



## **Dementia Friendly Nevada (DFNV) Statewide Meeting**

Tuesday, June 22, 2021 | 3:00 – 5:00 PM PST | Zoom Videoconference

In attendance: Jennifer Carson, Casey Acklin, Gini Cunningham, Tiarra Atkinson, Zachary Green, Rebecca Hepworth, Susan Hirsch, Nicolette Ketchum, Phil Kalsman, Kate Ingalsby, Michelle Harden, LeeAnn Mandarino, Peter Reed, Mary Lee Fulkerson, Rose Meza, Michael Tracy, Barbara Payne, Niki Rubarth, Esperanza Henslee, Ruth Almén, Alex Crocket

### **Co-Facilitators:**

- Jennifer Carson, Director, Dementia Engagement, Education and Research (DEER) Program, UNR, and Program Director, DFNV
- Casey Acklin, Coordinator, DEER Program, UNR, and Program Coordinator, DFNV

### **Community Group Co-Facilitators:**

- LeeAnn Mandarino, Kate Ingalsby, and Susan Hirsch, Cleveland Clinic Lou Ruvo Center for Brain Health, Dementia Friendly Southern Nevada Urban
- Tonya Brum, Nevada Rural Counties RSVP, Dementia Friendly Pahrump
- Carla Eben, Numaga Program, Pesa Soaname Advisory Group
- Gini Cunningham, Age- and Dementia-Friendly Winnemucca

### **Support:**

- Michelle Harden, MPA, BOLD Public Health Program Coordinator, Population Health and Wellness, Nevada Division of Public and Behavioral Health
- Tessa Swigart, PhD, Public Health Communications Specialist, Nevada Public Health Training Center, UNR
- Mekai Smedley, DEER Program, UNR, and AmeriCorps VISTA for DFNV

\* = Please see attachments that were sent with this agenda.

## Meeting Notes

### 1. **Welcome**

- a. As members are logging onto Zoom, please use the 'Chat Box' feature, using a single entry (hitting "return" only at the very end), to share your:
- Name
  - Role in supporting people living with dementia and/or family care partners
  - What is one thing that family, friends, and community members can do post-diagnosis to be of support?

Honoring the wishes and wants of the person who received a diagnosis.

Spreading the word about Dementia Conversations.

Keeping calm even when things might be chaotic.

Educating yourself about local, state, and national resources.

Empathetic listening.

- b. Let's warm the soil and have some fun on Zoom!

- c. Review Dementia Friendly Nevada mission and meeting purpose

- Mission: By working together, we aim to develop and promote communities that are **respectful, educated, supportive** and **inclusive** of persons *living* with dementia and their care partners.

d. Review one Dementia Friendly Nevada Mobilizing Belief\*

- **Mobilizing Belief #11:** Supporting engagement, autonomy and partnerships with people living with dementia will promote improvements to their quality of life and well-being, and strengthen the social fabric of communities. Elders need communities and communities need elders.
- Let's hear from 2 members about why this Mobilizing Belief is so important. Four Members:

Mary Lee Fulkerson: When I go out into the community with my family, people talk to them and not to me. I just wish that wouldn't happen anymore.

Zachary Green: I interview a lot of elders, and their stories are so important to me. A lot of young people don't realize how important those stories are, for those people and also for their communities.

Barbara Payne: People living with dementia are still people. We must not ever forget this. Always still people, and we must love them.

Peter Reed: Inclusion doesn't mean that people are told what to do, or that they have things done for them. It means that they're invited to participate, even if they participate in a way that is not normative. We need to embrace that way of engaging. Cognitive impairment does not deny them the ability to enjoy their fundamental human rights. Benevolent paternalism is still paternalism, and that is contrary to the value of inclusion. We must not take away people's self-determination.

## 2. REVITALIZE!

- a. Dementia Friendly Nevada is in a period of transformation. As restrictions surrounding the COVID-19 pandemic ease considerably, it is becoming more and more feasible for us to go back to “normal.” But the question becomes, do we like “normal?” Are we happy with how Dementia Friendly Nevada has operated since 2016? Are there changes we would like to make?

This conversation will serve as a foundation for a revitalization plan in the now seven Dementia Friendly Nevada Communities.

- b. First, let’s start with a brief reflection of what Dementia Friendly Nevada looked like prior to COVID-19. Here are some questions to consider:
  - What is one positive moment (your favorite day on the job, so to speak) that stands out to you from our pre-pandemic work?

Mary Lee Fulkerson: Being in a social group with people with some form of dementia was a positive experience. The Open Door Café created a support gathering without much structure, more of a natural support group.

Niki Rubarth: The first meeting in Washoe County. So many faces at the table, so many groups represented. The group brought so many people together in common cause. The most memorable part of the meetings were the social elements! Getting to know people, chatting and having coffee before and after, attending events that brought people together like *Walk With Me*.

Gini Cunningham: Evening in Winnemucca with a screening of "Cracked: New Light on Dementia" followed by conversation. The reception to the film was so positive, and the discussion was wonderful. It launched their recurring Movie Night series!

Susan Hirsch: It's the relationship building that made the Community Group meetings so special. Finding new ways to collaborate and come together. Building meaningful relationships is the most effective thing we can do to spread awareness.

Jennifer Carson: The inaugural Nevada Tribal Summit on Brain Health and Dementia, which brought people from all across the state together into conversation.

- What strengths do you feel existed (and perhaps remain) in your Community Group? What gaps might have been present?

Jennifer Carson: One of our biggest strengths is also one of our biggest gaps: engaging people living with dementia. Our Mobilizing Beliefs were written in partnership with people living with dementia, and our programs are developed in collaboration with people living with dementia. However, considering how many people there are in Nevada who are living with dementia, their representation is still relatively low in our movement.

LeeAnn Mandarino: We are a small state, and this has given us an opportunity to really build relationships, not only with our members but also with people in positions of influence. There are no former structures to get in the way of our work!

- Who did you feel was represented in your Community Group? Who was missing, and how did you invite those people to the table?

Gini Cunningham: Winnemucca is very fortunate to have a wide variety of folks at the table. Having the city of Winnemucca involved has allowed Age- and Dementia-Friendly Winnemucca to do work that they otherwise would not have been able to do. Gini tries to make every member of the group feel like they own it, like it belongs to them, having events at basketball games, getting involved in the

local magazine, and creating annual events for the community to become excited about.

Casey Acklin: Launching efforts and thinking outside of the box has been very beneficial. Working with community nonprofits like the Truckee Meadows Parks Foundation and the Ballroom of Reno has created partnerships that allow the community to come together in activities such as ballroom dancing and nature walks while building the capacity for inclusion among those partners.

Susan Hirsch: There is a huge diversity of people in the south that were interested in Dementia Friendly Nevada. A common trait among people who reached out were they wanted to be in a safe place with others who were going through similar life changes.

- How did you feel about your Community Group's goals?

Mary Lee Fulkerson: Taking the Open Door Café for an example, many of the Participants aren't in the loop with us anymore, and it's difficult to recruit new members, especially when people may be embarrassed about their condition. It's time to set new goals, to re-evaluate.

- How well did the statewide Dementia Friendly Nevada project support your Community Group's local work?

Due to limited time, this question did not get discussed.

- c. Now, let's chart a path into the future. As we revitalize our Community Groups, there are three main components to consider:

The notes below are summarized from discussions that occurred in two breakout rooms, and then reported out to the larger group.

- Who do we hope to recruit as members, and what are the best ways to connect with them?

One question that came up was who would we *not* want to invite to the table? There was discussion of how the values of some communities or sectors might not align with our own, and how it's important to make sure all parties have something to learn and gain from the experience.

Adult protective services, to ensure that all Dementia Friendly Nevada members know how to respond in instances of suspected abuse or neglect.

We must recruit doctors, nurses, and other medical professions to begin improving the messages that are given after a diagnosis of dementia.

It will be important to have specific tasks and expectations that come along with being a member of a Dementia Friendly Nevada Community Group, both for people living with dementia and other community partners.

Events that offer food are ALWAYS better attended. It's easier for people to attend if they are invited for breakfast or lunch, just to brainstorm and share ideas. Not asking anything of people except to be present and to learn more.

- What goals will members collaboratively pursue? Will we pick up where we left off, or start anew?

Since Nevada's communities are diverse, it is important that we continue approaching goals within a community-driven model. This can be supplemented by continued meetings of the statewide Dementia Friendly Nevada initiative to link the efforts of each Community Group and to identify opportunities for statewide action.

Goals should be considered from the perspective of all diverse stakeholder groups within the community, and it should be a goal to increase the diversity of our Community Groups to be truly representative of their communities.

- What process will be used to ensure that meetings are productive and also dementia-friendly and inclusive.

Creating specific agendas for meetings and specific next steps following meetings.

Ensure a balance between getting work done at meetings, but also providing opportunities for Community Group members to assist the Support Team in engaging with work to be done outside of meetings.

Having representatives from the Dementia Friendly Nevada Support Team focus on supporting inclusivity at the local level.

Setting aside personal agendas and prioritizing the community's agenda. Asking members to be present and to participate without too many expectations.

Creating many options for people to engage at different levels and in different fashions. An engagement buffet!

Being clear about our goals to help businesses feel more comfortable with joining and participating in events. Thinking about our language and delivery when communicating with businesses to make sure not to alienate them.

### 3. **Share** (5 min)

- a. Is there anything happening locally—or across the state or nation—that members of DFNV should know about and can possibly help promote?

#### **Age- and Dementia-Friendly Winnemucca**

- **Brain Health Conference:** Friday, September 17<sup>th</sup>, 2021, 8:00 AM – 5:00 PM, live and via Zoom
- **Sprint Triathlon:** Saturday, September 18<sup>th</sup>
- For registration information, email Gini at [gini@c25@gmail.com](mailto:gini@c25@gmail.com)

**Thank you for all that you do to make our communities and state dementia-friendly and inclusive!**