

December 2019

Dementia Friendly Nevada: Final Program Evaluation Report for the ACL-Funded Project Period

Dementia Friendly Nevada is an ongoing statewide, community-based initiative that was led by the Nevada Aging and Disability Services Division and funded by the US Administration for Community Living (ACL) between October 2016 – September 2019

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Executive Summary

Community Assessment

Community dialogue to shape community-specific action goals in this statewide initiative using a Participatory Action Research Approach to community change was informed by a statewide Dementia Community Assessment. Among other key elements, this community assessment included the administration of the Dementia Attitudes Survey (DAS) to **1,104 respondents statewide. Baseline results demonstrated an overall 74% positive attitude toward dementia**, with higher scores for “knowledge” (80%) of dementia than “comfort” interacting with a person living with dementia (71%). These results informed a wide-sweeping community priority to raise awareness of dementia and offer education to reduce stigma associated with dementia, which was a goal established by all six of the Community Action Groups, along with many other community-specific activities. A follow-up survey administered at the conclusion of the ACL-funded initiative, completed by 129 respondents, demonstrated a **statistically significant increase in the public’s attitude toward dementia with an overall positive score on the DAS of 81% representing a 9.5% increase during the ACL-funded project period**. Notably, there is a large difference in response rates from the baseline to follow-up survey, which should be considered when interpreting these results.

Statewide Programs and Services

Five of the six Dementia Friendly Communities selected the Dementia Friends program for community education and awareness raising. Through this project, a total of **664 people were trained, including 590 as Dementia Friends and 74 as Dementia Friends Champions** (i.e., trainers). A pre-post knowledge assessment survey demonstrated a **statistically significant (+17%) increase in dementia-related knowledge** among participants.

During this ACL-funded project period, there was a great deal of effort to expand existing support services for people living with dementia and their care partners, both within the Nevada Dementia Supports Toolbox and through the many new programs launched by the Dementia Friendly Community Action Groups. With a baseline established in FY’15, in which a total of 194 people living with dementia were reported to have received ADSD-supported services, the **total service utilization increased to 1,924 people living with dementia reported as receiving services in FY’19, representing an 892% overall increase**.

Community Action Group Activities and Outcomes

- To meet the goals of the grant, six Community Action Groups were convened and engaged in collaborative planning to create their own community-specific goals and activities.
- All communities created an education-related goal, with 5 of the 6 choosing *Dementia Friends* as their education program, with a total of 644 people trained (see above).
 - Dementia Friendly Southern Nevada Urban developed its own education program that focused on three specific areas: Business, Faith, and the Community. The program was successful in increasing the knowledge of 162 community members within both the Business and Community settings.
- Each community developed new programs and community-engagement opportunities to help raise awareness and increase the quality of life for people living with dementia:
 - Dementia Friendly Elko developed the *Friends Day Out* program, which provides both socialization and respite opportunities, including use of the *Java Music Club*.
 - Dementia Friendly Winnemucca developed the Weekly Art and Music (WAM) respite program, and *Let's Talk About It*, an early stage support group.
 - Dementia Friendly Washoe County a new mutual peer support program, the *Open Door Café*, among other innovative social engagement opportunities.
 - Dementia Friendly Southern Nevada Urban facilitated memory screenings in the community, reaching 395 people.
 - Pesa Sooname (Dementia Friendly Pyramid Lake Paiute Tribe) hosted multiple community outreach events, including the Nevada Tribal Summit on Brain Health and Dementia, which included representatives from 14 different tribal communities.
 - Dementia Friendly Pahrump hosted a very successful and innovative community education event, with 65 community members in attendance, highlighting *Cracked: New Light on Dementia*, a research-based play about living with dementia, as well as a report by the Nevada Task Force on Alzheimer's Disease (TFAD).

Background

The Dementia Friendly Nevada initiative, led by the Nevada Aging and Disability Services Division (ADSD), includes a collaboration between various partner organizations as well as Community Action Groups (CAGs) across the state. CAGs were convened by community volunteers in Clark County (Southern Nevada Urban), Elko County, Humboldt County (Winnemucca), Nye County (Pahrump), the Pyramid Lake Paiute Tribe (Pesa Soaname), and Washoe County. CAGs were selected by an RFP process as part of this grant project. Key partner organizations included in Dementia Friendly Nevada included: the University of Nevada, Reno School of Community Health Sciences Dementia Engagement, Education and Research Program (DEER Program); the University of Nevada, Reno School of Medicine Sanford Center for Aging; the Alzheimer's Association regional offices in both Northern and Southern Nevada; Access to Healthcare Network; Nevada Senior Services; Nevada Rural RSVP; the Cleveland Clinic Lou Ruvo Center for Brain Health; The National Association of Area Agencies on Aging; and the Nevada Task Force on Alzheimer's Disease. Each of these partners played a specific and unique role in contributing to the success of Dementia Friendly Nevada.

The goal of this grant-funded initiative was to engage Nevada communities, including people living with dementia, their family caregivers, health care professionals, and broader community partners/stakeholders in a dialogue about Alzheimer's and related dementias (ADRDs) in a way that would foster adoption of evidence-based supportive services at the community level. In addition to establishing community-based services, the grant sought to reduce stigma and enable people living with dementia to fully engage within their communities, while connecting families living with dementia with information, supports, and evidence-based services as early as possible through multiple connection points, improving the quality of life of individuals living with dementia and their care partners. The specific objectives of this project included the following:

- **Objective 1:** Begin fostering the development of a 'Dementia-Friendly Nevada' (DFNV) by initiating Community Action Groups in six (6) targeted areas throughout the state, aimed at transforming the culture of dementia in those communities, enabling conversation and participation by all citizens, especially those living with dementia.

- **Objective 2:** Facilitating/mobilizing community-driven change and decision making for local Community Action Groups.
- **Objective 3:** Enhance the reach and spread of Nevada’s Toolbox of available programs by making available for community action groups referring clients into existing Nevada’s Toolbox of Evidence-based care programs.

Community Action Group Engagement and Action Goals

Individual community leaders volunteered to help develop the local engagement facilitate the CAGs. These groups were responsible for selecting community-level action goals and developing activities to engage, educate or support community members in a way that would enhance the experience of people living with dementia. Support and guidance of this process of using a collaborative community-building approach to identify goals and pursue relevant action was provided as needed by a Dr. Jennifer Carson of the UNR DEER Program serving as a community facilitator. Dr. Carson’s support included serving as a CAG co-facilitator and was thus present to a greater degree, in Elko County, Pahrump, Pyramid Lake and Washoe County, than in Winnemucca and Southern Nevada Urban who relied on local volunteers for CAG facilitation. The community-developed action goals for the CAGs included the following:

Dementia Friendly Elko (Elko County)

- Goal 1: Provide at least one Dementia Friends information session per month July 2018 – July 2019, offered at the Terrace at Ruby View, and by invitation.
- Goal 2: Provide a weekly peer support/respite program at the Terrace at Ruby View in partnership with Nevada Rural Counties RSVP Rural utilizing the Java Music Club (“Friends’ Day Out”).

Dementia Friendly Winnemucca (Humboldt County)

- Goal 1: To increase visibility of outreach events and Alzheimer’s-related resources within Humboldt County / Winnemucca consistently year-over-year between 2016 and 2019.
- Goal 2: To educate and inform business owners, employees, and general public about Alzheimer’s disease and other dementias; including signs, symptoms, progression, and how to best help caregivers and individuals living with dementia.

- Goal 3: To offer REST (Respite Education and Resource Tools) training to expand knowledge of respite care and increase the number of respite workers in Humboldt County / Winnemucca.
- Goal 4: To create and launch an early-stage dementia support group.
- Goal 5: To create new Adult Day services within Humboldt County / Winnemucca.

Dementia Friendly Pahrump (Nye County)

- Goal 1: To improve geriatric clinical services in Pahrump with an aim to improve early detection and treatment.
- Goal 2: To provide comprehensive dementia education to family care partners in conjunction with respite care for people living with dementia.
- Goal 3: To provide community education and awareness.

Pesa Soaname (Pyramid Lake Paiute Tribe)

- Goal 1: Provide comprehensive geriatric clinical services in partnership with the UNR-Med's Sanford Center for Aging.
- Goal 2: Provide formal and informal opportunities for dementia education.

Dementia-Friendly Southern Nevada Urban (Clark County and surrounding areas)

- Goal 1: To develop programs and training tools to increase public awareness / knowledge about dementia.
- Goal 2: Implement community-based memory screenings.

Dementia Friendly Washoe County

- Goal 1: To build a robust offering of volunteer-driven, Peer Support opportunities for people living with dementia and their care partners through the creation of supportive environments designed specifically to meet their expressed needs.
- Goal 2: To offer opportunities for people living with dementia and their care partners to access services that promote holistic health and well-being within a dementia-friendly framework of support and inclusivity.
- Goal 3: To promote dementia awareness and supportive attitudes among the broader Washoe County community and to educate organizations and individuals to better serve and support people living with dementia.

Evaluation Approach

At the heart of the Dementia Friendly Nevada initiative was a community-building approach through which each community reflected on their needs and strengths and determined collaboratively how to best support their community members living with dementia. To align with this community-driven approach, under the leadership of Dr. Jennifer Carson the overall community-change approach was informed by the principles of Participatory Action Research (PAR), which includes a process of documenting action and community change as it unfolds organically at the community level.

The UNR Sanford Center for Aging (SCA) was contracted to conduct an overall evaluation of this initiative and did so in a manner that both met the evaluation goals of ADSD in looking at specific outcomes, while remaining aligned with the principles of PAR. Specifically, this included three major elements: 1) Community needs assessment to inform community dialogue in planning their community-specific goals; 2) community-specific evaluation to track the impact of individual community-level goals; and 3) statewide program and service data demonstrating the use of the Nevada Dementia Toolbox evidence-based programs.

To complete the Community Needs Assessment, SCA analyzed available data regarding the prevalence of dementia in each county and applied the formula developed by Dementia Friendly America for doing so. We also conducted a statewide and community-specific community needs survey that included assessments of the public's attitude toward dementia (using the Dementia Attitudes Scale) as well as the public's perception of both strengths and needs in terms of community resources related to dementia. SCA compiled these data and provided a complete community needs assessment report to each CAG for their review and consideration in establishing their own community-driven priorities (i.e., action goals).

To collect the needed data for documenting the community-driven goals and the statewide program delivery, the Sanford center received reports from the CAGs and other key funded partners, and also received data directly from ADSD on statewide programs utilization. SCA synthesized all data received from each of the collaborating partners into relevant summary reports. Each reporting organization was responsible for collecting or reporting their own data, while SCA was responsible for aggregating and managing that data.

Community Needs Assessment

Dementia in Nevada

To estimate the number of individuals living with dementia in Nevada, SCA used census data from the Nevada State Demographer and the formula developed by Dementia Friendly America. Overall, it is estimated that 11% of elders (i.e., individuals aged 65+) within the state are currently living with dementia, with 14% of these elders living alone. For individuals who are 85 or older, the percentage of individuals living with dementia is 33%. (See Table 1).

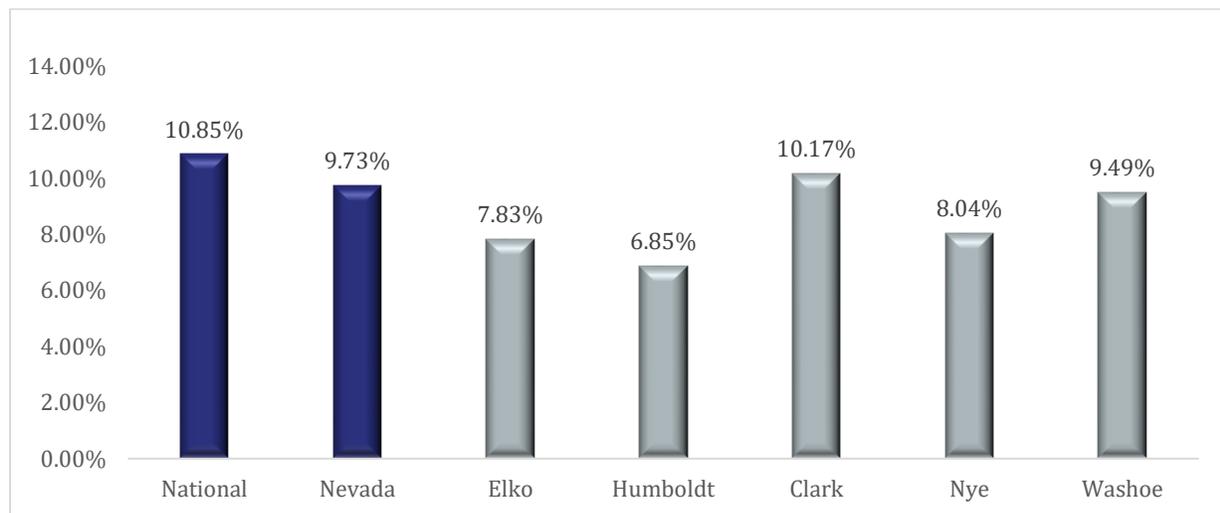
Table 1: 2016 Estimated Prevalence of Dementia in Nevada

	Population Estimate	Percent
Total Aged 65+*	410,270	--
Est. Aged 65+ Living With Dementia	45,586	11%
Est. Living With Dementia, Living Alone	6,513	2%
Total Aged 85+*	39,235	--
Est. Aged 85+ Living With Dementia	13,079	33%

Note. *Nevada State Demographer estimates based on 2010 census data.

Additionally, the Centers for Medicare and Medicaid Services (CMS) estimated that among Nevada Medicare beneficiaries (268,060), 26,083 (~10%) received services for Alzheimer’s disease or related dementias in 2017. Rates of Medicare ADRD service utilization are presented in Figure 1. Rates are not presented for the Pyramid Lake Paiute Tribal reservation as these data were not available.

Figure 1. CMS ADRD Service Utilization by Participating County in Nevada



Community Needs Survey

As part of the initial community assessment in the PAR process, SCA conducted a statewide, and community-specific, survey designed to assess community attitudes regarding dementia and determine perceived strengths and needs regarding resources for people living with dementia. Attitudes were assessed using the Dementia Attitude Survey (DAS; O'Connor & McFadden, 2010)¹. The DAS measures attitudes towards individuals living with dementia, with subscales assessing respondents' knowledge of dementia and level of comfort interacting with people living with dementia.

Baseline Assessment – Dementia Attitudes Survey

During the initial administration of the community needs survey (Fall 2017 through Fall 2018), 1,104 surveys were completed by community members across Nevada. Each CAG took responsibility for distributing both a link to an online survey and paper copies within their communities and across their social networks. In addition, ADSD published a link to the survey on their social media accounts. The response to the survey was exceptional and offered many insights into the view of community members regarding dementia.

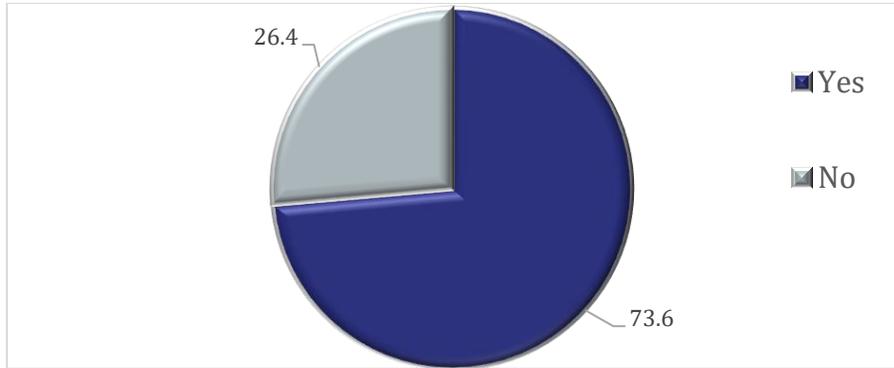
The majority of participants in this initial survey were non-Hispanic White (n = 800, 77%), women (n = 871, 82%) and had an average age of 54 years old, with age ranging among respondents from 11 to 99. Respondents were primarily reflected the broader aging and health services sectors, with respondents reporting being part of a community organization that offered supports and services (e.g., meals on wheels; n = 161, 15%), a government agency (n = 139, 13%), local hospitals (n = 130, 12%) or residential care homes (n = 71, 7%). There were ten (1%) respondents who indicated that they were living with dementia.

Results of the baseline survey indicated that approximately 74% (n = 806) of respondents had some form of personal experience interacting with someone living with dementia (*See Figure 2*). A majority of those respondents (n = 306; 38%) who reported that having experience interacting with someone living with dementia reported that their experience had been with a parent, while individuals having experience with a client living with dementia (n = 228; 29%) was the next most common relationship reported (*See Figure 3*). Participants also reported that

¹ O'Connor, M.L. & McFadden, S.H. (2010). Development and psychometric validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease*, 2010. doi: 10.4061/2010/45218.

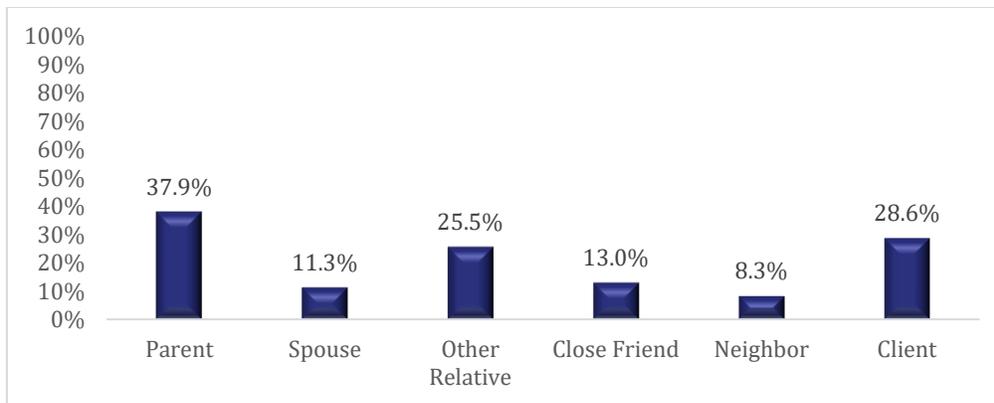
they had experience interacting with other relatives, such as grandparents or in-laws (n = 206; 26%) who were living with dementia.

Figure 2. Percent Reporting Having Personal Experience With Someone Living With Dementia



Note. Relationship could include individuals living with dementia.

Figure 3. Percent Reporting Relationship Between Self and Individual Living With Dementia



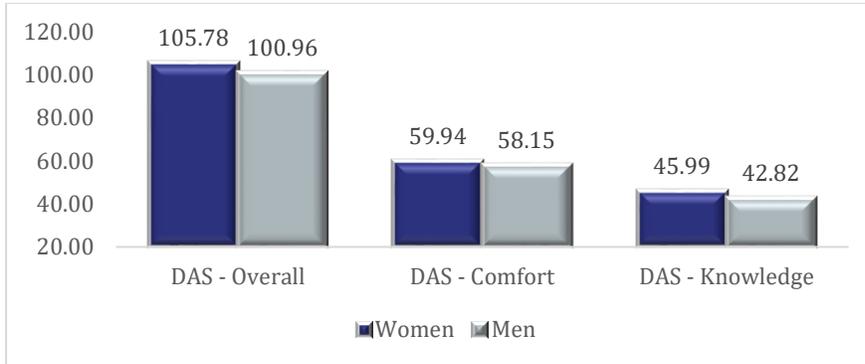
Note: Percents are not cumulative as multiple relationships could be reported. Other relative includes grandparents as well as in-laws. Client includes individuals listed as patients of the respondent.

Overall, mean scores for the DAS were high, with respondents reporting a mean score of 104 on the overall scale (Out of 140), indicating a 74% overall positive attitude toward dementia. Scores on the two subscales were also high, including a 71% positive response on one's *Comfort* with dementia ($M = 60$ out of 84) and an 80% positive response on dementia-related *Knowledge* ($M = 45$ out of 56)². Scores on the DAS differed by gender, with women reporting significantly higher overall scores ($M = 106$) than men ($M = 101$; $-3.04, p = .002$). Further, women reported

² Maximum score on the DAS is 140, with a minimum score of 20 as responses were coded from 1 (Strongly Disagree) to 7 (Strongly Agree). Maximum score on the Comfort subscale is 84, with a minimum 12. Maximum score on the Knowledge subscale is 56 with a minimum of 8.

significantly more positive attitudes towards individuals living with dementia than men on the *Knowledge* but not the *Comfort* DAS subscales (See Figure 4).

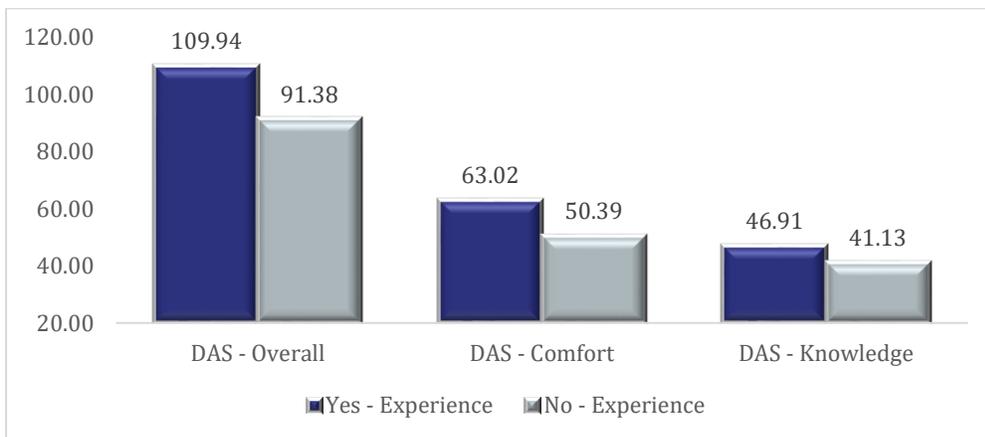
Figure 4. Mean DAS / DAS Subscale Score by Gender



Note. Mean difference significant at $p < .001$ for DAS-Overall and at $p < .001$ for DAS-Knowledge. Mean difference not significantly different for DAS-Comfort $p = .09$.

Individuals who reported having experience with dementia reported significantly more positive attitudes towards individuals living with dementia ($n = 806$, $M = 109.9$) compared to individuals who reported that they had no experience ($n = 287$, $M = 91.4$; $p < .001$). A similar pattern was observed on the DAS subscales, with individuals who reported having experience with individuals living with dementia reporting significantly higher scores on the *Knowledge* subscales ($p < .001$; See Figure 5) but not the *Comfort* subscale ($p = .10$). It is important to note that a chi-square analysis indicated that there were no significant differences in the percentages of men and women on whether or not they had experience with someone living with dementia ($\chi^2(3) = 4.15$, $p = .25$) suggesting that the observed difference is not due to gender difference.

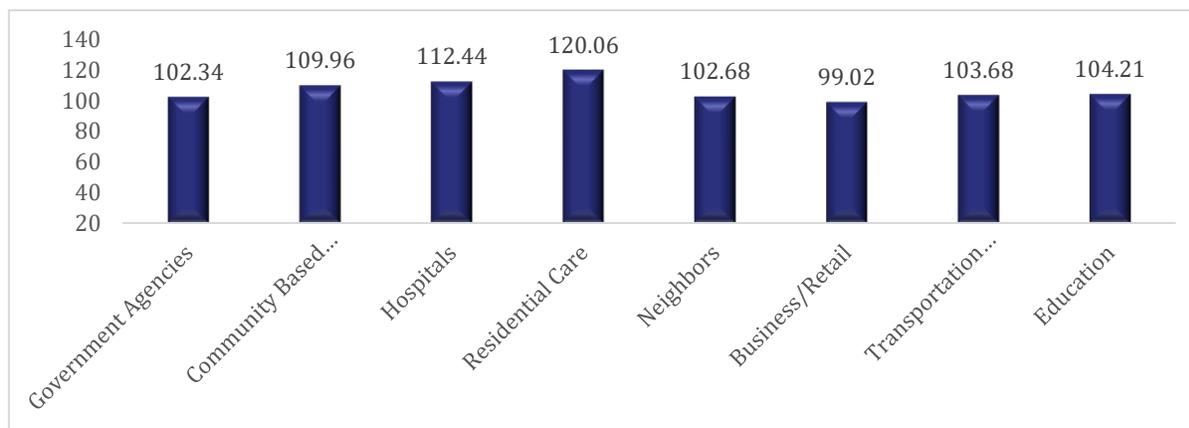
Figure 5. Mean DAS / DAS Subscale Score by Experience



Note. Mean difference significant at for DAS-Overall ($p < .001$), DAS-Knowledge ($p < .001$), and DAS-Comfort subscales ($p < .001$).

There were also differences between respondents' views regarding individuals living with dementia depending upon what sector the respondent represented (*See Figure 6*). Individuals who reported working in residential care homes and hospitals / medical services typically reported more positive attitudes towards individuals living with dementia compared to the other sectors. It is important to note that these sectors (i.e., residential care homes and hospitals) are more likely to be exposed to individuals living with dementia than the other groups. This exposure is likely to influence the overall perceptions of individuals living with dementia.

Figure 6. Mean DAS / DAS Subscale Score by Sector

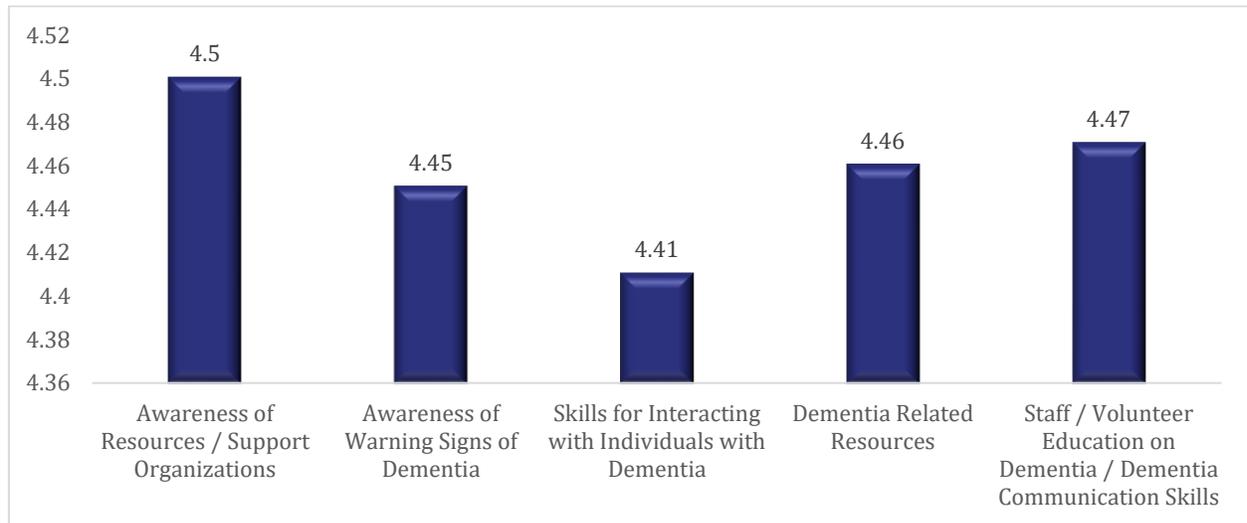


Note. Scores could range from 20 – 140.

Community Perception of Needs

In addition to attitudes towards individuals living with dementia, in the baseline community needs survey respondents also rated their priorities for possible areas of focus, using a rating scale of 1 – 5 (*See Figure 7*). Participants typically reported that increasing the increasing community awareness of the resources and organizations that can help support individuals living with dementia (4.5) was the most important priority. The other priorities, including increasing staff / volunteer education (4.47), increasing the number of dementia related resources (4.46), increasing community members' knowledge of the 10 warning signs of dementia (4.45) and increasing the community members' skills for interacting with individuals living with dementia (4.41) were all closely ranked.

Figure 7. Mean DAS / DAS Subscale Score by Reported Personal Experience



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

Follow-Up Assessment – Dementia Attitudes Survey

At the conclusion of the grant period (Fall 2019), a second wave of the Dementia Attitude Survey was undertaken to determine what, if any, changes had been made regarding attitudes about individuals living with dementia as a result of the grant activities. The same instrument that was used at baseline was again used (i.e., the DAS; O'Connor & McFadden, 2010; as well as the other dementia related questions posed to respondents)³. Similar to the previous wave, CAG members were asked to distribute an online link to the survey to their contact lists, and were provided Adobe documents that contained printable copies of the survey.

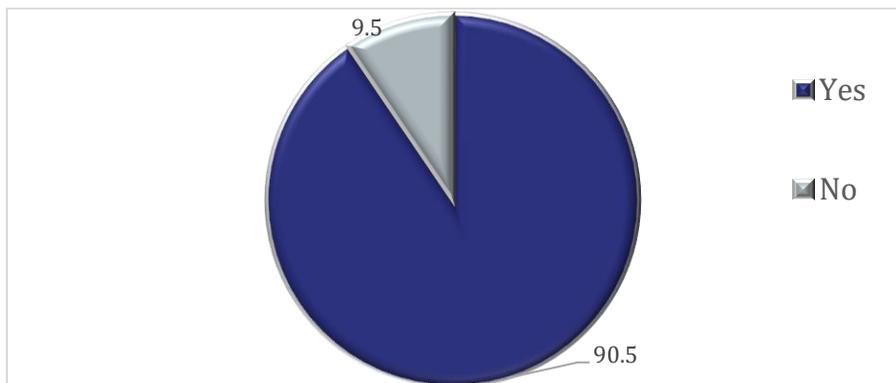
Participants in the follow-up wave (n = 129) were mostly non-Hispanic White (n = 96, 80%) and women (n = 107, 84%) with an average of 50 years old, with respondent ages ranging from 22 to 84. Similar to the first wave, respondents represented community supportive agencies (e.g., meals on wheels; n = 52, 41%) and government agencies (n = 23, 18%), although at follow-up there was a lower percent representing hospitals (n = 4, 3%) and residential care facilities (n = 5, 4%). Four (3%) respondents identified that they were living with dementia.

In terms of respondent experiences with dementia, a higher percentage (n = 114, 91%) reported that they had at least some experience interacting with someone living with dementia

³ O'Connor, M.L. & McFadden, S.H. (2010). Development and psychometric validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease*, 2010. doi: 10.4061/2010/45218.

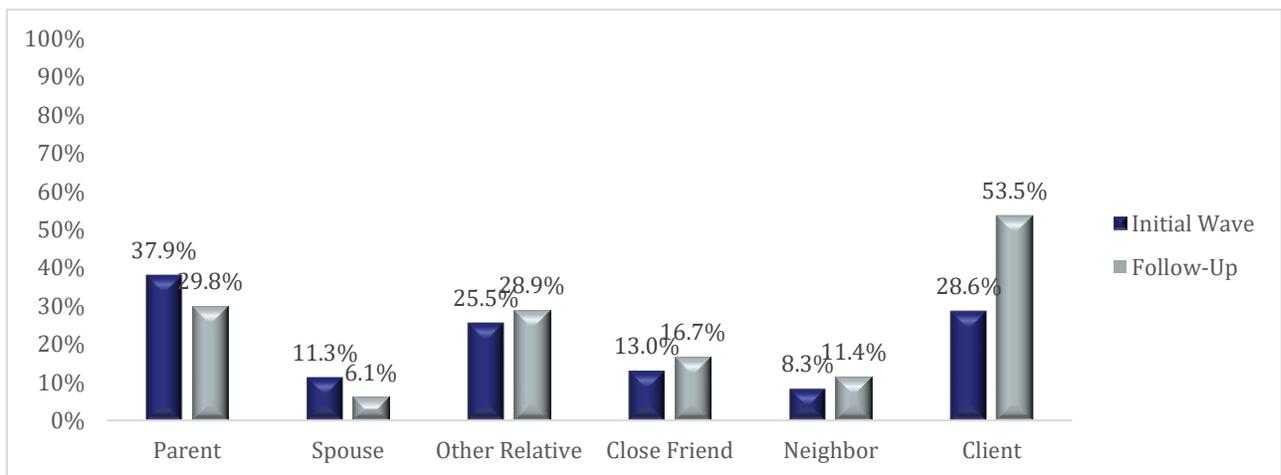
(See Figure 8) at follow-up than at baseline. A majority of those respondents (n = 61, 54%) reported that they had experience with a client living with dementia, with a slightly lower number (n = 34, 30%) reporting their experience was with a parent than at baseline. Participants also reported that they had experience interacting with other relatives, such as grandparents and in-laws (n = 33, 29%) who were living with dementia, similar to the rate as at baseline. These results mirror the results of the larger baseline assessment (See Figure 9).

Figure 8. Personal Experience With Someone Living With Dementia Reported at Follow-Up



Note. Relationship could include individuals living with dementia.

Figure 9. Relationship Between Self and Person Living With Dementia Baseline vs. Follow-Up



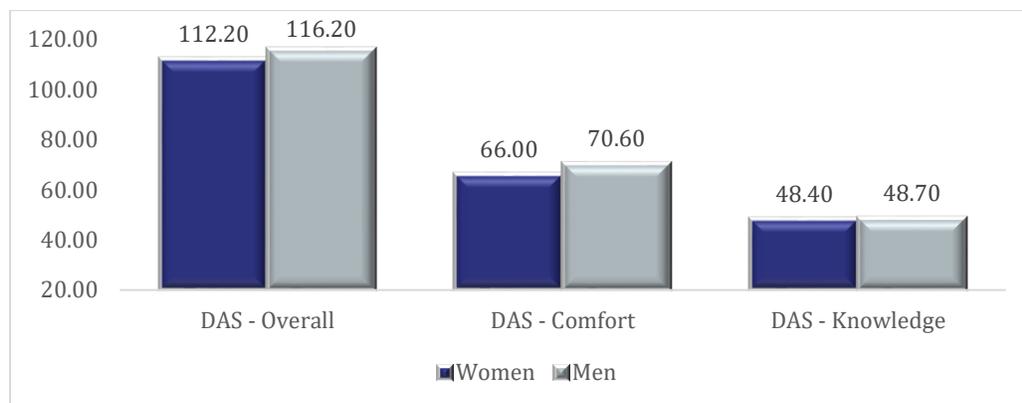
Note: Percents are not cumulative as multiple relationships could be reported. Other relative includes grandparents as well as in-laws. Client includes individuals listed as patients of the respondent.

While the results for the DAS are provided here at both baseline and follow-up for comparison and directional insights, it is important to note that drawing conclusions in the change attributable to the Dementia Friendly Nevada activities are greatly limited both by the

widely different survey response rates at time 1 and time 2 (1,104 versus 129 respectively) as well as potential external factors occurring throughout the initiative that may have influenced community member perspectives.

Overall, mean scores for the DAS were high, with respondents reporting a mean score of 113 out of 140 (81% positive attitude) on the overall scale, with scores on the *Comfort* ($M = 67$ out of 84; 80%) and *Knowledge* ($M = 49$ out of 56; 88%) subscales also high⁴. Unlike at baseline, there were no gender differences on the overall DAS ($p = .20$), the *Comfort* ($p = .1$) or the *Knowledge* ($p = .8$) subscales (See Figure 10).

Figure 10. Mean DAS / DAS Subscale Score by Gender at Follow-Up



Note. Mean difference non-significant for the DAS-Overall, DAS-Comfort, and DAS-Knowledge at $p > .05$ for all scales /subscales.

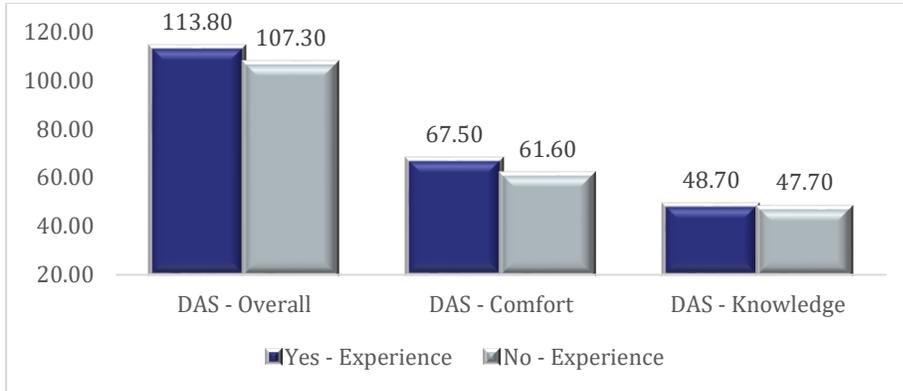
When looking at group differences between follow-up respondents who reported having some experience with individuals living with dementia ($n = 114$) and those that reported having no such experience ($n = 12$), there were no significant differences between the two groups (all p 's $> .05$; See Figure 11).

Similar to baseline, there were observed differences between the sectors, with respondents who represented hospitals reporting the highest scores on the DAS ($M = 122$, 87% positive), and respondents representing community-based supports and services (e.g., meals on wheels) also reporting high scores ($M = 114$; 81% positive; Figure 12). Unlike baseline, respondents representing residential care reported *lower* scores ($M = 109$; 78% positive). Again,

⁴ Maximum score on the DAS is 140, with a minimum score of 20 as responses were coded from 1 (Strongly Disagree) to 7 (Strongly Agree). Maximum score on the Comfort subscale is 84, with a minimum 12. Maximum score on the Knowledge subscale is 56 with a minimum of 8.

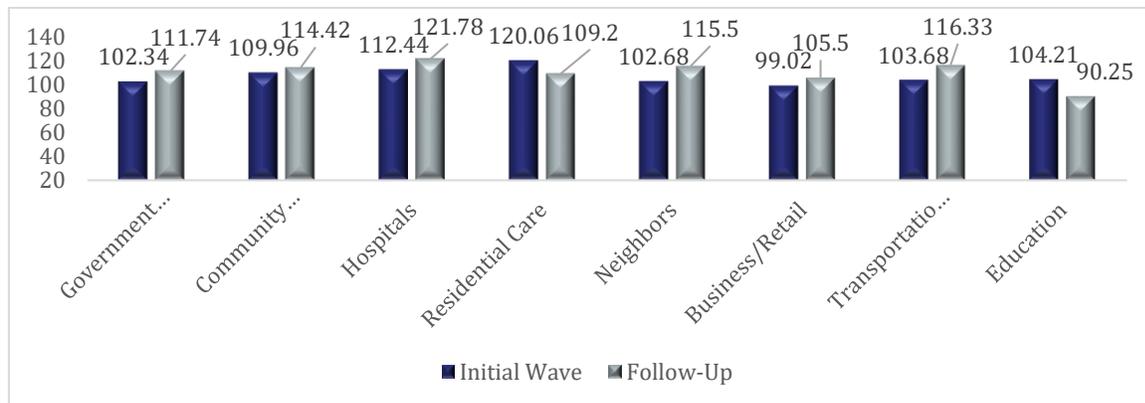
it is likely that the observed differences in mean score are the result of differences in the overall number of participants from those sectors.

Figure 11. Mean DAS / DAS Subscale Score by Experience at Follow-Up



Note. Mean difference non-significant for DAS-overall as well as both subscales (all p 's > .05).

Figure 12. Mean DAS / DAS Subscale Score by Experience Baseline vs. Follow-Up

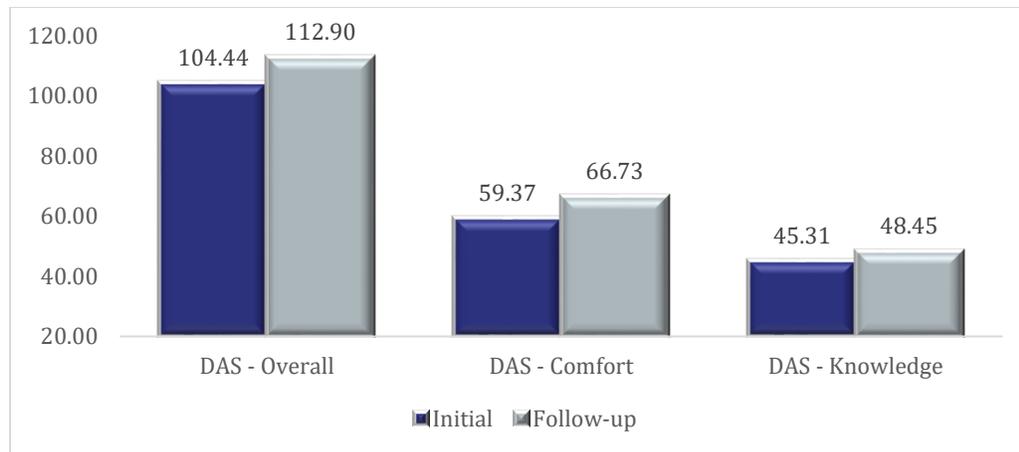


Note. Scores could range from 20 – 140.

Scores on the DAS between the two waves were compared using a summary independent samples t-test. There was a significant difference between the baseline ($M = 104$, 74% positive) and follow-up ($M = 113$; 81% positive) waves of the survey (+9.5%; $p < .001$; See Figure 13), with a higher positive attitude toward dementia at follow-up. There was also a significant difference between the baseline *Comfort* ($M = 60$; 71% positive) and the follow-up ($M = 67$; 80% positive) scores (+12.7%; $p < .001$) as well as between the baseline *Knowledge* ($M = 45$; 80%) and follow-up knowledge ($M = 49$; 88%) scores (+10%; $p < .001$). Despite these scores being significantly different, caution should be utilized when interpreting the results as there were more individuals who had experience with dementia during the follow-up (91% vs. 74%). It should be noted that for both of the current samples as well as in previous published studies,

individuals who reported having experience interacting with someone living with dementia tended to report a higher score both on the DAS and the subscales.

Figure 13. Mean DAS / DAS Subscale Score Baseline vs. Follow-Up



Note. Although mean differences are significant at $p < .001$ between the follow-up and initial waves, caution should be used when interpreting the results due to differences in the response rate and the number of individuals who reported having experience with someone living with dementia

Primary Activities and Impact

Statewide Impact

A key overarching goal of the Dementia Friendly Nevada initiative was to increase awareness of dementia by offering education to communities statewide. To support this goal, all six of the community action groups (CAGs) included *dementia education and awareness* as a community-specific goal in one way or another. In particular, five of the six CAGs delivered the *Dementia Friends Program* as their primary community education activity. Overall, there were 590 “dementia friends” created through community education as part of this grant-funded project, while both the initiative and education program continues beyond the end of the funded project. Additional details on the impact of *Dementia Friends* are provided below.

Another overarching goal of the Dementia Friendly Nevada grant was to increase the reach of program and services, including key evidence-based services in the Nevada Dementia Supports Toolbox in order to positively impact the lives of individuals living with dementia and their care partners. Several statewide programs were monitored during this initiative to determine if such an increase occurred. These programs included *Savvy Caregiver*, the Benjamin Rose

Institute on Aging Care Consultation (*BRI-Care Consultation*) program, the Care Partners Reaching Out (*CarePRO*), the Early Stage Partners in Care (*EPIC*) program. This evaluation also monitored the *REST Program*, offering respite services and an additional education program addressing the intersection of aging, dementia and intellectual disabilities, provided by Dr. Rebecca Arvans-Feeney. Finally, this evaluation monitored other state-funded programs intended to support individuals living with cognitive impairment. Each program is detailed below, and includes any participant data as well as changes in reach and participation over time where possible.

[The Dementia Friends Program](#)

The Dementia Friends program was developed by the Alzheimer’s Society in the United Kingdom and is administered in the United States by Dementia Friendly America. This program helps community members learn what dementia is, how it affects people who have the disease, and actions that can be taken to support individuals living with dementia. The program follows a train-the-trainer model, with organizations who wish to bring the program to their state appointing a “Master Champion” who is trained through materials provided by Dementia Friends USA. This Master Champion then provides additional champion trainings to others within the state who wish to become Dementia Friends Champions. Once an individual has become a Dementia Friend Champion, they are able to hold the awareness-raising sessions within their own communities to provide education about dementia. In Nevada, the Dementia Friends license was secured by the Nevada Geriatrics Education Center (NGEC), a part of the UNR Sanford Center for Aging, which offered implementation and data-collection support during the grant-funded project.

For the purposes of this ACL-funded project, the Dementia Friends program was evaluated using a pre / post session survey designed by SCA. Participants were initially asked to complete basic demographic information, as well as a short knowledge survey. After completing the information session, participants were asked to complete a short satisfaction survey, a post-session knowledge survey, as well as several behavioral intent questions.

Overall, there were 74 Dementia Friends Champions trained across the 5 participating CAGs (*See Table 2*). These champions went on to hold 52 Dementia Friends information sessions, reaching a total of 590 community members with the program.

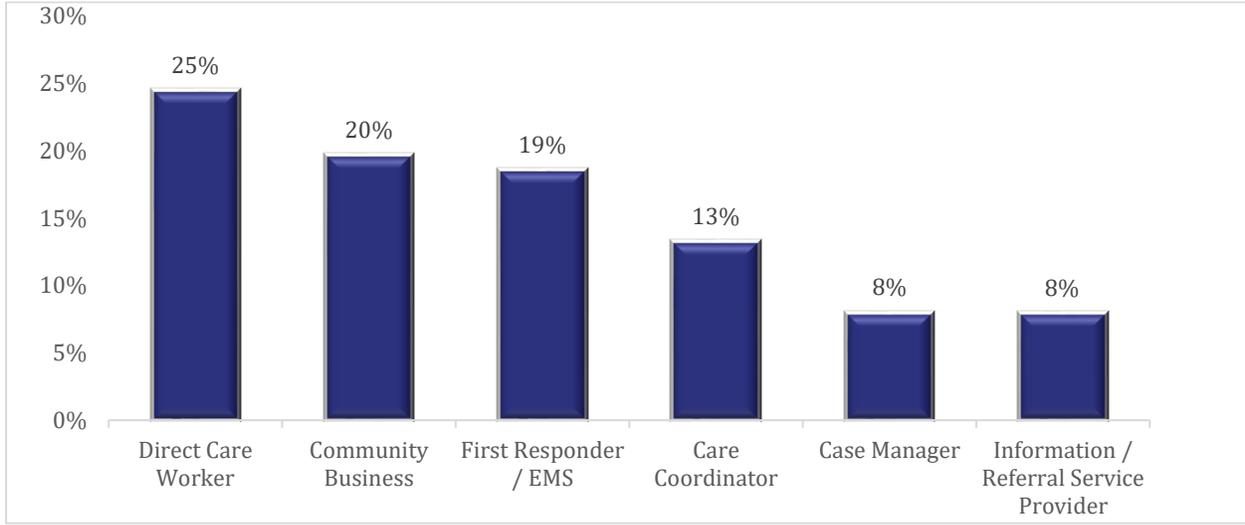
Across all of communities, a majority of participants in the Dementia Friends program were non-Hispanic White (75%), women (77%) who reported not providing care for someone living with dementia (76%). A high minority of attendees of the Dementia Friends information sessions (42%) reported that they were not involved in any of the sectors measured, with an additional 26% not answering the question. For those attendees who did identify a sector (n = 188), the most common sector was direct care worker (25%), with community business (20%), first responder / EMT (19%) and care coordinator (13%) the most common responses (*See Figure 14*).

Table 2: Demographics of Dementia Friends Champions & Friends

	Champion (n = 74)	Friend (n = 590)	Total (n = 664)
Number of Sessions*	6	52	58
Ave. Age	49.3	48.5	48.6
Gender			
Female	62	429	491
Male	11	134	145
I Prefer Not to Identify	0	2	2
Ethnicity			
Non-Hispanic White	50	411	461
African American / Black	0	8	8
Native American	7	13	20
Pacific Islander	0	8	8
Hispanic / Latinx	4	50	54
Asian American	6	40	46
Other	3	16	19
Race			
Hispanic / Latinx	5	66	71
Veteran Status (Yes)	7	49	56
Care Partner Status			
Yes	14	129	143
No	56	422	478
I am living with dementia	2	6	8

Note. *Only Champions trainings where all participants converted from Friends to Champions are reported as Champion trainings, the other trainings are reported as Friends sessions. For the Champion sessions, 1 individual did not report their gender, 4 did not report their race/ethnicity, 2 did not report Latinx status, 2 did not report veteran status, and 2 did not report care partner status. For the Friends sessions, 25 individuals did not report their gender, 44 did not report their race/ethnicity, 41 did not report their Latinx status, 36 did not report their veteran status, and 33 did not report their care partner status.

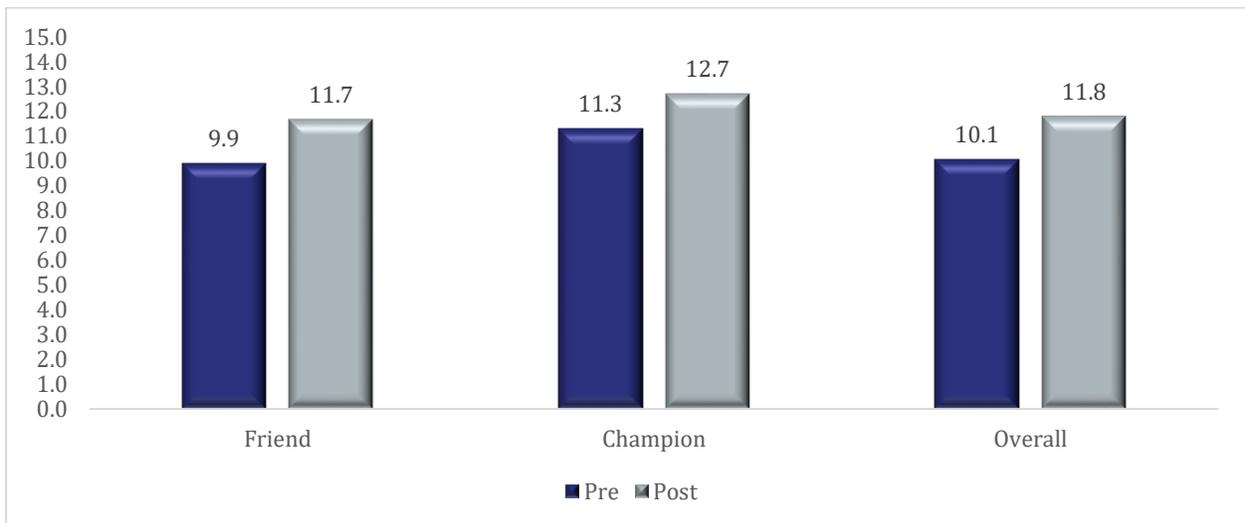
Figure 14. Dementia Friends by Sector – Statewide



Note. Only individuals who reported a sector on the list were included

For individuals who completed both the pre- and post-knowledge survey (n = 572) the program was successful in increasing the participant’s knowledge regarding dementia, with participants answering significantly more questions correctly (+17%) on the post-knowledge survey (M = 11.8 out of 15; 79%) compared to the pre-knowledge survey (M = 10.1; 67%; See Figure 15).

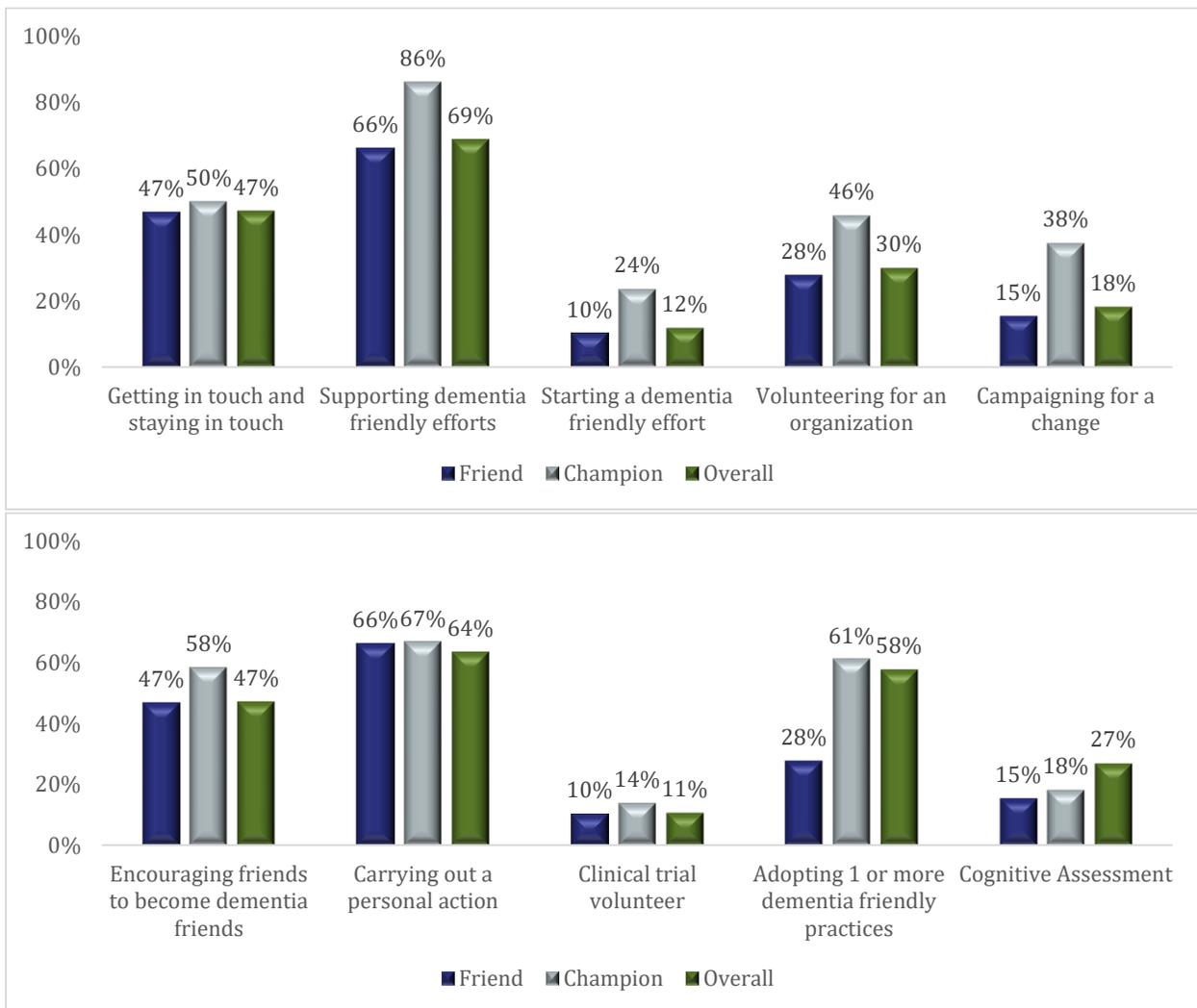
Figure 15. Dementia Friends Knowledge Change (Pre-Post)



Note. Mean difference for Friends (n = 500), Champions (n = 72), and Overall (n = 572) significant at $p < .001$. Total possible correct was 15.

Participants also completed several questions regarding behaviors that would benefit individuals living with dementia in their communities. Overall, a majority of participants in the Dementia Friends information sessions who answered the behavioral questions (n = 528) reported that they *would be supportive of dementia friendly efforts in their community (66%), would carry out a personal action when out in their community (63%), and would adopt one or more dementia friendly practices in their personal or professional life (57%)*; (See Figure 16).

Figure 16. Participant Behavioral Intention

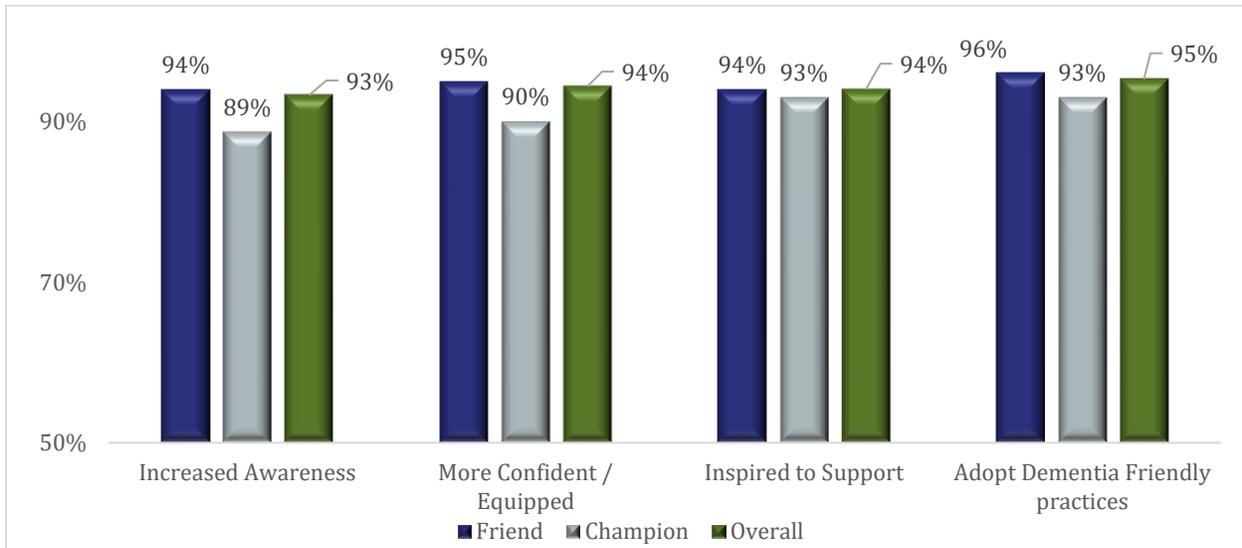


Note. Only individuals who completed both the pre- and post-knowledge survey were included. Friends (n = 500), Champion (n = 72), Total (n = 572).

In addition to the behavioral intent questions detailed above, participants also answered 4 program-specific questions related to the perception of what they gained from the program. Overall, most participants in the Dementia Friends information session reported that they *felt*

their awareness of ADRDs had increased (n = 468, 94%), felt more confident / equipped to offer support to an individual living with dementia trying to navigate their community (n = 473, 95%), felt inspired to offer support and be a friend to individuals living with dementia in their community (n = 470, 94.2%), and that they were likely to adopt a dementia friendly practice in their personal or professional life (n = 478, 96%); (See Figure 17).

Figure 17. Perceived Benefits of Program



Note. Only individuals who completed both the pre- and post-knowledge survey were included.

SAVVY Caregiver Program

The SAVVY Caregiver Program (SCP) is a care partner intervention designed to increase the skills and confidence of care partners of individuals living with Alzheimer’s or a related dementia (ADRD; Hepburn, Lewis, Sherman, & Tornatore, 2003)⁵. The training typically consists of 6 2-hour sessions that involve accomplishing various objectives for the care partners including learning about the disease and dealing with difficult behaviors. In addition to the in-person sessions, participants also typically receive a caregivers’ manual as well as an informational CD-Rom that contains videos of experts providing suggested behavioral interventions at multiple stages of dementia. Other studies that have examined a modified format

⁵ Hepburn, K. W., Lewis, M., Sherman, C.W., Tornatore, J. (2003). The Savvy Caregiver Program: Developing and testing a transportable dementia family caregiver training program. *The Gerontologist*, 43(6), 908-915. doi: <https://doi.org/10.1093/geront/43.6.908>

(e.g., reducing the number of sessions from 6 to 1 6-hour session) does not impact the overall utilization of SCP materials (Scharf, Bell, & Smith, 2006).⁶

During the grant-funded project the Northern Nevada regional office of the Alzheimer’s Association presented the SAVVY program a total of 9 times with a total of 66 participants. The sessions were split evenly between the normal 6-week sessions (4 sessions) and the 6-hour, single day sessions (4 sessions), with one session being offered in 3 4-hour sessions. Overall, most participants in the program were non-Hispanic White (n = 61, 92%) women (n = 50, 76%), and all (n = 66, 100%) participants were care partners for someone living with dementia (*See Table 3*). Further, two 2 sessions were held in Spanish (n = 21).

Table 3: SAVVY Caregiver Program Participant Profile

	Total (n = 66)
Number of Sessions	9
Age	
Under 60	24
60 +	40
Gender	
Female	50
Male	15
Ethnicity	
Non-Hispanic White	61
African American / Black	2
Race	
Hispanic / Latinx	21
Geographic Location	
Urban	50
Rural	16
Veteran Status (Yes)	2
Care Partner Status (Yes)	66

Note. Three individuals did not report their race/ethnicity, and 1 did not report their gender. Demographics are not available by session type.

As previous research has shown that there is no impact on the overall quality of the program when the number of sessions are modified (Scharf, Bell, & Smith 2006), all evaluation statistics combine all the sessions.

At the conclusion of the program, participants were asked to report on three questions regarding their knowledge, skills, and confidence in providing support to an individual living with dementia. Overall, all participants (100%) reported either strong agreement or agreement

⁶ Scharf, L., Bell, P.A., Smith, S.A. (2006). Number of training sessions does not change program effectiveness. *Dementia*, 5(4), 559-569. doi: 10.1177/1471301206069937.

with the statements, with no participants reporting that they disagreed, although participants in the Spanish language program responded in a more positive manner (See Figure 18).

Participants were also asked several program satisfaction questions. Similar to the knowledge questions, all participants reported either strong agreement or agreement with the statements and no participants reported that they disagreed. Participants in the Spanish language program also responded in a more positive manner (See Figure 19).

Figure 18. Savvy Caregiver Participant Response to Program

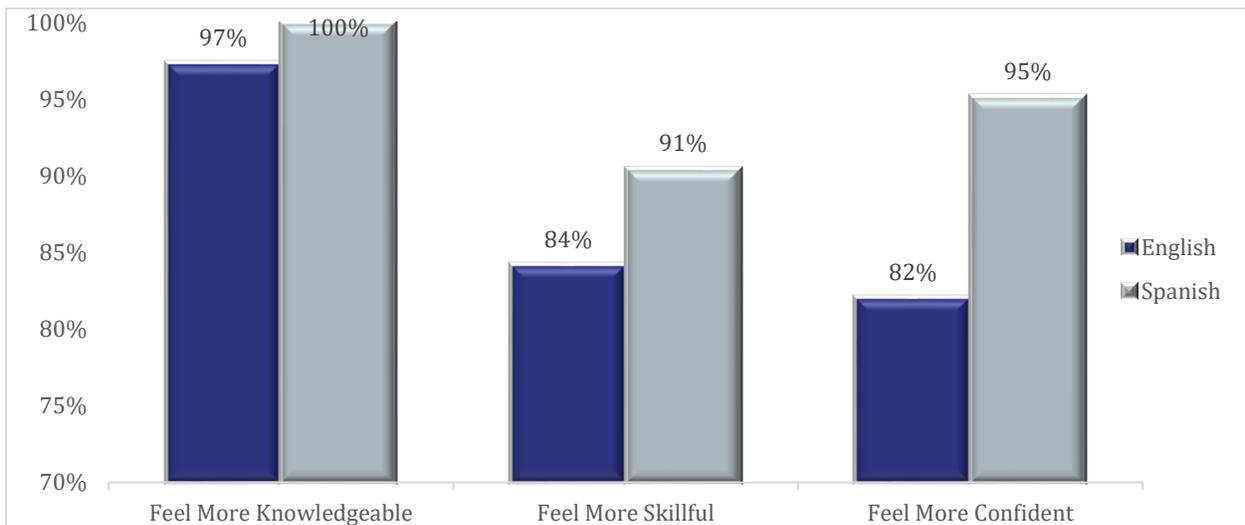
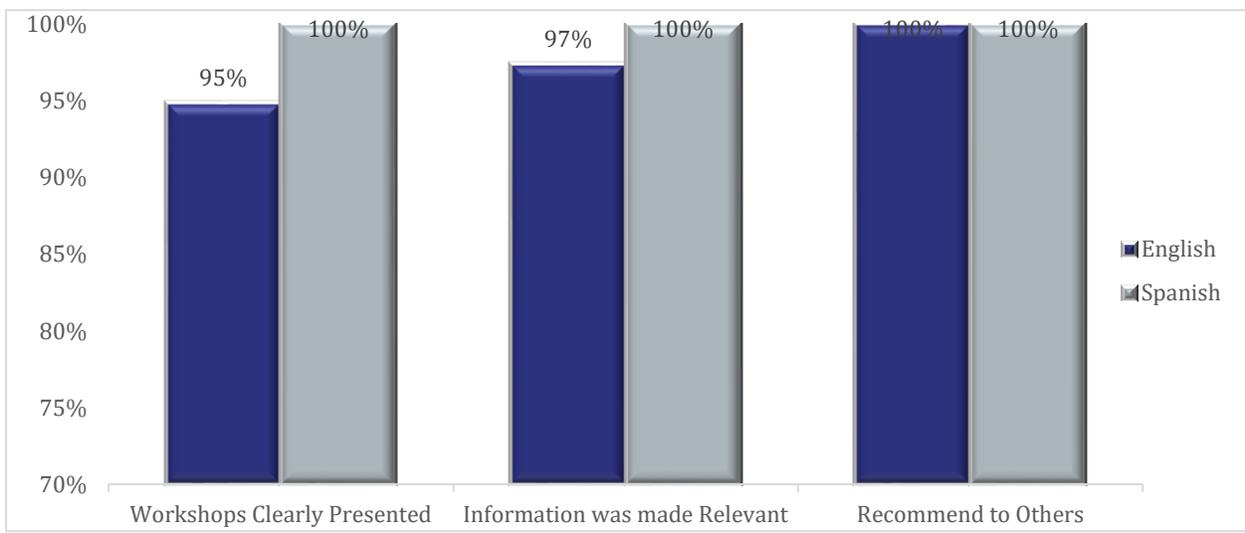


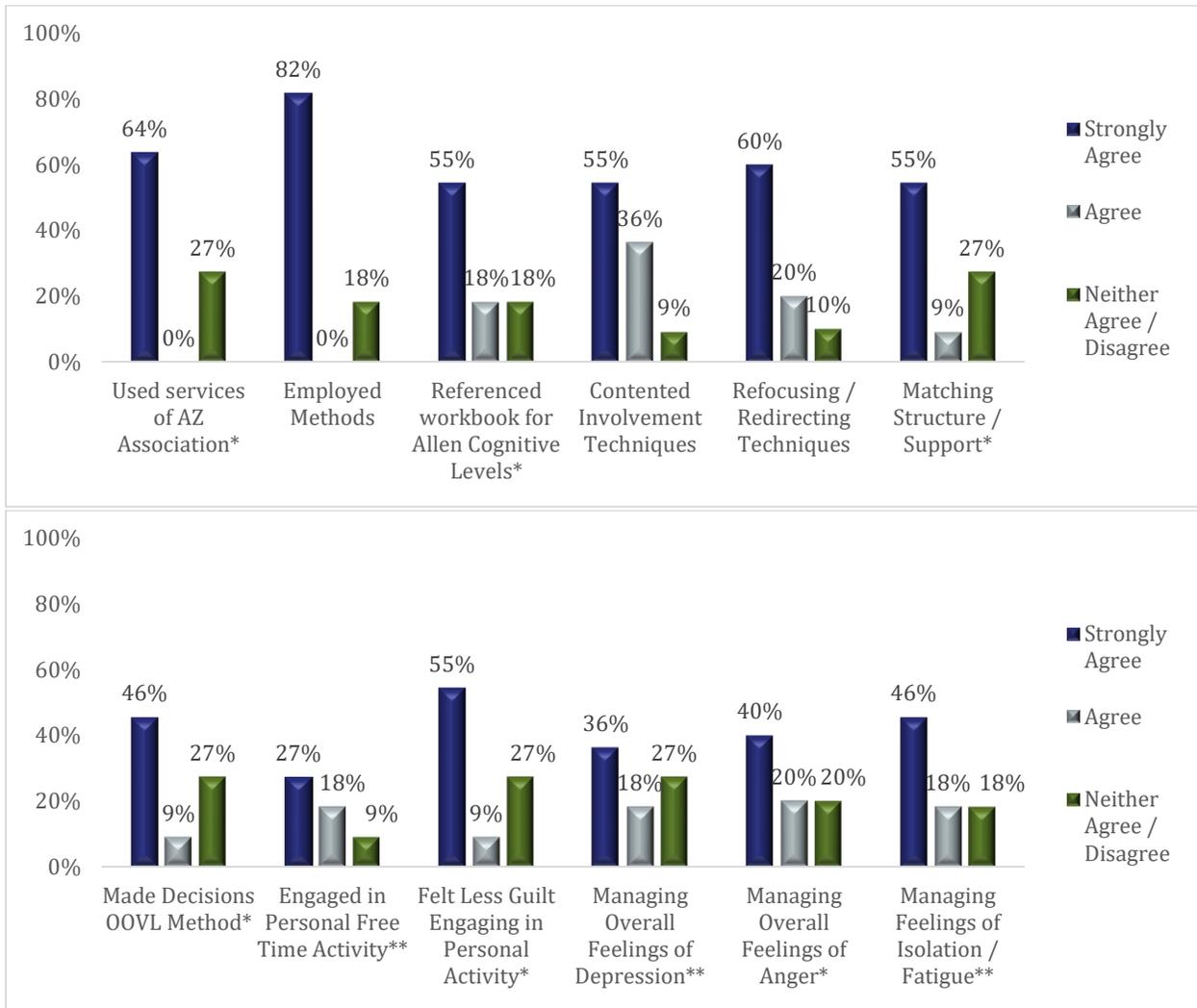
Figure 19. Savvy Caregiver Participant Program Satisfaction (by Language)



At 6-months, participants were invited to participate in a follow-up survey via mail. At the time of this report, only 11 participants (17%) had returned a follow-up surveys. A majority

of participants who did return the survey reported that they had used the services of the Alzheimer’s Association (n = 10, 91%), had employed the methods learned in the class (n = 11, 100%), and had referenced or used the workbook tutorials for reassessing the Allen Cognitive Levels (n = 11, 100%); (See Figure 20).

Figure 20. Savvy Participant 6-month Follow-up Survey Responses



Note. *One person reported strongly disagreeing with these statements. **One person reported strongly disagreeing and one person reported disagreeing with these statements.

10 Warning Signs of Dementia

In addition to the Savvy Caregiver Program described above, the Northern Nevada regional office of the Alzheimer’s Association also presented an education program that focused on the 10 warning signs of Alzheimer’s disease (See Table 4). The class, developed by the

Alzheimer’s Association National Office, was offered in both English and Spanish, and typically runs an hour in length. The program discusses the 10 Warning Signs of Dementia, and gives participants an introduction to the most common warning signs of Alzheimer’s with the goal that individuals experiencing memory loss can begin a conversation to take further action and potentially seek a diagnosis. Participants in the program should learn to describe typical age-related memory, thinking, and/or behavior changes, and are taught to recognize common warning signs of Alzheimer’s disease and other dementias. Participants are also educated on the importance of early detection, the benefits of diagnosis, and are introduced to possible tests and assessments that may be used during the diagnostic process. Finally, participants are taught how best to approach someone they believe may be experiencing memory problems. In addition to the education component described above, participants are also informed about the resources available through the Alzheimer’s Association and how best to access these resources.

Table 4: Participant Profile from the 10 Warning Signs Education Program

	Care Partner (n = 181)	Individual Living w/ Dementia (n = 2)	Total (n = 183)
Age			
Under 60	40	0	40
60 +	115	2	117
Gender			
Female	158	1	159
Male	30	1	21
Race / Ethnicity			
Non-Hispanic White	163	2	163
African American / Black	1	0	1
American Indian / Alaskan Native	2	0	2
Asian / Asian American	3	0	3
Native Hawaiian / Pacific Islander	0	0	0
Hispanic / Latinx	5	0	5
Geographic Location			
Urban	175	2	177
Rural	6	0	6
Veteran Status (Yes)	2	0	2

Note. Numbers may not add to total due to missing data.

[Benjamin Rose Institute on Aging: Care Consultation \(BRI-Care Consultation\)](#)

The Benjamin Rose Institute / Rosalyn Carter Institute Care Consultation (BRI Care Consultation) program uses trained care consultants to deliver interventions via electronic or regular mail. Care consultants establish an on-going relationship with an individual living with

dementia as well as their care partners. If the individual living with dementia is too impaired to effectively participate in their care, and/or care related decision making, the care consultant works exclusively with the care partner to develop and enact a plan of care. The intervention consists of three components: 1) an initial assessment administered by phone that addresses several domains for both the individual living with dementia and their care partner, 2) the development of an action plan that details the steps to be taken by the individual living with dementia, the care partner, and any additional family members or service providers that interact with the individual living with dementia, and 3) continued contact from the care consultant to monitor the individual living with dementia, and develop new action plans as they become necessary.

During this grant-funded initiative, the BRI Care Consultation program was implemented by Nevada Senior Services, and although not a direct recipient of grant funds, is an integral part of the Nevada Dementia Supports Toolbox as it has the ability provide resources to both individuals living with dementia and their care partners in rural areas of the state. BRI Care Consultation was also delivered by Access to Healthcare Network in Northern Nevada.

The BRI Care Consultation program was provided to 728 individuals across the state of Nevada between July 2016 and October 2019. A majority of participants in the program were non-Hispanic White (n = 468, 64%) women (n = 471) who lived in an urban setting (n = 606, 91%) despite the program being targeted toward individuals living in rural areas. In Northern Nevada, the BRI-Care Consultation program was administered by Access to Healthcare Network to 166 participants. A majority of participants were non-Hispanic White (n = 124, 75%) women (n = 104, 64%), who resided in an urban area (n = 93, 67%) and reported that they did not serve in the military (n = 115, 83%). In Southern Nevada, the BRI-Care Consultation program was administered by Nevada Senior Services to 546 participants. A majority of participants were non-Hispanic white (n = 329, 60%) women (n = 104, 64%) who resided in an urban setting (n = 503, 97%) and reported that they did not serve in the military (n = 483, 89%). Overall there was a significant increase of +443% in the number of both care recipients and care partners from FY16 (n = 60) to FY 19 (n = 326) (*See Table 5*).

Table 5: Participant Profile for BRI-Care Consultation for FY'16 – FY'19

	FY'16	FY'17	% Change	FY'18	% Change	FY'19	% Change	% Change FY'16-19
Care Recipients								
Number Enrolled	30	90	+196	73	- 18	163	+123	+ 443
Average Age	78.0	64.6		72.6		72.1		
Gender								
Male	18	49	+172	31	- 37	71	+129	+ 294
Female	12	40	+233	42	+ 5	91	+117	+ 658
Race / Ethnicity								
Non-Hispanic White	20	59	+195	48	- 19	102	+113	+ 410
African American / Black	7	19	+171	10	- 47	26	+160	+ 271
American Indian	0	0	~	0	~	2	~	~
Asian / Asian American	2	3	+ 50	1	- 67	8	+100	0
Hawaiian / Pacific Islander	0	0	~	1	~	2	~	~
Hispanic	0	3	~	10	+233	18	+ 80	~
Other / Two or More Indicated	1	5	+400	2	- 60	4	+100	+ 300
Hispanic	0	3	~	10	+233	20	+100	~
Location								
Urban	29	79	+172	57	- 28	131	+130	+ 352
Rural	1	4	+300	5	+ 25	19	+280	+1800
Veteran (Yes)	11	18	+ 64	11	+ 11	29	+164	+ 164
Care Partner								
Number Enrolled	30	89	+196	73	- 18	163	+123	+ 443
Average Age	64.6	61.8		59.3		59.4		
Gender								
Male	8	14	+ 75	15	+ 7	42	+180	+425
Female	22	75	+241	54	- 28	120	+122	+445
Race / Ethnicity								
Non-Hispanic White	21	62	+195	48	- 22	100	+108	+376
African American / Black	6	16	+167	10	- 38	26	+160	+376
American Indian	0	0	~	0	~	1	~	~
Asian / Asian American	2	1	- 50	1	0	7	+600	+333
Hawaiian / Pacific Islander	1	0	-100	0	~	5	~	+400
Hispanic	0	4	~	8	+100	17	+113	~
Other / Two or More Indicated	0	6	~	1	- 83	2	+100	~
Hispanic	0	6	~	8	+ 33	21	+163	~
Location								
Urban	28	81	+189	61	- 25	124	+103	+343
Rural	2	4	+100	5	+ 25	4	- 20	+100
Veteran (Yes)	3	5	+ 67	3	- 40	4	+ 33	+ 33
Total Enrolled	60	178	+197	146	- 18	326	+123	+443

Note. Only full fiscal years (FY16 – FY 19) are included.

[Aging and Intellectual Disability Education Program](#)

As part of her work at the Sierra Regional Center office of the Aging and Disability Service Division (ADSD), Dr. Rebecca Arvans-Feeney held four trainings attended by a total of 116 participants throughout Nevada on the intersection of intellectual disability and dementia. These trainings were designed to address the needs and concerns of those aging with intellectual and developmental disabilities (IDD). These programs specifically focused on the needs and concerns of the IDD population that has already received a diagnosis of Alzheimer’s disease or a related dementia (ADRD), or those who are at high risk of developing ADRD (*See Table 6*).

Table 6: Participant Profile for Aging and Intellectual Disability Education Program

	Care Partner (n = 57)	Individual Living w/ Dementia (n = 59)	Total (n = 116)
Age			
Under 60	2	5	7
60 +	2	3	5
Gender			
Female	4	2	6
Male	5	6	11
Race / Ethnicity			
Non-Hispanic White	33	39	72
African American / Black	0	0	0
American Indian / Alaskan Native	0	0	0
Asian / Asian American	3	0	3
Native Hawaiian / Pacific Islander	1	0	1
Hispanic / Latinx	0	0	0
Geographic Location			
Urban	57	59	116
Rural	0	0	0
Veteran Status (Yes)			
	17	18	35

Note. Totals may not add due to missing data.

[Rural Retired Senior Volunteer Program Respite Program – the REST Program](#)

The Rural Retired Senior Volunteer Program (R-RSVP) Respite Program provides family care partners a partner and respite weekly respite opportunities. All volunteers placed through the program are trained through the Respite Education Support Tools (REST) program, and attend dementia education sessions regularly. The program volunteers typically provide 2 to 3 hours of individualized respite care weekly to offer a break to the caregivers of a person living with dementia. Working with both the individual needing care and their care partners, volunteers develop a schedule and set of activities that work to support and enhance the care recipients’

quality of life. These plans are continually updated to ensure that they still meet the needs of the care recipient. (See Table 7).

Table 7: Rural RSVP Respite Program Participant Profile

	Care Partner (n = 28)	Individual Living w/ Dementia (n = 28)	Total (n = 56)
Age			
Under 60	4	1	5
60 +	24	27	51
Gender			
Female	20	14	34
Male	8	14	22
Race / Ethnicity			
Non-Hispanic White	27	27	54
African American / Black	0	0	0
American Indian / Alaskan Native	0	0	0
Asian / Asian American	1	1	2
Native Hawaiian / Pacific Islander	0	0	0
Hispanic / Latinx	1	2	3
Geographic Location			
Urban	13	13	23
Rural	15	15	30
Veteran Status (Yes)	4	9	13

Note. Totals may not add due to missing data.

Early-Stage Partners in Care (EPIC)

The Early-Stage Partners in Care (EPIC) program was delivered to a total of 79 participants by the Southern Nevada Regional Office of the Alzheimer’s Association. This program assists individuals with early-stage dementia and their care partners as dyads via education and training workshops. These workshops help to decrease the stress associated with a diagnosis of dementia by allowing individuals living with dementia and their care partners to collaboratively create a plan for future care. The program also provides techniques to help address behavioral and communication challenges often associated with dementia. (See Table 8).

Table 8: EPIC Program Participant Profile

	Care Partner (n = 41)	Individual Living w/ Dementia (n = 38)	Total (n = 79)
Age			
Under 60	7	2	9
60 +	20	23	43
Gender			
Female	25	21	46
Male	16	17	33
Race / Ethnicity			
Non-Hispanic White	27	25	52
African American / Black	3	3	6
American Indian / Alaskan Native	0	0	0
Asian / Asian American	0	0	0
Native Hawaiian / Pacific Islander	1	0	1
Hispanic / Latinx	4	4	8
Geographic Location			
Urban	33	33	66
Rural	5	5	10
Veteran Status (Yes)	3	3	6

Note. Totals may not add due to missing data.

[Additional State-Funded Services](#)

As part of this overall grant-funded initiative, the utilization of statewide resources for delivering support for individuals living with dementia were monitored. To help establish baseline program participation, this report draws upon resource utilization data compiled for previous ACL grants in Nevada (the ADSSP Dementia Capable grant and the expansion grant NV 90DS2022). These data were compiled by the Nevada Aging and Disability Services Division, and contains data from organizations that elected to collect and report their client’s dementia status, with a time period spanning FY’15 through the end of FY’19.

Table 9 presents the total number of unique participants served by ADSD-funded programs during FY’19 who were indicated by at least one provider as having some level of cognitive impairment or difficulties with memory.

Table 9: Utilization of Statewide Support Services for FY'19

	Regular Services FY'19	Expanded Services FY'19	Total FY'19
Clients (Unduplicated Total)	409	1522	1931
Providers (Total)	14	9*	17**
Average Age	77.6	76.9	77.1
Gender			
Female	267	923	1190
Male	142	596	738
Race / Ethnicity			
Caucasian	259	956	1215
Black	58	234	292
Asian	18	56	74
American Indian / AK Native	3	16	19
Hispanic	52	184	236
Native Hawaiian / Pacific Islander	3	16	19
Hispanic	55	190	241
In Poverty	171	653	824
Lives Alone	117	549	666
High Nutritional Risk	229	1035	1264
Rural	104	346	450
ADL Limitations			
0-1	155	552	707
2-3	116	519	635
4-5	81	244	325
6	36	91	127
IADL Limitations			
0-1	49	168	217
2-3	43	163	206
4-5	89	408	497
6+	207	669	876
Level of Impairment			
Early Onset	45	124	169
Mild	164	744	908
Moderate	131	423	554
Severe	69	224	293
Total	409	1515	1924

Note. Regular services are those service categories that were measured starting in FY15 and running through FY19. Expanded services are those services that reported serving individuals with cognitive difficulties but were not reported in previous FYs. Unduplicated fiscal year not reported as all reported participants are from FY'19. Totals may not add due to missing data. *Expanded services also include case management services provided by named individuals – these were consolidated into one item. **Providers may have offered more than one type of service and are not unique.

To ensure that data was compared equally across time periods, only services directed towards individuals with cognitive impairment in each fiscal year (i.e., FY'15 – FY'19) are included in Table 10.

Over the course of the fiscal years included in this report (i.e., FY'15 – FY'19), there was an increase in all categories, except the number of service *providers*, which *dropped* by 7% (FY'15 = 15, FY'19 = 14), as did the number of American Indian / Alaskan Natives (-75%; FY'15 = 12, FY'19 = 3) served. Of particular note, the total number of clients who received services increased by 108% (FY'15 = 197 to FY'19 = 409), and the total number of unique clients (i.e., clients that are only found in one fiscal year) also increased for both FY'19 (+270%) compared to FY'18 as well as compared to baseline (+44%). If the 'expanded services' reporting people living with dementia served in FY'19 are included the increase is monumental. **With a baseline established in FY'15, in which a total of 194 people living with dementia were reported to have received ADSD-supported services, the total service utilization increased to 1,924 people living with dementia reported as receiving services in FY'19 (including expanded services reported), representing an 892% overall increase in service utilization.** In addition, there were increases in the number of clients in rural communities (+121%: FY'15 to FY'19) and the number of clients who were in poverty (+90%: FY'15 to FY'19).

Table 10: Service Utilization for Statewide Aging Services from FY'15 through FY'19 (excluding expanded services)

	FY'15 Total (%)	FY'16 Total (%)	% Change	FY'17 Total (%)	% Change	FY'18 Total (%)	% Change	FY'19 Total (%)	% Change	% Change From Baseline
Clients (Unduplicated Total)	197	245	+ 24	247	+ 1	226	- 9	409	+ 81	+108
FY (Unduplicated Total)	197	137 (56)	- 31	99 (40)	- 28	77 (28)	- 22	285	+270	+ 44
Providers (Total)	15	13	- 13	10	- 23	6	- 40	14	+133	- 7
Average Age	79.6	79.2	~	78.7	~	78.7	~	77.6	~	~
Gender										
Female	129 (66)	160 (65)	+ 24	163 (66)	+ 2	140 (62)	- 14	267 (65)	+ 91	+107
Male	67 (34)	85 (35)	+ 27	84 (34)	- 1	86 (38)	+ 2	142 (35)	+ 65	+112
Race / Ethnicity										
Caucasian	116 (59)	135 (58)	+ 16	125 (51)	- 7	114 (50)	- 9	259	+127	+123
Black	20 (10)	34 (15)	+ 70	46 (19)	+ 35	34 (15)	- 26	58	+ 71	+190
Asian	7 (4)	8 (3)	+ 14	12 (5)	+ 50	9 (4)	- 25	18	+100	+157
American Indian / AK Native	12 (6)	9 (4)	- 25	8 (3)	- 11	1	- 88	3	+200	- 75
Hispanic	36 (18)	42 (18)	+ 17	42 (17)	0	32 (14)	- 24	52	+ 63	+ 44
In Poverty	90 (47)	100 (45)	+ 11	103 (47)	+ 3	77 (34)	- 41	171 (42)	+122	+ 90
Lives Alone	61 (31)	70 (30)	+ 15	58 (24)	- 17	34 (15)	- 10	117 (28)	+244	+ 92
High Nutritional Risk	107 (65)	125 (64)	+ 17	129 (67)	+ 3	116 (51)	- 10	229 (56)	+ 97	+114
Rural	47 (24)	55 (23)	+ 17	34 (14)	- 38	36 (16)	+ 6	104 (25)	+189	+121
ADL Limitations										
0-1	98 (52)	98 (42)	0	79 (34)	- 19	71 (34)	- 10	155 (38)	+118	+ 58
2-3	36 (19)	49 (21)	+ 36	54 (23)	+ 10	62 (29)	+ 15	116 (28)	+ 87	+222
4-5	41 (22)	54 (23)	+ 32	59 (25)	+ 9	49 (23)	- 17	81 (20)	+ 3	+ 98
6+	14 (7)	32 (14)	+129	42 (18)	+ 31	30 (14)	- 29	36 (9)	+ 20	+157
IADL Limitations										
0-1	30 (16)	30 (13)	0	17 (7)	- 43	13 (6)	- 24	49 (12)	+277	+ 63
2-3	20 (11)	19 (8)	- 5	20 (9)	+ 5	20 (9)	0	43 (11)	+115	+115
4-5	38 (20)	48 (21)	+ 26	49 (21)	+ 2	42 (20)	- 14	89 (22)	+112	+134
6+	102 (54)	137 (59)	+ 34	148 (63)	+ 8	138 (65)	- 7	207 (51)	+ 50	+103
Level of Impairment (Total):	194	245	+ 26	247	+1	226	-9	409	+ 81**	+111**
Early Onset	13 (7)	25 (10)	+ 92	30 (12)	+ 20	37 (16)	+ 23	45 (11)	+ 22	+246
Mild	89 (45)	100 (41)	+ 12	92 (37)	- 8	69 (30)	- 25	164 (40)	+138	+ 84
Moderate	65 (33)	80 (33)	+ 23	79 (32)	- 1	79 (35)	0	131 (32)	+ 66	+101
Severe	27 (14)	40 (16)	+ 48	46 (19)	+ 15	41 (18)	- 11	69 (17)	+ 68	+155

Notes: 1) FY'15 is considered baseline. 2) Participants may be in more than one Fiscal Year (duplicated year-over-year). 3) Race indicated as Hispanic, may be of mixed ethnicity. 4) Counts may not add to total clients due to missing values. 5) Percentages do not add to 100% due to rounding and are calculated out of the total number. ** These data exclude the FY'19 'expanded services, which increase the FY'19 total number of people living with dementia served to 1,924, representing an 892% in the number of people served in FY'19 over the FY'15 baseline.

Community Impact

A central goal of this ACL-funded initiative was to promote local action and change through community collaboration to create dementia friendly communities and ultimately a Dementia Friendly Nevada. This approach included creating a community-based dialogue between individuals living with dementia, their family care partners, health care professionals, and community partners/stakeholders to create community-driven solutions. To accomplish this broad level goal, two sub-goals were developed. First, the state supported the creation of six community action groups (CAGs), with a goal of transforming the culture of dementia in each of the specific communities, and to further facilitate community-driven change as it relates to supporting individuals living with dementia and their care partners. Second, the state would further enhance the reach of Nevada’s Dementia Supports Tool Box, and help CAGs increase the use of these programs within their communities.

The activities of each individual CAG are detailed below, and are based on the specific goals established by each community, as noted. Although each CAG was able to select the specific programs to be implemented in their community, there were consistencies across communities. As previously noted and reported, one wide-sweeping program across multiple communities was the use of the Dementia Friends program to increase awareness of dementia and educate community members. While the statewide results of the Dementia Friends program is detailed previously, including the aggregation of data from 5 of the 6 CAGs, each community-specific section includes a report of local education program data. This includes the one CAG which did not use the Dementia Friends program, but developed its own education effort.

Community Action Group Activities

Dementia Friendly Elko (Elko County)

The community-specific goals selected by the Dementia Friendly Elko CAG were to:

- 1) Provide at least one Dementia Friends information session per month July 2018 – July 2019, offered at the Terrace at Ruby View, and by invitation; and
- 2) Provide a weekly peer support/respite program at the Terrace at Ruby View in partnership with Nevada Rural Counties RSVP Rural utilizing the Java Music Club (“Friends’ Day Out”).

Goal 1: Provide at least one Dementia Friends information session per month July 2018 – July 2019, offered at the Terrace at Ruby View, and by invitation

To accomplish the first goal, the CAG elected to implement the Dementia Friends training program. As noted above, this program follows a train-the-trainer model, with community level Champions being trained by a state-wide Master Champion. These Champions then provide information sessions within their specific community. A majority of participants in the sessions held in Elko County were non-Hispanic White (n = 50; 86%) women (n = 47, 76%), and indicated that they did not provide care for an individual living with dementia (n = 46, 75%) (See Table 11).

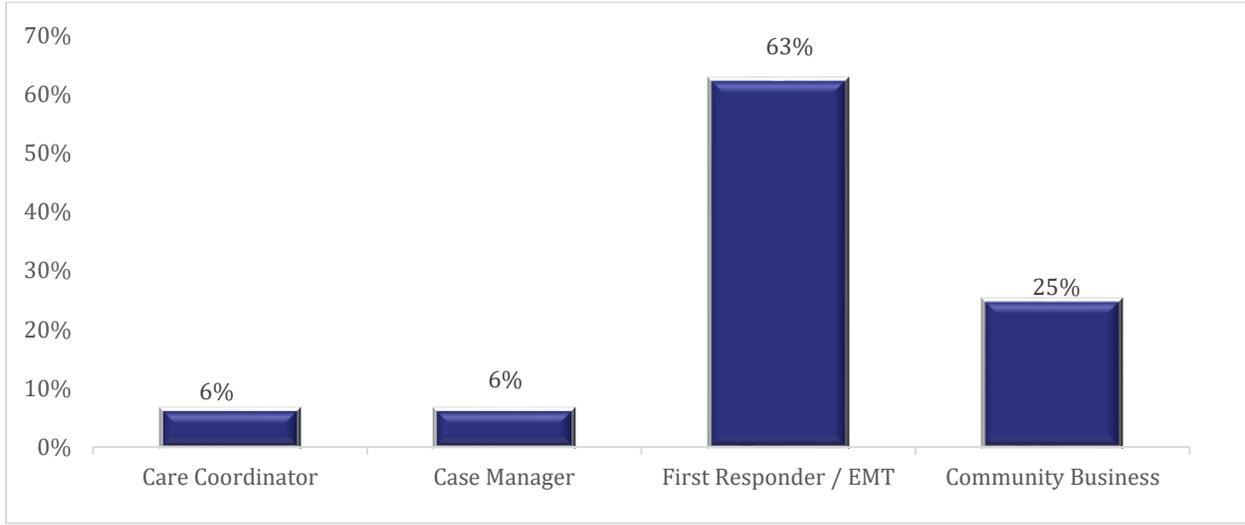
Twelve members of the CAG were trained as the initial Champions, with three additional community members receiving champion training. These Champions went on to hold eight information sessions, reaching a total of 47 community members with the program. A majority of the attendees of the Friends information session (60%) indicated that they were not involved in any of the sectors measured, however, for those attendees that did identify a sector, a majority indicated that they were First Responders / EMTs (63%), with individuals from community businesses (25%) also representing a large minority of trainees (See Figure 21).

Table 11: Dementia Friendly Elko Dementia Friends Participant Profile

	Champion (n = 15)	Friend (n = 47)	Total (n = 62)
Number of Sessions*	2	8	9
Ave. Age	56	58	57
Gender			
Female	14	33	47
Male	1	14	15
Ethnicity			
Non-Hispanic White	11	39	50
Native American	2	1	3
Hispanic / Latinx	2	3	5
Race**			
Hispanic / Latinx	2	5	7
Veteran Status (Yes)	2	1	3
Care Partner Status			
Yes	2	10	12
No	12	34	46
I am living with dementia	1	2	3

Note. 4 individuals, all Friends, did not report their race/ethnicity and 1 person did not report their care partner status. *One individual chose not to complete the Champion training and remained a Dementia Friend from Session 1, so this session was counted as both a Champion and Friend session. **2 individuals who reported being Hispanic/Latinx also reported their ethnicity as non-Hispanic White.

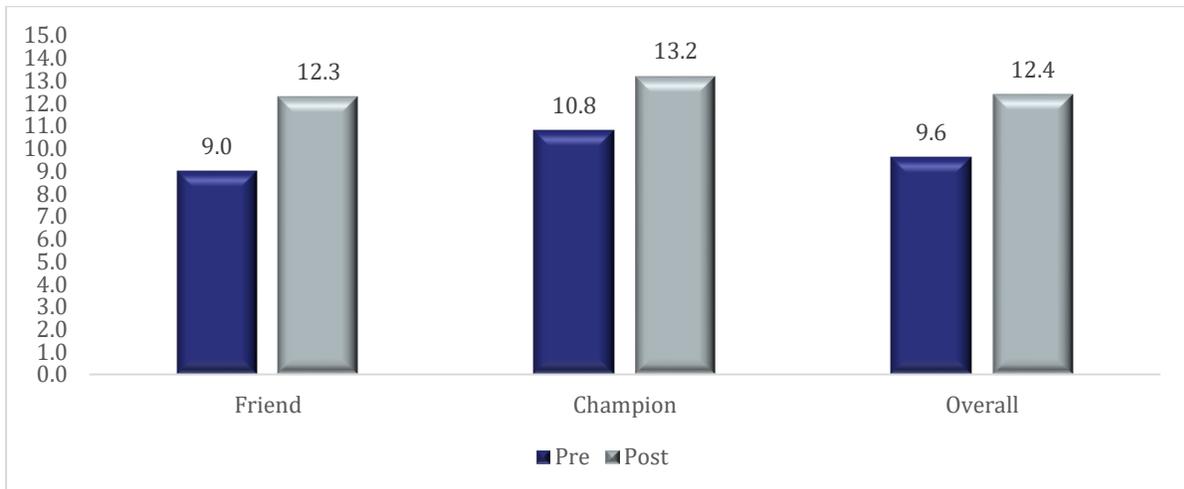
Figure 21. Dementia Friends by Sector – Dementia Friendly Elko



Note. Only individuals who reported a sector on the list were included (n = 16). Full sector list can be found in Appendix XX. Percents may not add to 100 due to rounding / other sectors not included in chart.

For those individuals who completed both the pre- and post-knowledge survey (n = 45), the program was successful in increasing the participant’s knowledge regarding dementia, with participants answering significantly more questions correctly on the post-knowledge survey ($M = 12.4$) compared to the pre-knowledge survey ($M = 9.6$; *See Figure 22*), by answering on average approximately 3 more questions correctly ($M = 2.8$; +29%).

Figure 22. Dementia Friends Participant Knowledge Change (Pre-Post) – Elko

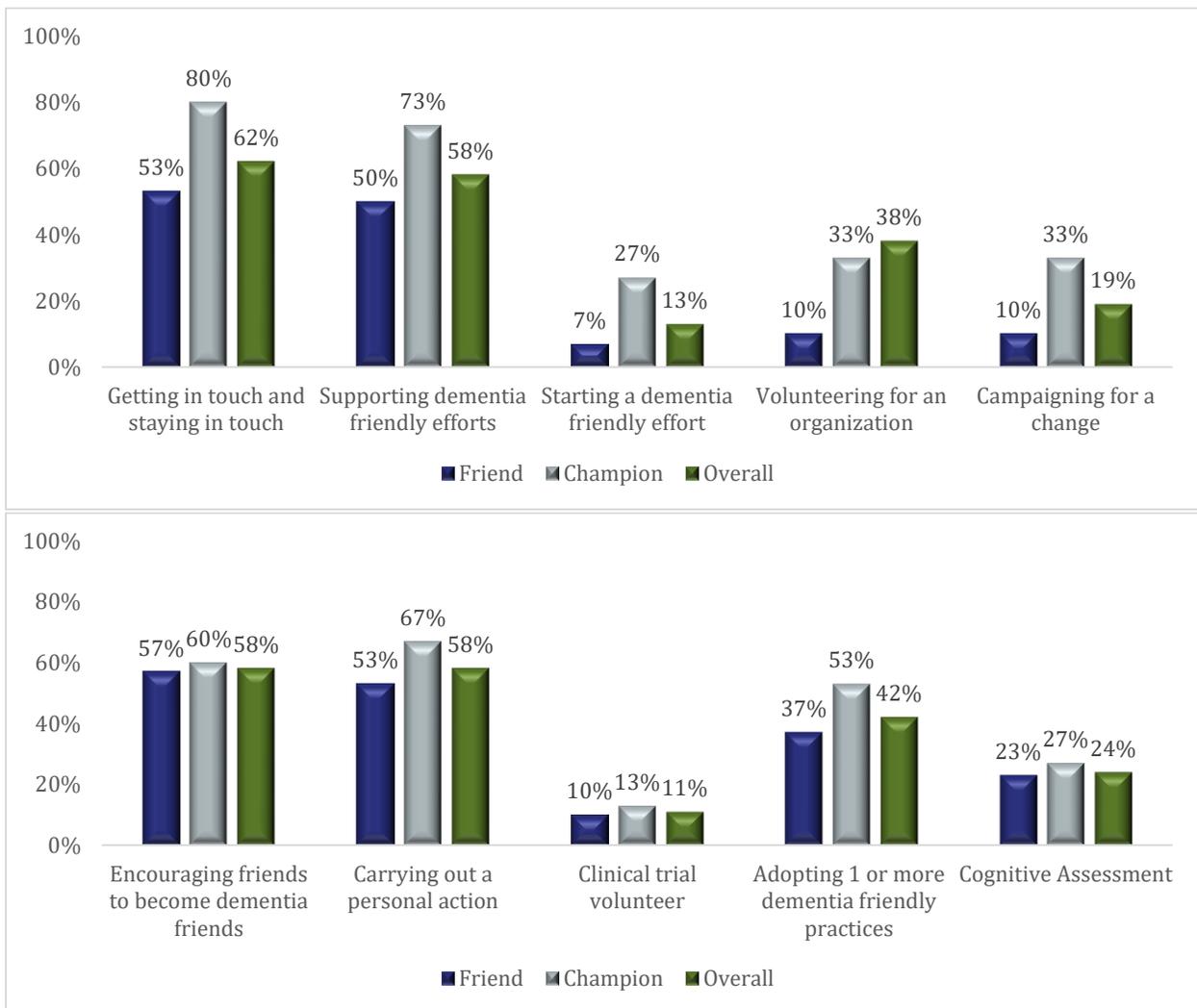


Note. Mean difference for Friends (n = 30) and Overall (n = 45) significant at $p < .001$. Mean difference for Champions (n = 15) significant at $p = .01$ ⁷. Total possible correct was 15.

⁷ Elko-CAG Champion knowledge change statistics were computed using non-parametric tests due to the low number of respondents (n < 30) who completed both the pre- and post-knowledge surveys.

Participants also completed several questions regarding behaviors that would benefit individuals living with dementia in their communities. Overall, a majority of participants in the information sessions who answered the behavioral questions (n = 30) reported that they would encourage friends to become Dementia Friends (57%), get in touch with someone they knew who was living with dementia (53%), and would be more patient with others in their community who may be living with dementia (53%); (See Figure 23).

Figure 23. Dementia Friends Participant Behavioral Intentions – Dementia Friendly Elko

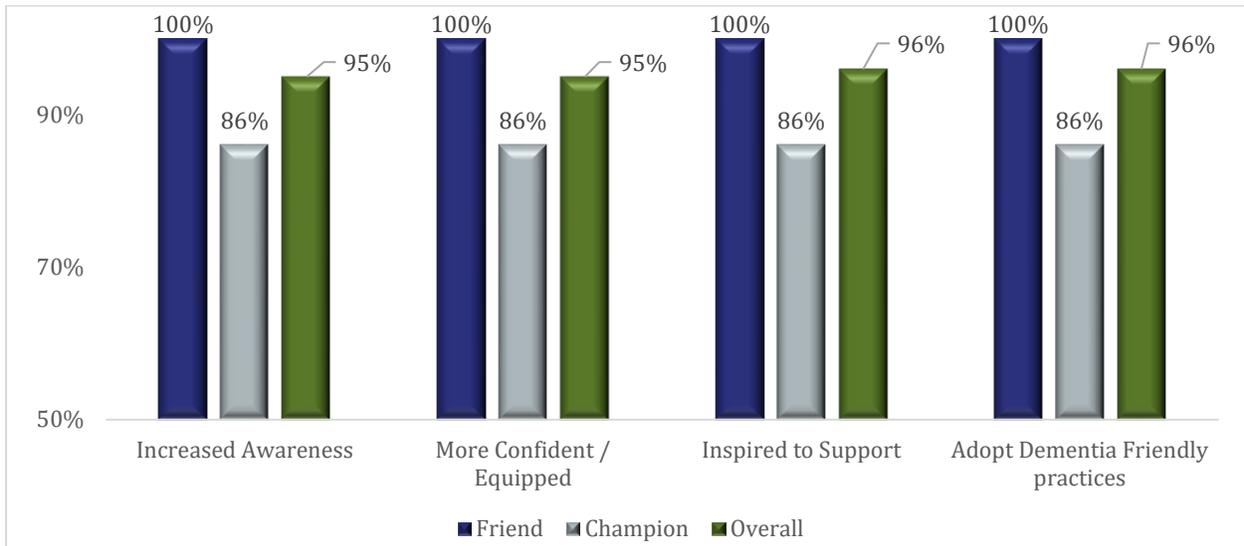


Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 15), Friends (n = 30), Total (n = 45).

Participants also answered 4 program-specific questions related to their impression of the program. Overall, all participants completing these questions (n = 30, 100%) reported that they felt their awareness of ADRDs had increased, that they felt more confident and equipped as a

community member to recognize the signs and offer support to the needs of an individual living with dementia within their community, felt inspired to offer support and be a friend to individuals living with dementia, and reported that they were likely to adopt dementia friendly practices in their personal life (See Figure 24).

Figure 24. Perceived Benefits of Program – Dementia Friendly Elko



Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 15), Friends (n = 30), Total (n = 45).

Goal 2: Provide a weekly peer support/respice program at the Terrace at Ruby View in partnership with Nevada Rural Counties RSVP Rural utilizing the Java Music Club (“Friends’ Day Out”).

Friends Day Out / Java Music Club

To achieve its second goal, the Dementia Friendly Elko CAG purchased the *Java Music Club* program and used it as part of a larger respice program, entitled ‘Friends Day Out’. The Java Music Club program is an evidence-based program with demonstrated results in reducing loneliness, facilitating friendships both among participants and group facilitators, increasing coping skills, as well as feelings of understanding and support (Theurer, Wister, Sixsmith, Chaudhury, & Lovegreen, 2014)⁸. A majority of participants in the Friends Day Out program were non-Hispanic White (n = 6; 55%) men (n = 7, 64%). Approximately half (n = 5, 46%)

⁸ Theurer, K., Wister, A., Sixsmith, A., Chaudhury, H., & Lovegreen, L. (2014). The development and evaluation of mutual support groups in long-term care homes. *Journal of Applied Gerontology*, 33, 387-415. doi: 10.1177/0733464812446866.

reported that they were living with dementia, with 4 (36%) reporting that they were caregivers to someone living with dementia (*See Table 12*). Attendance for the program was moderate, with approximately 8 individuals regularly attending each of the 26 sessions that were held.

Table 12: Friends Day Out Participant Profile – Dementia Friendly Elko

	Living With Dementia (n = 5)	Care Partner (n = 4)	Non-Care Partner (n = 2)	Total (n = 11)
Ave. Age	72	62	74	69
Gender				
Female	2	1	1	4
Male	3	3	1	7
Ethnicity				
Non-Hispanic White	2	2	2	6
Hispanic / Latinx	3	2	0	5
Race**				
Hispanic / Latinx	3	2	0	5
Veteran Status (Yes)	0	0	1	1

Note. Counts are unique participants only. A total of 11 unique participants attended at least a single session.

Dementia Friendly Winnemucca (Humboldt County)

The final goals selected by the Dementia Friendly Winnemucca Community Action Group (Humboldt-CAG) were to:

- 1) Increase visibility of outreach events and Alzheimer’s related resources within Humboldt county / Winnemucca;
- 2) Educate and inform business owners, employees, and the general public about Alzheimer’s disease and other dementias, including the signs, symptoms, progression, and how best to help caregivers and individuals living with dementia;
- 3) Offer the REST (Respite Education and Resource Tools) training to expand knowledge of respite care and increase the number of respite workers in Humboldt county; and
- 4) Create and launch an early-stage dementia support group.
- 5) Create new Adult Day services within Humboldt County / Winnemucca.

Goal 1: To increase visibility of outreach events and Alzheimer’s related resources within Humboldt county / Winnemucca

To accomplish its first goal, the CAG organized and participated in several different events within the community. Of note, during the ‘Tie-One-On’ event that was held during the Winter 2017 high-school basketball game against Elko, approximately 450 bows were handed

out to raise awareness of dementia. This event was not held in Winter 2018, but was held again in Winter 2019 with similar results of the 2017 event. The CAG participated at the local health fair, handing out informational brochures and items branded with the ADF-Winnemucca logo during all of the years of the grant. Of note, during the final year, several people who had been diagnosed with younger-onset Alzheimer's stopped by the table during the event to find out more information and receive guidance. Additionally, the CAG also helped sponsor the annual local 'Turkey Trot', with the event averaging 350 participants across the 3 years of the grant.

In addition to these specific events, several informational brochures were created by the CAG to be distributed at community events, as well as placed within strategic areas within the community. Advertisements were placed within the local community newspapers and radio stations, and the support groups developed and administered by the CAG leader have been reasonably well attended. Overall, the CAG reported that they saw an increased participation in dementia-specific events, and noted an increase in the number of people who were wanting to learn more about dementia.

Goal 2: To educate and inform business owners, employees, and general public about Alzheimer's disease and other dementias; including signs, symptoms, progression, and how to best help caregivers and individuals living with dementia.

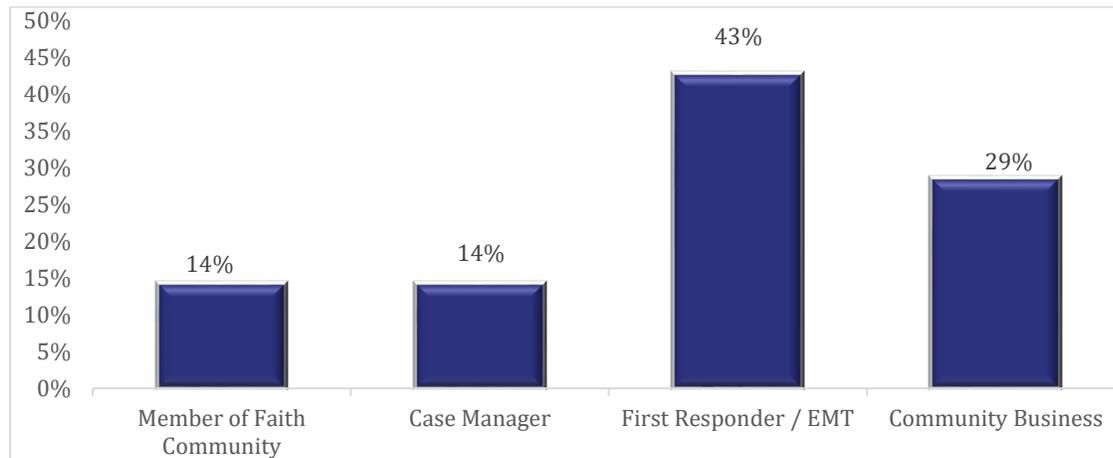
To accomplish this goal, the CAG elected to implement the Dementia Friends program. As noted in the above sections, this program follows a train-the-trainer model, with community level Champions being trained by a state-wide Master Champion. These Champions then provide information sessions within their specific community. The 5 members of the CAG were trained as the initial Champions (*See Table 13*). These Champions went on to hold 9 information sessions, reaching a total of 96 community members with the program. A majority of participants in the sessions held in Humboldt county were non-Hispanic White (n = 80, 90%) women (n = 71, 75%) and indicated that they did not provide care for someone living with dementia (n = 79, 85%). A majority of the attendees of the Friends information session (87%) did not respond to the sector question, with an additional 6% reporting that they did not belong to any of the sectors listed. However, for those attendees that did identify a sector, a majority (43%) reported that they were First Responders / EMTs, with individuals from community businesses (29%) being the next most common response (*See Figure 25*).

Table 13: Dementia Friendly Winnemucca Dementia Friends Participant Profile

	Champions (n = 5)	Friends (n = 96)	Total (n = 101)
Number of Sessions	1	9	10
Ave. Age	56.4	47.9	48.3
Gender			
Female	4	21	71
Male	1	67	22
I Prefer Not to	0	2	2
Identify			
Ethnicity			
Non-Hispanic White	4	76	80
Native American	0	2	2
Hispanic / Latinx	0	2	2
Asian American	0	2	2
Other	1	2	3
Race**			
Hispanic / Latinx	0	10	10
Veteran Status (Yes)			
		10	10
Care Partner Status			
Yes	1	12	13
No	4	75	79
I am living with dementia	0	1	1

Note. For Friend sessions only, there were 6 individuals who did not report their gender, 7 did not report veteran status, 8 did not report caregiver status, 9 did not report Latinx status, and 12 did not report ethnicity.

Figure 25. Dementia Friends by Sector – Dementia Friendly Winnemucca

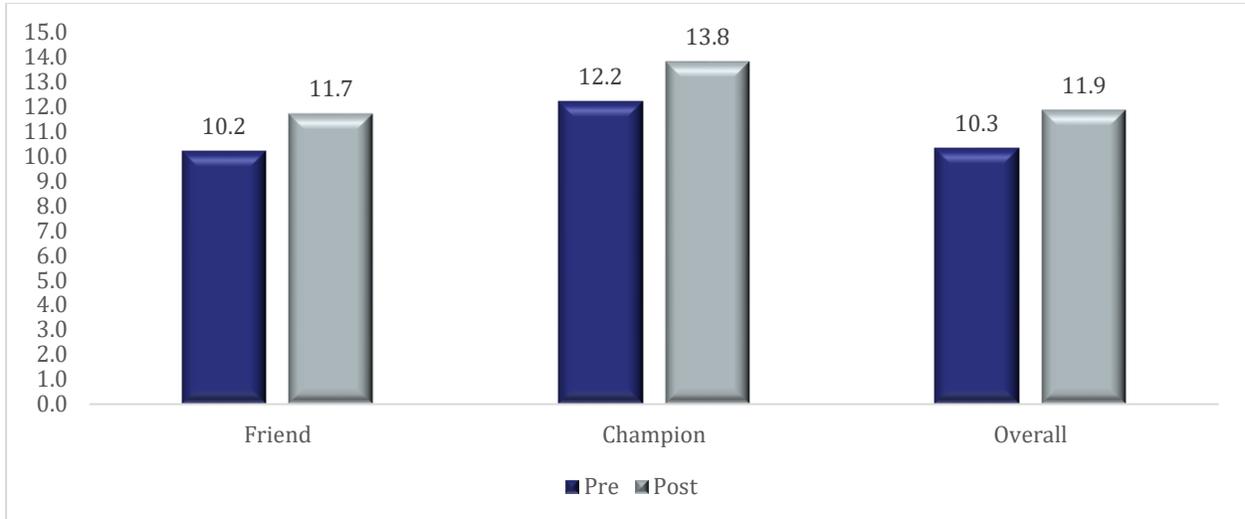


Note. Only individuals who reported a sector on the list were included (n = 7). Percents may not add to 100 due to rounding / other sectors not included in chart.

For those individuals who completed both the pre- and post-knowledge survey (n = 80), the program was successful in increasing the participant’s knowledge regarding dementia, with participants answering significantly more questions correctly on the post-knowledge survey ($M =$

11.9) compared to the pre-knowledge survey ($M = 10.3$); (See Figure 26), by answering on average approximately 2 more questions correct ($M = 1.5$; +14.6%).

Figure 26. Dementia Friends Participant Knowledge Change (Pre-Post) – Winnemucca

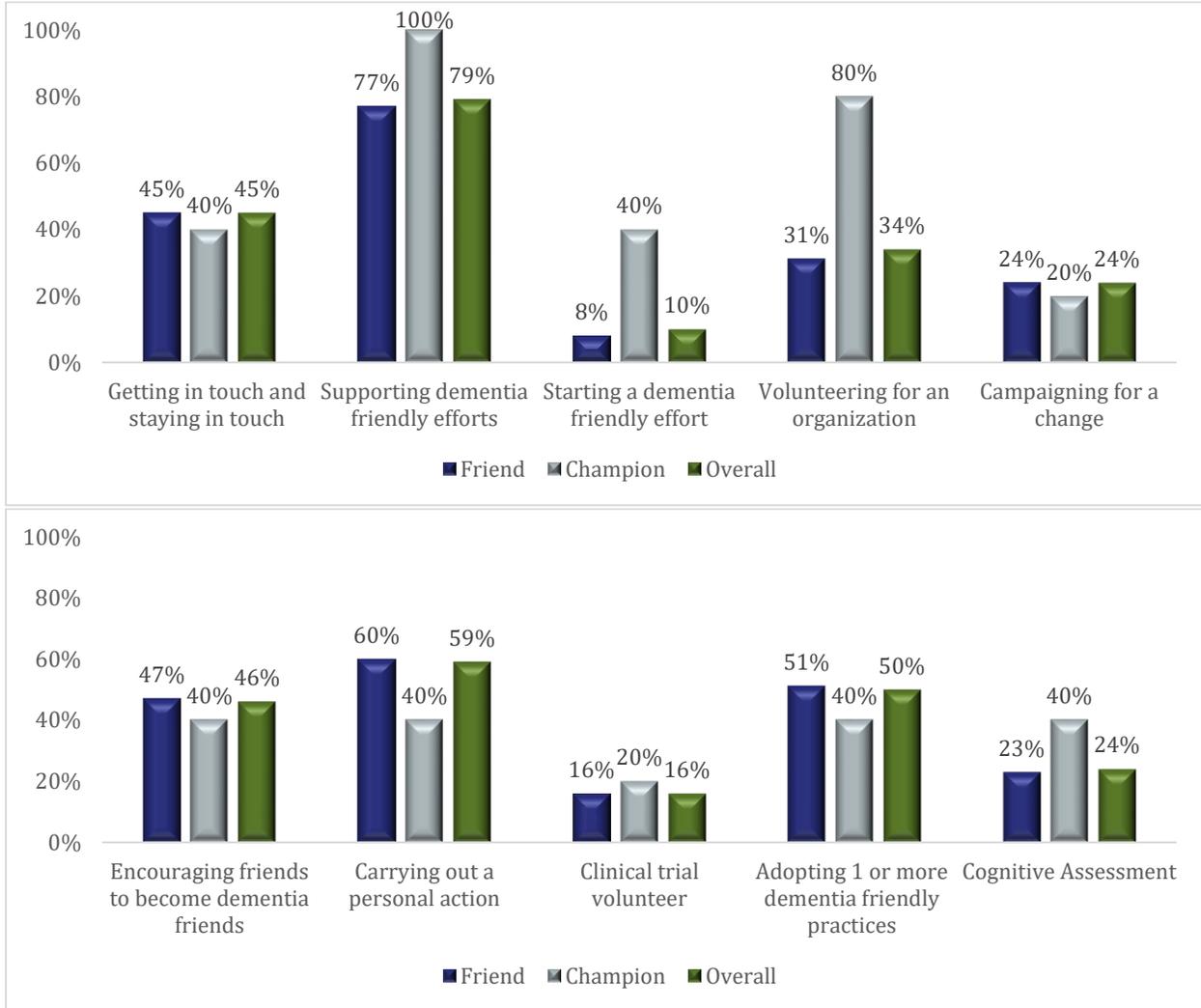


Note. Mean difference for Champions ($n = 5$) non-significant at $p = .11^9$. Mean difference for Friends ($n = 75$) and Overall ($n = 80$) significant at $p < .001$. Total possible correct was 15.

Participants also completed several questions regarding behaviors that would benefit individuals living with dementia in their communities. Overall, participants reported that they would support dementia friendly activities within their community ($n = 63$, 79%), would carry out a personal action such as being more patient while out in their community ($n = 47$, 59%), and/or would adopt dementia friendly practices in their personal or professional life ($n = 40$, 50%); (See Figure 27).

⁹ Humboldt-CAG knowledge change statistics were computed using non-parametric tests due to the low number of respondents ($n < 30$) who completed both the pre- and post-knowledge surveys.

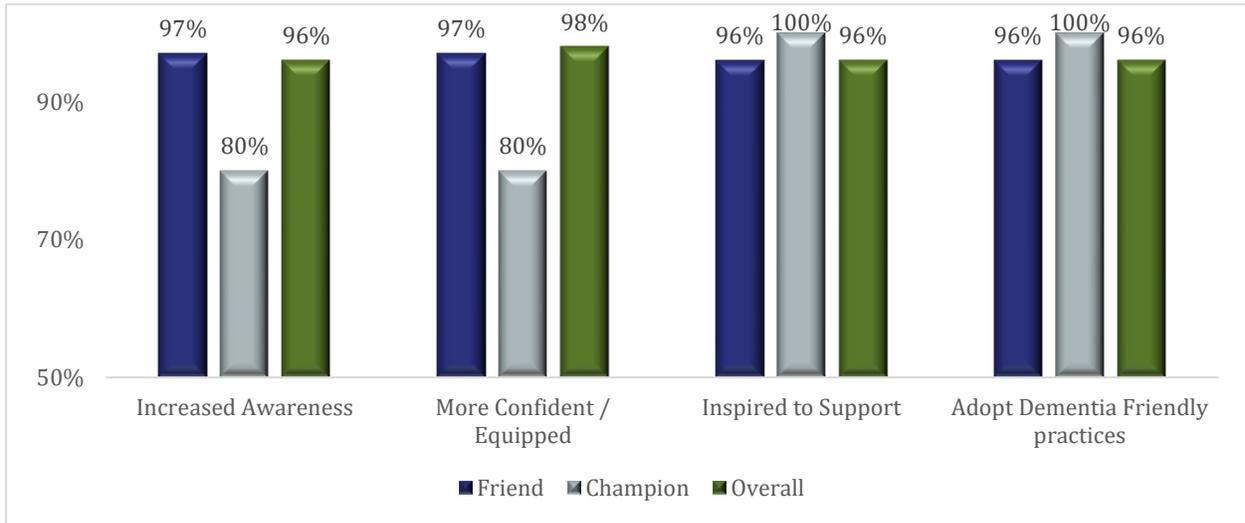
Figure 27. Dementia Friends Participant Behavioral Intentions– Dementia Friendly Winnemucca



Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 5), Friends (n = 75), Total (n = 80).

In addition to the behavioral intent questions described above, participants also answered 4 program specific questions regarding their experience in the program. A majority (97%) of participants in the Friends information session reported that they felt their awareness of ADRD had increased, that they felt more confident and equipped to recognize the signs and offer support to the needs of an individual living with dementia within their community (97%), felt inspired to offer support and be a friend to individuals living with dementia (96%), and reported that they were likely to adopt dementia friendly practices in their personal life (96%); (See Figure 28).

Figure 28. Perceived Benefits of Program – Dementia Friendly Winnemucca



Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 15), Friends (n = 30), Total (n = 45).

Goal 3: To offer the REST (Respite Education and Resource Tools) training to expand knowledge of respite care and increase the number of respite workers in Humboldt county.

Although the Dementia Friendly Winnemucca CAG had set a primary goal to increase the number respite volunteers, they reported that the volunteer resources provided by the local Retired & Senior Volunteer Program (RSVP) had the resources and connections to better provide respite services in the area. Thus, Rural RSVP led the REST training and respite services for this community. Results are detailed in the ‘Statewide Impact: Respite’ section of this report. However, Dementia Friendly Winnemucca CAG members did help to recruit both volunteers and participates and were responsible for and adding 3 respite volunteers to the service.

Goal 4: To create and launch an early-stage dementia support group.

Dementia Friendly Winnemucca also set a goal to develop an early-stage dementia support group. However, the focus of the group shifted to meet the demands of the community members. The modified focus of the group was to allow participants to ask questions, share concerns, and/or share resources with other community members who may be experiencing symptoms of early stage dementia. Despite not being a formal ‘support group’ for individuals living with early stage dementia, the group has met with guest speakers to help guide their discussions, and has begun working to develop a training session to increase police officer / first responder awareness of dementia in the community.

The CAG members noted that one difficulty in developing an early stage support group is the stigma surrounding dementia. The members noted that family members who have concerns about a loved one as well as individuals who recognize that they may be developing symptoms of dementia have come and received answers to both common and important questions. Despite this information, the members noted that although family members / individuals may come in with concerns, there are others, sometimes including the individual themselves, who may still deny experiencing symptoms of dementia. Despite these challenges, the CAG has established 2 different groups (“Let’s Talk About It” and a general Alzheimer’s support group), with each group being attended by between 3 and 30 community members at any given meeting.

Goal 5: To create new Adult Day services within Humboldt County / Winnemucca.

Dementia Friendly Winnemucca also sought to create a new adult-day service within Humboldt county. Although not formalized as an official, licensed adult day program, CAG members have been able to provide temporary respite services (called “WAM”) through session including between 1 and 7 participants. These sessions are typically held 2 days per month, and both the attendees and the family care partners have expressed that the service is greatly appreciated. Additional volunteers have been recruited, with one individual receiving enough training to provide the service independently should the need arise. Engagement activities during the respite sessions include art, music, and other attendee-directed activities.

Combined, the “Let’s Talk About It” support group and the WAM respite program served 87 individuals with a majority (n = 47, 54%) being women. No other demographic information was reported from these programs.

Dementia Friendly Southern Nevada Urban (Clark County and surrounding areas)

The goals selected by the Dementia Friendly Southern Nevada Urban Community Action Group were to:

- 1) Develop programs and training tools to increase public awareness / knowledge about dementia; and
- 2) Provide community-based memory screenings.

Goal 1: To develop programs and training tools to increase public awareness / knowledge about dementia.

To accomplish their first goal, the CAG developed and tested a new education program designed to address the needs of the business, faith, and general community in regards to dementia education. Volunteers from the CAG were recruited to become Master Trainers and to help create the presentations for each domain. These trainers worked intensively with the staff at the Cleveland Clinic to develop the modules, while also developing their skills as group facilitators. The information developed by the trainers focused on the dementia friendly communication techniques, as well as ways that the physical environment of the community could be modified to support individuals living with dementia and their care partners.

A total of 190 community members participated in the new program during the ACL-funded initiative, including representatives from the business (n=126) and faith sectors (n=28). A majority of participants in the sessions were non-Hispanic White (75%) women (74%). Care partner status was not collected for this program; (*See Table 14*).

Table 14: Dementia Friendly Southern Nevada Urban Education Program Participant Profile

	Business (n = 126)	Faith (n = 28)	Community (n = 36)	Total (n = 190)
Sessions	7	2	2	11
Age				
Under 60	56	6	16	78
60+	58	11	20	89
Gender				
Female	100	17	23	140
Male	26	11	13	50
Location				
Urban	116	27	36	
Rural	10	1	0	
Ethnicity				
Non-Hispanic White	96	16	30	142
Native American	1	0	0	1
Asian American	2	0	1	3
Black / African American	7	1	4	12
Native Hawaiian / Pacific Islander	2	0	0	2
Race**				
Hispanic / Latinx	6	0	4	10
Veteran Status (Yes)	4	0	2	6

Select participants (43%) were asked to complete a pre- and post-knowledge survey for the three different modules. Sector information was not collected for this program. As each topic

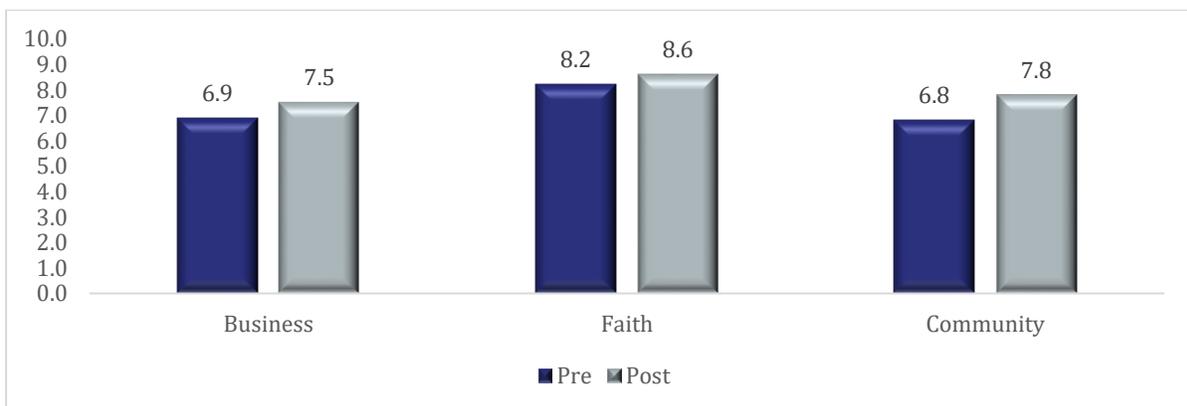
area included different questions that were specific to that area, analysis of the pre- and post-knowledge surveys were split by topic area. There were no behavioral intention or program specific questions asked of participants.

For those individuals who completed both the pre- and post-knowledge survey for the business sector module, the program was successful in increasing participant knowledge about the challenges faced by individuals living with dementia in that setting with participants answering statistically significantly more questions correctly on the post-knowledge survey ($M = 7.5$) compared with the pre-knowledge survey ($M = 6.9$) by answering on average 1 more questions correctly ($M = .7$; +10%); (See Figure 29).

For those individuals who completed both the pre- and post-knowledge survey for the faith sector, the program was *not* successful in achieving a statistically significant increase in participant knowledge about the challenges faced by individuals living with dementia, with participants answering approximately the same number of questions correctly on the post-knowledge survey ($M = 8.6$) compared to the pre-knowledge survey ($M = 8.2$);).

For individuals completing both the pre- and post-knowledge survey for the general community, the program was successful in increasing participant knowledge about the challenges faced by persons living with dementia, with participants answering significantly more questions correctly on the post-knowledge survey ($M = 7.8$) compared with the pre-knowledge survey ($M = 6.8$; +14.7%).

Figure 29. Southern Nevada Urban Sector-specific Training Knowledge Change¹⁰



Note. Mean difference statistically significant for Business ($n = 34$; $p = .01$) and Community ($n = 18$; $p = .03$), but not for Faith ($n = 5$; $p = .2$). One possible reason for failure to reach significance is the low number of respondents to that specific sector. Total possible correct was 10.

¹⁰ Both Faith and Community training statistics were computed using non-parametric tests due to the low number of respondents who completed both the pre- and post-knowledge surveys.

Goal 2: To provide community-based memory screenings.

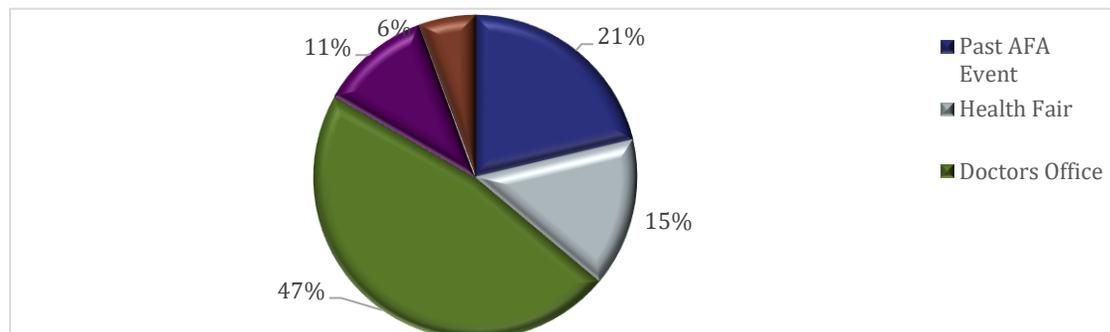
To accomplish this goal, the CAG partnered with 6 local organizations to help host memory screening clinics. Each clinic asked respondents to complete a memory screen tool developed by the Alzheimer’s Foundation of America (AFA). Due to the sensitive nature of the screening tool, results of the screens were not collected, however general demographic data regarding participants is available (*See Table 15*). During this ACL-funded initiative, there were a total of 395 participants, a majority of whom were non-Hispanic White (65%), women (71%) with an average of 70.8 years of age, who had not had a memory test before (73%) and came to the screening alone (54%). Of note, the age of participants ranged from 29 to 93.

Table 15: Dementia Friendly Southern Nevada Urban Memory Screening Participant Profile

	Total (n = 395)
Number of Sessions*	6
Average Age	70.8
Gender	
Female	279
Male	100
Ethnicity	
Non-Hispanic White	256
Hispanic / Latinx	19
African American / Black	37
Asian American	63
Native American	2
Other / Multiple Selected	17
Prior Memory Test (Yes)	108
Did You Come With Anyone (Yes)	180
Will You Share Results With Anyone	365

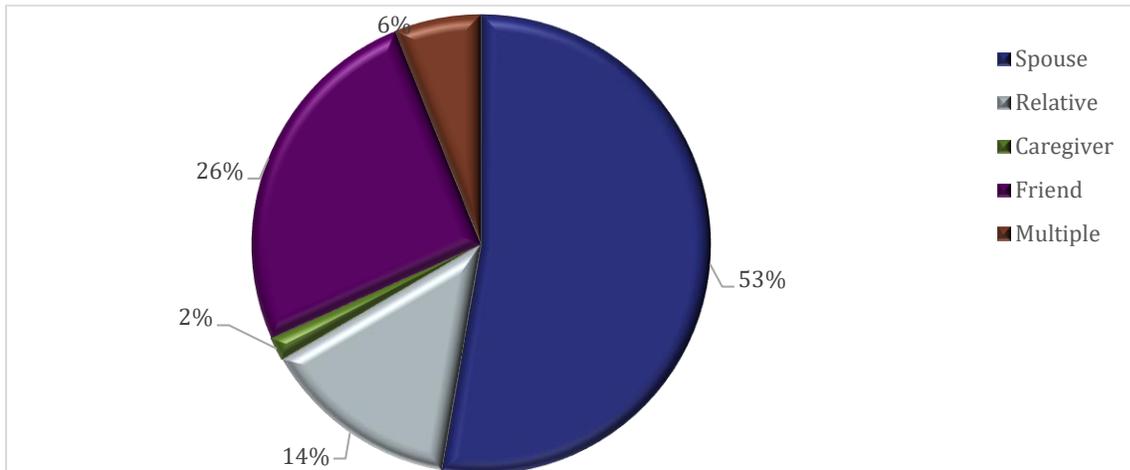
For individuals who reported a previous memory screen (27%), a majority reported that they had received the screening in their doctor’s office (*See Figure 30*).

Figure 30. Percent Reporting Having Had Memory Screen by Location (n=108)



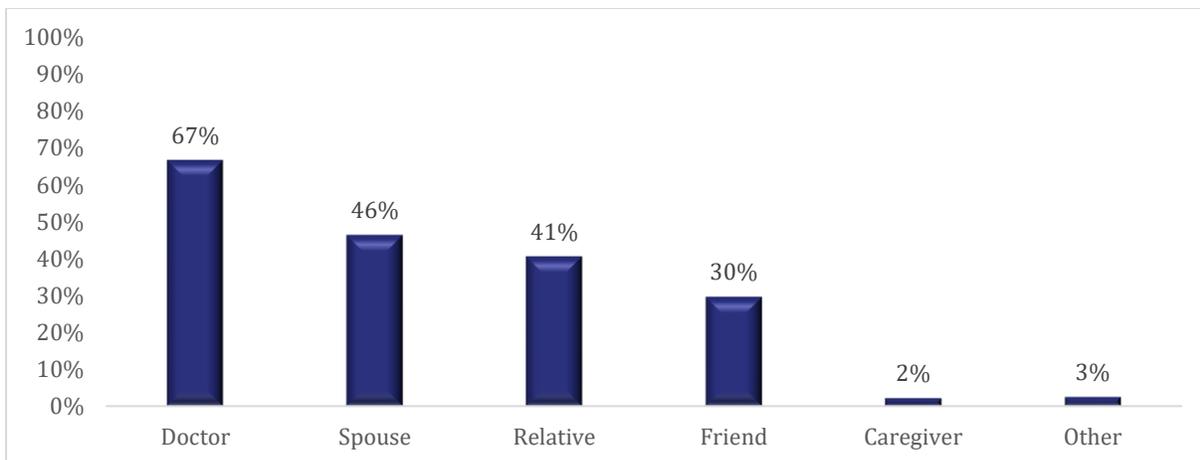
For those individuals who reported that they had attended the current screening with someone else (46%), a majority reported that they had come with a spouse (*See Figure 31*).

Figure 31. Attending Screen with Someone Else by Relationship (n=180)



For attendees who reported that they would share the results of the screen with someone (n = 92%), a majority (67%) reported that they would share the results with their doctor, while a large minority reporting that they would share the results with a spouse (46%) or other relative (41%); (*See Figure 32*).

Figure 32. Participant Sharing Results with Someone

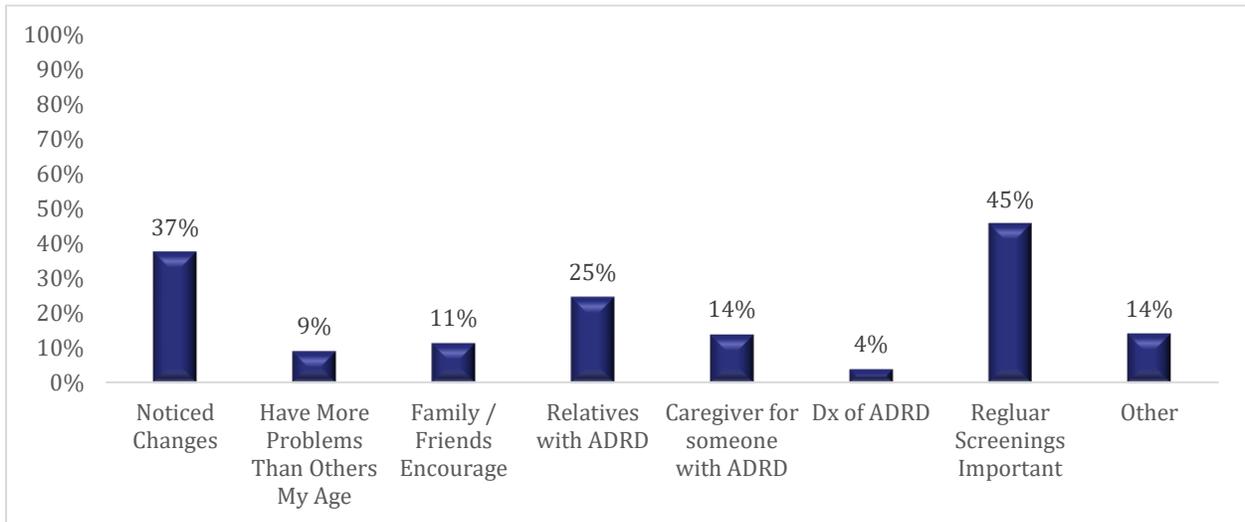


Note. Counts displayed are not exclusive as participants could select more than one. For display purposes, individuals who reported that they would share the results with a child were included in the relative count, individuals who reported sharing the results with a neighbor were included in the friend count.

Participants were also asked to report the reason that they had attended the memory screening event. For those participants who indicated a reason (n = 392), a large minority of

participants reported that they felt regular memory screening was important (45%), with 37% reporting that they had noticed some change in their memory over the past year (*See Figure 33*). For participants who selected “Other” (n = 55), 38% reported that they were simply curious about the process or wanted to know where they were cognitively compared to others of their age, whereas the next most common other reasons were balance issues (10%) or a diagnosis of a different degenerative brain illness (10%), with 29% reporting some other reason.

Figure 33. Reason for Participating in Memory Screening



Note. Counts displayed are not exclusive as participants could select more than one.

Dementia Friendly Pahrump (Nye County)

The community-specific goals selected by the Dementia Friendly Pahrump were to:

- 1) Improve geriatric clinical services in Pahrump with an aim to improve early detection and treatment.
- 2) Provide comprehensive dementia education to family care partners in conjunction with respite care for people living with dementia.
- 3) Provide community education and awareness.

It is important to note that Dementia Friendly Pahrump joined the ACL-funded initiative as part of the second cohort (in year 2), and thus pursued action on their goals for an abbreviated period.

Goal 1: Improve geriatric clinical services in Pahrump with an aim to improve early detection and treatment.

Throughout this ACL-funded project, discussions were held regarding how to best foster a relationship between Nye county primary care providers (PCPs) and the geriatrics specialty providers at the Sanford Center for Aging Geriatrics Specialty Clinic. The Sanford Geriatrics Specialty Clinic offers interdisciplinary, comprehensive geriatric assessment, which includes assessments of cognitive impairment, via telemedicine for rural communities. In her role as co-facilitator of Dementia Friendly Pahrump, Dr. Jennifer Carson directly led the CAG in identifying local PCPs appropriate to engage in conversation regarding their potential participation in telemedicine geriatrics services for people living with dementia. The CAG also outlined an outreach plan to recruit PCP participation. Using future funding provided to the UNR Sanford Center for Aging through a HRSA Geriatrics Workforce Enhancement Program (GWEP) Grant, Dr. Carson continues to engage Dementia Friendly Pahrump, along with other rural Dementia Friendly groups in Nevada, in implementing this goal of connecting rural patients with geriatrics clinical services via telemedicine. She is also connecting rural PCPs with geriatrics training via Project ECHO.

Goal 2: Provide comprehensive dementia education to family care partners in conjunction with respite care for people living with dementia.

To fulfill this goal, the CAG fostered a partnership with the Alzheimer's Association Regional Office in Las Vegas through which they delivered the CarePro caregiver education and support program to caregivers in Pahrump. Because this was considered a 'statewide' service/program, data are reported in the earlier section on "Statewide Impact" included under "additional State-funded services.

Goal 3: Provide community education and awareness.

Dementia Friendly Pahrump elected to implement the Dementia Friends program within their community to accomplish raise community awareness of dementia. As noted in the above sections, this program follows a train-the-trainer model, with community level Champions being trained by a state-wide Master Champion. These community Champions then provide information sessions within their specific community. Overall, there were 14 members of Dementia Friendly Pahrump who were trained as the initial Champions (*See Table 16*). These

champions held 8 Dementia Friends information sessions, reaching a total of 88 community members with the program. A majority of participants in the sessions held in Nye county were non-Hispanic White (n = 71, 76%) women (n = 72, 73%) who reported not providing care for someone living with dementia (n = 63, 64%).

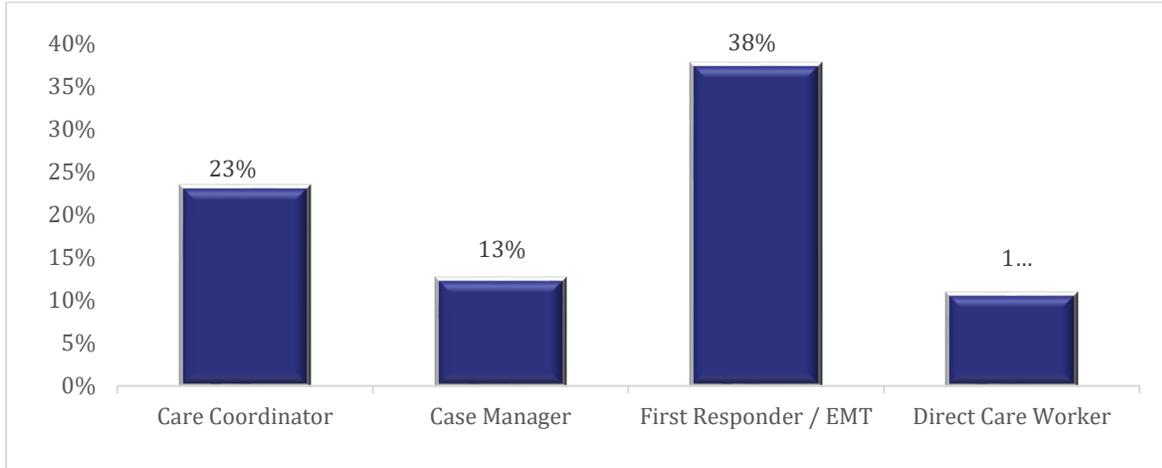
A majority of attendees of the Dementia Friends information session (n = 25, 31%) reported that they did not belong to any of the sectors listed, with an additional 7 individuals not answering this question. For those attendees who did answer identify a sector, a majority (38%) reported that they were First Responders / EMTs, with individuals reporting that they were either a care coordinator (23%) or case manager (13%) the next most common responses (*See Figure 34*).

Table 16: Dementia Friendly Pahrump Dementia Friends Participant Profile

	Champion¹ (n = 14)	Friend (n = 88)²	Total (n = 102)
Number of Sessions*	1	6	7
Ave. Age	66.8	54.3	56.0
Gender			
Female	11	61	72
Male	2	25	27
Ethnicity			
Non-Hispanic White	9	62	71
African American / Black	0	4	4
Native American	1	1	2
Hispanic / Latinx	0	2	2
Asian American	1	6	7
Pacific Islander	0	4	4
Other	0	3	3
Race**			
Hispanic / Latinx	0	3	3
Veteran Status (Yes)	3	15	18
Care Partner Status			
Yes	6	57	63
No	5	28	33
I am living with dementia	1	1	2

Note. * One session had a participant who did not complete the Champion training and so is counted as both a Friend and Champion session. **One individual reported both Latinx status as well as an additional race/ethnicity. ¹ For the Champion session, 1 person did not report their gender, 3 did not report their race, and 1 did not report Latinx or veteran status and 2 did not report care partner status. ²For the Friend sessions, there were 2 individuals who did not report their gender, 6 did not report their race/ethnicity, 6 did not report Latinx status, 3 did not report veteran status, 2 did not report caregiver status.

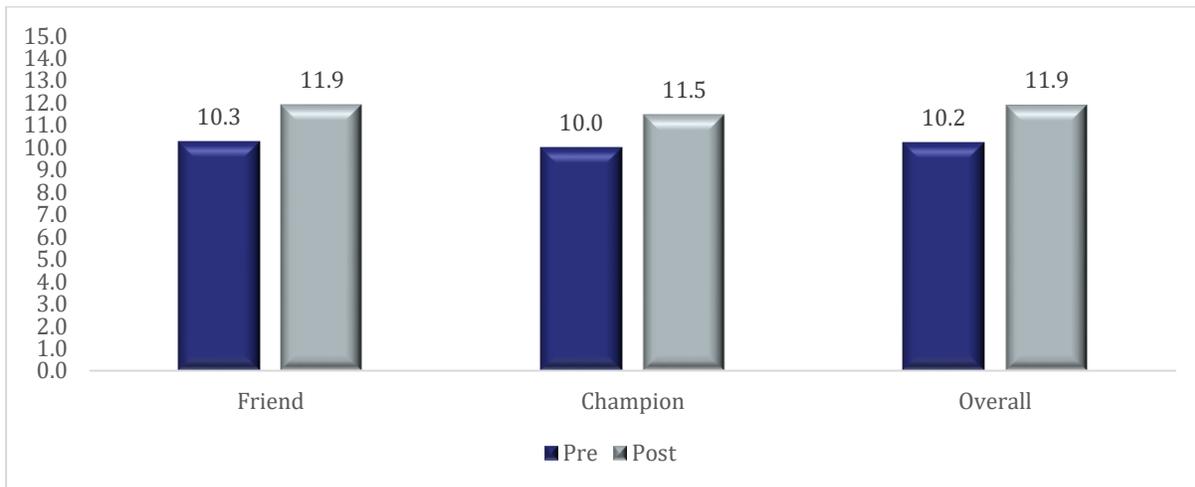
Figure 34. Dementia Friends by Sector – Dementia Friendly Pahrump



Note. Only individuals who reported a sector on the list were included (n = 81). Percents may not add to 100 due to rounding / other sectors not included in the chart.

For those individuals who completed both the pre- and post-knowledge survey (n = 80) the program was successful in increasing the participant’s knowledge regarding dementia, with participants answering significantly more questions correctly on the post-knowledge survey ($M = 11.9$) compared to the pre-knowledge survey ($M = 10.6$) (See Figure 35), by answering on average approximately 2 more questions correctly ($M = 1.7$; +12.3%).

Figure 35. Dementia Friends Participant Knowledge Change (Pre-Post) - Pahrump

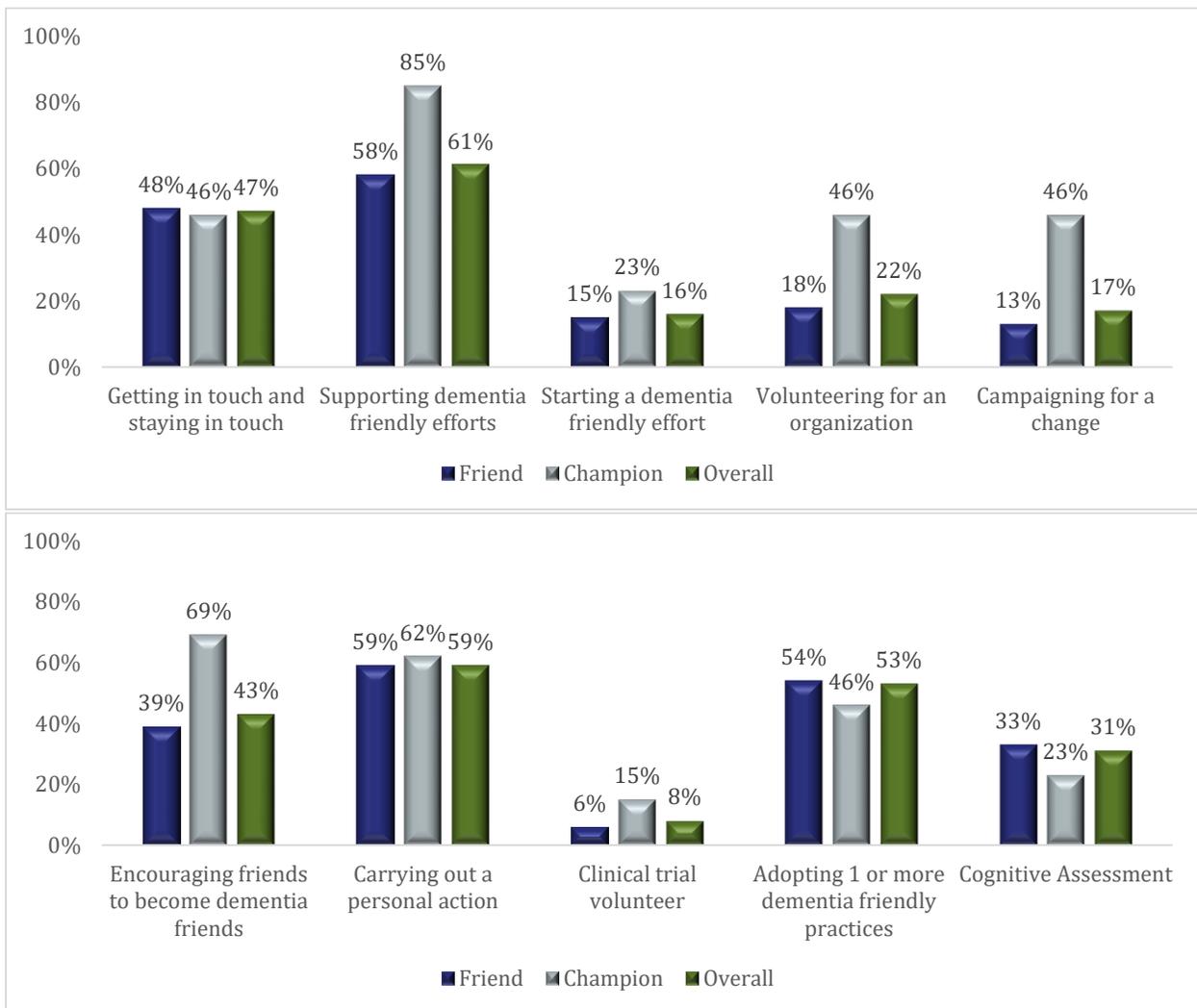


Note. Mean difference for Champions (n = 13) significant at $p = .02^{11}$. Mean difference for Friends (n = 80) and Overall (n = 93) significant at $p < .001$. Total possible correct was 15.

¹¹ Pahrump-CAG knowledge change statistics for Champions were computed using non-parametric tests due to the low number of respondents (n < 30) who completed both the pre- and post-knowledge surveys.

Participants also completed several questions regarding behaviors that would benefit individuals living with dementia in their communities. Overall, a majority of participants in the Friend information sessions who answered the behavioral questions (n = 80) reported that they would carry out a personal action when out in their community (59%), support dementia friendly activities within their community (58%), and integrate one or more dementia friendly practices in their personal / professional life (54%); (See Figure 26).

Figure 36. Dementia Friends Participant Behavioral Intentions

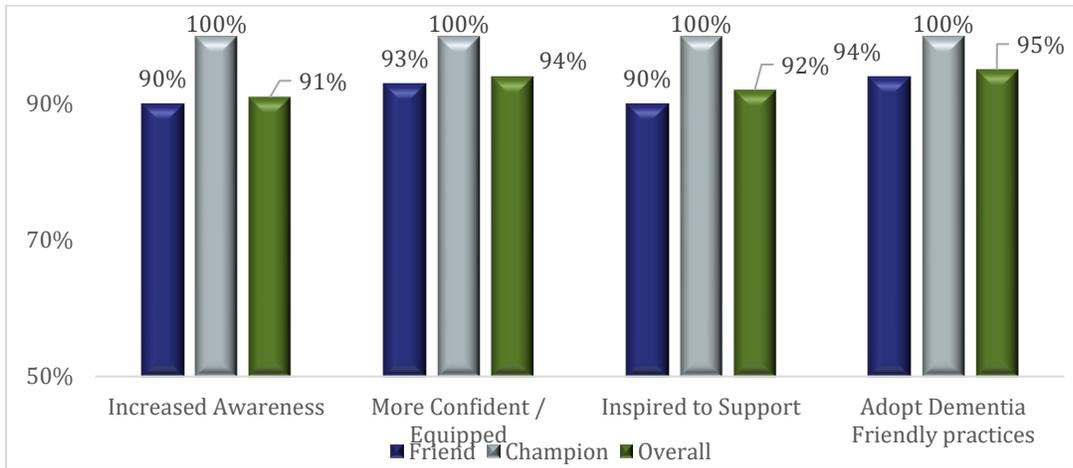


Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 15), Friends (n = 30), Total (n = 45).

In addition to the behavioral intent questions described above, participants also answered 4 program specific questions regarding their experience in the program. Overall, most participants in the Dementia Friends information session (90%) reported that they felt their

awareness of ADRDs had increased, with a similar number (93%) reporting that they felt more confident / equipped to offer support to an individual living with dementia trying to navigate their community, 72 (90%) reported that they felt inspired to offer support and be a friend to individuals living with dementia in their community, and 75 (94%) reporting that they were likely to adopt dementia friendly practices in their personal or professional life (See Figure 37).

Figure 37. Perceived Benefits of Program



Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 15), Friends (n = 30), Total (n = 45).

Dementia Friendly Washoe County

The goals selected by the Dementia Friendly Washoe County CAG were to:

- 1) Build a robust offering of volunteer-driven, Peer Support opportunities for people living with dementia and their care partners through the creation of supportive environments designed specifically to meet their expressed needs.
- 2) Offer opportunities for people living with dementia and their care partners to access services that promote holistic health and well-being within a dementia-friendly framework of support and inclusivity.
- 3) Promote dementia awareness and supportive attitudes among the broader Washoe County community and to educate organizations and individuals to better serve and support people living with dementia.

Goal 1: To build a robust offering of volunteer-driven, Peer Support opportunities for people living with dementia and their care partners through the creation of supportive environments designed specifically to meet their expressed needs.

Open Door Café

To achieve this goal, Dementia Friendly Washoe County members developed the concept of an “Open Door Café.” This program enables individuals living with dementia and their care partners to enjoy companionship and support in a safe and welcoming environment. Across 13 different sessions tracked in this evaluation, a total of 20 unduplicated participants were recorded as attending the Open Door Café, with more care partners (65%) than people living with dementia (35%). Also, more slightly men (55%) attended the sessions than women (45%). A majority of the participants in the Open Door Café program were non-Hispanic White (94%) women (63%) with 38% reporting that they were currently providing care for someone living with dementia (*See Table 17*).

Table 17: Door Café Participant Profile – Dementia Friendly Washoe County

	Living With Dementia (n = 7)	Care Partner (n = 13)	Non-Care Partner* (n = 15)	Total (n = 35)
Ave. Age	74.0	71.9	64.6	69.7
Gender				
Female	2	7	10	22
Male	5	6	5	13
Ethnicity				
Non-Hispanic White	6	11	13	30
Asian	0	0	1	1
Other	0	1	0	1
Race**				
Hispanic / Latinx	0	1	0	1
Veteran Status (Yes)	0	5	3	8
Live Alone (Yes)	1	2	4	7

Note. *Non-care partner includes individuals that did not report their dementia status or their caregiver status (n = 2). For individuals reporting that they are living with dementia, 1 individual did not report their race/ethnicity, Latinx, or veteran status. Counts are unique participants only. A total of 35 unique participants attended at least a single session.

To evaluate this new program, two focus groups were held with participants. The first focus group was held in December 2018. During this initial focus group, participants reported that they were appreciative of the opportunity to socialize with others who also understand the intricacies of the disease and were able to move beyond the normal ‘getting to know what to expect’ quicker and move on to more ‘normal’ conversations. Further, participants reported that

they appreciated the Open Door Café because it was flexible and engaging, but that they would also benefit from a bit more in the way of structured activities during the meetings.

During August 2019, a second and final focus group was conducted. Similar to the initial session, participants noted that the social aspect of the program was extremely important to them, as was the opportunity to experience “normal” social interactions without the experienced stigma of a dementia diagnosis. Several participants echoed the sense of community that had developed within the Open Door Café program, and stated the opinion that without the program they believed they would not have the same social opportunities and would likely be more socially isolated. The reported benefitting from the mutual support of the other participants.

Continuing the theme of increased social engagement, some participants noted that before coming to the Open Door Café they felt isolated from engaging in social conversations due to the communication difficulties that can be experienced by individuals living with dementia (e.g., repeating oneself and forgetting the flow of a conversation). These individuals reported that being able to interact with others who knew of these difficulties, and were accepting of them, had allowed them to regain a sense of normalcy within their own lives. Some participants also noted that simply talking about having dementia within the space created by the Open Door Café had helped them be more comfortable disclosing their diagnosis to others who may not know about their diagnosis.

Despite the social benefits experienced by the group, some of the focus group members did vocalize concerns that the group itself was isolated from the larger public, although difficulties associated with finding a space to meet were acknowledged. They sought a way to bring in more participants and make the program more visible in the community. Several participants also spoke about the need to engage with other community groups in order to both increase participation in the Open Door program as well as to increase the general communities understanding of dementia and how best to engage with an individual living with dementia.

Java Music Club

Dementia Friendly Washoe County also planned and pilot tested the evidence-based mutual peer-support program *Java Music Club* as a way to provide further opportunities for individuals living with dementia to connect with others socially. The Java Music Club is designed to reduce loneliness, facilitate friendships among participants and group facilitators, increase coping skills,

as well as offer positive feelings of understanding and support (Theurer et al., 2014)¹². Dementia Friendly Washoe County started Java Music Club in August 2019 as a relatively new addition their community engagement and support efforts. In their initial program pilot, a total of 11 people participated, including 6 people living with dementia (55%) and 5 others (45%). A majority of participants in the program were non-Hispanic White (90%), female (73%), and reported that they did not provide care for an individual living with dementia (100%); (See Table 18).

Table 18. Java Music Club Participant Profile – Dementia Friendly Washoe County

	Living With Dementia (n = 6)	Non-Care Partner* (n = 5)	Total (n = 11)
Ave. Age	82.0	83.2	82.6
Gender			
Female	3	5	3
Male	3	0	3
Race			
Non-Hispanic White	5	4	5
African American / Black	1	0	1
Ethnicity**			
Hispanic / Latinx	0	3	3
Veteran Status (Yes)	3	1	4
Live Alone (Yes)	1	1	2

Note. *Non-care partner includes individuals that did not report their caregiver status (n = 2). For individuals reporting that they are neither a care partner or living with dementia, 1 individual did not report their race/ethnicity, 2 did not report their Latinx status, and 1 did not report their veteran status. Counts are unique participants only. A total of 35 unique participants attended at least a single session.

Goal 2: To offer opportunities for people living with dementia and their care partners to access services that promote holistic health and well-being within a dementia-friendly framework of support and inclusivity.

To support this goal, the Dementia Friendly Washoe County CAG explored to partnerships intended to foster programs that contribute to physical, social and emotional well-being: 1)

Dementia Friendly Nature Walks and 2) *Dance With Me: Dementia Friendly Partner Dancing*.

¹² Theurer, K., Wister, A., Sixsmith, A., Chaudhury, H., & Lovegreen, L. (2014). The development and evaluation of mutual support groups in long-term care homes. *Journal of Applied Gerontology*, 33, 387-415. doi: 10.1177/0733464812446866.

Dementia Friendly Nature Walks

Dementia Friendly Washoe County partners with and supports an existing local program known as the Dementia Friendly Nature Walks (formerly the Idlewild Health Walks). These walks are hosted through a partnership between the Sanford Center for Aging and the Truckee Meadows Parks Foundation. Funding for this program included a 1-year grant from ADSD through its ‘innovative programs’ funding cycle during FY’19, but has not been sustained. Despite that, the program continues due to the commitments of the Sanford Center, Parks Foundation, and now, Dementia Friendly Washoe County. The program meets every Tuesday morning at Idlewild Park in Reno (with occasional other special locations) for a guided nature walk including narrated highlights of the various phenology points by the Parks Foundation team. Walk participants include people living with dementia and their care partners. The program is typically attended by approximately 8 – 10 participants with an equal number of volunteers (at a one-to-one volunteer-to-participant ratio). The program helps to promote both social connections and physical activity.

Dance With Me: Dementia Friendly Partner Dancing

The *Dance With Me* partners dance class was officially launched on September 4, 2019 and is being offered weekly. The Dance With Me action team is currently seeking funding to grow and sustain the program, including research grants (in partnership with faculty from the University of Nevada, Reno) and donations. Three couples, each a dyad of a person living with dementia and their care partner, participated in three test classes, provided feedback, and are now participating in the weekly class itself. Our hope is to grow the offering from one class once per week to three classes four times per week for optimal therapeutic benefit, should future funding permit. The Dance With Me program was recently tapped to be showcased on the local aging-oriented news program *Aging and Awesome with Ky Sisson*, with the episode airing later in October.

Goal 3: To promote dementia awareness and supportive attitudes among the broader Washoe County community and to educate organizations and individuals to better serve and support people living with dementia.

To educate the public and raise awareness, Dementia Friendly Washoe County implemented the Dementia Friends program. The Dementia Friends program follows a train-the-trainer model, with community level Champions being trained by a statewide Master Champion.

These Champions then provide information sessions within their specific community. A total of 21 members of the Dementia Friendly Washoe County CAG were trained as Champions, with an additional 15 individuals being trained as Champions over the course of the project (See Table 19). These Champions held 28 information sessions, reaching a total of 352 community members trained as “Dementia Friends”. A majority of participants in the sessions held in Washoe County were non-Hispanic White (71%) women (79%) and reported that they did not provide care for someone living with dementia (77%).

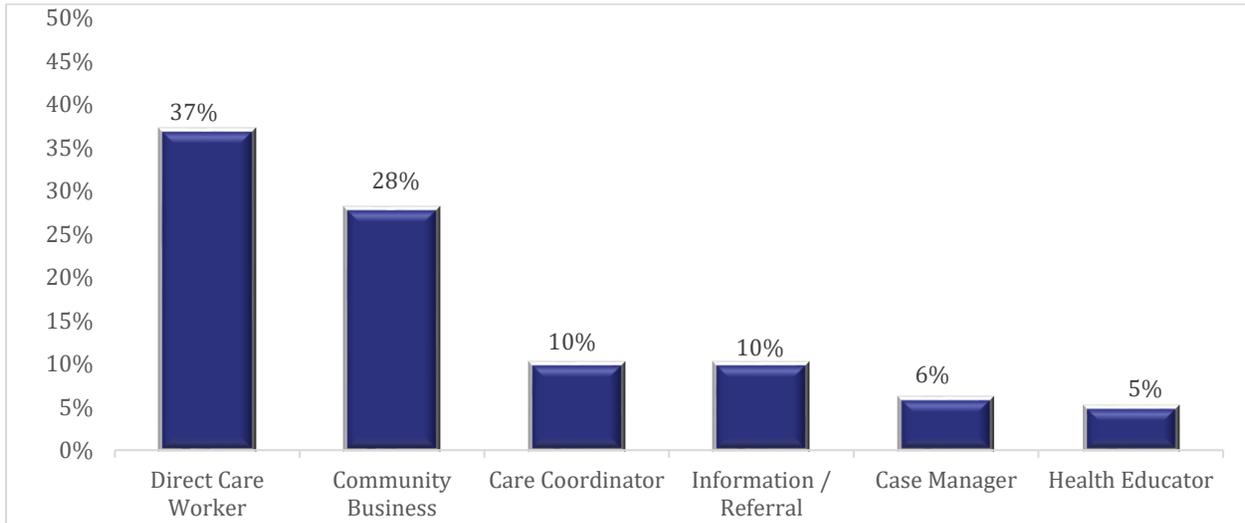
Table 12. Dementia Friendly Washoe County Dementia Friends Participant Profile

	Champion (n = 36)	Friend (n = 352)	Total (n = 388)
Number of Sessions*	3	28	32
Ave. Age	38.4	46.1	45.4
Gender			
Female	29	264	293
Male	7	72	79
Ethnicity			
Non-Hispanic White	25	234	259
Native American	1	3	4
Hispanic / Latinx	2	43	45
African American / Black	0	4	4
Pacific Islander	0	4	4
Asian American	5	32	37
Other	2	11	13
Race**			
Hispanic / Latinx	3	48	51
Veteran Status (Yes)	1	23	24
Care Partner Status			
Yes	6	78	281
No	30	251	84
I am living with dementia	0	2	2

Note. *One session (n = 3) did not send the pre- / post-knowledge surveys so no demographic data was recorded for those participants. For the Champion sessions, 1 person did not report their veteran status, Latinx status, or race/ethnicity. For the Friends sessions, 24 individuals did not report their veteran status, 16 did not report their gender, 21 did not report their caregiver status or race/ethnicity, 22 did not report Latinx status, **6 individuals who reported being Hispanic/Latinx also reported their ethnicity as non-Hispanic White.

A majority of attendees of the Friends information session (63%) reported that they were not involved with any of the sectors listed in the survey, with an additional 16% not answering. However, for those attendees that did identify a sector, a majority indicated that they were direct care workers (37%) or worked in a community business (28%); (See Figure 38).

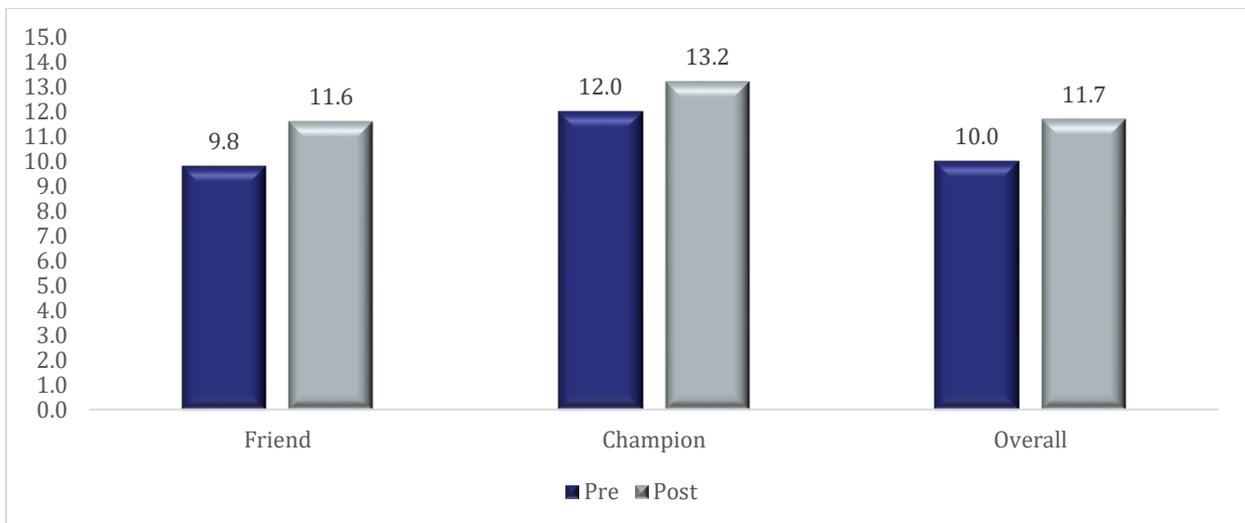
Figure 38. Dementia Friends by Sector – Dementia Friendly Washoe County



Note. Only individuals who reported a sector on the list were included (n = 166). Percents may not add to 100 due to rounding / other sectors not included in the chart.

For those individuals who completed both the pre- and post-knowledge survey (n = 344) the program was successful in increasing the participant’s knowledge regarding dementia, with participants answering significantly more questions correctly on the post-knowledge survey ($M = 11.7$) compared to the pre-knowledge survey ($M = 10$) by answering on average approximately 2 more questions correctly ($M = 1.7$; +17%); (See Figure 39).

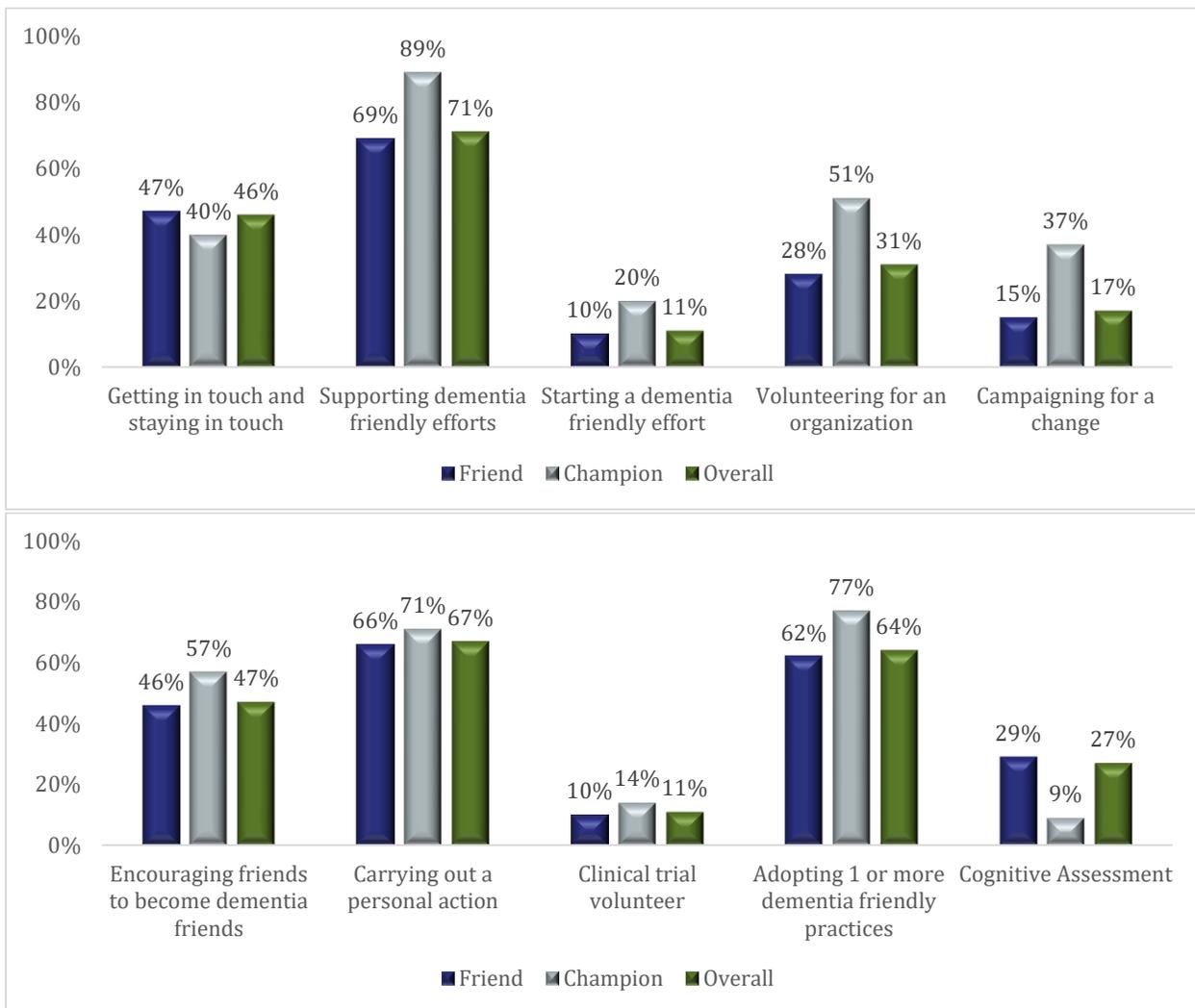
Figure 8. Dementia Friends Participant Knowledge Change (Pre-Post)



Note. Mean difference for Champions (n = 35) significant at $p = .007$. Mean difference for Friends (n = 309) and Overall (n = 344) significant at $p < .001$. Total possible correct was 15.

Participants also completed several questions regarding behaviors that would benefit individuals living with dementia in their communities. Overall, a majority of participants in the Friends sessions who answered the behavioral questions (n = 309) reported that they would be supportive of dementia friendly efforts in their community (69%), would be more patient while out in their community with others (66%), and would adopt at least 1 dementia friendly practice (62%); (See Figure 40).

Figure 40. Dementia Friends Participant Behavioral Intentions

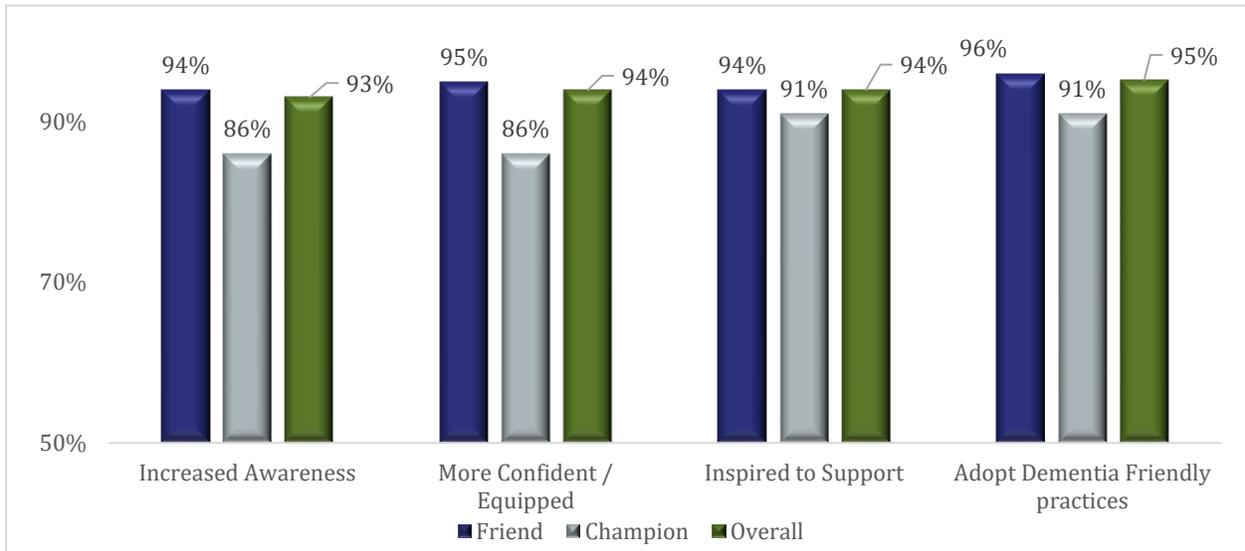


Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 35), Friends (n = 309), Total (n = 344).

Participants also answered 4 program-specific questions related to their impression of the program. Overall, most participants in the Dementia Friends program (94%) reported that they felt their awareness of ADRDs had increased, with a similar number (95%) reporting that they

felt more confident / equipped to offer support to an individual living with dementia in their community, while 94% reported that they felt inspired to offer support and be a friend to individuals living with dementia in their community, and 96% reported that they were likely to adopt dementia friendly practices in their personal or professional life (See Figure 40).

Figure 40. Perceived Benefits of Program



Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 35), Friends (n = 309), Total (n = 344).

Pesa Sooname (Pyramid Lake Paiute Tribe)

The goals selected by the Pesa Sooname Community Action Group of the Pyramid Lake Paiute Tribe were to:

- 1) Provide comprehensive geriatric clinical services in partnership with the UNR-Med’s Sanford Center for Aging.
- 2) Provide formal and informal opportunities for dementia education.

It is important to note that Pesa Sooname joined the ACL-funded initiative as part of the second cohort (in year 2), and thus pursued action on their goals for an abbreviated period.

Goal 1: Provide comprehensive geriatric clinical services in partnership with the UNR-Med's Sanford Center for Aging.

By the conclusion of the ACL-funded grant period, discussions were still being held regarding the development of a relationship between Pyramid Lake Paiute Tribal Health Clinic primary care physicians and the geriatrics specialty providers at the Sanford Center Geriatrics Specialty Clinic. This included an outreach visit by Dr. Jennifer Carson to present to the Pyramid Lake Tribal Health Clinic providers on the availability of geriatric clinical services (as part of the Sanford Center's HRSA GWEP rural community outreach). This outreach and associated discussion have been productive, and it is hoped that this will result in the needed geriatrics services being available to elders in the community.

Goal 2. Provide formal and informal opportunities for dementia education.

To accomplish the first goal, Pesa Sooname elected to implement the Dementia Friends information program. The Dementia Friends program follows a train-the-trainer model, with community-level Champions being trained by a statewide Master Champion. These Champions then provide information sessions within their specific community. Four members of Pesa Sooname were trained as the Dementia Friends Champions within that community (*See Table 20*) along with 7 Dementia Friends in the initial training. The Champions had not held additional information sessions at the time of the conclusion of ACL-funded project, but intend to do so moving forward. A majority of participants in the session (n=11) on the Pyramid Lake Paiute Reservation were Native American (90%), women (80%), and one individual (10%) reporting that they provided care for someone living with dementia.

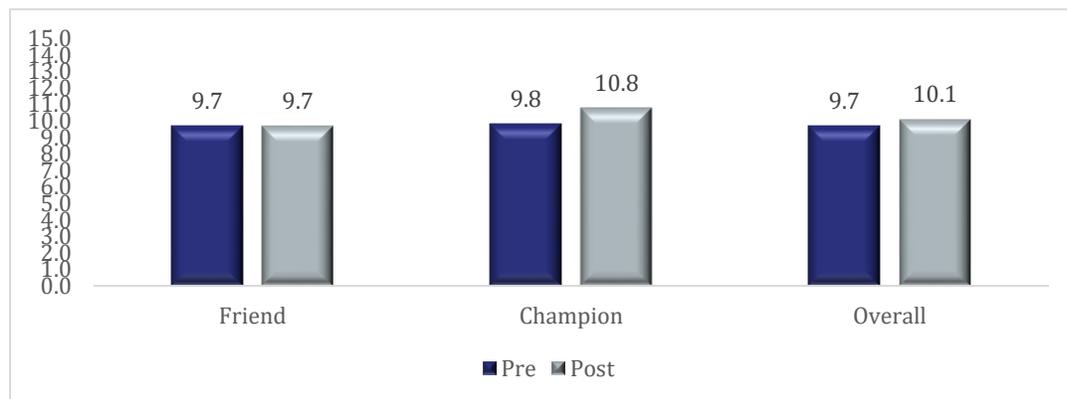
Table 20. Pesa Soaname Dementia Friends Participant Profile

	Champion (n = 4)	Friends (n = 7)	Total (n = 11)
Number of Sessions	1	1	1
Ave. Age	53.3	43.3	47.3
Gender			
Female	4	4	8
Male	0	2	2
Ethnicity			
Non-Hispanic White	1	0	1
Native American	3	6	9
Race**			
Hispanic / Latinx	0	5	0
Veteran Status (Yes)	1	6	1
Care Partner Status			
Yes	0	1	1
No	4	5	9
I am living with dementia	0	0	0

Note. For the Friends sessions, 1 individual did not report their veteran status, gender, 1 did not report their caregiver status or race/ethnicity, 2 did not report Latinx status.

For those participants who completed both the pre- and post-knowledge survey (n = 10) the program was *not* successful in increasing the participant’s knowledge regarding dementia, with participants answering approximately the same number of questions correctly on the post-knowledge survey (M = 10.1) compared to the pre-knowledge survey (M = 9.7) answering on average less than one additional correct answer (M = .4); (See Figure 41). These results are likely due to the overall low number of participants.

Figure 41. Dementia Friends Participant Knowledge Change (Pre-Post)

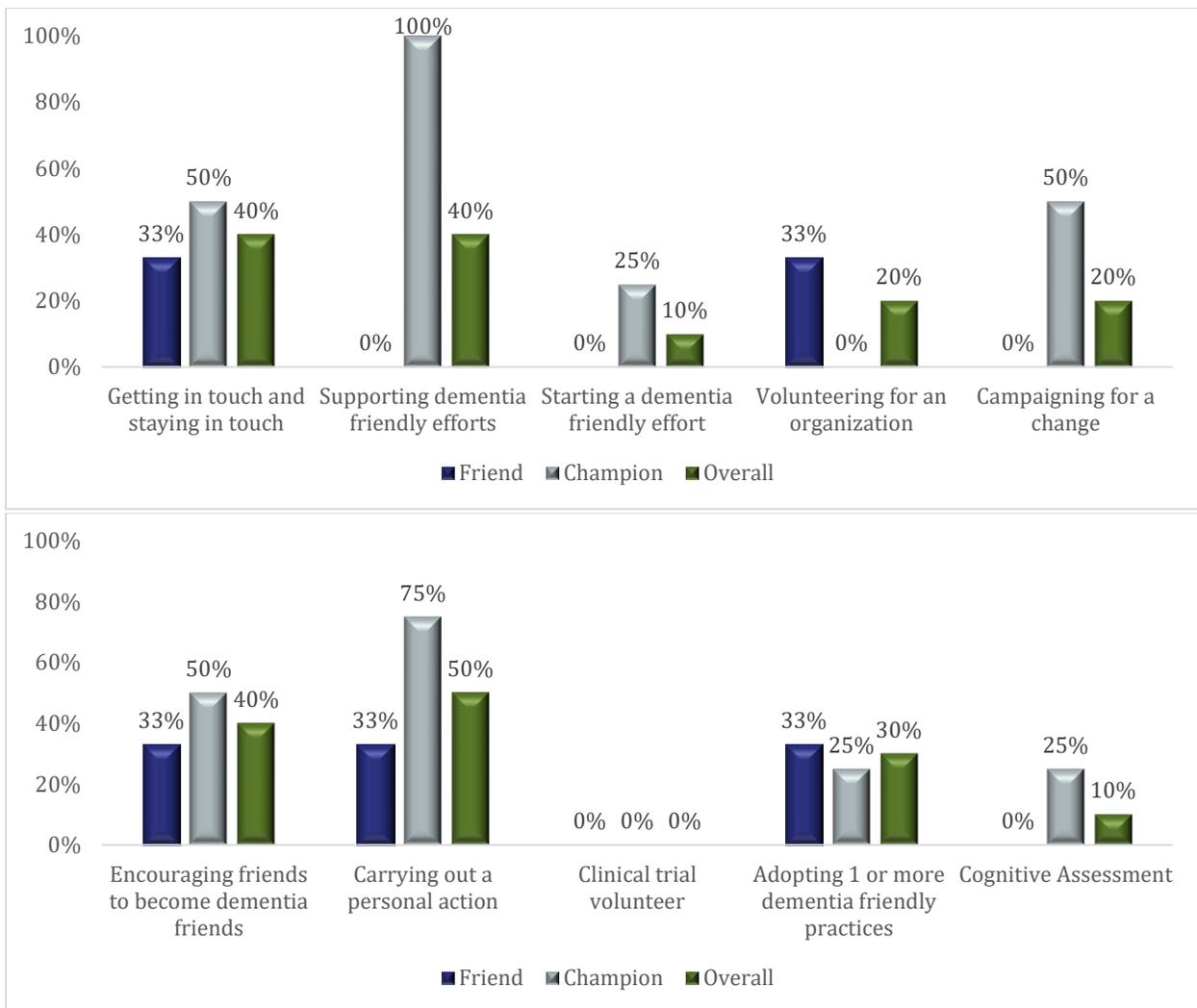


Note. Mean difference for Champions (n = 4; p = .10), Friends (n = 6; p = 1.0), and Overall (n = 10; p = .48) all non-significant¹³. Total possible correct was 15.

¹³ PL Paiute Tribal Reservation-CAG knowledge change statistics were computed using non-parametric tests due to the low number of respondents (n < 30) who completed both the pre- and post-knowledge surveys.

Participants also completed several questions regarding behaviors that would benefit individuals living with dementia in their communities. Overall, a high minority (33%) of participants in the Dementia Friends session who answered the behavioral questions (n = 6) reported that they would get in and stay in touch with someone they know living with dementia, would volunteer for an organization that helps individuals living with dementia, encourage their friends to become Dementia Friends, carry out a personal action when out in their community, and adopt one or more Dementia Friendly practice in their personal or professional life (See Figure 42).

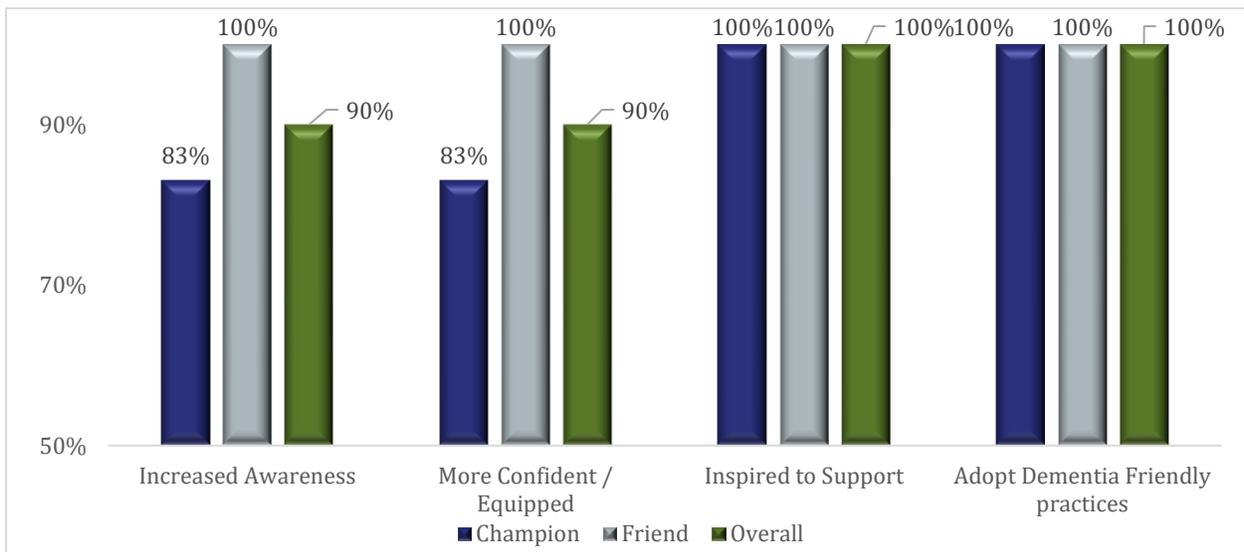
Figure 42. Dementia Friends Participant Behavioral Intentions



Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 4), Friends (n = 6), Total (n = 10).

Participants also answered 4 program-specific questions related to their impression of the program. Overall, most participants in the dementia Friends information session (83%) reported that they felt their awareness of ADRDs had increased, felt more confident / equipped to offer support to an individual living with dementia trying to navigate their community, and felt inspired to offer support and be a friend to individuals living with dementia in their community. All participants (n = 6) reported that they were likely to adopt a dementia friendly practice in their personal or professional life (See Figure 43).

Figure 43. Perceived Benefits of Program



Note. Only individuals who completed both the pre- and post-knowledge survey were included. Champions (n = 4), Friends (n = 6), Total (n = 10).

In addition to launching the Dementia Friends Program, Pesa Soaname also hosted various outreach events to raise awareness of dementia and available resources. During the ACL-funded project period, there were a total of five events (other than Dementia Friends trainings), including 2 community workshops (n = 16), 1 presentation at the Pyramid Lake Health Fair (n = 16), a presentation at the Nevada State Tribal Consultation Meeting (n = 20), and the Nevada Tribal Summit on Brain Health and Dementia (described below).

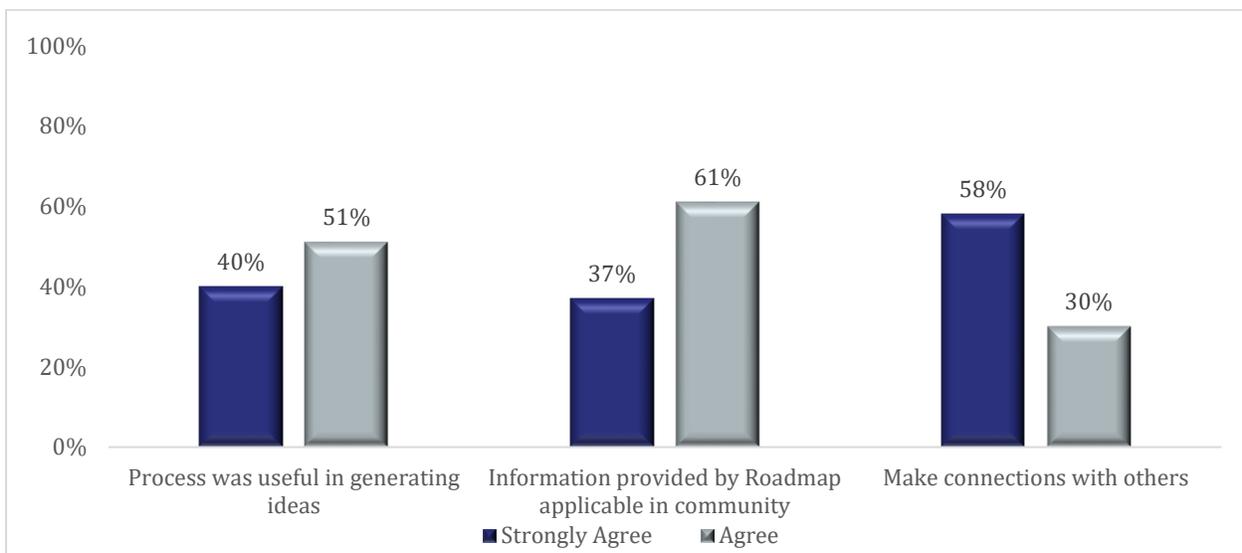
Nevada Tribal Summit on Brain Health and Dementia

In August 2019, Pesa Soaname hosted the first-ever Nevada Tribal Summit on Brain Health and Dementia, which brought together 113 participants, including representatives from 14 different Native American tribal communities, to discuss dementia and other aging related issues within and across Nevada’s tribal communities. The Summit highlighted the newly-released

Health Brain Initiative: Road Map for Indian Country (CDC, 2019)¹⁴, and discussed ways that the guidebook could be customized to meet the specific needs of the tribal communities within Nevada.

As part of the activities of the summit, participants were asked to complete a short evaluation form about their experience (n = 45, 40%). One person reported that they were living with dementia and 6 individuals reported that they were providing care for someone living with dementia. Overall most participants (n = 39, 91%) reported that engaging in the process was helpful in generating ideas related to how to implement the *Roadmap for Indian Country* in their community, the information provided by the Roadmap was applicable to their community (n = 42, 98%), and that the summit allowed them the opportunity to make connections with others who they may have otherwise not met (n = 38, 88%); (See Figure 44).

Figure 44. Nevada Tribal Health Summit Participant Response



Note. One individual (2%) reported strongly disagreeing with all questions. 3 (7%) individuals reporting being neutral about the process being helpful and 4 (9%) individuals reported being neutral with the ability to make connections.

In addition to these evaluation questions, nearly all participants (n = 44, 98%) reported that they would like to see a similar event happen every year, with one person not answering the question. Participants were also asked to give general comments. All comments were extremely positive, with one participant noting that “This event was very useful! I work with the elders of

¹⁴ CDC (2019). *Healthy Brain Initiative: Road Map for Indian Country*. Retrieved from <http://https://www.cdc.gov/aging/healthybrain/Indian-country-roadmap.html>

Fallon Tribe. What was talked about today has been topics myself along with others have been talking about. Very useful. Thank you!” and another noting that this information may help them by “strengthening our history”.

Limitations of Program Evaluation

Several key limitations to the data reported herein should be mentioned. First, data collected from the state is dependent upon individual agency reporting. Although clear definitions of the categorical variables are available, it is likely that some data entry errors occur during the process. In addition to data entry errors, the state reporting form uses a general category to record ADRD (i.e., cognitive limitations). However, as the grant was focused on expanding resources for individuals who are both living with ADRD and/or IDD, including IDD individuals in the counts of participants in state funded programs, it does not deter from the validity of the data. Despite this, it is important to note that many of the activities described in this report were focused on ADRD only, possibly limiting the overall impact of the activities described herein.

A second limitation is the significantly different response rates observed between the initial and follow-up waves of the Community Needs Survey. It is likely that a significant contributor to this low rate was the fact that during the initial wave, CAG members were focused solely on distributing and collecting responses to the survey. During the follow-up wave, CAG members were more likely to be engaged activities related to their goals. Evidence supporting this assertion is the overall participation rates shown within each CAG section detailed above.