

Dementia Friendly Southern Nevada  
General Meeting

Date: Friday, January 27, 2017, 9:00AM-11:00AM

Attendance:

1. LeeAnn Mandarin- Cleveland Clinic Education Department Manager
2. Isaac Santa Ana- Cleveland Clinic Education Coordinator
3. Greg Martin- Government Liaison, Alzheimer's Advocate
4. Edward Guthrie- Opportunity Village
5. Randy Bolsinger- Powerful tools for caregivers volunteer
6. Kat Hartley- Healthy Brains project, ambassador of AA
7. Lynda Hascheff- AARP
8. Mary Harrison- Geriatric Psychologist, VA
9. Carla Hedeem- Veterans Psychologist, VA
10. Linda Freimanis- Homeinstead Senior Care
11. Cindy Justesen- ADSD community based care
12. John Davis- Southwest Protective Agency
13. Bonnie Reppert- HomeInstead Senior Care, Education programs development
14. Donna Liguori- HomeInstead, homecare consultant, East
15. Jeff Doucet- ADSD, grants and community outreach
16. Maria Dent- AARP, state director
17. Nichole Nalder- ADSD care support coordinator, grants at the state level
18. Jennifer Carson- Assistant Professor UNR, Northern Nevada.
19. Lisa Radin- Board of Directors for FTD, Support group.
20. Gabriel Leger- Cleveland Clinic Neurologist
21. Michelle Gold- Medical Services of America Home Health and Hospice
22. Sharon Goldstrohm- ADSD community development services, outreach for Nevada senior services, dignity health
23. Barbara Payne- Alzheimer's Association Pahrump
24. Alonso Thornton- Nurse Manager, Veterans
25. Julie Picconi- company OneEleven LTD, home remodeling for independence at home
26. Susan Hirsch- Nevada Senior Services, resources for care partners, home modification
27. Sandra Miner- Caregiver volunteer
28. Jaqueline Jones- DeVita Medical Group, President of NSAW, policy and grants for friends with Parkinson's, social worker, Speaking on Feb 10<sup>th</sup> at MonteVista & Red Rock Behavioral Health Hospital
29. Roxanne Lee- MonteVista & Red Rock Behavioral Health Hospital, provide in/out patient care
30. Sue Cook- Homewatch Caregivers. Education and care to clients and families of clients dealing with dementia. Education, to educate the public on what goes on when someone has dementia.
31. Jane Bjorklund- Cleveland Clinic research department and caregiver
32. Susan Farris- Cleveland Clinic Education Department student and training program, residents and fellows.
33. Ericka Shipley- Cleveland Clinic Education Department.
34. Jennifer Young- Cleveland Clinic Library, work with patient for resources, patient advocacy.
35. Anish Puri- MPH at UNLV, Healthcare and Government Sectors
36. Kristopher Kaplan- MPH at UNLV, Community Services and Care Partners Sectors
37. Karen Taylor- Independent at home, August Services LLC, Pahrump.

[Meeting Notes]

Dementia Friendly Southern Nevada Recap:

LeeAnn Mandarin-

- Since May 2016. Phase 1-Convener and keep a steady engagement with the community. We established support from key stakeholders. DFA identified 8 sectors (Care Partner Services, Community Services, Government, Healthcare, Business, Financial/Legal, Faith, and Rural) as a group we are going to focus on 4 initial sectors (Care Partner Services, Community Services, Government, and Healthcare). Phase 2-Engage our members. We broke off into 4 sector groups, reviewed the questionnaires, customized them and published them on our website. We are in the process of getting results from these questionnaires, our community gaps and strengths. The next phase (Phase 3-Analyze) will be to analyze our community questionnaires and create action plans. This is a grassroots effort and we welcome your suggestions.

Questionnaires Update:

Anish Puri-

- Healthcare questionnaires: 43 questionnaire responses getting to 100
- Government questionnaires: 31 questionnaires, a majority of responses from ADSD
- Common Themes: Alzheimer's Association as a resources. Keep working with Alzheimer's Association; 80% directly affected by Dementia. People want to be involved.
- Adequate awareness in resources- the clinic felt that there were more adequate awareness of resources than government. To focus on government we should direct what resources they can use.
- Government consensus on developing a dementia friendly community- unsure.

Kristopher Kaplan-

Questionnaire Timeline: correlation between events and complete questionnaires

- August- DFA website has just been created
- October- Announcement for questionnaires
- January- Alzheimer's Every Minute Counts
- Care partner services- 42 questionnaires
- Community services- 27 questionnaires
- Care partner services and Community services- Knowledge gaps, there were outliers; focus is primarily on affordable care services, home services and resources.
- Our community currently has adequate awareness of resources. However, across the board questionnaires show people do not think our community is adequately aware of the resources.
- There is a large agreement that the Alzheimer's Association is a great place to start, but from there, what then to do?
- Transportation was another big issue, we do not know if it is due to... time, cost.
- Media outlets (TV & Social Media) are favorable modes of communication.

Questionnaire Update Questions:

- Part of what we need to do is to help people be aware of the resources. Part of the challenge is not having enough people on the ground. Whoever is on the front lines? HMO our doctors only have a limited amount of time. If there is a possibility of memory loss, it's another 3 months until their next visit. Doctor refers to Social Worker, to Alzheimer's Association, to respite. On

the ground floor, everything that has been said is absolutely true. People are calling for resources and direction. We need the feet on the ground. We can have as much resources, but underutilization gives the impression there isn't any need. Hotlines and 800 numbers are overwhelmed. We are looking to train and educate people. We need to start a movement for more volunteers.

- Gathering methods for questionnaires, there was a function in November, Healthcare & Survey for Government. Part of the problem was that there was a great interest, but the attention span was limited. Towards the end over, anything over three minutes, interest declines. Create an app, Isaac. Partner with Healthy Brains, Kat Hartley-Mack & Brook Hurd.

#### Grant Updates:

Jeff Doucet-

- Responsible for grants for the State of Nevada, for Dementia Friendly.
- 1<sup>st</sup> Alzheimer's Grant: Ends in September 2017, Toolbox for caregivers and patients with Alzheimer's. Not necessarily a renewable grant. There could be another competitive grant in the future. Part of the Affordable Care Act.
- 2<sup>nd</sup> Alzheimer's Grant: Expansion, focuses on early diagnosis and community involvement. Evidence-based care transitions model to reduce readmissions. Still working on details with ADRC. More information to come.
- 3<sup>rd</sup> \$1M grant, requires \$33,000 match. We have several partners, Dr. Carson, Dr. Peter Reed, Alzheimer's Association, Nevada Senior Services, and Cleveland Clinic. Calls for seven communities, but have not been identified yet, urban and rural. Grant started in September 2016, meant for 3 years. Currently meeting with federal partners. There is a connection to the Nevada toolbox, with outcomes and methodologies for selecting communities. February 6<sup>th</sup>, to identify the need and vetting process for selecting seven communities. Requesting input for selection process from Nicole Nalder, ADSD; Susan Hirsch, Nevada Senior Services; LeeAnn Mandarino, Cleveland Clinic; Kelli Kristo, Alzheimer's Association.
  - Task Force on Alzheimer's Disease (TFAD). January. Webpage. Nevadaadsd.gov, there are two documents describing grants there.
  - Task Force on Alzheimer' Disease: <http://adsd.nv.gov/Boards/TaskForceAlz/TFAD/>
  - Handouts: <http://adsd.nv.gov/Boards/TaskForceAlz/Agendas/> (January 11, 2017 Meeting Materials)
    - <http://adsd.nv.gov/uploadedFiles/adsdnvgov/content/Boards/TaskForceAlzheimers/Project%20Summary%20-%20Update%201%2011%202017.pdf>
    - [http://adsd.nv.gov/uploadedFiles/adsdnvgov/content/Boards/TaskForceAlzheimers/Dementia%20Grants%20Summary\\_December%202016.pdf](http://adsd.nv.gov/uploadedFiles/adsdnvgov/content/Boards/TaskForceAlzheimers/Dementia%20Grants%20Summary_December%202016.pdf)

#### Nevada Toolbox:

Jeff Doucet & Susan Hirsch-

- Toolbox focuses on care Consultation and awareness issues. Telephone based program for caregivers. Evidence-based program. All done by telephone, it is statewide. When you call in, an assessment takes 3-4 months to understand what their most critical concerns are. Working wherever the care partner is; lasts about a year, and may continue over time. There is opportunity for ongoing support. Care consultant delivers the intervention. Critical pieces is an empowerment program and a teaching tool. After receiving the support, they have the tools to teach and learn about what they do in a difficult situation. Benjamin Rose. No manual per se. Empowerment to help themselves. Received the Award for no deficiencies.

- Toolbox includes EPIC & CarePro: EPIC, delivered by Alzheimer's Association. CarePro, more intense, more detailed for caregivers.

Comments from the Nevada Toolbox & Grants Update:

- When we reach out. Reach out to Tech Companies, support does not have to be financial. Propose an exchange for promotion. UNLV has an excellent IT department. We have a spokesperson with collecting data. What do we fall under when applying for Grants? 501c How do we strategize? State Government. DFA is a 501c.
- We need to know where the patients and caregivers are.

Defining community action group:

Dr. Jennifer Carson-

- Defining geographic locations with Jennifer Carson.
- Dr. Jennifer Carson is co-facilitator with Dementia Friendly Nevada. New professor at UNR, Community Health Science. Doctorate at Waterloo, part of the A3 grant.
- Working in partnership in dementia care alliance to mobilize change at the Provincial Level to sustain engagement. Participated in a 2 year research program in partnership with people with Dementia. Worked with Geriatrician Dr. Bill Thomas, North American Tour, Sponsored by AARP. Disrupt Dementia Show, after each show Jennifer talks to people about DFA and Dementia Friends. Discuss how people can mobilize change in their communities. And teaches at UNR. Describes herself as a researcher and activist. She's a participatory action researcher with people living with Dementia. She facilitates community action groups. Jennifer role is to ensure people living with dementia are included in the process. Also the work is documented. She develops processes to reflect on how we are achieving our goals and aspirations. She helps communities make plans to make continued action.
- She will be utilized to help facilitate and to work alongside champions, support, document, reflect, and publicly share the action and great work you're doing. Jennifer will understand what each community action group is doing and cross pollinate success.
- Community Action Group comes with Jennifer and a graduate student to take copious notes. Comes with evaluation support from Sanford Center for Aging. Comes with start-up funds. A3 grant goals are 3 fold.
  - Identify own local dementia friendly goals.
  - Community action groups understand how we can create stronger awareness and participation with all of the resources through Nevada Toolbox. Increase access and participation.
  - To identify where there are gaps to develop new programs to meet community gaps.
- 7 community action groups. 3 this year. 4 next year. Champions attend steering committee meeting. Champions from community action groups to share successes. Statewide group on February 6, will be selecting first 3 Community Action Groups. Proposal process will be drawing on what dementia friendly America says, through their community readiness questionnaire. Steering committee will be selecting communities that are ready, but are hoping other community action groups will apply: Urban, Rural, North, and South. DFA: sometimes smaller is better. 2 community goals at a time, each year.

Comments/Suggestions on Community Action Groups:

- What have other urban communities have done? Do a little research on Dementia Friendly Seattle and Dementia Friendly Tempe, AZ. Ontario research. UK Dementia Friends.

### Concerns with Community Action Groups:

- Concern, because we are in our infancy and worried about biases. We want to define our own things. Can we stay our course, but still utilize our resources? Language in the grant is to identify dementia friendly goals through 4 sectors, each action group identify 2 goals. Only thing different is awareness and participation with Nevada Toolbox. Identify unmet needs. Never to express statewide agenda, but to help mobilize community action. We are identifying needs in the existing resources.
  - Response: It can evolve, community action groups do not to be absorbed in another agenda.
- The magic is what we do with our community. We can define it multiple ways. The problem would be, we have a lot of goals. The frame by Jennifer, looking at it in addition to patients but the care partners. As you look over the course of the illness, and the roles to some degree, there are emphases at different points of time. Our bias is the choices of where we want to live for the rest of our lives.
  - Response: Each community action group needs a minimum of 2 goals or more. Feel free to exceed.
- Have the casinos have adult day care? Like children care.
  - Response: Consider this as a potential action plan.
- Excellent program. The part I'm struggling with is buying in. Not only is it going to take buy in there is additional support. There is a task force step. The way to strengthen A3 is endorsement from subgroups. NASW would like to endorse and know what we're doing. At some point we really need to get to the frontline and our constituents. Education, empowerment, and a voice. What do the people of Henderson say? Buy in at the community level, as we go back to our respective places, we have to get the information out to these places. It has to get down to the roots. We have dynamic leadership. We need to know who are representing the people, "nothing about me, without me".
- We call Dementia Resources a Toolbox.
- Organization of Dementia Friendly America. Funding and population disbursement in the State of Nevada. Do we continue on our path or do we go into our smaller communities?
  - Pluses and minuses. Proposal process on Feb 6. We are looking at receiving 1/7 of the resources. We almost have to set up sub jurisdictions. It's a competitive process. Operating in a silo, currently we have a one up.
- Does everyone know that needs to know? Specifically talking about, "Do we put something in the news, about what Nevada has the opportunity in the bigger picture?" The more the community knows, the more people can make an informed decision. Concerned people have awareness, and buy in. On the ground level we need a way when we go to our representative places that information filters goes where the needs are.
  - Response: There is additional funding for A3 to achieve more than just 7 community action groups, maybe 50 community action groups. What supports success? Research and support. The 7 will be rigorously documented, evaluated, and disseminated as research stories in peer review journals and state-wide publications to learn from the 7.