



**Pesa Sooname Advisory Group Meeting Notes**  
**Wednesday, January 8, 2020 from 12:30 - 2:30 PM**  
**Numaga Program | 705 Highway 446, Nixon, NV 89424**

In attendance: Jennifer Carson, Carla Eben, Casey Acklin, Alex Crocket

1. The group provides updates.
  1. Carla's friend at the Reno/Sparks Indian Colony is requesting materials on dementia.
    1. Perhaps this means that we should move forward on putting together the Pesa Sooname Resource Notebooks, considering that there is an expressed need among other tribes.
  2. Jennifer reviews current funding: \$1750 for each Community Group.
    1. The funding is centralized at UNR, and purchases can be made through Jennifer or Casey.
  3. Jennifer discusses the blog posts that were commissioned from journalist and Dementia Friendly Washoe County member Matt Perry.
    1. For each blog, we are looking for an accompanying photo.
      1. For the blog about the Tribal Summit, we will use the photo of the Summit that was used on the Dementia Friendly Nevada Trifold.
2. The group discusses the upcoming Pesa Sooname Talking Circles, the first of which will be held on Wednesday, January 29.

## 1. Program:

1. Carla will provide an introduction to Pesa Soomame and the Talking Circles
2. The talking circle will take place. Carla will facilitate, and Jennifer will ask questions to shape the discussion.
3. A survey will be given to participants.
4. Dinner will be served.

## 2. What questions will be asked at the Talking Circle?

1. The group decides that we will cover all questions outlined in the Road Map for Indian Country at the first Talking Circle.
2. The second Talking Circle will then go deeper on particular questions.
3. The third Talking Circle will focus on identifying a path forward, to turn the conversations into action.

## 3. How will the discussion be documented?

1. Jennifer presents two main options, which are not mutually exclusive:
  1. Rigorously document the conversations with the goal of eventually presenting the transcripts to the developers of the Road Map for Indian Country so that they might be used in research on the Road Map's implementation
  2. Casually document the conversations with the goal of using them for community development
2. The group is in agreement that rigorous documentation would be ideal, however we would need to identify a means of doing so that would be feasible and would not interfere with the conversations.
  1. The venue for the Talking Circles has very bad acoustics, rendering an audio recording impractical. Additionally, Carla believes that people would feel uncomfortable being recorded, even if their personal identities would be hidden.

2. Typing the transcript as people are speaking is also impractical because people tend to talk over each other.
  3. Alex suggests taking notes on flipchart paper.
    1. The main benefit is that this creates a visual, which people respond to and remember better. People could also write notes and post them on the flipchart, making the process interactive.
  4. Jennifer presents the idea of Graphic Recording, where an artist produces illustrated notes in real time. The notes are visible to participants throughout the discussion, making things visual and slightly interactive, and the result can be put on display after the Talking Circle to be viewed by the broader community.
    1. Jennifer shows some examples of Graphic Recording work that she has commissioned in the past, and the group is unanimous that we should pursue this option.
    2. Jennifer and Casey will look for a local graphic recorder and will report back to the group.
  5. Casey will also do his best to type the transcript of the conversation in real time, so as to add an extra layer of rigor to the documentation.
4. What will be on the survey given to participants at the end of the Talking Circle?
1. We could ask if, at subsequent Talking Circles, participants would be okay with being recorded. The group agrees.
  2. The group poses other potential questions on topics such as the participants' knowledge of brain health and dementia, and whether the Talking Circles are helping to build awareness of these topics.
    1. Casey recounts that during a meeting with Zebbedia Gibb—an expert regarding survey development—he suggested

refraining from collecting data unless we can identify the reason why we want to collect those data and how those data will be used.

2. The group acknowledges that perhaps these questions aren't necessary for us to collect.
3. We could ask participants which Road Map questions they would like to return to in the next Talking Circle. The group agrees.
4. We could seek to identify which participants are care partners so that we can connect them with services in the community, such as caregiver vouchers through the tribe. The group agrees.
5. The group ponders the question of whether we need a survey at all, since surveys are not particularly accessible to people living with dementia.
  1. Alex suggests that we could instead do a "Caregiver Bingo," where each person fills out a bingo card, with each square being a particular activity of providing care.
    1. Casey expresses his concern that this approach is very focused on care-partners and, though maintaining a focus on care partners is important, it is also important to make sure we are focusing on people living with dementia. How would such an activity feel for as participant who is living with dementia and thus not providing care?
    2. As a result of the discussion, and a realization that there probably is not enough time to conduct such an activity, the group decides to go with a traditional survey.
      1. Casey will work on developing a draft survey and will email it to the group for review.
5. What will we provide for dinner?
  1. Carla will order dinner through Port Of Subs.
6. Jennifer will pick up "participant incentives" to give out at the Talking Circle.

7. The group discusses dates for the second and third Talking Circles.

1. Thursday, March 26 in Nixon (hopefully at the Tribal Chamber) and Tuesday, May 19 in Wadsworth.

3. Niki Rubarth, Regional Director of the Alzheimer's Association of Northern California and Northern Nevada, wants to come to Pyramid Lake and share information about opportunities through the Association.

1. These opportunities include:

1. Respite vouchers for family care partners to receive a stipend and mileage reimbursement for the care they are providing to a loved one.
  2. Family care partner support groups.
    1. There are existing support groups both in Reno and online. The group acknowledges that the group in Reno would likely be farther than tribal members would like to travel, and that participation in the online support group would be unlikely.
    2. The Alzheimer's Association is also able to train a tribal member to facilitate a support group at Pyramid Lake. The group thinks this is a much more viable option.
  3. Educational programs that could be offered at Pyramid Lake, or that could be facilitated by a newly trained tribal member.
    1. Jennifer mentions that though the Association is working toward developing culturally-appropriate educational offerings, as of right now they are not in any way tailored to American Indian culture. She therefore suggests waiting to take advantage of education through the Association until they have culturally-appropriate options.
2. The PLPT senior advisory board said at its last meeting that there is a need for tribal members to receive help with paperwork required to access services, such as those offered through the Association. However, it is first

important that tribal members are equipped with the knowledge of which services are available.

1. Niki is not available prior to the Talking Circles to provide any information. The group decides to invite Niki and Association employee Charae Wamsley to do a 15-minute presentation regarding Association services, and to ask Niki to stay for dinner to allow her time to talk with tribal members about what future services they need that could be developed by the Association.
2. A follow-up can then be scheduled for Niki and/or Charae to return to Pyramid Lake and assist tribal members in completing the paperwork required for them to access the discussed services. This assistance would likely have to happen one-on-one.
  1. Carla will post a question in her upcoming newsletter, asking tribal members if anybody needs one-one-one help with paperwork.