials that are for the community, parents, youth, etc.
- Other resource:
 - <https://www.health.state.mn.us/communities/practice/resources/phqitoolbox/docs/AuthenticPrinciplesCommEng.pdf>
 - [AUCD Spanish-Language Materials Development Protocol](#)
 - [Plain Language Resources](#)



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