

August 14, 2018

Dementia Friendly Nevada: Statewide Community Assessment

A Statewide initiative of the Nevada Aging
and Disability Services Division

'Dementia-Friendly Nevada'

Prepared by: Zebbedia G. 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 45,586 individuals aged 65+, including 13,079 individuals aged 85+, living with dementia in Nevada.
 - It is estimated that 6,513 of those individuals aged 65+ who are currently living with dementia live alone.
- 1068 residents of Nevada completed a Community Awareness Survey, 74% of which were completed online.
- Top ‘sectors’ completing the survey were: government agencies (13%), community-based supports (15%), hospitals (12%), residential communities (7%), and business/retail (6%).
- 74% of respondents reported some form of personal relationship with someone who is currently living with dementia or who had lived with dementia.
- Overall, respondents in Nevada reported 75% positive attitudes toward individuals living with dementia, with a score of 105 / 140.
 - Respondents reported a 71% level of comfort in engaging with individuals living with dementia 60 / 84
 - Respondents reported an 80% level of knowledge about dementia 45 / 56
- Considering sectors, individuals from Residential Care (120) reported the highest positive attitudes, whereas individuals from the business/retail (99) sector reported the lowest scores.
- Key community strengths reported included: 1) area support groups, 2) several specific community-based organizations, and 3) general community based supports and services.
- Key community gaps/weaknesses included: 1) education regarding dementia, 2) lack of clinical services, and 3) lack of access to support groups, transportation, and long-term care options.
- Key community resources recommended included: 1) the Alzheimer’s Association, 2) a clinical service provider, and 3) ADSD and county services.
- Service priorities, as ranked (in order) by the community were: 1) raising awareness of available resources and supportive services; 2) increasing staff and volunteer training in helping individuals living with dementia; 3) increasing dementia related resources; 4) increasing awareness of the warning signs of dementia; and 5) increasing community members’ skills in interacting with individuals living with dementia.

PROJECT OVERVIEW – Dementia-Friendly Community Assessment

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 University of Nevada, Reno Sanford Center for Aging conducted a comprehensive community assessment in four initial counties (2017) and two additional communities (2018), to determine the landscape of living with dementia in 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 Elko, Humboldt, Clark, Nye, and Washoe counties, as well as the Pyramid Lake Paiute Tribal reservation. 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 each community. These estimates are based on the formula provided by Dementia Friendly America and use data obtained from the Nevada State Demographer for the counties, and from the U.S. Census Bureau for the Paiute Tribal reservation. 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 (using the established Dementia Attitudes Scale: O'Connor & McFadden, 2010) as well as perceptions of dementia-related services within the county. This report consolidates and details the findings of each of these community assessments to provide a statewide dementia-friendly assessment for the state of Nevada.

DEMOGRAPHICS OF DEMENTIA

To estimate the number of individuals living in Nevada with dementia, data was gleaned from the Nevada State Demographer. Overall, it is estimated that 11% of elders within the state are currently living with dementia. This estimate increases to 33% for elders aged 85+. 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 within the state.

Table 1: 2016 Estimated Dementia Demographics – Nevada

Nevada State Demographer	
Total Aged 65+	410,270
Est. Total with Dementia	45,586
Est. Living Alone	6,513
Total Aged 85+	39,235
Est. Total With Dementia 85+	13,079

Additionally, the Centers for Medicare and Medicaid Services (CMS) estimated that approximately 7.94% of Medicare beneficiaries, received services for Alzheimer’s disease or related dementia in 2015 within Nevada¹.

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 offered for individuals living with dementia currently offered throughout the state, a short survey was administered to the members of the community action groups in Elko (n = 5), Humboldt (n = 5), Washoe (n = 22), Clark (n = 19), and Nye (n = 9) counties. This survey assessed dementia-friendly community action group members' knowledge regarding the state's 'dementia care and support 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-stage 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 program. A majority of respondents (n = 51) were aware of the core services offered by the Alzheimer's Association, as well as the EPIC (n = 40) and general Dementia Toolbox (n = 41) programs. A minority (n = 15) were aware of the BRI / RCI Care Consultation program. Of those respondents who reported being aware of the programs, most reported little to no knowledge regarding the specifics of the programs. A little over two-thirds of respondents were able to identify additional resources (beyond the Toolbox or Alzheimer's Association program) for individuals living with dementia within their specific community.

Table 2: Knowledge Regarding Dementia Services in Nevada
(n=60)

	Aware	Very / Quite Knowledgeable	Little / Not at all Knowledgeable	No Prior Knowledge
Nevada Dementia Toolbox	41 (68.3%)	12 (29.3%)	29 (70.8%)	19 (31.7%)
EPIC Program	40 (66.7%)	16 (40.0%)	24 (60.0%)	20 (33.3%)
BRI Care Consultation	15 (25.0%)	6 (40.0%)	9 (60.0%)	45 (75.0%)
CarePRO	33 (55.0%)	15 (45.5%)	18 (54.5%)	27 (45.0%)
AZ Core Services	51 (85.0%)	23 (45.1%)	28 (54.9%)	9 (15.0%)
Other County Services	39 (68.4%)	~	~	~

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 Action Group surveys were not available from the Pyramid Lake - Paiute Indian reservation.

COMMUNITY 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, including: 1) subscales on level of comfort interacting with people living with dementia and 2) knowledge of dementia. Finally, participants completed questions to assess their personal experiences with people with dementia, as well as their experiences with dementia-related services within their communities.

In total, 1,104 surveys were completed between fall 2017 and fall 2018. To help identify the geographic spread of the survey and link respondents to the specific dementia-friendly communities, participants were asked to report their mailing zip code. Seventeen (17) individuals did not report or reported an invalid zip code, and an additional 19 individuals reported a zip code outside the state of Nevada. These were removed, leaving a total of 1,068 valid responses.

The paper version of the survey was administered to members of the community by community action group members at several different locations within each of the communities, resulting in 279 (26%) completed surveys, including 50 Spanish language 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 789 (74%) community members completing the survey, including 6 Spanish language surveys; Total Spanish language surveys = 56 (5%).

Table 3: Survey Completion by Method of Administration

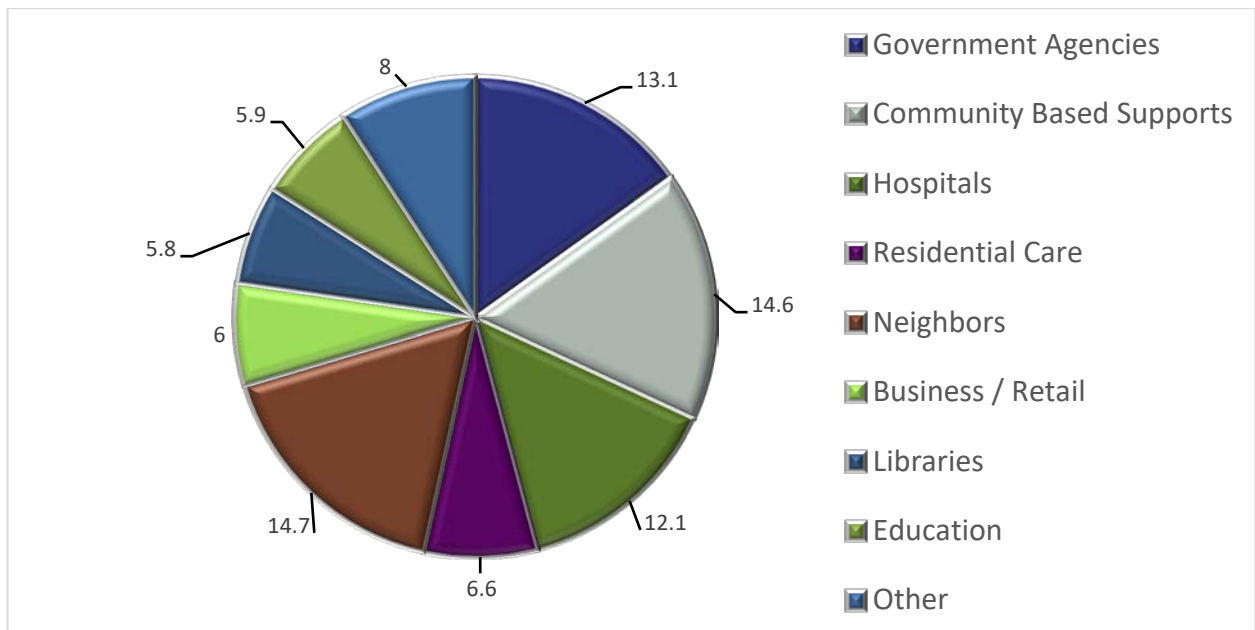
Region	# of Responses	Online	Paper
Elko County	163	112 (69%)	51 (31%)
Humboldt County	119	55 (46%)	64 (54%)
Nye County	89	53 (60%)	36 (40%)
Pyramid Lake Paiute Tribe	43	40 (93%)	3 (7%)
Southern Nevada Urban	195	142 (73%)	53 (27%)
Washoe County	391	323 (83%)	68 (17%)
Non-CAG Nevada County	68	64 (94%)	4 (6%)

Total (Nevada)	1068	789 (74%)	279 (26%)
-----------------------	-------------	------------------	------------------

BASIC DESCRIPTION OF RESPONDENTS

A majority of respondents to the survey were non-White Hispanic (777, 83%), women (n = 871, 82%), and approximately middle aged (average 54 years old), with ages ranging from 11 to 99. Respondents were primarily employed in government (13%), or community based supports (15%). Additionally, some respondents reported working in either local hospitals (12%) or residential care homes (7%; Figure 1). An additional 8% selected 'Other' as their sector, and 15% indicated they were general community members. Approximately 1% (n = 10) of respondents indicated that they were currently living with dementia.

Figure 1. Percent Representing Specific Sectors



Note. Neighbors includes both caregivers and retired persons.

A majority of respondents (74%; see Figure 2) reported having personal experience with someone living with dementia. The most common relationship type was having a parent living with dementia (38%), with client (29%) and other relative (26%) the next most common relationship type (see Figure 3).

Figure 2. Percent Reporting Personal Experience with Dementia

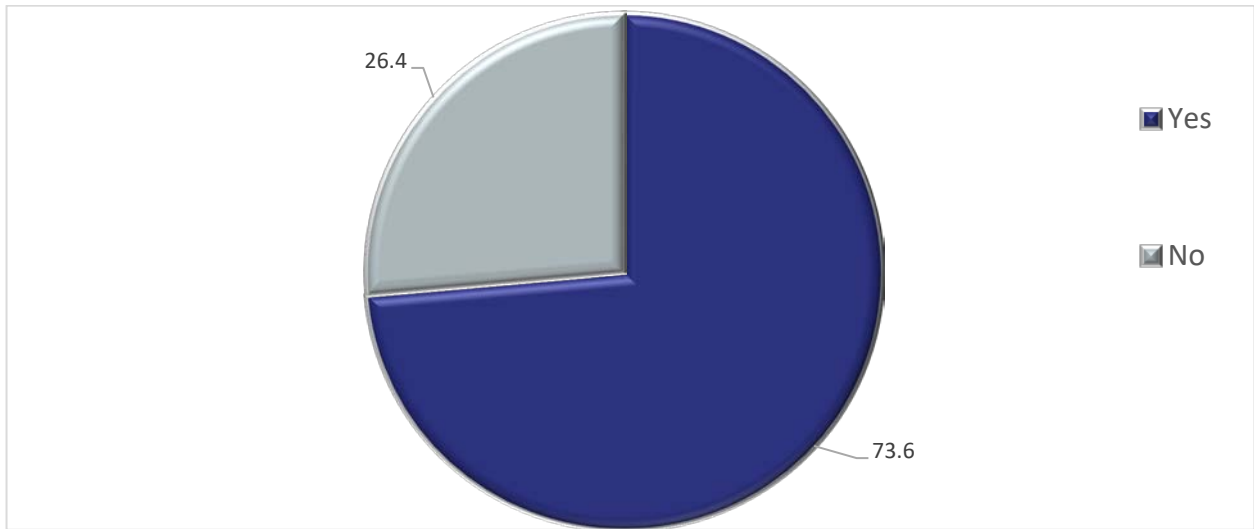
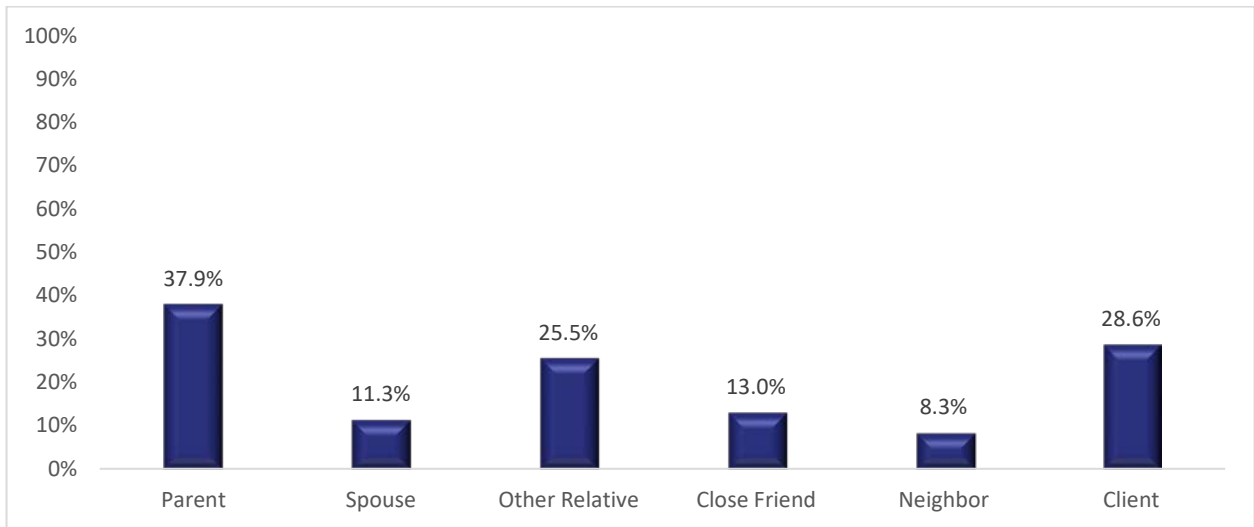


Figure 3. Relationship Between Self and Person Living with Dementia



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 subscales (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 4.

Possible scores on the DAS range from 20 to 140. Overall, Nevada residents reported 75% positive attitudes toward individuals living with dementia, with a score of 105 out of 140.

- With a possible range of 12 – 84, Nevada residents scored a 60 (71%) on the social comfort subscale.
- With a possible range of 8 – 56, Nevada residents scored a 45 (80%) on the dementia knowledge subscale.

Table 4. Means and Standard Deviations for DAS by Specific Demographic Groups (n=1068)

	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	105	20.09	60	13.66	45	8.28
Gender:						
Male	101	20.61	58	13.46	43	9.18
Female	106	19.64	60	13.63	46	7.80
Online	108	18.11	61	13.00	46.65	7.22
Paper	96	22.68	55	14.28	42	9.93

Table 5. Means and Standard Deviations for DAS by State and County

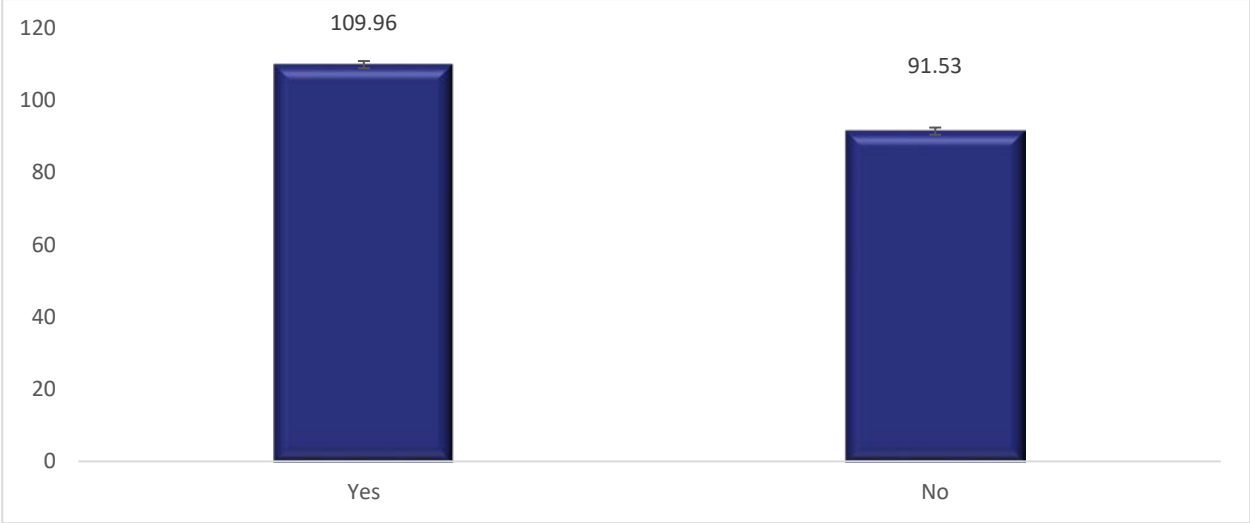
	N	Overall	Subscale 1: Comfort	Subscale 2: Knowledge
Statewide Total	1068	105 (20.09)	60 (13.66)	45 (8.28)
Participating County				
Elko	163	102 (19.57)	57 (13.68)	46 (8.06)
Humboldt	119	101 (21.79)	57 (14.26)	45 (8.81)
Washoe	391	106 (18.86)	60 (13.43)	46 (7.70)
Southern Nevada (Clark)	195	103 (21.46)	60 (13.36)	43 (9.51)
Pyramid Lake*	43	106 (19.61)	60 (12.62)	46 (8.70)
Nye County	89	104 (21.52)	60 (14.82)	46 (7.21)
Non-Participating Nevada County	68	112 (17.36)	64 (12.13)	48 (6.95)

Note. Overall scale range is 20 – 140. Subscale 1 range is 12 – 84; Subscale 2 range is 8 – 56. Means are fixed to 0 decimal places and standard deviations are given in parenthesis. *Includes both tribal- and non-tribal members. For Tribal membership breakdown, see Appendix B, Table 1.

Further, there was a clear difference in positive views of individuals living with dementia

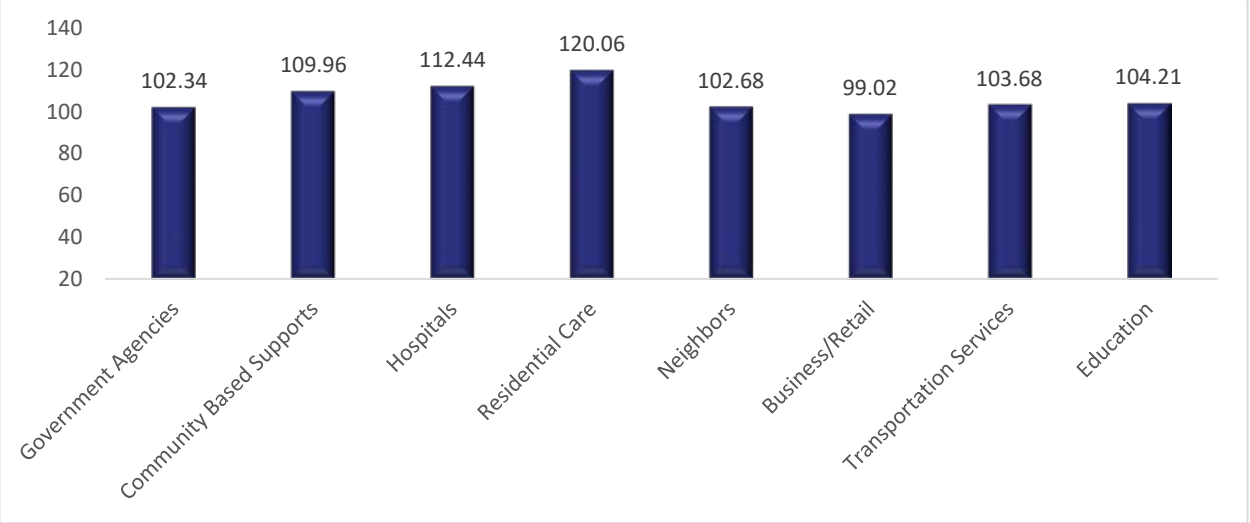
between respondents reporting that they knew or currently know a person living with dementia versus those who reported not knowing a person living with dementia, similar to the results reported by the authors of the DAS (Figure 4).

Figure 4. DAS by Knowledge of a Person 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 residential care homes and hospitals/medical services reported more positive attitudes toward individuals living with dementia than the other sectors. It is important to note that 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 individuals living with dementia.

Figure 5. DAS by Self-Reported Sector



STRENGTHS WITHIN NEVADA FOR INDIVIDUALS LIVING WITH DEMENTIA

Respondents were asked to report what they viewed as the strengths in Nevada in regards to meeting the needs of individuals living with dementia. In total, 402 (38%) individuals commented on this question.

Most people mentioned the support groups within their community (n = 147), including those support groups offered by either the Alzheimer's Association or RSVP as a strength. Community members also mentioned community agencies (general, n = 52), and local residential care facilities (n = 50) as strengths. Several organizations were mentioned by name, including the Alzheimer's Association (n = 51), RSVP (n = 9), the Cleveland Clinic / Lou Ruvo Center (n = 11), the Sanford Center for Aging (n = 11), and the University of Nevada, Reno (n = 6). Complete comments are provided in Appendix E.

Forty-nine individuals reported that Nevada had no strengths when it came to dementia care, and 20 individuals reported that they didn't know.

GAPS WITHIN NEVADA FOR INDIVIDUALS LIVING WITH DEMENTIA

Similar to the strengths of Nevada, individuals were also asked to report on the perceived gaps within the community for individuals living with dementia. In total, 442 (41%) individuals commented on this question.

The highest number of responses were from people who reported that they felt Nevada lacked education regarding dementia (n = 97), a lack of clinical services (n = 83), as well as a lack of access to support groups (n = 56), transportation (n = 51), and long-term care resources (n = 46). Additionally, a lack of overall awareness of resources (n = 51), as well as funding for individuals living with dementia (n = 37) were noted as lacking within the state.

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. In total, 386 (36%) individuals commented on this question.

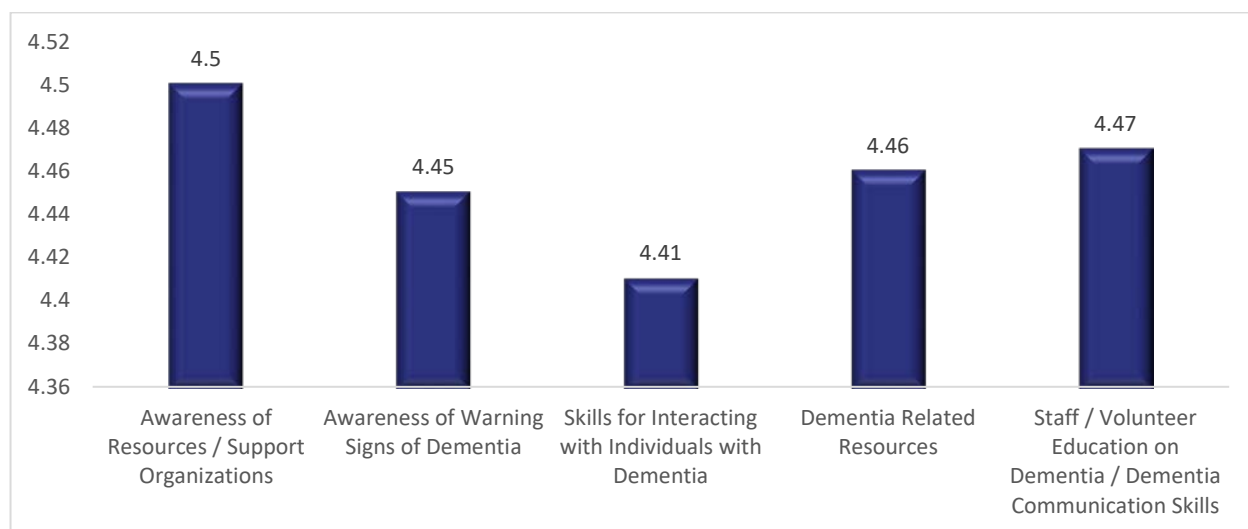
The highest number of responses were from people who reported that they would recommend the Alzheimer's Association (n = 142). Others (n = 56) reported that they would recommend the individual seek advice from their doctor or other clinical service, with 50 respondents indicating that they would recommend reaching out state agencies. Several agencies besides the Alzheimer's Association were identified, including the Cleveland Clinic / Lou Ruvo Center (n = 48), the Continuum (n = 17), the Sanford Center for Aging (n = 16), and Nevada Senior Services (n = 11).

SERVICE PRIORITIES FOR NEVADA

Finally, participants were asked to independently rate several pre-selected priorities. These

priorities were ranked from High (Strongly Agree) to Low (Strongly Disagree). A small minority (< 5%) of the sample reported strongly disagreeing with each of the pre-selected priorities, with a slightly higher percent (<10%) reporting that they neither agreed nor disagreed with the pre-selected priorities. Mean scores for each priority are presented in Figure 6. Overall, respondents reported that increasing community awareness of the resources and organizations that can help support individuals living with dementia (4.50) was the most important. The other priorities, including increasing staff/volunteer education and training on dementia (4.47), increasing the amount of dementia related resources (4.46), and increasing community members' knowledge of the 10 warning signs of dementia (4.45), and increasing community members' skills for interacting with individuals living with dementia (4.41) were all closely ranked. These results mirror the frequency that education and awareness regarding resources were identified as a gap for Nevada. State- and county-level data are presented together in Appendix B, Figure 1.

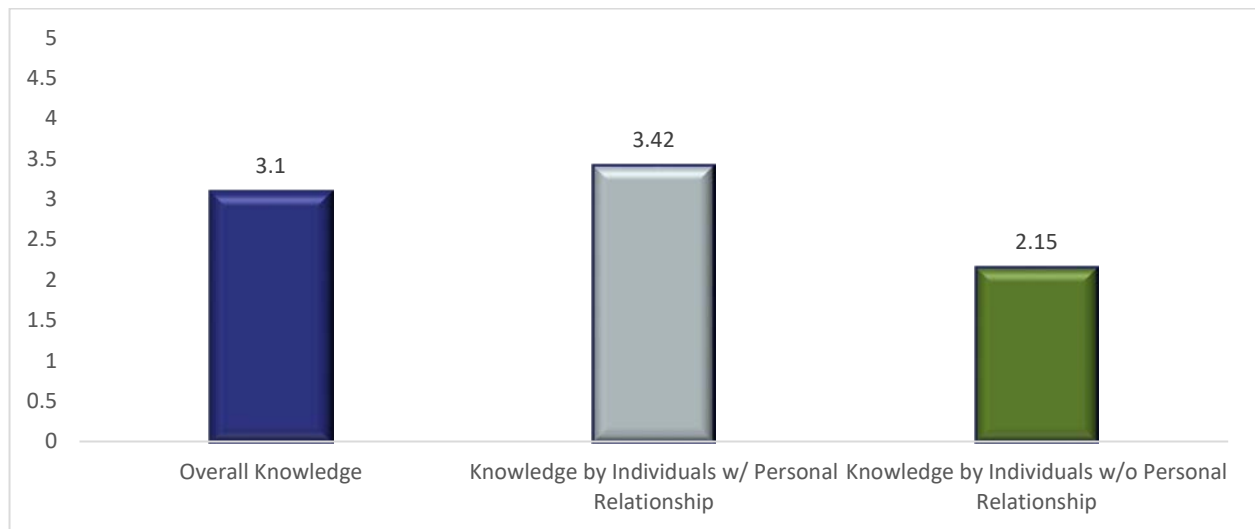
Figure 6. Recommended Priority Focus Areas for Dementia-Friendly Nevada



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, Nevada respondents reported a moderate (3.10) level of knowledge regarding the warning signs of dementia, with individuals who also reported a personal experience with dementia reporting a higher familiarity (3.49) than those who reported not having such experience (2.15; Figure 7). Familiarity with the warning signs of dementia may lead to earlier detection. Early detection benefits the person who receives 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 both community and relational resources, increasing quality of life and well-being, and allowing the individual living with dementia to remain in an environment of their choosing longer.

Figure 7. Knowledge of the 10 Warning Signs of Dementia



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

LIMITATIONS

The current report is limited in that it uses the combined data from all community surveys. Each county Community Action Group (CAG) was responsible for distributing and setting the active dates of the survey. Data analysis was completed on each survey as it closed to help ensure community groups had the information they needed to move forward with the Dementia Friendly process planning their community action group goals. These community reports included only those respondents who listed a zip code within the target area. Some respondents received a link to a survey that was meant for a different county than they reside in, resulting in that survey not being counted in the respective community report. Thus, there is some inconsistency in the overall statewide report and the individual community reports. Table 6 shows the difference between the number of respondents included in each original community report and the number of respondents identified to reside in that county for the final data set. Detailed analysis indicated that the means given in the current report do not differ significantly from those given in the original reports, however, suggesting that the original reports are accurate despite a difference in the number of respondents.

Table 6. Respondents Included in County and Statewide Reports

	Included in Community Reports	Included in Statewide Report
Elko County	161	163
Humboldt County	111	119
Nye County	85	89
Pyramid Lake – Paiute Tribe	22	43
Southern Nevada	179	195
Washoe County	363	391
Southern Nevada	179	195
Non-Participating County	~	68

Note. Final numbers presented may differ from county specific reports due to respondents living in one county but responding to a survey for a different county.

APPENDIX A: SUMMARY OF PHASE 1 MATERIALS

Table A1

Summary of Phase 1 Materials

Evaluation Goal	Measure Name
Determine basic demographics of individuals living with dementia within Nevada	Dementia Friendly Initiative Demographics Sheet
Determine initial knowledge of dementia specific programs of community leaders within Nevada	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: Comparison Between State and County Level Data for Selected Questions

TABLE 1. PYRAMID LAKE DAS SCORE BY TRIBAL MEMBERSHIP STATUS

	N	Overall	Subscale 1: Comfort	Subscale 2: Knowledge
Tribal Member	16	92 (18.69)	52 (11.42)	41 (9.42)
Non-Tribal Resident	27	113 (15.97)	65 (10.82)	49 (6.94)

FIGURE 1. PYRAMID LAKE PRIORITY FOCUS AREA BY TRIBAL MEMBERSHIP STATUS

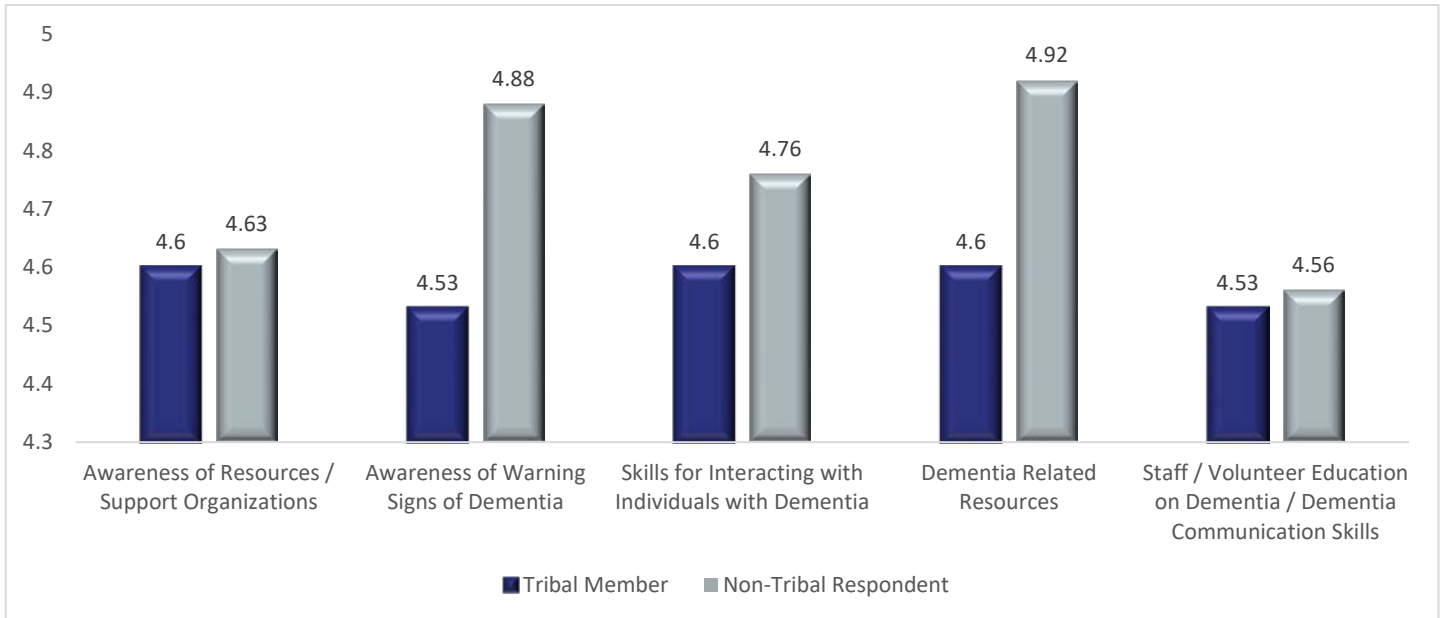
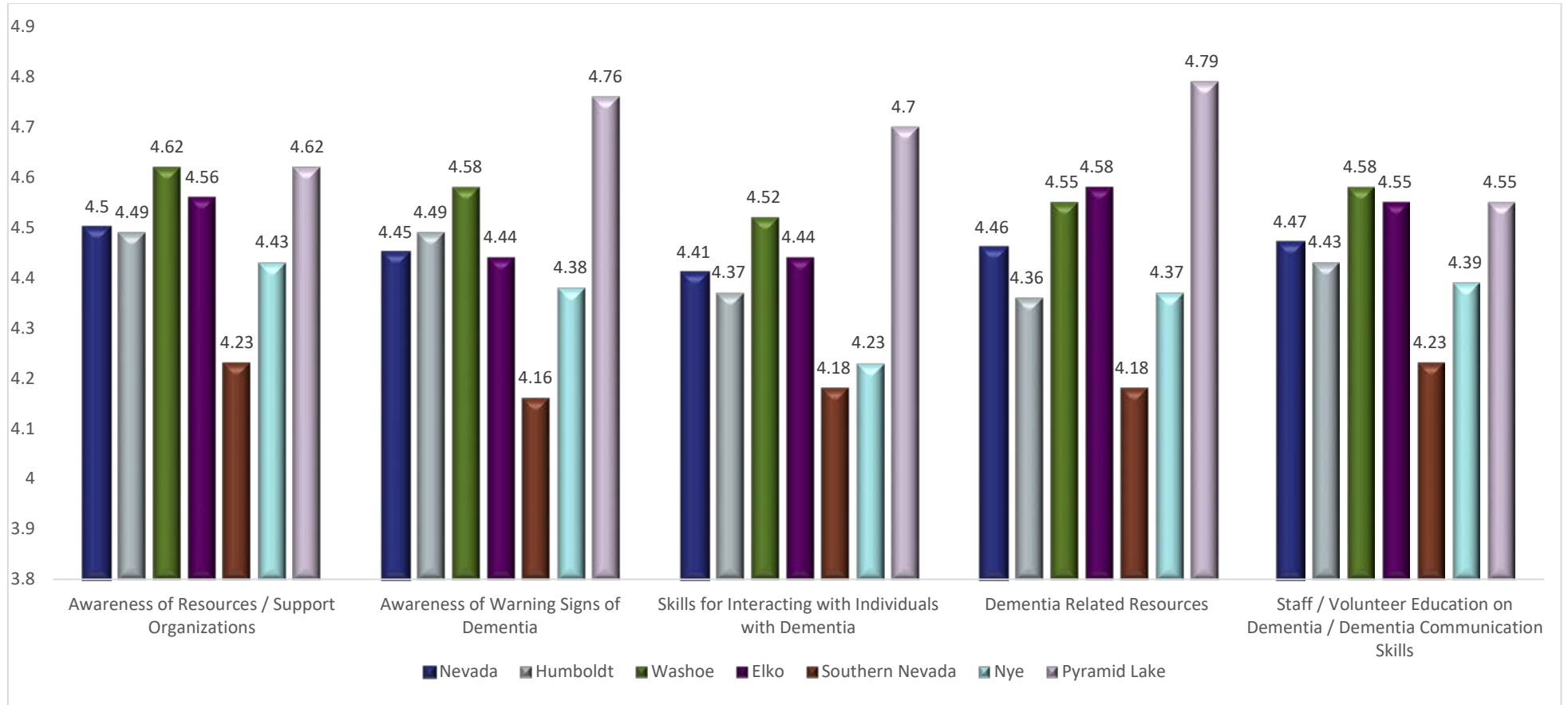
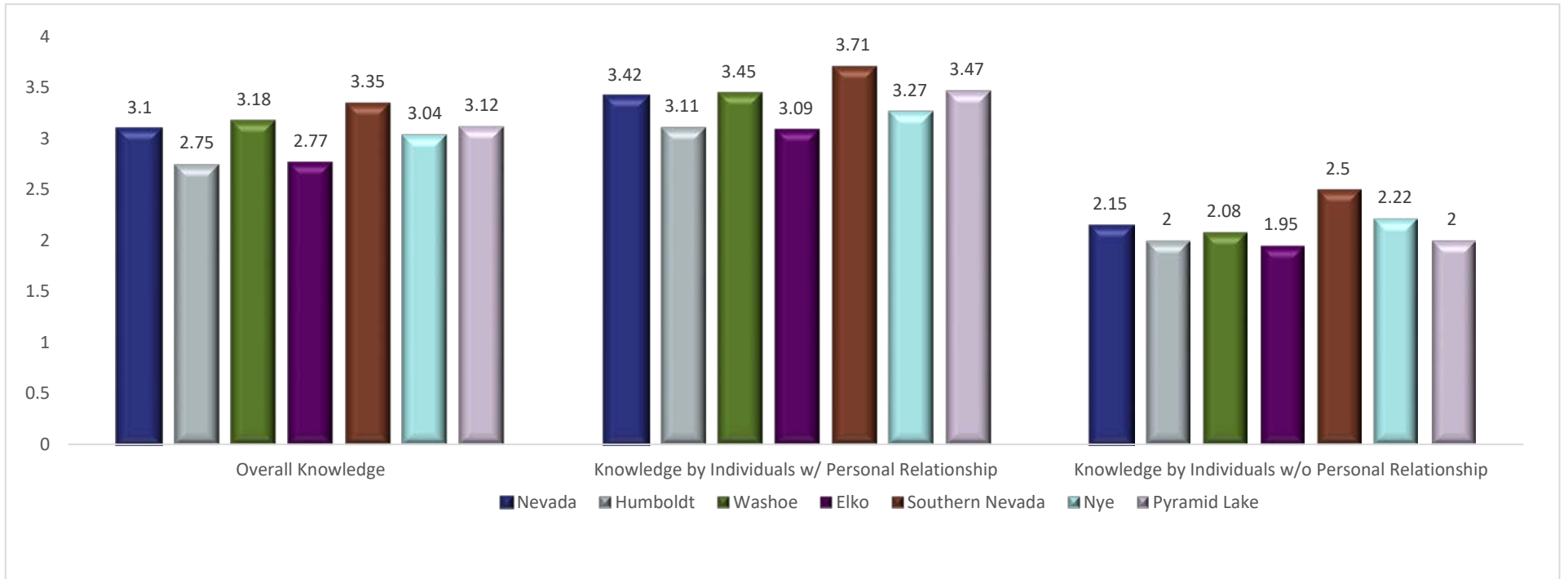


FIGURE 1. PRIORITY FOCUS AREAS FOR DEMENTIA FRIENDLY BY STATE AND COUNTY



Note. Each item was rated independently and scores could range from 1 (Strongly Disagree) to 5 (Strongly Agree).

FIGURE 2. MEAN KNOWLEDGE OF 10 WARNING SIGNS OF DEMENTIA BY STATE AND COUNTY



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

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

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 XX, 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.

APPENDIX D: 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.