

**Cultural Adaptations in Respite Services and Outreach  
Breakout Room Discussion Notes**

**July 15, 2021**

*Facilitator: Susan Summers*

**Questions centered on participants’ ideas and experiences related to incorporating cultural adaptations into respite services.**

<b>Responses to Questions — First Steps</b>	<b>Observations/Comments</b>
Ronelle spoke about the need to listen to the unique perspectives from specific groups and to never assume that you know about another’s experiences.	This speaks to the importance of learning from rather than learning about.
Nick Slentz talked about identifying the groups present in your state. He also spoke about the need for cultural brokers to assist caregivers in navigating the respite system, and to assist in communicating with providers.	This speaks to the concept of attunement, in addition to adaptations, presented by Lauren. Use cultural brokers/liaisons.
Mary Weltz (ND) spoke about working with elder tribal communities and encountering difficulties in communicating about bureaucratic programs, policies and funding — concepts that are more commonly understood in the dominant culture. She noted that one can’t assume that definitions and assumptions are shared, that it is important to be able to start at the beginning, assume nothing and explain everything in jargon-free language.	Importance of clear communication— explaining in lay language what we do and why we do it in, and asking the relevance of what we do to our administrative partners.
Alicia Blater talked about the limitations of using Spanish translations of documents, including sometimes inaccurate translations, and the erroneous assumption that literacy rates among Spanish-speaking caregivers match the reading level of documents. She also talked about the challenge of finding and hiring Spanish speaking staff who can help caregivers navigate the system, and how this affects cultural attunement. She spoke about the need for sustained funding that would support development and maintenance of this part of program infrastructure, and commented that without it, she question whether we are helping at all with some populations.	Really important point about human infrastructure.  Hire staff who are fluent in the language of the population served.
Nick Slentz (VA) said that they are in the process of translating voucher materials into Spanish to help with consumer directed services. He shared that he studies Spanish every day, and commented that “this is the future of the country” — we need to be able to competently	

serve non-English speaking populations.	
Ronelle agreed, saying, "Yes. All of that." She shared an example that really worked in Oklahoma's Sooner Success program: the program hired a bi-lingual director providing a "brilliant bridge" between the program and Spanish-speaking families, and helping families locate and navigate available services in their communities. This person's roles and responsibilities combined direct service and leadership.	Use cultural brokers/liaisons.
Megan (CO) spoke about historical trauma and distrust that may be present and contribute to hesitancy to use services. She shared that they never ask for information about citizenship to access services. Megan also spoke about finding places (such as faith-based organizations) where underserved populations may congregate, and provide outreach.	Consider history when thinking about issues of access and hesitancy. Locate underserved populations and conduct outreach.

<b>Response to Questions — Self-Assessment</b>	<b>Observations/Comments</b>
Oklahoma is planning to conduct a self-assessment this year, but didn't have specific information.	This question seemed to be novel to participants, and they didn't seem sure how to respond to it.

<b>Response to Questions — Successes</b>	<b>Observations/Comments</b>
Alicia Blater spoke about their purposeful associations with the Office of Rural Health and loose associations with Hispanic and historically Black churches. She spoke about the demands from the community placed on the churches because they serve as the "go to" entities for cultural change. She expressed concern that respite act as good partners and engage in reciprocal exchanges that offered them something of value to them rather than just talking from them. She observed that these organizations need infrastructure support and did not always have the deep resources to the "asks" outside organizations made to them.	Another important observation about the importance of attunement and the role reciprocity in this.

<b>Response to Questions — Challenges</b>	<b>Observations/Comments</b>
Ronelle spoke about challenges associated with rural areas including the lack of internet and cellphone service access that make basic contact and social networking impossible. She also said that on Tribal Trust Lands in Oklahoma, personal addresses are not always used, so	Technological challenges.

written communication can be challenging.	
Nick Slentz talked about the digital divide and how Virginia is trying to increase services to rural and native populations. He talked about having a strong relationship with one of the nine tribes in Virginia, and learning from them about what works in order to strengthen relationships with other tribes. A general conversation ensued about the individuality of tribes and the importance of not making assumptions about all tribal populations based upon one tribal population.	Learn about what works in terms of process, but realize that what you learn may not apply to all populations.
Alicia Blater spoke about the need for incentives for grant partners when respite grantees ask them to engage in MOUs/MOAs, recognizing that they may need resources to support their engagement. Alicia commented that this is something ACL could consider incorporating in grant contracts.	Funding/infrastructure support that could support cultural adaptations at the program level.

**Cultural Adaptations to Respite Services and Outreach**  
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**July 15, 2021**

*Facilitator: C. Firman*

**For those of you just starting to consider making services more culturally and linguistically sensitive and responsive to those you serve, what first steps could you take?**

The general consensus was that it is critical to have partnerships with community leaders who are from the cultures being served. Everyone in this breakout group agreed that relationships had to be built with the community. They relied on champions in the community who could help bridge relationships and build trust. “We have learned that listening to people is critical. Not just translating, but making sure multiple folks review the translations and look for cultural as well as linguistic appropriateness.”

Some comments included:

AZ: There are many languages spoken in Arizona, especially because of the large number of tribes in the state, so they can't get all their documents translated for all, although that is what they would like to do. They get champions in various communities including tribal liaisons to help with outreach and communication between the respite programs and caregivers. Helping communities define respite. The champions need to be from the community—trusted in the community. It is an ongoing process to recruit and maintain the community members who act as champions.

IL: Trust is huge. We have information in Spanish and others who can help with translations. A diverse board of directors who are active helps. They can help with translations and outreach with diverse populations. Ensuring caregivers have ‘walk-ins’ to help people fill in forms. When possible, meet with clients in their community—such as libraries or Dunkin’ Donuts—so folks do not feel put off by a government building.

Trainings of care providers need to include the families.

ID: Personalized high-touch navigation services. A navigator meets with a caregiver, by phone or by zoom, for about 45 minutes to really get to know the caregiver and find out what their needs are. When possible, the navigator should be culturally and linguistically matched, if possible. The navigator helps the caregiver develop a care-plan and maintains ongoing contact

with the family to People just want people to take them by the elbow and walk them through the process of developing care plans and walking them through the navigation process.

We have learned that listening to people is critical. Not just translating, but making sure multiple folks review the translations and look for cultural as well as linguistic appropriateness.

We meet people where they are: at farmers' markets, for example. Meet people where they are, physically and culturally.

**Have any of you engaged in formal or informal self-assessment to gauge your agency's or your coalition's readiness to begin making cultural adaptations to services? If so, what tools or processes were helpful to you?**

One common thread in responding to this question was the importance of knowing the demographic makeup of the state and comparing it to the service population. This is an excellent starting point for assessing an agency's effectiveness at outreach to diverse populations. Not all have followed a formal process of assessment.

Some comments included:

Some staff received anti-bias training. The depth of this training is profound. So much of what we are told about cultural sensitivity is just 'boilerplate.' You really have to be talking with the actual people you are trying to serve. Any training should not be a packaged training, but bring in the people who you are trying to serve. Bring in the people. Focus groups.

Right now, we want to actually know who is in the state. Compare the demographics in the state with the demographics of the people living in the states. When we find that our service population does not match the state's actual population we ask, 'why not'? We have learned we need a better outreach plan. By looking at this statewide data and comparing it with service data, we learn so much.

At every team meeting, we ask ourselves why the people we are serving are not reflective of the population at large.

**For those of you who have worked to identify and reach underserved populations, what outreach strategies have been most successful?**

We found the best way to identify and reach underserved populations is to hire people from underserved populations. Engage the families to help train staff.

Many families do not want outsiders coming in to offer support.

Agencies should not promise everything for people because once the promise is broken, trust is broken.

The Brave Warriors Project in Wenatchee, Washington is an example of successful community outreach. They actively

Programs agreed that money and time is necessary to ensure services are culturally and linguistically attuned to the community.

## **Cultural Adaptations in Respite Services and Outreach Breakout Room Discussion Notes**

**July 15, 2021**

*Facilitator: Ray Kirk*

*Notetaker: Tracy Kahlo*

### **Offer experiences you are having or may be having with hard-to-reach populations coupled with lived experience, ethnic or cultural, language and rural?**

- IL – Nebraska has the highest resettlement populations of 20+ countries with Lutheran Services. Learned communities can be closed and identify persons who could be cultural brokers, elders, and young leaders. Informal identification from businesses who knew others in his Latino community who were caregivers to be a cultural broker. Respect of each community's culture, language, and practices. Language translation could not be relied on given the literacy of the terminology in one's language, so relationship building is key.
- Researchers seen as someone to remain cloaked and utilizing researcher brokers to assist with building confidence, trust, and relationships to build allyship.
- Cultural Advisory Team – leaders, cultural influencers, adjust, and provide information and when disseminated the team members did so for their communities. Idea: all states build and create Multi-Cultural Advisory Committee. This reduces one person being all things to all people.
- Tribal Communities – outside hesitancy into homes, providing training to build caregivers in their community who are known, understand their culture, practices, and preferences. Taking it to the grass roots level. Acknowledge trauma, healing to be done, and support the wisdom of the various recognized Tribal communities and Tribal members within unrecognized by the Federal Gov't.
- WI – Tribal families have various connections with early intervention to respite. Contracts with 1 tribe to be the negotiator, facilitator, and communicator for other Tribes. The learning was other Tribes not feeling represented so changed course. DEI project kicked-off by Governor and other state leaders to offer a starting point. Additional populations for Laos – what gets translated and what doesn't remain a point of frustration and barriers for adaption.
- WI – for respite trying to launch into the various communities by partnering with cultural brokers, gaining insights, learning before disseminating information. To assure
- Person first language. ARCH could lead – blog, drop-in, build the wisdom, some may be region specific, - to build our learning nationally.
  - Idea: Convene a National Cultural Advisory Team and then by regions to assist us all

- Translating in Latinx – mindfulness that our various communities may not be literate in “one’s language.”
  - Infographics can be helpful with a heavy dose of mindfulness of accessibility for our blind and low vision communities we serve = alt text
  - Dialects may have variations of meaning as local languages adapt to nuances

**Big Themes:**

- **Convene Multi-Cultural Advisory Committee**
  - **Develop materials and information for best practices**
- **Translation of documents and information does not necessarily equal understanding with the written word; other ways to assure outreach, build relationships, connections, and services**
- **Regulatory Practices and variances across the nation**

## **Cultural Adaptations in Respite Services and Outreach Breakout Room Discussion Notes**

**July 15, 2021**

*Facilitator: Jill Kagan*

During introductions, people offered what populations that serve. NV pointed out that they are particularly concerned about diverse group who also are in isolated rural areas.

**For those of you just starting to consider making services more culturally and linguistically sensitive and responsive to those you serve, what first steps could you take?**

A number of states offered what they have done as first steps toward being more culturally and linguistically sensitive and responsive:

A NY agency has a robust phone line intake system with language interpretation. A good first step would be to ensure that intake is available in all languages.

It is important to have connections with leaders in the community that we can turn to for feedback and guidance. MT, through their Alzheimer's grant, met with Native American leaders in the state and asked them to review a survey developed by ACL on dementia capability to ensure that it was culturally sensitive. They also worked with Title VI Native American Family Caregiver Support program directors to help get the survey completed by caregivers in tribal communities.

RI has been successful working with trusted organizations that work within diverse communities to help them do the outreach and to overcome language and cultural barriers. Having a champion in the community to share information and make initial contacts is important.

NV routes calls from various cultural and ethnic groups to their intake services at their ADRC that can provide language services. In their voucher pilot, they used person-centered approach when offering respite to families allowing them to work one on one with the family caregiver to identify and meet their respite needs. Also, the self-directed services offered allow caregivers to select the respite they prefer they are most comfortable with. Many ethnic groups choose to use family and friends they trust from their own networks.

Meeting individual needs is more challenging in facility-based respite program, but the facilities' response has been that most of the workers are people of color, but often they are still not trusted by families. Dr. Parker identified the act of hiring staff of color, but not altering the basic structure to meet the needs of those served, as cultural attunement rather than adaptation

**Have any of you engaged in formal or informal self-assessment to gauge your agency's or your coalition's readiness to begin making cultural adaptations to services? If so, what tools or processes were helpful to you?**

Several group members said that their state agencies already provide cultural diversity training and how to be sensitive to cultural differences, but not really about how to do cultural adaptations. Pandemic slowed training opportunities.

**Follow up question: Does training just help you address how to identify diverse population or does it address how to reach those populations?**

In MT, training is mostly about identifying populations.

NY provided training offered by the Diverse Elders Coalition. on the needs of diverse caregivers of older adults, We also have in our area, racial and equity justice groups we have formed to engage in self-reflection and discussion about our own attitudes that may affect the people we work with.

In NV, training has been more about how to be more accessible to a large number of people, through using appropriate reading levels, preparing materials for certain populations to make sure they are represented in images, etc.

**Would a self-assessment tool prepare you to serve diverse populations?**

NV is transitioning to an advisory board structure and working on onboarding materials and a self-assessment tool for them would be helpful to answer the question, How well do we think we are serving diverse populations?

**For those of you who have worked to identify and reach underserved populations, what outreach strategies have been most successful?**

DEAP in MT works with families on the reservation to provide developmental services and we have one employee from that community who promotes lifespan respite to this population. It is important to find a champion from within the community to help educate and promote services.

State programs are often developed from the top down rather than from the community up and then they don't work because we are not providing what they need or what they define the problem or unmet need to be.

Advice -- Check your arrogance. When you think you understand that culture, that's when you lose your generosity and ability to listen and really see and hear. Need to just keep plugging away.

**For those of you who have already started working to make cultural or linguistic adaptations to services, what have you done that has been successful? What challenges did you face?**

Not sure we have been successful; we make inroads but then people leave their positions and we lose ground. Always looking for new opportunities.

Dr. Parker suggested that the [BOLD Public Health Center on Dementia Caregiving](#) can offer resources and training and TA.

We have seen disparity during Covid with people being more reluctant to come back to services. If we could convince state programs and services to be more self-directed, there could be more success. But self-direction is not just about leaving people alone; it's about walking with them a little bit along their journey and making sure they have the tools and resources. We have proved that self-direction works. What does that mean for future development of services? With self-direction, we can be more culturally competent.

Our state is already serving lots of people, but they lose track of who they are NOT serving.

**Other resources** provided during the discussion include materials from the Diverse Elders Coalition's [Caregiver Toolkit](#) and the service that Sara Vogler from ACL mentioned -- the New York Academy of Medicine (NYAM) that serves as the Coordinating Center for the five-member organizations of the Older Adults' Equity Collaborative (OAEC). They maintain a [resource library](#) on cultural diversity among older adults and their caregivers.

In NV, we have cultural groups that have formed to meet needs of their own populations that we would like to do targeted approaches with as possible providers of respite, and offer them resources to do this, even if that is not something they normally do. We'll let you know if we have success.

**How do we encourage service use among some populations who are resistant to using services?**

Dr. Parker talked about word of mouth being an important strategy, but how do we create word of mouth? Many programs had people of color working there, but there are other ways to

enhance the welcoming aspect of a program – to show people they belong. Things like food, music, and games offered (older black men love dominoes and spades) and when people see these men playing, it makes others feel comfortable coming there.

Dr. Parker visited an adult day center that had separate language rooms that provide a welcoming aspect, but is it intentional or unintentional separation? What happens to shared resources?

Dr. Parker also suggested that for certain cultures, especially Hispanic, talking about how the service benefits the entire family may help make services more attractive. Having an advisory team from various cultural groups can also offer insight into how to provide services.