

Dementia Friendly Southern Nevada
General Meeting

Date: Tuesday, February 28, 2017, 9:00AM-11:00AM

Attendance:

1. Isaac Santa Ana
2. Barbara Payne
3. Alonzo Thornton
4. Madison Lane
5. Sharon Goldstrohm
6. Connie Hollenbeck
7. Pappy Helgren
8. Jeff Doucet
9. Cheyenne Pasquale
10. Linoa Gelingier
11. Dona Liguori
12. Michelle Gold
13. Mario Guzman
14. Cassandra Cotton
15. Ed Martin
16. Anne Marie Martin
17. Patricia Stone
18. Cleveland Johnson
19. Daniel Stone
20. Corey Lutz
21. Virgil DeSio
22. Cary Huddleston
23. Kristopher Kaplan
24. Jane Bjorklund
25. Susan Hirsch
26. Marissa Shoop
27. Karen Taylor
28. Nichole Nalder
29. Kat Hartley
30. Julie McIntosh
31. Sue Woolf
32. Cindy Justensen
33. Karen Mariano
34. Aura Mungura
35. Katrina Fowler
36. Jacqueline Jones
37. Rowena Apuya
38. Cherrie Lugay

39. Gregory Martin
40. Steven McBride
41. LeeAnn Mandarino
42. Anish Puri

Alzheimer's Association
Cleveland Clinic

ADSD – Presentation of the Toolbox

- Building out the toolbox as a part of grant initiatives
- Cheyenne Pasquale
- Jeff Doucet – Grant Programs
- Marissa Schoop – Care partners Institute
- Polls on the Toolbox – Vast majority have heard of the toolbox, few have used the toolbox
- The No Wrong Door Initiative – 4 Key Components centering around getting public support
 - o Linking 211 with Resource Centers, Assess my Needs, State Services and Community Providers (essentially improving cooperatively between the different “sectors”)
- 4 Resource Centers in Southern Nevada
 - o Provide services to anyone (income, disability, and all are discounted)
 - o Options Counseling, helps individuals understand information that can be complex, contradictory or confusing.
 - o Also provide caregiver support and veteran services
- NevadaCareConnection.org
 - o Self Assessment
 - o List of Resource centers
 - o Caregiver Section
 - Information on the Toolbox, Respite services
- The Caregiver Toolbox
 - o Alzheimer's Federal Grants have discovered needs
 - o Partners
 - o Dementia Specific
 - o Caters to All populations
 - o CarePRO
 - Psychoeducational
 - Skills Building
 - Group Based Intervention
 - How many sessions a year? 4
 - o Early Stage Partners in Care
 - Early Stage Alzheimer's or other Dementia
 - 6 Group Sessions and 1 at home session
 - o Respite Education and Support Tools (REST)

- Train the Trainer
 - Provides skills and tools needed to provide quality respite
 - Care Consultations
 - Educational Programs, Support Groups, Community Resources
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- Marissa: Caregiver Support – Provides education to caregivers how to be effective caregivers
 - BRI Care consultation
 - Telephone Based Support
 - Evidence based Care Coaching Program
 - RCI Reach Program
 - Caregivers of people with Alzheimer’s or other forms of dementia
 - 1:1 Caregiver support and education program
 - No waiting list
 - How many people are utilizing these programs
 - Care Connection Resource Center → Over 1,000 Consumers
 - Reach Program → About 120 Clients
- Idea that the most important thing to do is create a **continuum** and linkage between all the programs
- Audience comments on the effectiveness of the Care Support Program → **highly effective**
- How is this information getting out? What are the outreach programs → **connecting with community partners, health fairs, etc.**
- What is next? Care Transition program, Expanded Early Stage Engagement and Dementia Friendly Nevada
 - Working with Alzheimer’s Association to Destigmatize Alzheimer’s.
 - Expand Early Stage Engagement

Kristopher Kaplan

- Presentation of different Dementia Friendly Programs around the Nation
 - Minneapolis (Largest Dementia Friendly Program)
 - Wisconsin (Not officially with Dementia Friendly, but quite well situated)
- Care Partner Analyses
 - 57 Questionnaires submitted
 - Over 10 years of experience on average
 - 5 community Strengths
 - Adult Day Care
 - Alzheimer’s Association
 - Family, Friends, Volunteers
 - 5 community weaknesses
 - Affordable Care Services
 - Early Detection, Diagnosis
 - Dementia Awareness
 - Belief that there needs to be more awareness of resources

Community Action Plans Strategies

- **Susan Hirsch:** Thinking outside of the box. Every program has more capacity due to the fact that many of the services are free (Toolbox, etc)
 - o Determine which services are affordable and which are not (Sometimes it IS the issue, but sometimes it isn't)
 - o Determine a way to create more awareness. What motivates people to ask for help
- Affordability is not the issue but rather the access to care. Most services are only available during business hours, while a caregiver's job is 24/7. We have the framework for services but the access needs to be improved. We need to meet people at the point of need in their environment which is convenient to them (transportation, timing, etc).
- Targeted Outreach? Essentially the idea of meeting people where they are at, where it is convenient for them. Hospital Emergency Rooms, Clinics, Homeless Prevention Programs, Veteran Service, Physician offices, Senior Centers, Wellness Centers. Reach out to organizations like MTFs, Nursing Boards.
 - o Nurses don't need to provide care but provide awareness since they have so much interaction with patients.
- What do we have control over? Figure out what we can actually affect and attack those points. Community Outreach isn't necessarily about education but rather about engagement. Have to go to where people are. Health Fairs are **not effective**. We need to get people sitting, talking and having conversations. Small groups so that people are engaged and interested → take the idea home.
- **Alonzo:** What is the marketing plan though? Dementia Friendly Services should be on every government document and application. The community has to know that the services are AVAILABLE. The toolbox is extremely strong, now individuals need to know that the toolbox is there. Once we get the data collected, we need a good marketing plan. Form a partnership with federal groups and give the general public the knowledge that dementia resources are available. On the applications there should be a checkbox for dementia services (applications for Medicare, etc.)
- One thread that is consistent with patients. **How did I get here? Why didn't my doctor diagnose me earlier?** Go to the Doctor, get people to the doctors and EDUCATE THE DOCTORS since they are not educated in this field enough.

- Reaching out to the Faith community? Go to institutions that individuals go to on a regular basis. How do we plug back into the “trusted advisors”? How do we connect to daily life, as well as the professional communities? Alzheimer’s and Dementia is one of the most feared diseases. People are scared of losing their lifestyle. How do we deal with the stigma at a **DAILY LEVEL?**
- Bring together multiple groups of care partners to see where they got their resources
- Nurses are not aware of what they are dealing with. ER situations are not conducive to dementia. Individuals regress without their loved ones. Food situation in the hospital? Caregivers should never be separated from their loved ones with dementia, yet nurses don’t have time and nurses don’t understand the importance that regression is going to happen. Nurses need to be educated on the disease.
- Focus group with the “face of dementia” – **Patricia.**
 - o Do we have patient and caregivers together?
 - Some individuals say NO due to caregivers/patients not sharing enough information because they don’t want to hurt feelings.
 - o Do we have multiple focus groups in the different areas of Vegas?
 - o Teleconference?
 - o Jacky – North Las Vegas
 - o Susan – Wherever
 - o Alonzo – Boulder City
 - o Karen Barbara – Pahrump
 - o Madison – Henderson/Blue Diamond/Green Valley
 - o Create a structured set of questions so that it is standardized.
- Channel 2? Community Channel

Need to think of a set of questions or conversation starters for the focus group.

Susan – Think outside of the box to find something affordable. Every program has more capacity, it's important to differentiate what services are free and what are not. It's important to find out what information is important and what is not. We try to do the same thing over and over and it's not working. We need to communicate more effectively. We have not been successful in reaching out to the faith community whatsoever. By the time we get to a social worker or other place, it is too late. We need to think about how we can connect to people in their daily life that way we can get them help before it's too late. People are scared to admit they have a memory disorder because of the stigma and the potential negative outcomes that may occur. Need to get information straight from the caregivers (multiple focus groups?) to find out what works, what doesn't, what needs improvement, etc.

The people that have direct contact with the patient could be the voice of the patient or the voice of the caregiver. Somebody that understands what is really going on. And we could do this during our focus groups, which could be located at multiple locations across the city.

Caregivers are having to stay in ER's for weeks at a time because our healthcare system is unable to help. Separation from the caregiver causes regression and it's imperative that this disconnect doesn't occur. It's difficult because caregivers aren't able to receive help or attend groups because they are too busy taking care of their loved one. We would need to do these groups with the caregiver and the loved ones at the same time.

People are in a crisis situation and the first questions caregivers receive are "What do I do?" and "Where do I go". It would be nice to have available resources to answer these questions at that moment in time.

A lot of this has to deal with accessibility of services. It's not convenient because the hours of these services do not co-align with caregiver's needs (such as on the weekend and outside of 8-5). We need to meet people at their point of need, in their environment, and on their time. People struggle due to socioeconomic status and this hinders their access to care. People are going to clinics and hospitals to receive care that's not really necessary but we could meet them at this point of contact. Target outreach defined as meeting them where they are at rather than handing out resources. Catholic Charities has hundreds of people that we could provide information to on the ground floor. Inviting people to us does not work so we must go to them. Patient application services and wellness centers. Reach out to groups such as MFTs, counselors, social services, nursing boards.

We need to get people to go back to their doctors (PCPs) and see how they got there.

Attack what we can control and don't fret about the things we can't. Community outreach is more about engagement rather than education. We need to go where the people are. We need to get people in a small setting where they can grasp the information about what is being presented and then go home and apply that and come back later and ask questions.

Alonzo – Dementia Friendly services should be on every document or application that goes out for assistance. (Think along the same lines as receiving housing, food, medical care). This should be as comfortable as receiving care in other avenues. Perhaps a marketing plan that we could co-align with our legislature. All about trying to get rid of the stigma and setting up a care plan from the onset of the disease.