

December 14, 2017

Dementia Friendly Washoe County: Community Assessment

A Community Action Group of the Nevada
Aging and Disability Services Division
Dementia-Friendly Nevada Initiative

Prepared by: Zebbedia Gibb and Peter Reed



University of Nevada, Reno
School of Medicine
Sanford Center for Aging

KEY FINDINGS

- According to the Nevada State Demographer, there are an estimated 6,390 individuals aged 65+, including 1,706 individuals aged 85+, living with dementia in Washoe Co.
 - It is estimated that 913 of those individuals aged 65+ who are currently living with dementia live alone.
- 483 residents of Washoe County completed the Community Awareness Survey, 85% of which were completed online.
- Top sectors completing the survey were: Government Agencies (14%), Libraries (16%), and Community Based Supports / Services (13%).
 - Of note, the business / retail sector comprised 5% of responses.
- 80% of respondents reported some form of personal relationship with someone who is currently living with or who had lived with dementia.
- Overall, respondents in Washoe County reported positive attitudes toward individuals living with dementia with a score of 106/140 (75%).
 - Respondents reported a moderately high level of comfort in engaging with individuals living with dementia 53/84 (63%).
 - Respondents reported relatively high knowledge 46/56 (82%).
- Considering sectors, individuals from Residential Care (122) reported the highest positive attitudes, whereas individuals from the business/retail and government sectors (103) reported the lowest score.
- Key community strengths reported include: 1) area support groups, 2) several specific community-based organizations, and 3) general community based supports and services.
- Key community gaps/weaknesses reported include: 1) education regarding dementia, 2) lack of awareness of community-based supports, and 3) the cost associated with care of individuals living with dementia.
- Key community resources recommended include: 1) the Alzheimer's Association, 2) a clinical service provider, and 3) ADSD and county services.
- Service priorities, as ranked by the community were: 1) raising awareness of available resources and supportive services, 2) raising awareness of the warning signs of dementia, 3) increasing staff and volunteer training in helping individuals with dementia, 4) increasing available dementia related resources, and 5) increasing community members' skills in interacting with individuals with dementia.

PROJECT OVERVIEW

The Dementia-Friendly Nevada initiative, led by the Nevada Aging and Disability Services Division, is intended to engage community action groups (CAGs) across the state in developing local priorities for enabling people living with dementia to live well within the community. To inform community dialogue, the Sanford Center for Aging conducted a comprehensive community assessment, determining the current status within each community. Specifically, this evaluation project was undertaken to develop an understanding of individual community dementia capability based on existing and new data sources within Washoe County. To that end, population estimates were calculated, estimating: 1) the number of elders (individuals aged 65+) who were currently living with dementia, 2) the number of elders aged 85+ who were currently living with dementia, and the number of elders 65+ who were currently living alone with dementia within the community. These estimates are based on the formula provided by Dementia Friendly America and use data obtained from the Nevada State Demographer. In addition to this demographic information, two surveys were conducted by the Sanford Center for Aging to determine: 1) community leader knowledge of state-wide programs for individuals with dementia, and 2) basic community attitudes and knowledge of dementia and dementia related services within the county. This report details the findings of each of these community assessments in Washoe County.

DEMOGRAPHICS OF DEMENTIA

To estimate the number of individuals currently living in Washoe County with dementia, data was gleaned from the Nevada State Demographer. Overall, it is estimated that 11% of elders aged 65+ within Washoe County are living with dementia. This estimate increases to 33% for elders aged 85+ within the community. Of those elders 65+ who are currently living with dementia, it is estimated that 14% live alone. Table 1 presents data estimates of the elder and dementia population in Washoe County.

Table 1: 2016 Estimated Demographics – Washoe County

	Nevada State Demographer
Total Aged 65+	57,509
Est. Total with Dementia	6,390
Est. W/ Dementia Living Alone	913
Total Aged 85+	5,118
Est. Total With Dementia 85+	1,706

Additionally, the Centers for Medicare and Medicaid Services (CMS) estimated that approximately 8.22% of Medicare beneficiaries, or 4,226 individuals, received services for Alzheimer’s disease or related dementia in 2015 within Washoe County¹.

¹ The most current year data has been released by CMS. Data can be found at www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Dashboard/chronic-conditions-county/cc_county_dashboard.html

DEMENTIA-SERVICE RELATED KNOWLEDGE

To understand the level of knowledge regarding services specifically targeted towards individuals living with dementia currently offered through the state, a short survey was administered to the 22 Washoe County Community Action Group members. This survey assessed knowledge regarding the state’s ‘dementia toolbox’, as well as additional programs that may be available in the community. Most toolbox programs are offered by the Alzheimer’s Association, including the Early Partners in Care (EPIC) program, the Care Partners Reaching Out (CarePRO) program, along with the Association’s other core services, such as education and support groups. In addition to these services, as part of the Nevada Dementia Toolbox, Nevada Senior Services offers the BRI/RCI Care Consultation model via telephone across the state.

This survey asked about respondents’ awareness of the specific programs in the dementia toolbox, and if the respondents were aware of the service, asked about their level of knowledge regarding the programs. A majority of the respondents (15) were aware of the core services offered by the Alzheimer’s Association, as well as the EPIC program. A minority (7) reported knowing about the services provided by Nevada Senior Services. Of those respondents who reported being aware of the programs, most reported little to no knowledge of the specifics about the program. A little over half of respondents were able to identify other resources for individuals with dementia living in Washoe County, including long-term care resources and community based supports (Table 2).

Table 2: Knowledge Regarding Dementia Services in Washoe County (n=22)

	Aware	Very / Quite Knowledgeable	Little / Not at all Knowledgeable	No Prior Knowledge
Nevada Dementia Toolbox	14 (64%)	4 (18%)	11 (50%)	7 (32%)
EPIC Program	20 (91%)	6 (17%)	14 (64%)	2 (9%)
BRI Care Consultation	7 (32%)	2 (9%)	5 (23%)	15 (68%)
CarePRO	12 (55%)	7 (32%)	5 (23%)	10 (46%)
AZ Core Services	19 (86%)	6 (27%)	14 (64%)	2 (9%)
Other County Services	11 (52%)	~	~	~

Note. ~ Specific question not asked across participants. Knowledge question only asked of those individuals who reported knowing about the service. One participant did not answer the question regarding other community services.

COMMUNITY DEMENTIA ATTITUDE SURVEY

To assess community attitudes regarding dementia, the Sanford Center for Aging developed a survey intended to be administered community-wide to any community members willing to provide their perspectives. Attitudes were assessed in this survey using two tools selected by the Sanford Center for Aging. First, participants completed basic demographic questions, including a question asking them to identify the specific sector that they represent. Next, the Dementia Attitude Scale (O'Connor & McFadden, 2010), a scale designed to measure attitudes towards people living with dementia, was completed. The goal of this measure was to determine the attitude of the community at large towards individuals living with dementia. Finally, participants completed questions to assess their personal experiences with people with dementia, as well as their experiences with dementia-related services within the Washoe County community.

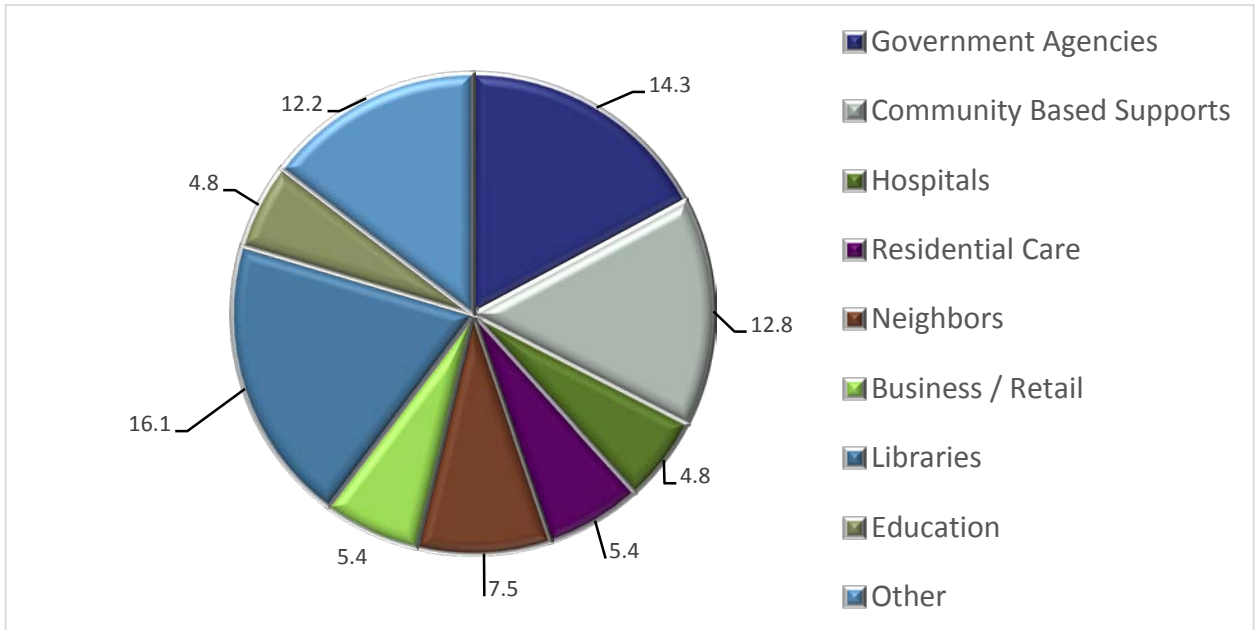
A total of 483 Washoe County community members completed the survey, either online or through a paper survey administration during the Fall of 2017. A paper version of the survey was administered to members of the community by community action group members at several locations within Washoe County, resulting in 74 (15%) completed surveys. Members of the community action groups also helped spread the link to the online survey via their electronic personal and professional contact lists, resulting in 409 additional community members (85%) completing the survey.

To help identify if the link spread outside of Washoe County, participants were asked to report their mailing zip code. Participants who did not report one of the zip codes belonging to Washoe County were excluded from the current data analysis (see Appendix D for zip codes identified in the current study as belonging to Washoe County). A zip code analysis indicated that 115 (24%) online survey respondents and 4 (1%) paper survey respondents were from outside Washoe County, while 23 (5%) did not provide a zip code. These surveys were excluded from analyses, as the major goal of the current assessment is to determine the attitudes and needs of individuals living within Washoe County. These exclusions resulted in a total of 341 surveys analyzed for the Washoe County results.

BASIC DESCRIPTION OF RESPONDENTS

A majority of respondents to the survey were non-Hispanic White/Caucasian (87%), women (82%), and approximately middle aged (56.3), with ages ranging from 19 to 95. Respondents were primarily employed in government (14%) or libraries (16%). Additionally, some respondents reported working at either local hospitals (5%) or residential care homes (5%; Figure 1). An additional 12% selected 'other' as their occupation.

FIGURE 1. PERCENT REPRESENTING SPECIFIC SECTORS



A majority of respondents (80%; Figure 2) reported having personal experience with someone living with dementia. The most common relationship type between the respondent and the individual with dementia was other relative (63%), with a parent (48%) the next most likely (Figure 3).

FIGURE 2. PERCENT REPORTING HAVING PERSONAL EXPERIENCE WITH DEMENTIA

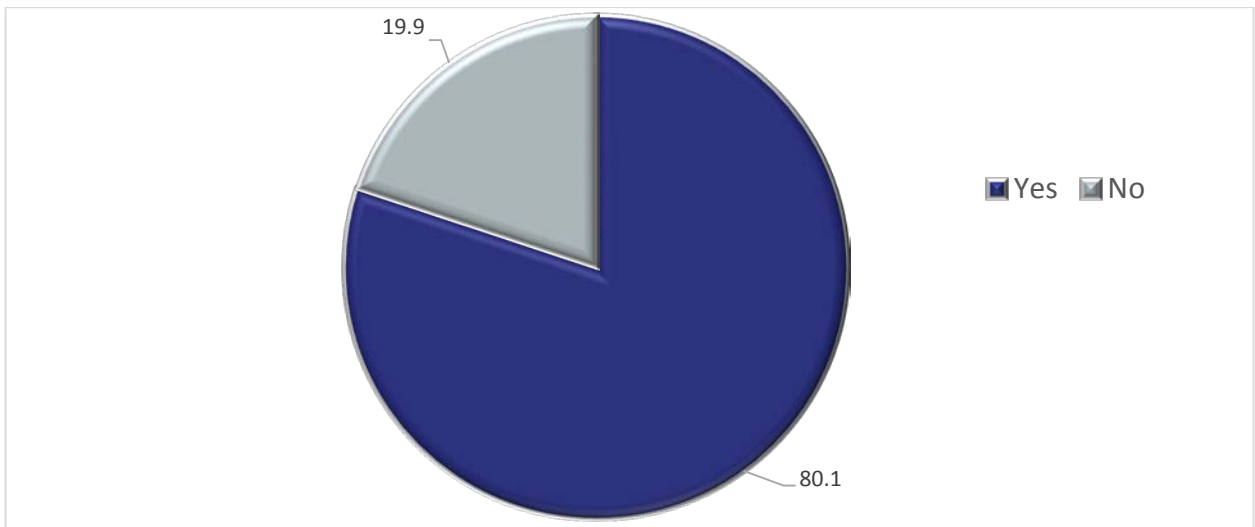
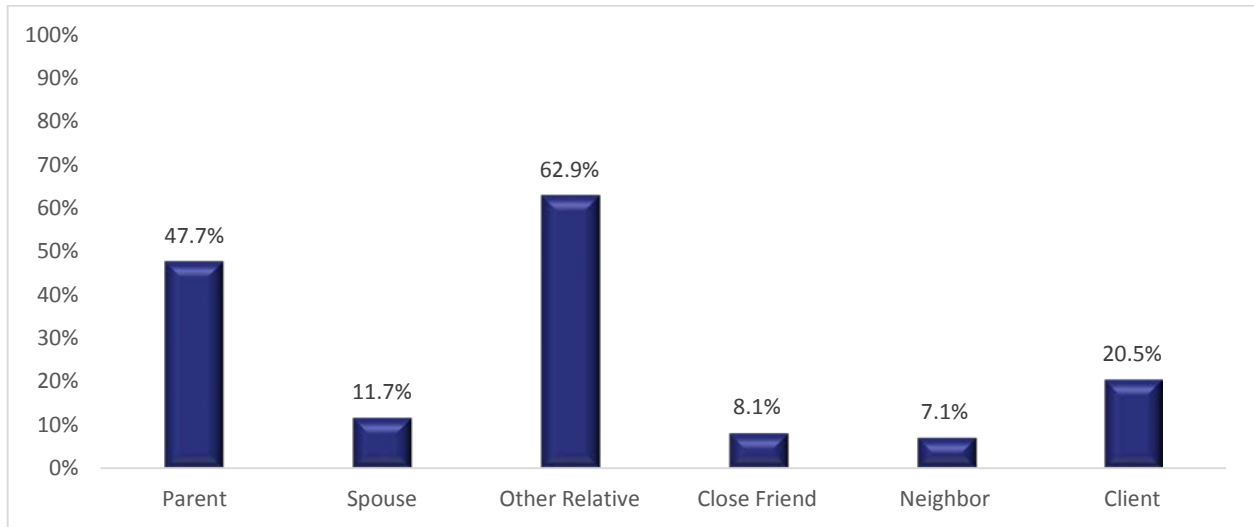


FIGURE 3. PERCENT REPORTING RELATIONSHIP BETWEEN SELF AND INDIVIDUAL WITH DEMENTIA



Note: Percents are not cumulative as multiple relationships could be reported. Other relative includes grandparents as well as in-laws. Client includes individuals listed as patients of the respondent.

DEMENTIA ATTITUDES

The Dementia Attitude Scale (DAS) was chosen to measure respondent attitudes towards individuals living with dementia. This scale consists of 20 items and contains two sub-scales (see Appendix H for scale items broken down into sub-scales). The first sub-scale is labeled “social comfort” and contains items measuring an individual’s overall comfort level interacting with individuals living with dementia. The second, “dementia knowledge” contains items measuring individual knowledge regarding dementia and the experience of living with dementia. Subscale items are listed in Appendix H. Full results of the DAS are presented in Table 3.

Possible scores range from 20 to 140 on the DAS. Overall, Washoe County community members reported generally positive attitudes toward individuals living with dementia, with a score of 106, or 78% of the possible positive score.

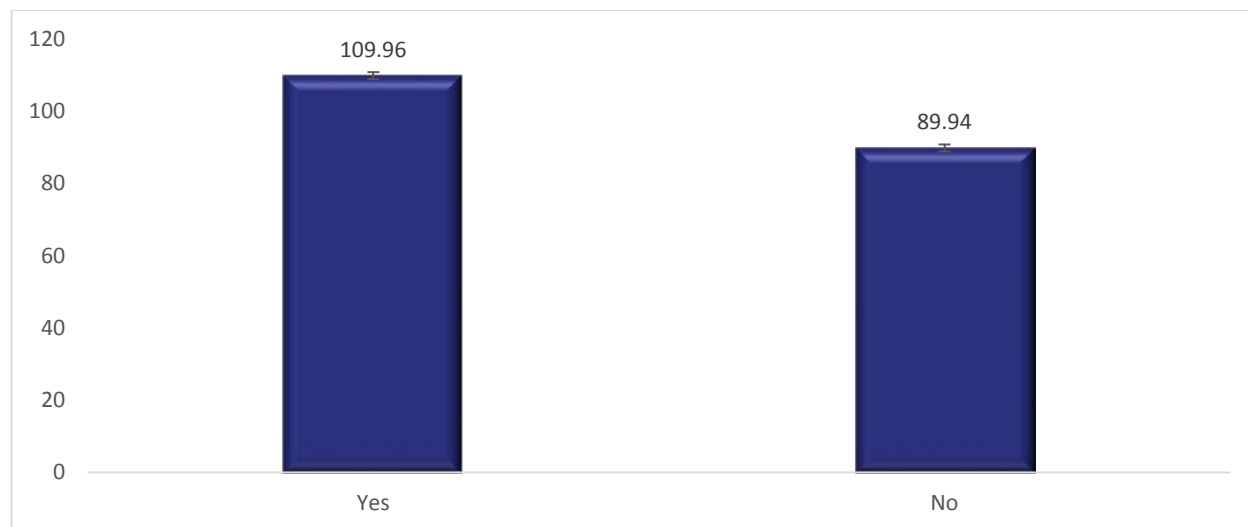
- With a possible range of 12 – 84, Washoe County community members scored a 53 (63%) on the social comfort subscale.
- With a possible range of 8 – 56, Washoe County community members scored a 46 (82%) on the dementia knowledge subscale.

Table 3: Means and Standard Deviations for DAS by Specific Demographic Groups (n=341)

	Overall		Subscale 1: Comfort		Subscale 2: Knowledge	
	<i>Range: 20 – 140</i>		<i>Range: 12 – 84</i>		<i>Range: 8 - 56</i>	
	Mean	SD	Mean	SD	Mean	SD
Overall Sample	106	18.90	53	8.07	46	7.87
Gender						
Male	102	19.83	52	8.14	43	9.53
Female	107	17.47	53	8.01	47	7.38
Online	106	17.86	43	7.98	46	7.80
Paper	105	18.25	52	8.67	45	8.31

Further, there was a clear difference in positive views of individuals living with dementia between respondents reporting that they know a person living with dementia versus those who do not, similar to results reported by the authors of the scale (See Figure 4).

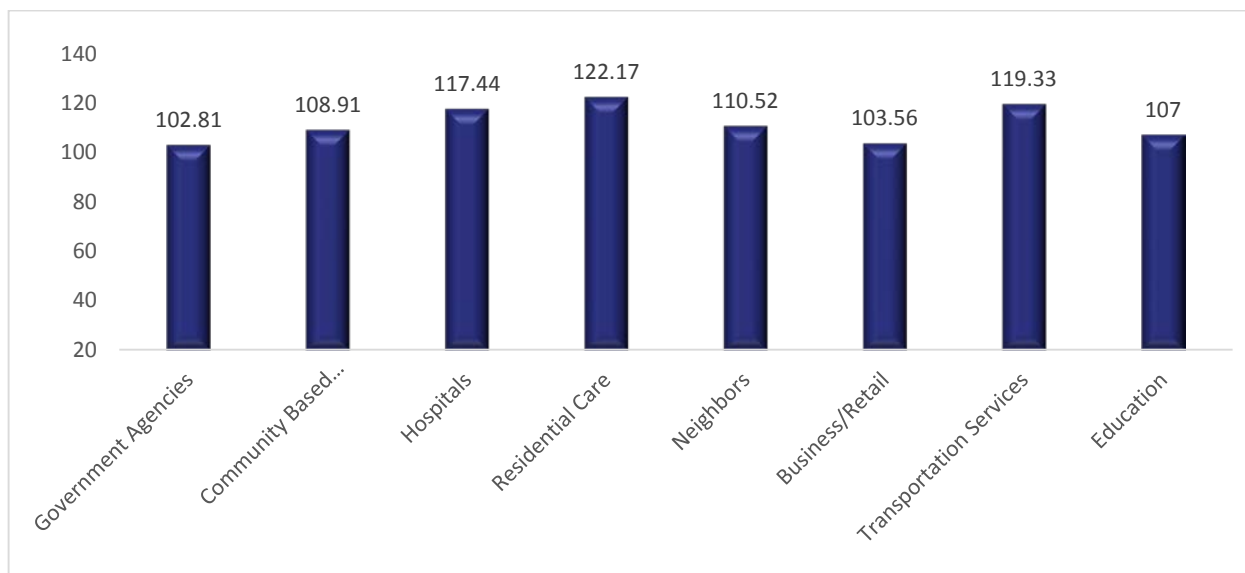
FIGURE 4. MEAN DEMENTIA ATTITUDE SCORE BY KNOWLEDGE OF ANOTHER LIVING WITH DEMENTIA



There were also differences between respondents’ views regarding individuals living with dementia depending on which sector the respondent reported representing (See Figure 5). Individuals who reported working in the transportation sector, residential care homes and

hospitals reported holding higher levels of positive attitudes toward individuals with dementia than the other sectors. It is important to note that, perhaps with the exception of transportation, these sectors are more likely to be exposed to individuals who are living with dementia than the other groups. This exposure is likely to influence the overall perceptions of these individuals. Additionally, it is important to note that only 3 respondents reported working for the transportation sector, likely skewing this number.

FIGURE 5. MEAN DEMENTIA ATTITUDE SCORE BY SELF-REPORTED SECTOR



Note. Scores could range from 20 – 140.

STRENGTHS WITHIN WASHOE COUNTY FOR INDIVIDUALS LIVING WITH DEMENTIA

Individual participants were asked to report what they viewed as the strengths of Washoe County in regards to meeting the needs of individuals living with dementia. In total, 166 individuals commented on this question.

Some people (n = 47) listed area support groups, including support groups offered by the Alzheimer’s Association. Several organizations were mentioned by name, including the Alzheimer’s Association (n = 35), the Sanford Center (n = 12), and The Continuum (n = 8) as strengths within the community. Participants also reported community based supports more generally (n = 23) as well as the community’s efforts to help individuals living with dementia (n = 11). Complete comments are provided in Appendix E.

Five individuals reported they were unaware of any strengths within the community or that they had no experience with dementia services within the community.

GAPS WITHIN WASHOE COUNTY FOR INDIVIDUALS LIVING WITH DEMENTIA

Similar to the strengths of the Washoe County community, individuals were also asked to report on the perceived gaps within the community for individuals living with dementia. In total, 178 individuals commented on this question.

The highest responses were from people who reported that they felt Washoe County lacked education regarding dementia (n = 39), a lack of overall awareness of resources (n = 23), as well as the cost of care for individuals living with dementia (n = 22) and a lack of clinical services for individuals living with dementia (n = 22). Additionally, participants reported that transportation was an issue (n = 20) as well as respite (n = 16) and they felt community-based supports (n = 15) were lacking within the Washoe County community. For complete comments, see Appendix F.

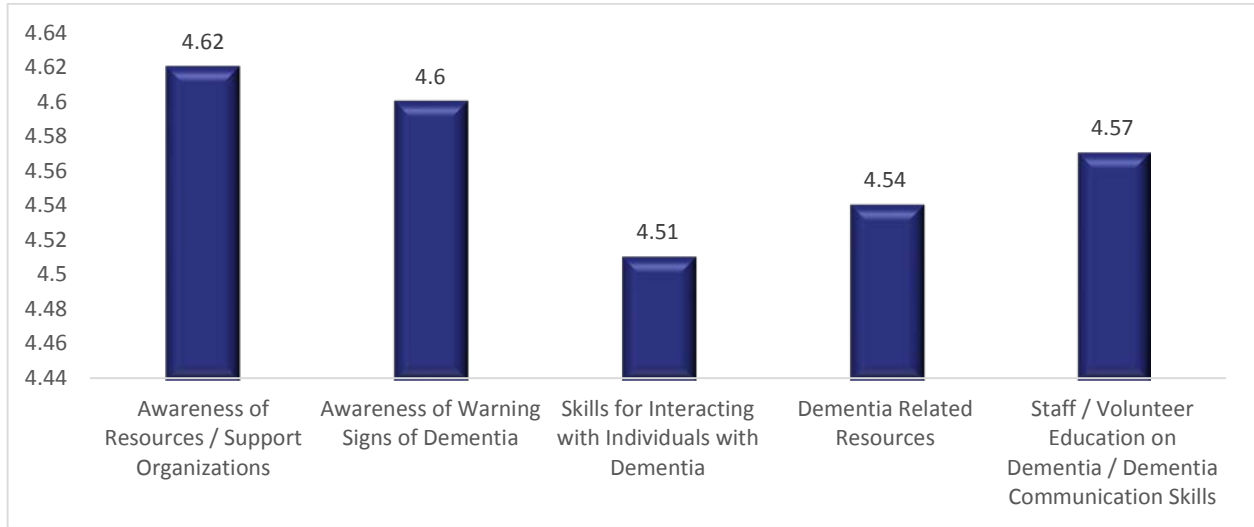
RECOMMENDED RESOURCES FOR INDIVIDUALS LIVING WITH DEMENTIA

Participants were also asked to report what resources, if any, they would recommend to others who had either received a recent diagnosis of dementia, or who had had a family member or care partner diagnosed with dementia. A large minority (n = 86, 47%) of respondents indicated that they would recommend the Alzheimer's Association, with the next most common recommendation seeking help from a primary care provider (n = 23), ADSD (n = 20) or Washoe County (n = 18). In addition, an approximately equal number of people reported that they would recommend The Continuum (n = 17), the Sanford Center (n = 17) or a general adult day center (n = 14) to others who had received a dementia diagnosis. Complete comments are provided in Appendix G.

SERVICE PRIORITIES FOR WASHOE COUNTY

Finally, participants were asked to independently rate several pre-selected priorities. Priorities were ranked from High (Strongly Agree) to Low (Strongly Disagree). No participant rated any priority as low (Strongly Disagree / Disagree), although a minority did report some of the priorities were only moderate (Neither Disagree / Agree). Mean scores for each priority are presented in Figure 6. Overall, respondents reported that increasing education regarding the warning signs of dementia and awareness of resources and supportive services should be the highest priorities (4.6). Providing training for staff and volunteers on dementia and dementia related communication techniques, increasing dementia related resources, and increasing community members skills in regards to interacting with individuals with dementia were approximately tied, although increasing staff and volunteer training was slightly higher than the other two. These results mirror the frequency that education and awareness regarding resources were identified as a gap for Washoe County.

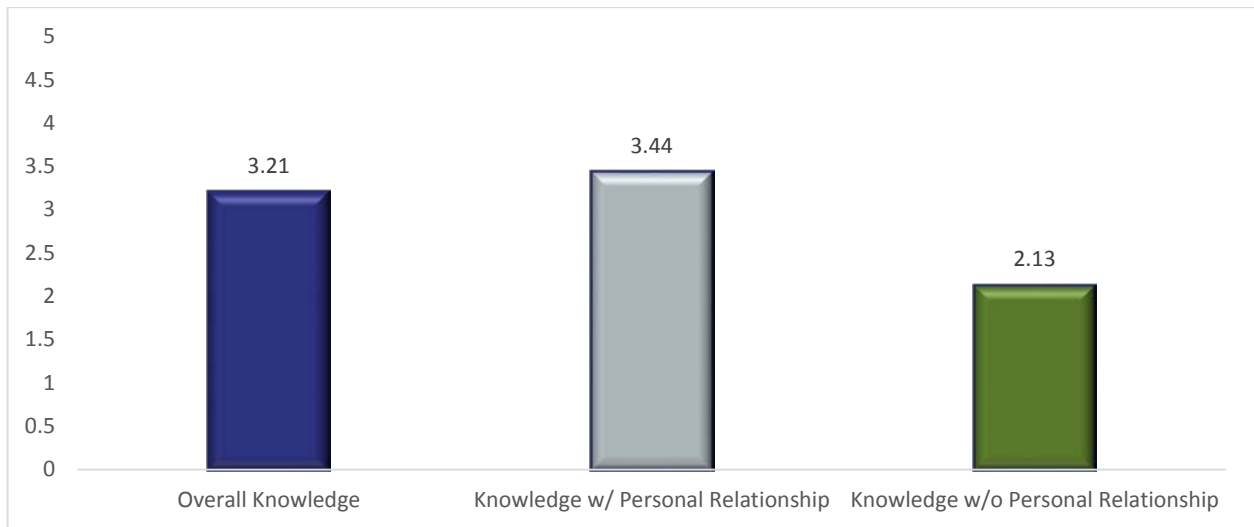
FIGURE 6. PRIORITY FOCUS AREAS FOR DEMENTIA-FRIENDLY WASHOE COUNTY



Note. Scores could range from 1 (Strongly Disagree) to 5 (Strongly Agree).

As noted above, participants reported that increasing the overall knowledge of the warning signs of dementia should be a high priority. Overall, Washoe County respondents reported a moderate (3.21) level of knowledge regarding these signs, with individuals who reported a personal experience with dementia reporting a higher familiarity (3.44) than those who reported not having a personal experience with someone living with dementia (2.13; Figure 7). Early detection of dementia has benefits for the person receiving the diagnosis, often allowing for more effective treatment options and a greater involvement in their overall care plan. Additionally, early detection allows for the earlier activation of resources, decreasing overall caregiver burden.

FIGURE 7. MEAN DEMENTIA KNOWLEDGE OF 10 WARNING SIGNS



Note. Scores could range from 1 (Not At All Knowledgeable) to 5 (Very Knowledgeable).

APPENDIX A: SUMMARY OF PHASE 1 MATERIALS

Table A1

Summary of Phase 1 Materials

Evaluation Goal	Measure Name
Determine community readiness to engage in dementia friendly activities	Dementia Friendly RFP
Determine basic demographics of individuals living with dementia within Washoe County	Dementia Friendly Initiative Demographics Sheet
Determine initial knowledge of dementia specific programs of community leaders within Washoe County	Dementia Toolbox Programs Awareness Survey
Determine community members' basic attitudes towards individuals with dementia, as well as personal experience with individuals with dementia and dementia related services	DAS / Dementia Friendly Initiative Community Member Questionnaire

APPENDIX B: WASHOE COUNTY RFP

APPLICATION FORM Section A:

Contact Information Applicant/lead agency:

Jacob R. Harmon, Regional Director, Alzheimer's Association, Northern Nevada
1301 Cordone Ave, Suite 180
Reno, NV 89502
775-786-8061
jharmon@alz.org

Name or description of community or communities within the project:

Reno and Sparks, also some outlying communities in Washoe County.

Preferred start date for funding (circle one): **May 2017** or January 2018

Contact person: Jacob R. Harmon

Mailing address: 1301 Cordone Ave, Suite 180, Reno NV 89502

Telephone: 775-786-8061

Fax number: 775-786-1920

Email address: jharmon@alz.org

Name, address, and signature of person authorized to submit an application for funding and commit the applicant organization to the project:

Jacob R. Harmon, Regional Director, Alzheimer's Association, Northern Nevada
1301 Cordone Ave, Suite 180
Reno, NV 89502
775-786-8061
jharmon@alz.org

(The narrative descriptions for Section B should not exceed two (2) single-spaced typed pages in a minimum of 12-point font.) Section B:

Community Readiness Questions 1. Can you identify several organizations and individuals, including representatives from at least four (4) community sectors, who are willing to be involved in a community action group to collectively address how to become dementia friendly and inclusive? **Yes**: No: Maybe, with these conditions/exceptions:

Please describe: (While it is not required, please attach any letters of commitment from potential community action group members)

We have hosted several Dementia-Friendly Nevada meetings in Reno with consistent and dedicated participation from not only people living with Alzheimer's and their family carepartners, but also service providers, local government, law enforcement, hospitals, retail, community faith organizations, financial institutions, and transportation sectors.

The list of willing partners in the Reno/Sparks area is:

UNR, Washoe County Sheriff's Department, Reno Police Department, Sparks Police Department, Reno City Council, Washoe County Board of Commissioners, Catholic Charities, AARP, Truckee Meadows Parks Foundation, Epworth United Methodist Church, United Federal Credit Union, Regional Transportation Commission, REMSA, Edward Jones, The Alzheimer's Association.

2. Does your community have an influencer/champion who is willing to endorse, kick off and co-facilitate a community action group and serve on the Statewide Advisory Team, and who can help the broader community commit to dementia friendly and inclusive principles? **Yes:** No: Maybe, with these conditions/exceptions:

Please describe: We have several different options ranging from people like Dr. Peter Reed, who have expertise in this area, to George Stewart, a representative of a local bank, who has a lot of interest. The Alzheimer's Association would engage with all of these folks to bring together a community action group who would then select their representative to the Statewide Advisory Team. Additionally, several city council members and county commissioners are willing to serve as champions for this discussion.

3. Has your community shown an interest in dementia awareness, dementia capable, dementia friendly, or dementia inclusive initiatives in the past, specifically through involvement in local or regional efforts or related initiatives? **Yes:** No: Maybe, with these conditions/exceptions:

Please describe: Not only have we hosted several Dementia-Friendly Nevada meetings, but Reno has also hosted several well attended presentations and performances aimed at raising awareness about dementia and our community's capability to support citizens living with Alzheimer's. Additionally, we have local officials who have identified dementia as a priority for them, and are working with us to start the process of social change to enable citizens living with dementia to participate in our community more completely.

4. The process for becoming dementia friendly takes at least 18 months and is ongoing. With support from ADSD project partners, it engages the community through a community assessment, followed by data analysis and reporting, and then developing and implementing an action plan that addresses at least two (2) dementia friendly goals. Do you believe that with support your group can follow and accomplish this process? **Yes:** No: Maybe, with these conditions/exceptions:

Please describe: The group that has met in Reno several times has lots of ideas and enthusiasm, but requires some guidance and focus through a process of facilitating a community conversation.

This survey is part of an evaluation of Dementia Friendly Nevada, funded by the NV Aging and Disabilities Services Division

APPENDIX C: PROGRAM AWARENESS SURVEY

Dementia Care and Support Services Awareness Survey (pre)

Thank you for agreeing to complete this short survey designed to measure public understanding of Nevada’s ability to provide care and supportive services to individuals living with dementia and their care partners. These responses will be used to help raise awareness of these services, as well as to implement new services in your community. Please mark only one response per question.

Thank you.

What is today’s date? _____

1. Are you aware that there is a *Nevada Dementia Supports Toolbox* of care and support services hosted by the NV Aging and Disability Services Division?

Yes No

IF YES: How knowledgeable are you about the *NV Dementia Supports Toolbox*?

Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

2. Are you aware of the Early-Stage Partners in Care (EPIC) program offered by the Alzheimer’s Association?

Yes No

Dementia Friendly Nevada Initiative – Washoe

This survey is part of an evaluation of Dementia Friendly Nevada, funded by the NV Aging and Disabilities Services Division

IF YES: How knowledgeable are you about the EPIC program?

- Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

3. Are you aware of the Benjamin Rose Institute (BRI)-Care Consultation program offered by Nevada Senior Services?

- Yes No

IF YES: How knowledgeable are you about BRI-Care Consultation?

- Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

4. Are you aware of the Care Partners Reaching Out (CarePRO) program offered by the Alzheimer's Association?

- Yes No

IF YES: How knowledgeable are you about the CarePRO program?

- Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

Dementia Friendly Nevada Initiative – Washoe

This survey is part of an evaluation of Dementia Friendly Nevada, funded by the NV Aging and Disabilities Services Division

5. Are you aware of the core services provided by the Alzheimer’s Association (Information & Referral, Care Consultation, Education, Support Groups, and Safe Return)?

Yes No

IF YES: How knowledgeable are you about the core services provided by the Alzheimer’s Association?

Very Knowledgeable Quite Knowledgeable A Little Knowledgeable Not at all Knowledgeable

6. Within Elko County, are you aware of any other community programs that offer care and/or support for individuals living with dementia or their care-partners?

Yes No

IF YES: Please provide the names of these programs in the spaces below.

Dementia Friendly Nevada Initiative – Washoe

This survey is part of an evaluation of Dementia Friendly Nevada, funded by the NV Aging and Disabilities Services Division

Please tear off this sheet and turn it in separately.

Would you be interested in helping create a dementia friendly community?

Yes No

Would you like to be periodically updated on how the project is progressing?

Yes No

If you marked “Yes” to either question above, please tell us your contact information below.

Name:

Mailing
Address:

City:

Zip Code:

Phone Number:

Email Address:

APPENDIX D: WASHOE COUNTY ZIP CODES

Table D1
Zip Codes Identified as Being Within Washoe County

89508	89502
89405	89412
89450	89451
89424	89510
89501	89519
89512	89521
89511	89503
89523	89509
89506	89502
89441	89434
89431	89436
89433	89439
89442	89704

APPENDIX E: STRENGTHS WITHIN WASHOE COUNTY FOR INDIVIDUALS LIVING WITH DEMENTIA (DIRECT COMMENT TRANSCRIPTION)

- Where to go/ find information about dementia. Possibly classes people can take
- we have excellent options for adult daycare, 24 caregiver support information, many avenues to become connected to people to help caregivers and those affected by Alzheimer's
- We don't have many
- Washoe County has some programing, but not enough. Needs more state assistance as well
- Washoe County Daybreak Program is outstanding. We don't utilize any other resources.
- very little support in the Reno area.
- UNR, The Continuum, RTC Access, Alzheimer's Assoc
- Unfortunately Nevada has only opportunity to improve. Existing services are inadequate and could not remotely be expressed in terms of strength.
- Transportation, case management for home-bound seniors, ADRC supports, senior find and Lyon County MOST team.
- Transportation Services
- Transportation services
- transportation services
- Transportation and community based services.
- They need support group and services with knowledge on how to care, understanding on how to divert the behavior of a person with dementia because forgetful and unable to verbalized what they want and need, they felt horrible and frustrated end up to exhibiting behavior.
- There are a number of support groups, programs, agencies, etc. to help with caring for someone with dementia
- There are a few support groups, but ...
- The VA, my family, Day Break and St Mary's Hospice.
- The Sanford Center, Senior Services, some local physicians
- The many support services and options for living communities.
- The Lou Ruvo Center in Las Vegas has free seminars and activities for the patients and caregivers. Also Nevada Senior Services provide activities and programs for the patients and the care givers. The state also provides PCAs to come in their homes to take care of them or a facility for them to live in, besides transportation to appointments.

- The local Alzheimers association provides excellent informative programs.
- The local Alzheimer's Association chapter is a great resource.
- The Daybreak service provided by Washoe County is valuable.
- The Alzheimer's Association
- supportive services in home, caregiver support groups
- Support to families who are no longer able to care for a loved on with this disease our community is so great at easing anxiousness and helping them make the transition at any stage.
- support groups, such as walking outings at the park
- Support groups, some nice memory care communities, training through the Alz Assoc.
- Support groups, respite help, classes and workshops.
- support groups, respite care
- Support groups, education classes, transportation
- Support groups, community based services, transportation services
- Support groups, community based services
- Support groups, community agencies, education classes, others living with dementia who share their stories.
- support groups, assisted living facilities, Alzheimer's association
- Support groups, advocacy
- support groups, adult day care programs
- Support groups, memory care units, other community based services
- Support groups that help and educate not only the family but also the caregivers of the dementia patient is the best strength for addressing this issue. Second is the financial aid to help the dementia patient to be place in a right home.
- Support groups in Reno, in city transportation, care providers are available in Reno
- Support groups for caregivers let caregivers feel they are not alone. The art classes held in Reno on 2nd and 4th Tuesdays let people interact and are enjoyed.
- Support groups for caregivers and family is so important
- Support groups are very important & supportive, classes, friendships with other people who have family members w/ Dementia & legislation issuers @ facilities being changed & improved. Better trained caregivers in the Memory care facilities...
- Support groups and volunteer opportunities through Sanford Center
- Support groups and RSVP for volunteers
- Support groups and qualified communities to care for individuals with dementia

- Support groups and community based services
- support groups and Alzheimer's Association
- Support groups - information on topic
- Support Groups Financial assistance for families that cannot afford dementia care Just someone to talk to when needed
- Support groups
- Support groups
- Support groups
- Support groups
- Support groups
- support groups
- support groups
- support groups
- support groups
- Support group.
- Support from specific agencies
- Some clinical providers and community based services AND research coming out.
- Some Clinical and some residential services
- small (10 or fewer people) group care/assisted living facilities
- Services available through hospitals, senior and community centers
- Services are available, however, very expensive (assisted living).
- Senior Day Care Programs Alzheimer's Association
- Senior centers, respite for caregivers, meals on wheels, community based case management services, transportation services.
- Senior centers and I am pretty sure there is a caregiver support group
- Senior Center, RSVP, Seniors Helping Seniors, 1 support group in Carson to caregivers
- Senior Center, clinical services
- Sanford Center, Alzheimer's groups are most of what I know
- Sanford Center @ UNR Caregiver training
- Sanford Center - Caregiver Training Elvirita Lewis Respite Grant DayBreak Program
- Presence of university and health care and community support groups

- Our rural community offers a few support groups and clinical services for persons living with dementia and their families/caregivers but there is a need for more services. Transportation is often utilized within our community to travel to needed services.
- Our community is blessed with a number of resources
- Options for adult day care and residential care, but only if have money.
- Often there is not much time to research and figure out options, social workers are often a valuable resource. There are many facilities in town, depending on needs.
- Nevada is woefully lacking in adequate services at multiple levels.
- Nevada has made many changes towards acceptance of Dementia, but there is still more support needed. Transportation is needed specifically for accommodation of behavioral and mental health need. Dementia frightens the public.
- N/A senior center has been a great resource
- N/An/a
- N/A clinical services
- N/A there is a lot of awareness
- N/A Support groups, training or information through Alzheimer's Association, day care services available
- N/A - I'm still new to the community so I do not know yet what the community offers.
- N/A Sanford Center for Aging, continuum day program, memory care facilities
- N/A Resources
- N/A NOT MUCH
- N/
- My mother passed away in 2008. From 2006-2008, I utilized the Nevada Caregiver Support Center (caregiver coach Claudia Drossel)
- Medicaid Waivers allow for my husband to receive care so I can continue working. Transportation and payment to an adult day care is provided also.
- Main Strengths: many support groups for caregivers. Alz.org is strong and many services are provided - if it suits your particular instance.
- Lou Ruvo center/Cleveland Clinic, some mental health clinics like Red Rock Behavioral Health, Volunteers in Medicine of Southern NV, maybe some FQHCs.
- Lou Ruvo Center Support Groups Very active Alzheimer's Association Chapter
- lots of support groups and community support
- In my experience I see no strengths
- I'm noticing a few more programs that were not around when we needed support.

- I'm just now learning about this disease and can tell you the UNR Sanford Center for Aging has been a godsend. They have been fabulous to work with as well as the northern NV Alzheimer's Association. I would like to see more resources, perhaps in the way of support groups for people.
- I think we have a strong Alzheimer's Association, 3 excellent adult day health programs, numerous caregiving agencies with skilled caregivers, and appropriate memory care units in our community.
- I think there is always room for improvement as this disease presents differently for each person.
- I think there is a commitment in our community to help address the issue of dementia and we have a lot of caring individuals.
- I think that although there may be a variety of resources available, they are not necessarily known or promoted due to the large number of social media, and media platforms used but the communities in our area.
- I search for ways to keep my client busy when she was at my senior center building. I know UNR have a Caregiver Support and is helpful, I did referred her family for assistance.
- I really appreciate all of the day programs who focus on providing an environment for socialization for people with cognitive impairments. Our area has many options for various levels of care facilities from SNF, IL, AL, memory care and group homes.
- I only know of a few, but have not interacted with any.
- I must honestly say that our community lacks resources for people with dementia and their caregivers. Alzheimer's Association is the best resource that is known to the community.
- I have support from Alzheimer's and dementia services, they have a lot to offer. I am unable to take advantage of the education Services and support groups due to a lack of support and physical disabilities. I have tried to get help from RSVP at this time with no avail. I have also tried to get help from senior and service to no avail. So what funding I have received is from Alzheimer and dementia services. Unfortunately it's not enough to get myself healthy.
- I believe we have good clinical services for dementia patients in Las Vegas. There are also many support groups for both clients and their family members.
- I believe the community services available for persons living with dementia and their care partners understand dementia and can frame it in a positive manner.
- I believe the Alzheimer's Association works to provide support and resources, but the community needs more awareness and access to resources.
- I am grateful for the Alzheimer's group. I have personally reached out to them with questions. My mother in law has Medicaid and since there is no transportation where she lives, a taxi is sent to take her to adult day care.

- Home visits and companionship for those still living in their homes
- Home Health and Home Aides
- Having daily help from places like the Continuum. Also, the local Veterans Hospital has been helpful.
- Good Alzheimer's Assoc. chapter in Reno. # of day care facilities in community are adequate.
- Fundraisers
- Excellent geriatric physicians. A caring team of community resources for those afflicted w/ dementia.
- Engaged and connected stakeholders and advocates. Support groups.
- Education!
- Education, support groups and transportation
- Education and respite
- Desired main strength would be widespread agency/group/individual knowledge of a starting point for services and information which is easily accessed. Not only free services (considered for 'poor' people), since some families don't want to be considered 'needy'
- DayBreak Senior Day Care program; great variety of nursing homes with memory care units
- Daybreak facility through Washoe County
- Community Resources. Alzheimer's Associations, Cleveland Clinic, Hospitals, Community and Community Centers, People
- community focused on developing needed services such as a respite network. Support groups, specialized community services to support individuals and families living with dementia, clinical services available
- community based services, clinical services
- Community based services and clinical services. People who have served as caregivers and are willing to support others in that situation.
- Community based services - group home care for those whose families cannot care for them
- Community based services
- community based services
- community based services
- community based services
- Clinical services with Dr. Rogina

- Cleveland Clinic/ Lou Ruvo Many families do not feel that their needs will be met by going to the Clinic
- Circle of Life Hospice has given me incredibly good help and support during the final phase of my wife's life. I do not know how I could have survived without their service. (It is still on-going after Margie's death in June of this year.
- Caring and concerned citizens
- Caregiver support resources. Willingness to help.
- caregiver support groups and info available
- Boulder City has a volunteer organization called Lend A Hand that is a great model for how to provide support for families in need.
- Bigger cities have more resources available, rurals do not.
- awareness to the community- Alzheimer's Walk caregiver support group
- Associations, support groups, rehabilitation/education for family
- Assistance to the person providing care to a person with dementia like respite, physical care, home modification etc.
- Alzheimers association re generations transportation support groups
- Alzheimer's support group, senior citizens center
- Alzheimer's caregivers meet at the senior center.
- Alzheimer's Association, support groups, early stage opportunities, The Continuum.
- Alzheimer's Association, NV Care Givers, Sanford Center, Division of Aging, Respite Care
- Alzheimer's association saved my life. The VA helped with adult day facilities. The facilities were very helpful but it would be more helpful for families to have more times than just during the day hours, add evening and weekend hours too. The Rtc bus was very helpful for day care. The lack of affordable Alzheimer's housing was frustrating- dad was a wanderer so special care would be needed and the cost was so prohibitive. Only one VA facility and it's in Vegas for home care.
- Alzheimer's Association resources and groups.
- Alzheimer's Association and Lou Ruvo are great resources for the families of those going through dementia. Seems to help them a lot to understand the disease process
- Alzheimer's Association Sanford Center for Aging Caregiver's Support Center Adult Day Clubs Memory Care Facilities RTC Access
- Alzheimer's Association Group Homes/AL
- Alzheimer's Association In home nurses Manor Care/ Arbors, Etc.
- Alzheimer's Assn and their support groups are wonderful.

- Alzheimer Association
- Alz. Association, support groups, one-on-one care conferences, respite care grants
- ALZ support groups are a great help to caregivers. it is a way to express their anxiety and helpful to others when asking how they cope with their loved ones.
- Alz Association, Sanford Center, John Smith, Ted Young
- Alz Assoc.; UNR Sanford
- All of our Nursing Home staff is trained in Dementia care, a few being Certified Dementia Practitioners. The Nursing Home offers much support to families in need. Family support groups and Dementia education are soon to be offered.
- Aging and Disability Services
- adult daycare
- adult day health
- Active Alzheimer's group, adult day care, Renown Hospital support groups
- A lot of the strengths in northern Nevada are helping care for people, however the biggest problem I see (And this can be the answer for the next two questions as well) is that people still feel ashamed to let the world around them they have the disease. You can walk to anyone on the street and say Alzheimer's and they will know what is going on, with no government intervention or training. People easily understand 'Memory problems', so I think and feel the best thing we can do for our friend and family with Dementia is to make it acceptable to let others around know about it, so they can go 'Oh, no big deal then' and adjust.
- A desire for culture change exists. Our community has many wonderful passionate community partners who are willing to help create that change.
- A couple Adult Day Care Centers provide great service to semi-invalid, passive females with a consumer orientation. There is almost nothing for healthy, assertive males who like to create things, participate in building , mechanics, or scientific activities.
- 1) Nevada has stronger memory care facility inspection laws and requirements than California --- and they stick to the inspection schedule unlike California. 2) Leadership of memory care facilities in Reno/Sparks work together to help families make the right placement for their loved ones -- not focused strictly on sales. 3) Additional resources like Moments of Memory, Kindred Kings, and student volunteers from UNR who help enrich the lives of people living with dementia.
- -Aging and Disability Services Division -Alzheimer's Association -caregiver support groups -RTC Access -Washoe County Senior Services.
- support groups for caregivers, county run day care that I took advantage of.
- alzheimers assoc.
- support groups

- Alzheimer's Organization/ support groups, continuum regenerations, transportation is lacking in South Reno, Clinical services are few
- support and community awareness through facilities such as the Continuum
- day programs
- services such as Alzheimer's Assoc, church groups, and care centers like continuum. RSVP + other groups are helpful in adding Respite care + other state + governmental agencies
- Continuum Regenerations, Alzheimer's Assoc, transportation, support groups
- support groups, community based services
- we have a great support with all of the above listed as well as grant funding
- doctors
- spiritual evolution
- Alzheimer's assoc very willing to help. There is a state org that tells about care homes
- families
- don't know enough about current level of services
- accepting them as part of the community it could be any of us, a parent, spouse, child. Its nobody fault.
- not sure, my family member lives in another state
- the homeless I believe most have a form of dementia and they need help
- community based services (eg adult day care)
- I used the Alzheimer's Association, they were a great resource
- more choices for the sick
- education, the book *The End of Alzheimers*
- support services
- recreation adult day car (community based), caregiver services, transportation service, memory care facilities, accessibility
- none of any conversation where exact known of information within speaking concerning the subject or topic or does not apply
- hospices
- Aware of the Alzheimer's Association
- all services can be greatly improved
- I have no idea what's available here

- there was a caregiver support group there UNR that was extremely knowledgeable & helpful, there are walks in the park etc. Keeping them engaged
- support groups, home health care, MDs specializing in this field, church + media support in publicity and caregiver training
- but education of the public. What is dementia? How is it different from mental illness? Are they treated differently? How can the public help What is the best/compassionate way to react to a person with dementia.
- safe living conditions
- don't see much except there is a need for a percent people that need help onward creating a better future
- support for the patients and caregivers (support group)
- all of them are very good
- clinical services, social worker has been very helpful too
- affordable respite care, more social services for the low income
- there is definitely more awareness +services being offered to people dementia their families. The media, newspaper, internet, social websites, neighbors & friends

APPENDIX F: WEAKNESSES WITHIN WASHOE COUNTY FOR INDIVIDUALS LIVING WITH DEMENTIA (DIRECT TRANSCRIPTION)

- We need more memory care units that accept Medicaid. More funding for help at home.
- We do not have anything for care givers in Incline Village. N/A
- Waitlist on most of programs available for people with Dementia and/or caregivers. Limited immediate resources: personal assistance services, transportation, respite assistance. Gap on benefits for clients above poverty guideline. Poor discharge planning from hospitals.
- University Med School and Sanford Center detachment and competition with community providers. Poor communication between University and Community. Duplication of services.
- Transportation, facilities, lower income support
- Transportation, clinical services.
- Transportation, caregiver support, affordable services
- Transportation to adult day care. Need more adult day care facilities that are not so expensive. Just a few days or hours a week are beneficial to the caregiver.
- transportation services, clinical services, supporting people living in their homes, training for individuals that are caring for individuals living with dementia.
- transportation options, education community on dementia, limited specialists which means it takes a long time to get in to see one.
- To get caregivers so the family member could have respite care. When my mom was alive and had dementia, having time to myself was important. I would take her to the Continuum on Moana Lane which was wonderful. My mom enjoyed it also and it gave me a much needed break.
- There needs to be more and better prepared neurologists in Reno to help dementia patients. My mom was originally misdiagnosed by a local neurologist, prescribed the wrong medication which accelerated her early onset Alzheimer's. It wasn't until we went to UCSF did she get proper care and proper support from their social worker. Families shouldn't have to go out of state for proper care.
- There is a need for public or government run residences for people living with dementia or other mental challenges.
- There is a gap in funding for quality services
- There is a need for more respite facilities, day care facilities, etc.
- there are some memory care units but they are very expensive. the community center should have a scheduled access bus to pick people up
- the supports groups keep filling up before I have a chance to join. Also, they cost money.

- The few memory facilities that are NOT private pay are mostly glorified 'rest homes.'
- The Alzheimer's Association and UNR (your organization) provide good services. I haven't paid as close attention since my mother passed away.
- Support staff must be trained to help with dementia issues, but then we believe folks living with dementia can easily connect with others struggling with the disease! They can't recall training, and peculiar behaviors confuse them. It is hard to create a happy atmosphere for a group beyond 'entertainment settings.'
- support groups, community misunderstanding, not enough dementia trained physicians
- Support groups for specific levels/kinds of dementia. 'One size does not fit all.'
- Support groups for caregivers. Activities/respice activities.
- Support groups and respice care
- support groups and community based services
- support groups and community based services
- Support groups and clinical services outside of the Sanford Center for Aging.
- Some community based services like shopping assistance.
- Services in general, placement choices, transportation, in home low cost care services, low cost respice services, community engagement with housing and incorporation of the client and family in streamline community living
- rural services, education
- Respite, Adult Daycare (medical model) extended care on weekends, no funding to provide monetary assistance to familial caregivers who provide 100's of thousands of hours each year and prevent nursing home placement, saving taxpayers millions of dollars.
- Respite for the unpaid caregivers whose lives are turned upside down caring for people with dementia saving Billions of dollars in SNF expenditures. Weekend Adult Day Care program
- Respite care, adult daycare
- respice care for care givers; affordable care
- Realistic education regarding how to accept that the disease cannot be controlled.
- reaching out to those with dementia to include them in activities.
- Re: Oral Health, in relation to infection control and overall health- a serious gap remains. I am the only RDH entering communities on a regular basis to see patients and a very small percentage elects care; staff is not knowledgeable, turnover rates negate my training; very few get any care. People are dying from dirty mouths.
- Public transportation needs more assistance outside of Washoe County. There is a lack of education on dementia for public transportation drivers.

- Poor people who suffer from dementia don't get treatment. They seem to have to battle it on their own.
- Persons with dementia who do not have the financial support to be able to live in facilities when they can not stay at home or participate in day programs.
- People, family and caregivers need to have the education for better understanding and better help their family or clients.
- People need to be educated about dementia
- Organization of process once a family member is diagnosed, where to start, who to talk to, addressing money, transportation, care-taking, modifications for home, adaptations, education for family on how to talk/act. There are lots of resources, but it would be nice for families if it were stream-lined, or if their doctor could really direct them in an organized fashion.
- One needs to be a health advocate and do much of the legwork. There are few resources/people who can guide those helping a loved one.
- Nothing's perfect. I have received considerable help over the years since the onset of Margie's disease. Alzheimer's is a horrible disease. The real goal is to find a cure for the disease and a means for its prevention.
- not sure but possibly affordable care, some of the caregivers sent from Home Instead were not well trained or very engaged - just slept or texted!
- Not advertised enough. You need to make the information easier to find, as well.
- Need to advertise more, educate and make services availability more public.
- Need more resources & funding for lower income seniors w/ dementia. Also for those diagnosed with early onset dementia in mid to late 50's.
- need more day care type settings to give care givers some time off
- Need more community / provider trainings.
- Need more case managers and protective services response from county/state
- need for respite care for families, group homes, places for people w/ dementia to gather
- N/An/a
- N/A, However, we all need to be more cognizant of dementia and other mental considerations, and definitely treat all people with respect and dignity and endeavor to fine out their needs and encourage and strengthen their abilities!
- N/A people need to understand that it is not curable
- N/A - I'm still new to the community so I do not know yet what the gaps are in the community yet.
- N/A Services

- My experience has been poor care - people 'lost' from a care center and the family not notified until the next afternoon (gone more than 24 hours at a 24/7 facility); also over/under drugged persons; and being treated in undignified ways (hand down the pants to check the diaper in a way that was no respectful)
- Most Americans think Medicare will pay for long-term care or that they can hire someone to move in to their loved one's home and get free rent for providing 24/7 care and both are just not the case. Nevada has no infrastructure for the seniors that have moved here for the no State tax as they age and we are in crisis.
- More types of day care like daybreak and respite care.
- More public education regarding the various forms of dementia- that is overcoming the belief that any cognitive/memory impairment is Alzheimer's Disease. Change the discourse to understanding and supporting the person with dementia with minimal care taking.
- More Dementia focused care - locked facilities, more dementia training for caregivers
- more community based services needed for caregivers, more transportation services needed
- Medicare services, so people can stay in their homes.
- Medical professionals are impatient. One assessing psychologist was ready to routinely diagnose and treat before test results were obtained or studied. Same psychologist recommended antidepressants as a general rule for family member caregivers, saying that is what usually is needed. She was trained at UNR. I was offended and appalled. There is no recognition for the whole (or holistic) picture of what the individual and family experiences every moment (communication difficulty, physical strain of helping the person stay mobile, the time it takes to do each and every thing, grief and loss as the person has changed significantly, personality changes). I'm not getting information about support groups, and it would be hard to break into that kind of support even though I need support every day. None of the other services listed are advertised or distributed as available in the community. Medication made the situation worse with nightmares and further personality changes. Finally, the stigma of dementia is a major gap for the individual and family.
- many medical providers do not know about all the resources available to people and caregivers re: dementia. Community does not work well to keep those without caregivers safe in the community, many are vulnerable to exploitation, self harm and harming others in the community. I feel that there will be a story on the news in our community some day about a person with dementia being harmed, killed or causing emergency due to their dementia and not having enough oversight.
- Making sure that people who care for someone with dementia are aware of the resources available
- lack of understanding how much help a caregiver needs
- Lack of knowledge, understanding, and community resources.

- Lack of information or training especially out here in Rural Nevada...
- Lack of funding to help promote services. Service providers not adequately trained.
- Lack of funding and I don't think there is a good understanding of how large this issue is and the understanding of how it will grow.
- Lack of education for first responders, doctors, medical personnel, ER personnel about this disease and how to better deal with patients and family members.
- lack of awareness, low priority
- Lack of awareness of existing resources, lack of geriatricians, lack of quality, affordable assisted living housing
- lack of available beds in safe/secure units for persons with dementia. High cost of care for people who CAN access those limited beds.; I was told last night it can cost, personal pay, \$6400 per month! Few people have that. As a full-time, educated, well paid professional, I earn 1/2-3/4 of that per month. Social Security will NEVER get me close to that. And thinking to our culture and what was happening 50-70 years ago, those men and women certainly did not earn that kind of money and those are the people who currently need the care. There's a huge discrepancy.
- Knowledge of those resources and how to access them
- Knowledge of the disease
- Insufficient resources for people who need in home care or higher levels of care; insufficient resources for persons caring with loved ones with dementia
- Information for friends and neighbors of people with dementia so they know how to interact, that people are still people and not just the disease. Their caregivers would already know some information.
- In my mind, (perhaps inaccurate), dementia is on par with mental illness and we (not just our community, all of American society) cannot seem to get a handle on how to deal with the mentally ill through treatment. We cannot assume the mentally ill will seek treatment for themselves or realize they should.
- I'm not sure what resources are available, but I would imagine supporting families and caregivers would be very impactful.
- I think that the gap is knowledge of what is available within our communities.
- I think resources for respite care and mental well being are very limited in this county for those caring and supporting friends or family members with dementia.
- I think people aren't aware of the services and programs out there
- I have the sense that that there are gaps in initial referral systems. I think early care providers and identifiers should get together and make a list of the 'first 10 steps' to take after you or a loved one has been identified with dementia. Then id resources and providers in the community, and nation who might help.

- I have felt very alone for two years while trying to find resources to answer my questions and to help me care for my mom. I have asked about support groups and not one medical provider or residential facility has known where I could get help. I recently found an online support group.
- I had to discover Alz. Assoc & UNR Sanford on my own. Our PPD and Neurologist didn't inform us.
- I guess a gap would be that not everyone is aware of services that they might have access to. I helped care for someone with dementia and wasn't aware of any programs that could assist me with their condition.
- I believe social experiences are very limited for those living at home.
- Homeless individuals living with dementia need shelter and care.
- higher quality home delivered meals more adult day health better financial support for families acting as caregivers through wrap around services, government funding of medical and social services
- Helping community better understand how to help people living with dementia when they are in the public. Treat them with respect not pity. Allow them their dignity
- Getting more information out more often to the community. More PSA's by any form of communication.
- getting assistance and help in outlying area, transportation - medical- care assistance respite care in rural areas - huge need in Truckee/Lake Tahoe
- Free Health care, and support (that is easy to find) for those who care for people with dementia.
- Financial assistance to help provide care, a better understanding of true needs of people with dementia, especially the last few stages.
- Financial assistance for in home care.
- Fear and lack of knowledge
- families and individuals knowing of the support groups and services available.
- ER and 1st Responder training
- Education at all levels is needed about dementia and more caregiver support. Also, more assistance with guardianship and other support services needed for advanced dementia clients.
- Education and probably many other things I'm not even aware of
- Education about dementia including how families can work with people suffering from dementia. I think frequently people with dementia are at first glance seen as 'crazy.' Which treatment options are available. Affordable care for people with dementia and their families!
- Education about dementia and how to safely interact.

- Educating caregivers re: the importance of self-care -- and where to find support. The existence of programs like Wandering Prevention.
- Desperately need more facilities in Reno/Sparks vs. all of the apartments, housing and related going up. We do a poor job caring for those that came before us in this community overall as does the US in comparison.
- day care, respite care
- Community services, Transportation services
- Community services that claim they work with demented individuals act like they don't know anything about dementia. Problem behaviors in the demented are seen as deliberate. Most agencies and facilities just want to get rid of anyone that might be a challenge. Frequently, they want a guardian in place for the demented person to make it easier for themselves. The guardian in turn will make all the decisions whether the elder wants it or not--shameful!
- community day programs clinical services
- community bases service, transportation services
- community based services
- CNA training and certification requirements for in-home health and at facilities
Difficult and expensive navigating of the legal and financial system Lack of education about the range of cognitive impairment Medicare not covering long-term care
- clinical services.
- Clinical services
- Clinical education; Funding for services, including for caregivers; Consumer education
- caregiver support
- Caregiver help
- Care facilities that are affordable & are equipped to care for those with dementia.
Trained nurses & respite care for family members caring for them in their homes
- Better understanding of how to communicate, more resources for financial support for primary care partners
- Awareness, integrative programs with non-dementia groups,
- Awareness - more information about regional get meetings
- Aware of WashoeCaregivers.org
- Availability of memory care housing, medical care
- Assistance and knowledge of services available, such as nurses and education for family members
- As I currently don't know, you need to work on your advertising and outreach.

- Affordable care.
- Affordable care!
- affordable care at home
- Affordable care
- ADA transportation does not service all areas
- 1) Desperate need for sensitivity training among the hospital community. Doctors have very little understanding or patience for dealing with dementia patients. They inappropriately push to limit diagnostic tests and push hospice/comfort care with the explanation 'would they really want to live like this?' As if the patient (or their loved ones) actually had a choice in the matter. Shameful treatment of family and patients, especially by Renown. Exception is that the nurses in this community are wonderful and very much in tune with needs of dementia patients and their families, probably because so many of the nurses have gone through caring for a loved one with dementia and have empathy. 2) Tactic employed by the hospitals under the guise of 'social work' are shameful x 1000. Continual push to move dementia patients out of hospital under cruel circumstances (e.g., pushing to move patient who is within hours of passing). Upshot, the medical community (except for nurses) needs to change their attitude about patients with dementia and realize they are worth treating and saving when possible.
- Minimal affordable housing options - Insufficient transportation services, geriatric specialists and mental healthcare. -Not enough reliable and affordable caregiving companies for home-based care.
- financial and medical
- No transportation or clinical services in South Reno
- Transportation
- I don't see a gap or gaps
- I'm new to the area so I don't know
- At home financial assistance. Most caregivers would prefer to have A1 Dementia Family member at home rather than in an medical or institutional setting.
- Getting people aware of the things available
- Support groups, Community based services
- I don't know of any gaps
- Community based services would be most helpful. Even people who are not in need of services regarding dementia could benefit if and when a need arises.
- Homes
- They have NOT! Successfully dealt with the drug problem, so it's difficult to address this!
- The main gap is that they need to feel that they are part of the community.

- Not sure
- Help-my dad- I couldn't help unless I paid over \$5,000 for lawyers-it was a hard time for him and me.
- Something that informs people the pathway to getting help
- Workplace needs more info so they understand what caregivers go through as helpers to family.
- More support groups
- Education-Improve life style
- Cold uncaring people
- Early identification of dementia. Transition period from normal to diagnosed dementia, specifically, for those living alone, a central contact point with personal info if person begins to wander/missing.
- Exact information concerning history and geography, the math and vocabulary scores, reading comprehension gives intelligence ID
- Clinical services
- I don't <<>> enough to <<>> the gaps, but I can <<>> the needs of people without <<>>
- Transportation is the largest gap, especially for people on a fixed or low income. This is also difficult for families who have the funds.
- Lack of knowledge of available services for family or in home caregivers. If person does not have family or friends.
- Limited respite care services, more male CNA's are needed and home health aides.
- Transportation
- Clinical services with a need for greater outreach to combat isolation.
- Even though I believe they are good in this area, there can always be more to be done.
- All of the above
- More services need to be educated in handling or intervening when having to work with one with dementia. Police, EMT, hospitals, ER's, home care agencies. Last but not least we have a shortage of neurologists.

APPENDIX G: RESOURCES FOR INDIVIDUALS LIVING WITH DEMENTIA (DIRECT TRANSCRIPTION)

- Washoe County Health Department.
- Washoe County
- Visits to nursing homes
- Veteran's administration
- UNR, The Continuum, RTC Access, Alzheimer's Assoc, Visiting Angels
- The VA was a big help, as was Daybreak.
- The same organizations I mentioned above.
- The Continuum, Meals on Wheels, VA Hospital services
- The Continuum, a professional evaluation, meeting with a geriatric care manager
- The Continuum Adult Day Program
- the continuum -re generations alzheimers assoc
- Support groups, counseling alz.org, etc.
- Support groups for family members
- support groups and community based services
- Support groups
- State aging services and Washoe County human services
- Start at libraries, senior services, churches.
- Senior Center on 9th and Wells
- See previous answers
- Sanford Center, ADSD, Center for Independent Living, Elvirita Lewis grant
- Sanford Center for the Aging
- Sanford Center for Aging, Alzheimer's Association, Nevada Caregiver Support Center
- Sanford Center for Aging Senior Services Center for Independent Living Alzheimer's Association
- Sanford center for aging
- Sanford Center and ADSD Aging services
- Sanford Center
- RSVP and the Alzheimer association.
- Resources at the library to become more knowledgeable about improving one's health and prevention of diseases, including Alzheimer's and dementia.

- Reno Alzheimers Association
- Physician
- People with and dealing with someone with dementia need a contact to help with various needs. I have had to research myself and I had no idea where to start.
- Our county and state social services should have great resources for people with dementia, their family members and friends. I have no idea if this is so. But I know that takes a lot of funding. I would support that funding be provided.
- NV Caregiver Support Center
- none
- N/An/a
- N/A care center
- N/A The Continuum
- N/A The Alzheimer's Association has been a tremendous help to my family
- N/A Home Health and Hospice
- N/A Alzheimer's Association
- Most certainly hospice during the final phase. (Planned well before the end.) There are a few day services such as The Continuum. Unfortunately, Margie was too uncooperative to remain in the program.
- More To Life, Bailey's Group Home, Love n Joy Group Homes
- Moments of Memory (as they have art opportunities for the general public -- not just as a resident of a memory care facility) Washoe County Senior Services
- Medical professionals or mental health professionals.
- It would be wonderful to have seminars by Teepa Snow!!! And even better to have educational DVDs and workbooks available locally. She has several videos on You Tube which truly deal with issues faced by both the care partner, and the person facing dementia.
- It may take a few phone calls to human services and google searching to get started and a day or so after that to get really specific answers.
- It has been many years since my grandmother, who had dementia, has passed. I think if I were to begin working with those with dementia, I would start my research at the Senior Center or clinics who work with that population
- I would suggest they contact the Reno Alzheimer's Association chapter.
- I would identify local supports for the individual and their family to obtain education on the topic and a service to help them identify a person centered care plan.

- I wish I knew honestly, as my parents lifelong doctor avoided all of the signs that could have eased my parent into dementia as well as helped to better prepare family. Unfortunately this was beyond any sort of priority with this, now retired, doctor.
- I really don't know except to see a neurologist, and be careful who you choose. I'm so sad the psychologist identified in the community for this type of diagnosis is so cavalier about her work and so disrespectful to the patient and her family member.
- I highly recommend our facility in Reno called Continuum I would like to see more of this type of child care/ dementia care.
- I filled out a questionnaire a few months ago to connect with a group assisting people or families members with AD. My maternal grandfather died, at the age of 69. He had not been diagnosed with AD, but his symptoms were very similar to my mom's. My mother passed from AD at the age of 67 more than twenty five years ago. I had watched the change in her behavior when I came to visit her because we lived in different cities. My mom lived in Cleveland, Ohio; and, I lived in San Jose, California. My sister, my only sibling, lives in Washington DC. My mom took care of my maternal grandmother in her home which took up a lot of her time because my maternal grandmother was overweight as well as sedentary. I suggested to my sister that we buy our mother a puppy in order to give her an opportunity to get out of her home at least once or twice a day to walk her puppy, as well as enjoy the opportunity to visit with neighbors nearby. The more I watched her behavior, the more I felt that my mom may be getting AD. My sister and I agreed that given the changes in her behavior, she should be closer to one of us. So, my sister sold her home in Cleveland to purchase a smaller condominium approximately a ten minute ride from my sister's home. And, because I was a Flight Attendant at the time, I bid flights that would give me an opportunity to give my sister a break because my mothers did not understand that the small child she was holding was her granddaughter. My sister finally acquiesced and agreed that my mom should live with me because mom did not understand that my sister's babies were her granddaughters. She lived with
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- I do not know of any specific facilities/resources, however, I would have no problem finding them.
- I could only recommend the online group I have found for caregivers. I do not have any local resources I could recommend to patients or their families.
- Honestly, I would like to learn more about what's out there.
- Health care
- get correct diagnosis
- First thing provable visit primary Doctor, Neurologist or Psychiatric
- First step is getting an accurate diagnosis. There are many variations of types of dementia many have different methods of approach. Getting a clear idea of strengths and weaknesses increase my ability to assist the person maintain their highest level of

independence. I enjoy having complete functional evaluations completed wonderfully by the staff at the Continuum PT, OT and ST staff.

- Evaluation regardless of whether they can afford it or not
- Education about early warning signs
- Early diagnosis and education for patient and family regarding what to expect along with realistic expectations of care.
- Depends on client need & situation. Resources can vary from in-home resources to relocation. Caregiver companies, adult day programs, hospice or home health, geriatric physicians to assisted living resources are just a few resources.
- DayBreak, Sanford Center, Alzheimers Association, The Continuum
- Daybreak
- county senior services to start
- community based services and resources...ie. Sanford Center for Aging
- Clinical studies by someone like Dr. Hershewa
- Certainly Alzheimer's Assoc.; Respite programs for their caregivers; Various memory care units
- Centers on aging.
- Call local ADSD regarding resources in the area.
- Begin with diagnosis, then research memory care living communities
- Alzheimers Association Renown, Northern Nevada Medical Center, and St. Mary's Senior Services for Washoe County, Reno, Sparks The Library
- Alzheimers Assoc.
- alzheimers assoc.
- alzheimers assoc.
- Alzheimers Assoc of NN & NC RSVP-respite
- Alzheimers Assn.
- Alzheimer's Society, The Continuum, More to Life
- Alzheimer's Org, Renown
- Alzheimer's group, Sanford Center, Adult day care, Neurologist, Geriatric Specialist.
- Alzheimer's Association. Or I refer back to primary care for further assessment. Or to Senior Services for needs assessment and further referrals as needed.
- Alzheimer's Association.
- Alzheimer's association!

- Alzheimer's Association, Washoe County Senior Services, AARP, Meals on Wheels, Elder Protective Services, Senior Coalition of Washoe County
- Alzheimer's Association, VA if they are a veteran, The Continuum, More to Life, Daybreak
- Alzheimer's Association, The Continuum
- Alzheimer's association, senior services
- Alzheimer's association, senior centers, senior bridges program, home health agencies, respite programs, attorneys to assist with advance care planning,
- Alzheimer's Association, Sanford Center for Aging, Lou Ruvo Cleveland Clinic Brain Center in Las Vegas
- Alzheimer's Association, Sanford Center for Aging, adult day care for respite
- Alzheimer's Association, Local Hospitals, Community Living Facilities, Senior Centers, County/State Offices.
- Alzheimer's Association, Daybreak at Senior Services, More To Life, The Continuum, State of Nevada ADSD
- Alzheimer's association, Community foundation Caregiver guild book, Medical/Legal/Financial professionals. Find out who in the community knows about the disease and not just trust the doctor.
- Alzheimer's Association, Basic Q&A Handout from website, The Continuum for speech, OT, PT to learn what can be modified vs remediated in addition to their Regenerations Adult Day Club for respite and support.
- Alzheimer's association, adult day programs, HCBW services, caregiver support center, Washoe County Senior Services
- Alzheimer's Association Senior Day Care Programs
- Alzheimer's Association Sanford Center for Aging Caregiver's Support Center Adult Day Clubs Memory Care Facilities RTC Access
- Alzheimer's Association Nevada Caregiver Support Center Caregivers Association
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- Alzheimer's Ass, Legal services for estate and advanced medical planning, state licensing for group or nursing homes, Senior Services.
- Alzheimer Association
- Alzheimer assoc. senior centers caregiver association V.A Dr. Fredericks Neuro doctors/primary care doctor Daybreak/adult day care online resources about same for caregiver/clients SOS respite care services Sanford Center for Aging
- Alz.org/local Alzheimer's Association chapter Home Instead Senior Care
- alz.org
- ALZ of N. Nevada is a great resource for families coping with dementia.
- Alz Northern Nevada, Care options & respite relief
- Alz Association, health care provider
- ALZ Assn, ADSNv
- Aging and Disability Services Division to see if the person may qualify for home based care services and also for resources. The individual's doctor, local county senior services organization, Alzheimer's Association
- Aging and Disability Services Division - State of Nevada
- Aging and Disability Services
- Adult Day Club at The Continuum
- 'Keeping the Smiles' is my Program for Preventive dental hygiene services serving the entire state. As The Traveling Toothfairy, I have served N. Nevada sites for over 5 years.

Implementation is possible only where a dental hygienist takes the Program on...so Reno/Sparks are the only areas I can physically serve right now (few RDH's have gotten approval, yet they could); science shows a relationship between dementia and Periodontal disease, so prevention is paramount. I would suggest continuing preventive oral care at their dental home, until the point where that is no longer safe or feasible due to the consequences of dementia; that is where my Program is to be considered.

- Please see my previous list
- Sanford Center for Aging helped our family; Continuum day program is very good I have heard,
- support groups and social activities
- Alzheimer's Association, Senior Services on 9th Street, Continuum
- family doctors, government grants and aids, local programs, adult groups
- alz.org
- Alzheimer's Assoc + state agencies
- Alzheimer's Assoc, Continuum Regenerations and places alike
- Alzheimer's Assoc
- day care, puzzles, Alzheimer's Assoc are very helpful
- I recommend Alzheimers Associations incc they have an extensive list of referrals such as doctors, legal matters, etc
- hospitals
- hospital
- alzeihmers assoc
- Alzheimer's organization
- safety issues like wandering off and getting lost
- there is only one the Alzheimer's Assoc
- alz.org
- Alzheimers (as a start)
- Alzheimers Association, Daybreak Washoe County
- seek help first
- *The End of Alzheimers*
- church groups, families
- not family physician, who is most often hardest to convince, would like to know best resources for evaluation, many opportunities in community for rec dept, exercise + social interaction

- I give not ever suggestions opinions, or advice. I personalize information so that one self can have their own choice choosing with best chosen decision
- contact the Alzheimer's Assoc
- education of the community so they are better able to interact and help in community events and situations
- sr. services, renown, UNR med
- alzheimers association, primary care physicians, gerontologists, home health agencies, living facilities with several levels of care
- library, museum trips
- clinical resources, outreach based upon regional demographics
- support groups & day care so the person can get some respect
- alz assoc
- Alzheimer's association + also to not be afraid to have the person tested for dementia. Many people are afraid to have their loved ones tested.
- if you have no family support close by, more social services, as checking in on patients +making sure they have food, meds, etc
- first and foremost see alz assoc, no Nevada hopes, Sanford center for aging

APPENDIX H: DAS (O'CONNOR & MCFADDEN, 2010) SUBSCALES

Subscale 1 Comfort:

- I feel confident around people with dementia.
- I am comfortable touching people with dementia.
- I feel uncomfortable being around people with dementia.
- I am not very familiar with dementia.
- I would avoid an agitated person with dementia.
- I feel relaxed around people with dementia.
- I feel frustrated because I do not know how to help people with dementia.
- It is rewarding to work with people with dementia.
- I cannot imagine caring for someone with dementia.
- I am afraid of people with dementia.
- People with dementia can be creative.
- Every person with dementia has different needs.

Subscale 2 Knowledge:

- People with dementia like having familiar things nearby.
- It is important to know the history of people with dementia.
- It is possible to enjoy interacting with people with dementia.
- People with dementia can enjoy life.
- People with dementia can feel when others are kind to them.
- We can do a lot now to improve the lives of people with dementia.
- I admire the coping skills of people with dementia.
- Difficult behaviors may be a form of communication for people with dementia.