Nevada Aging and Disability Services Division Alzheimer's Disease Supportive Services Program (ADSSP): Dementia Capable Systems

Program Evaluation Report (Final)

Evaluation Period: July 2014 – June 2017

November, 2017

This evaluation report for the Nevada Aging and Disability Services Division Alzheimer's Disease Supportive Services Program grant was prepared independently by the University of Nevada Reno Sanford Center for Aging. The report includes data reported during the project period including FY'15 – FY'17.

PI: Peter Reed, PhD

Project Manager: Zebbedia Gibb, PhD

DISCLAIMER

Data collected to compile this evaluation is based solely on data received from reporting organizations and is potentially not inclusive of all organizations serving individuals with ADRD in Nevada.

BRIEF PROJECT BACKGROUND

The Nevada Alzheimer's Disease Supportive Services Program – Dementia Capable Systems (ADSSP) grant, led by Nevada Aging and Disability Services Division (ADSD), includes a collaboration between the Alzheimer's Associations (AA) of Northern & Southern Nevada, Nevada Senior Services (NSS), and the University of Nevada Reno's Sanford Center for Aging (SCA) as primary contributors. The initiative's specific goal is to: "Expand Nevada's toolbox to assist individuals with dementia and their family caregivers." Thus, the focus of the program evaluation is to document the available dementia-related programs, and to determine the reach of the programs over the three-year project period. It should be noted that a second ADSSP grant, an expansion grant, was received by ADSD to continue these efforts through February 2018, and to introduce the evidence-based BRIDGE care transitions program into the "Nevada Toolbox".

Several organizations serve as key partners on this initiative to both develop and deliver Alzheimer's-related programs and services, as well as roll out new evidence-based Alzheimer's support programs. The following are the funded collaborators:

Alzheimer's Association (Northern and Southern Nevada)

The Alzheimer's Association works on a global, national and local level to provide care and support for all those affected by Alzheimer's and other dementias. They are committed to eliminating Alzheimer's disease through the advancement of research, to providing and enhancing care and support for all those affected, and to reducing the risk of dementia through the promotion of brain health. In this project, the primary role of the two AA chapters in Nevada (Northern and Southern) is continuing and expanding the delivery of their core services, and rolling out two evidence-based programs, Early-Stage Partners in Care (EPIC) and Care Partners Reaching Out (CarePro).

Nevada Senior Services

Nevada Senior Services provides respite for caregivers as an alternative to expensive in-home care. Their approach provides the ability to keep loved ones at home longer while they receive needed nursing care and social interaction. For this initiative, NSS' primary role is to implement the Benjamin Rose Institute / Rosalyn Carter Institute evidence-based Care Consultation model.

Sanford Center for Aging

The University of Nevada Reno Sanford Center for Aging mission is to enhance the quality of life and well-being among elders through education, translational research, and community outreach. To fulfill this mission, it offers a variety of community-based programs, clinical services, and a gerontolocial academic program. SCA serves as the independent evaluator for this ADSSP grant. SCA provided annual reports documenting the reach of Nevada's dementia care and support programs for FY'15 and FY'16, and is responsible for developing this final project evaluation report spanning all three project years.

EVALUATION PURPOSE & QUESTIONS

Evaluation Purpose

The goal of this ADSSP initiative in Nevada, led by ADSD, is to expand the availability of dementia-capable support services for persons living with Alzheimer's Disease and Related Dementias (ADRD), their families and their caregivers throughout the state of Nevada. This goal will be achieved by: 1) enhancing the ability of state systems and programs to embed dementia-capability in their service networks; and 2) by delivering dementia-capable supportive services using evidence-based and/or evidence-informed interventions to support persons with dementia and their caregivers.

The purpose of the program evaluation of this initiative is to determine the reach (i.e., number of people served) of available Alzheimer's services throughout the state, and to track the trends in reach from fiscal year (FY) 2015 to fiscal year 2017 (July 2014 – June 2017), as specified in the ADSSP grant parameters. In this way, this is an evaluation of statewide dementia capability, but is not a program-specific evaluation assessing the impact of individual programs.

This evaluation should be useful to all organizations providing services for persons living with dementia and/or their care partners by comparatively assessing services levels, and can further be used to determine gaps and duplication of services to better direct financial resources.

Key Evaluation Questions

1) What services are currently available in Nevada?
2) How many people living with dementia are currently accessing services in Nevada, relative to the number of people that could potentially be using services.
3) What has been the growth in service delivery during the three-year project period?
4) What are the demographics of people utilizing services?

EVALUATION METHODS

This evaluation utilizes data collected by the individual organizations statewide, funded by ADSD, which report information to ADSD, along with additional program data from the key funded partners (AA and NSS). SCA synthesized all data received from each of the collaborating partners on the ADSSP grant, while ADSD provided data from their funded programs to SCA. Each reporting organization was responsible for collecting or reporting their own data.

ADSD Data Sources

In the final year of this project (FY'17), 10 organizations reported serving individuals living with dementia or their care-partners (see Table 1 for a list of ADSD-funded organizations and the types of services provided). These organizations reported their data using the Nevada's SAMS system, an online database that tracks community organizations funded by the state. Starting in FY'17, organizations had the option of indicating who was utilizing the service. This information is included for those organizations that choose to disclose this data. One limitation is that for these funded programs, while data is available on the numbers of people living with dementia, data specifically on caregivers as program participants was limited.

Table 1. ADSD-funded organizations and service types

County / Organization	Service
Carson City	
Rural Retired & Senior Volunteer Program	Volunteer Care
Clark	
Nevada Senior Services	Adult Day
Catholic Charities of Southern Nevada	Volunteer Care
Cleveland Clinic	Diagnostic, medical and social services
Helping Hands of Henderson	Volunteer Care
Helping Hands of North Las Vegas	Volunteer Care
Helping Hands of Vegas Valley	Volunteer Care
Lend a Hand	Volunteer Care
Douglas	
Rural Retired & Senior Volunteer Program	Volunteer Care
Elko	
Cleveland Clinic	Diagnostic, medical and social services
Rural Retired & Senior Volunteer Program	Volunteer Care
Humboldt	
Cleveland Clinic	Diagnostic, medical and social services
Lyon	
Rural Retired & Senior Volunteer Program	Volunteer Care
Nye	
Rural Retired & Senior Volunteer Program	
Washoe	
Catholic Charities of Southern Nevada	Volunteer Care
Reno-Sparks Indian Colony	Volunteer Care
UNR-SCA Senior Outreach Services	Volunteer Care

Alzheimer’s Association Data Sources

In addition to data provided through the ADSD-SAMS database, AA (Northern and Southern) were asked to provide data detailing delivery of their core services within the state (e.g., information and referral, care consultation, education, support groups, and Safe Return), as well as their experiences delivering both the EPIC and CarePRO evidence-based programs. These data were sent directly from the AA chapters to SCA for inclusion in this report.

Nevada Senior Services Data Sources

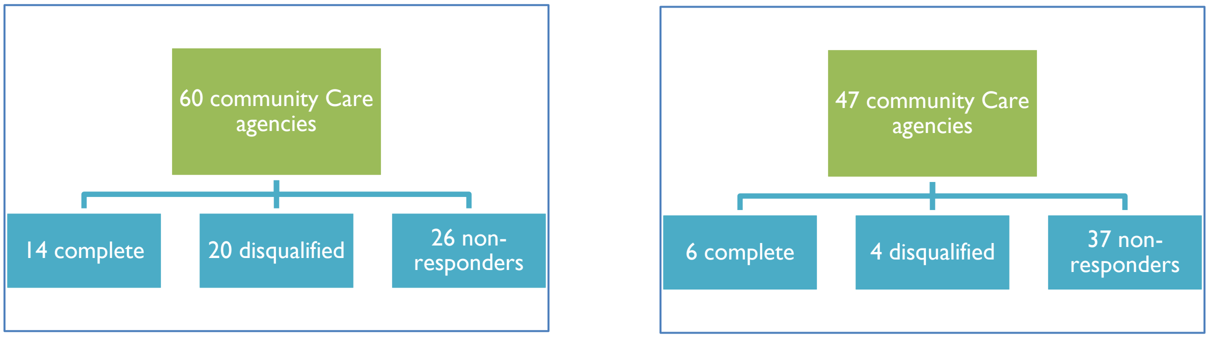
NSS provided data on their implementation of the evidence-based BRI/RCI Care Consultation program. These data were sent by NSS to SCA for inclusion in this report. These data are presented in the special section devoted to this specific program.

SCA Environmental Scan & Electronic Survey

To identify additional organizations not captured in the data sources listed above, SCA conducted an environmental scan to determine organizations in Nevada that are not involved with the ADSSP grant that are serving people living with dementia or their care partners, excluding any long-term care services (i.e., assisted living and nursing homes). This scan, first conducted in 2015), initially found 60 organizations potentially providing relevant services. Through further evaluation in 2016, it was determined that 47 organizations were likely to provide dementia services. These organizations were asked to complete an electronic survey regarding activities within their communities.

The electronic survey was created and implemented by SCA using Survey Gizmo. Survey questions pertained to demographic information for participants in all types of dementia-related services offered by each organization. For the FY'15 annual evaluation report, the survey was sent via email to 60 organizations, with an email follow up reminder sent one week following the initial survey. If an organization did not report within 30 days, a follow-up phone call was placed with the possibility to complete the survey at that time via telephone or re-sending the survey. Thirty-four organizations responded out of 60 targeted with the survey; a response rate of 57%. However, twenty of the responding organizations reported that they did not provide services to individuals with dementia or their care partners, and were thus disqualified. This survey yielded additional data for this report from fourteen, otherwise, not included organizations in FY'15. Using the same process for the FY'16 annual evaluation report, an even lower response rate was recorded, yielding little data for inclusion. In FY'16, the survey was distributed to 47 organizations, with 10 completing the survey (21%), four of which were disqualified due to a lack of dementia service provision. As the community survey did not prove to be a significant data source in its earlier administration, it was not replicated for FY’17.

Figure 1. Survey response rate (FY’15 & FY’16)



FY’15 Survey response results

FY’16 Survey response results

FINDINGS

Reach of State Funded Services in Nevada

As previously noted, the state of Nevada (ADSD) funds several organizations to provide services to community dwelling elders (CDE) who are living with dementia. These services range from broad (e.g., Information and referral services provided by the regional AA or volunteer care services) to more specific (e.g., Adult day programs) services. It is likely that other programs (e.g., Meals on Wheels) also serve individuals with cognitive impairment, however, these programs may not collect or report cognitive impairment information and are thus not included. Table 2 provides overall demographic information for persons living with dementia served by the ADSD-funded programs, with year-over-year trends for FY’15 – FY’17.

Overall, in FY’17, 10 ADSD-funded organizations reported providing services to individuals with cognitive impairment, down from 15 (33% decline) in FY’15. In FY’17, these 10 organizations served 247 CDE, a slight increase compared to FY’16 (0.8%). However, the FY’17 program reach was much higher relative to the baseline year of FY’15 (20%). See *Figure 2* for specific participant counts year-over-year. One possible reason for this observed increase was an increased push from the state asking reporting organizations to report the cognitive status of their clients.

Throughout this initiative, ADSD-funded organizations were asked to use a new item in SAMS to identify the cognitive status of their clients using the following categories: 1) Early Onset, 2) Mild, 3) Moderate, and 4) Severe. Between FY’16 and FY’17, there was an increase in the number of CDE identified as having Early Onset (20.0%) and Severe (15.0%) cognitive impairment (see Table 2). Compared to FY’15, there was an increase in the number of CDE identified across all cognitive impairments (Figure 3), which again, is likely the result of an increased emphasis by ADSD for their funded organizations to report these data.

Table 2. Demographics of Clients Receiving Services Funded by ADSD by FY

	FY 15 Total (%)	FY 16 Total (%)	% Change	FY 17 Total (%)	% Change
Total Number of Clients Served	197	245	+24	247	+0.8
Total Number of Services Reporting	15	13	-13	10	-23
Unduplicated N	~	137 (56)	~	99 (40)	-28
Average Age	79.56	79.23	~	78.72	~
Gender					
Male	67 (34)	85 (35)	+27	163 (66)	-1
Female	129 (66)	160 (65)	+24	84 (34)	+2
Race/Ethnicity					
Non-Hispanic White	116 (59)	135 (58)	+16	125 (51)	-7
Black	20 (10)	34 (15)	+70	46 (19)	+35
Asian	7 (4)	8 (3)	+14	12 (5)	+50
American Indian / Alaskan Native	12 (6)	9 (4)	-25	46 (19)	+411
Hispanic	36 (18)	42 (18)	+17	42 (17)	0
Hispanic	39 (20)	45 (18)	+15	48 (19)	+7
In Poverty	90 (47)	100 (45)	+11	116 (53)	+16
Lives Alone	61 (31)	70 (30)	+15	58 (24)	-17
High Nutritional Risk	107 (65)	125 (64)	+17	129 (67)	+3
Rural	47 (24)	55 (23)	+17	34 (14)	
ADL Limitations					
0-1	98 (52)	98 (42)	0	79 (34)	-19
2-3	36 (19)	49 (21)	+36	54 (23)	+10
4-5	41 (22)	54 (23)	+32	59 (25)	+9
6	14 (7)	32 (14)	+129	42 (18)	+31
IADL Limitations					
0-1	30 (16)	30 (13)	0	17 (7)	-43
2-3	20 (11)	19 (8)	-5	20 (9)	+5
4-5	38 (20)	48 (21)	+26	49 (21)	+2
6+	102 (54)	137 (59)	+34	148 (63)	+8
Level of Impairment					
Early Onset	13 (7)	25 (10)	+92	30 (12)	+20
Mild	89 (45)	100 (41)	+12	92 (37)	-8
Moderate	65 (33)	80 (33)	+23	79 (32)	-1
Severe	27 (14)	40 (16)	+48	46 (19)	+15

Notes. 1) Fiscal Year 15 is considered baseline. 2) Participants may be in more than one Fiscal Year (duplicated year-over -year). 3) ~ = Value not calculated due to comparison against baseline. 4) Race indicated as Hispanic, may be of mixed ethnicity. 5) Percentages do not add to 100% due to rounding.

Figure 2. Total number of clients (people living with dementia) by fiscal year

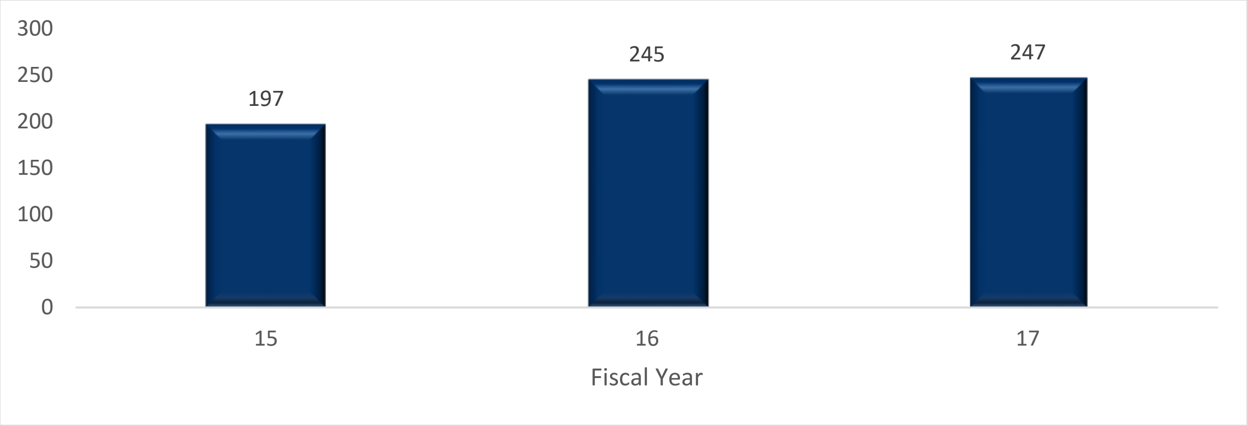
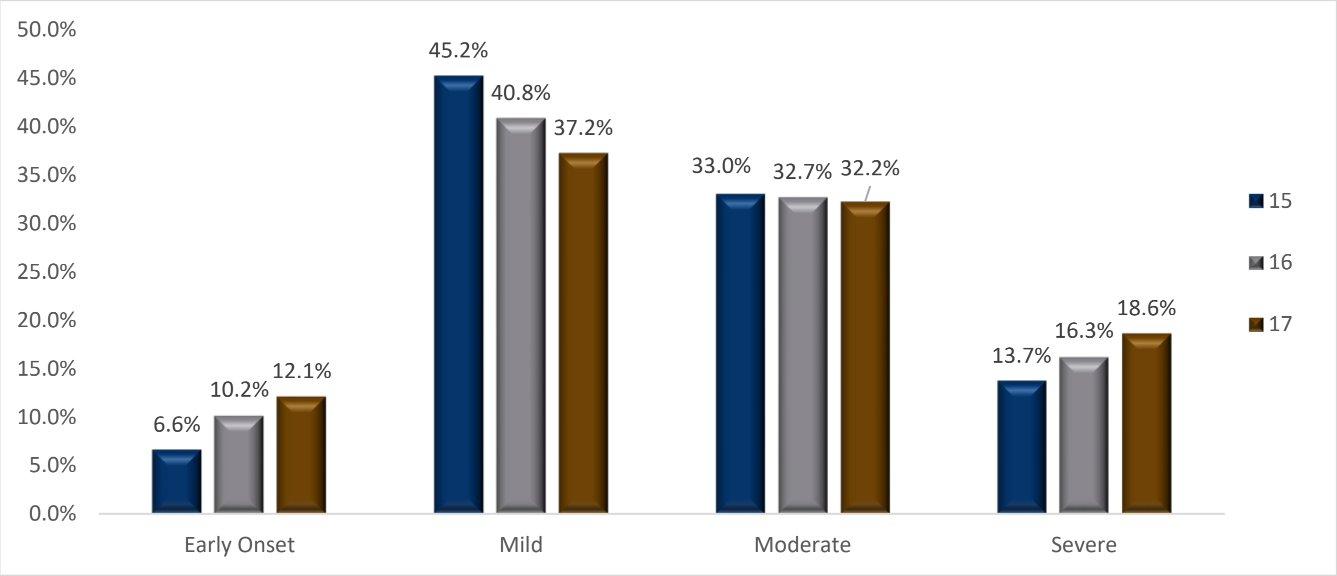


Figure 3. Client cognitive status by fiscal year



It is of interest to note that approximately 60% of individuals who received services in FY’17 were also found in at least one other FY. This is potentially an indicator that these individuals with cognitive impairment are remaining within the community, an outcome that suggests programs are supporting the well-being of these individuals, and which has the result of reducing the costs associated with their care.

Reach of Alzheimer’s Association Programs in Nevada

While there is certainly a meaningful level of service being provide by both AA chapters in Nevada, the data submitted from them to SCA is incomplete. The AA Northern Nevada chapter provided data on the delivery of their core services (see below), excluding Safe Return, for FY’15 and FY’17, but did not provide FY’16 data. The AA Southern Nevada chapter provided data on their core services, excluding Safe Return, as well as data on three additional services (supportive services training, client community support, and respite) for FY’15 only. No data was received for FY’16 and FY’17. Thus, the ability to trend changes year-over-year for Association service delivery is minimal.

Both chapters routinely provide five core services that include: information and referral, family care consultation, support groups for people living with dementia and their care partners, various education programs for people living with dementia and their care partners, and the Safe Return program. For many of the core services offered, including information and referral, support groups, and care consultation, there was no demographic data provided, only the number of participants served. Further, there was no programmatic data provided for Safe Return.

In FY’15, the AA-Northern Nevada reported serving a total of 3,724 individuals across all reported services. For FY’17, the chapter reported serving a total of 2,492 individuals across all reported services, an overall decrease of 33%. In FY’15, the AA-Southern Nevada reported serving a total of 1,618 individuals across all reported services. A complete breakdown by service type for both chapters is presented in Table 3.

Table 3. Alzheimer's Association reach by core service

	FY'15	FY'16	FY'17	% Change
Northern Nevada				
Information and Referral	719	~	1240	+73
Family Care Consultation	348	~	410	+18
Education	1425	~	842	-41
Support Groups	1232	~	369	-70
Southern Nevada				
Information and Referral	616	~	~	~
Family Care Consultation	431	~	~	~
Education	0	~	~	~
Support Groups	39	~	~	~
Supportive Services Training	203	~	~	~
Client Community Support	132	~	~	~
Respite	197	~	~	~
Total AA-NN	3724	~	2492	-33
Total AA-SN	1618	~	~	~
Total AA	**5342**	~	**2492**	**-53**

Notes: Significant data is missing for these programs beyond the baseline year. This dramatically hinders the ability to report accurate service numbers.

Early-Stage Partners in Care (EPIC) service delivery

In addition to their core services, both Northern Nevada and Southern Nevada AA chapters were funded by ADSD in this initiative to begin implementation of EPIC, under the guidance of Arizona State University (ASU). This program was launched in FY'15 as part of this initiative, and continued delivery throughout the three-year project period. EPIC is intended to assist individuals with early-stage dementia and their care-partners via education and training workshops. The overarching goal of the program is to increase well-being by providing both training and informational sessions. EPIC seeks to reduce the stress associated with a dementia diagnosis by allowing individuals living with dementia and their care partners to collaboratively create a plan for the future. The EPIC program also provides techniques designed to help address behavioral and communication challenges often associated with dementia. Staff members trained in the EPIC program are able to identify unique situations and ensure adequate application of delivered information. For a full description of the EPIC program and its implementation in Nevada, provided by Dr. David Coon, please see *Appendix A*.

During this initiative, the Northern Nevada chapter recruited 15 dyads for the EPIC program, with 12 (80%) actually completing the 8-week workshop. However, demographic data was only reported for 10 of these dyads. During the same period, the Southern Nevada chapter reports serving 51 dyads. Thus, a total of 66 dyads were served through EPIC in Nevada between FY'15 and FY'17. EPIC participant demographics are presented in Tables 4 and 5.

Table 4. Northern Nevada Alzheimer's Association EPIC demographics FY 15 through FY 17

	Individuals With Dementia	**Care-Partners**
N	10	11
Age		
Under 60	1	~
60+	8	9
Relationship to Partner		
Spouse	10	9
Child	0	2
Gender		
Female	6	6
Male	4	5
Ethnicity		
Hispanic / Latino	7	2
Not Hispanic / Latino		7
Race		
Non-Hispanic White/Caucasian	5	7
White – Hispanic	~	2
Veteran	1	1
Urban	8	8
Rural	2	3

Note. Numbers may not add to total due to missing values. ~ Indicates missing value.

Table 5. Southern Nevada Alzheimer's Association EPIC demographics FY 15 through FY 17

	Individuals With Dementia	**Care-Partners**
N	51	51
Age		
Under 60	1	4
60+	14	11
Relationship to Partner		
Spouse	~	11
Child	~	2
Gender		
Female	6	13
Male	9	2
Ethnicity		
Hispanic / Latino	1	1
Not Hispanic / Latino	14	13

Note. Numbers may not add to total due to missing values. ~ Indicates missing value.

Care Partners Reaching Out (CarePRO)

The AA chapters also implemented the CarePRO program as a part of this initiative, again under the guidance of ASU. CarePRO is a series of skill-building workshops for persons caring for loved ones who are coping with dementia such as Alzheimer's disease and related disorders. David W. Coon, PhD, an ASU professor who is one of the nation's leading experts on caregiver support, designed the program based on research done at Stanford University. Each CarePRO session engages seven to ten caregivers in workshops that provide education about dementia and its impact on families. Caregivers will be trained in ways to manage stress and techniques to help them cope with the disease and communicate better with loved ones suffering from memory loss. The program also includes personalized telephone "coach" calls that help caregivers implement the new skills introduced in the workshops. Respite care for the person with dementia is available so caregivers may attend the sessions without having to worry about leaving their loved ones alone. Through this initiative, a total of 607 caregivers participated in the CarePRO program in Nevada. The Northern Nevada chapter reported delivering CarePRO to

10 participants, but did not provide any demographic data, while the Southern Nevada chapter report delivering CarePRO to 597 participants. Full demographic data for CarePRO in Southern Nevada, as well as trends for participation year-over-year are provided in Table 6.

Table 6. Southern Nevada CarePRO Program Numbers

	FY'15	FY'16	% Change	FY'17	% Change
Race / Ethnicity					
Non- Hispanic White	94	150	+ 60	77	- 49
Black / African American	6	21	+ 250	20	- 5
Hispanic	82	85	+ 4	127	+ 50
Age					
< 60	58	79	+ 36	28	- 65
60 +	131	173	+ 32	96	- 45
Gender					
Male	47	58	+ 23	33	- 43
Female	142	207	+ 46	119	- 43
Relationship to Person w/ Dementia					
Spouse	86	113		80	
Child	87	120		35	
Friend	0	18		0	
In – Law	10	10		9	
Other Relative	6	4		0	
Total Attendees	**189**	**265**	**+ 40**	**143**	**- 46**

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

Reach of BRI/RCI Care Consultation (Nevada Senior Services)

With funding from ADSD in this initiative, NSS provided care consultation services based on the Benjamin Rose Institute/ Rosalynn Carter Institute care consultation model. This program uses trained care consultants to deliver the intervention via electronic or regular mail. These care consultants establish an ongoing relationship with the client, as well as with the care partners. If the care recipient is too impaired to effectively participate in care and/or care related decision-making, the care consultant works exclusively with the primary caregiver.

The intervention consisted of three components: 1) an initial assessment administered by phone addressing several domains for both the care recipient and the caregiver; 2) development of an action plan that details the steps to be taken by the care recipient, the caregiver, and any additional family members or service providers; and 3) continued contact from the care consultant to monitor the care recipient, and develop new action plans as they become necessary.

For the project period of FY'15 through FY'17, NSS served 95 dyads. A majority of care partners enrolled in the program were female (83.2%), White (69.0%), non-Hispanic (93.8%), and married (60.2%). Their relationship with the care recipient was likely to be spouse or significant other (48.6%) or child (34.5%). Only a minority of care partners held power of attorney (POA) (32.1%), guardianship (11.6%) or healthcare POA (29.5%) statuses.

The distribution of care recipients enrolled in the program was less skewed, with approximately 55% of care recipients being men. Similar to care partners, a majority were White (65.5%), non-Hispanic (95.6%), with a high minority (49.6%) being married. A majority (56.3%) of care recipients had an active dementia diagnosis, with 33% having an active Alzheimer's disease diagnosis.

Additionally, NSS administered surveys to gauge the impact of the program to the degree possible. Through this effort, caregivers were asked to rate the care recipient's quality of life, using the QOLS (Burckhardt & Anderson, 2003). Burckhardt and Anderson reported that scores could range from 16 to 112, with higher scores equaling greater quality of life. For the 20 clients who reported both pre-and post-quality of life, there was no statistically significant change, with a mean pre-score of 41.15 and a mean post-score of 39.40.

Of the 95 participants, 55 care providers reported on their satisfaction with the program. Based on the summary data provided by NSS, most clients who received the service rated their service as either good (19%) or Excellent (79%). Importantly, many of the individuals served by the program stated that they felt the care consultation staff cared about them as a person (79%)

and explained program materials in a way that was understandable. However, there was a small percentage (1%) of individuals who reported not being satisfied with how much the care consultant spoke with them or reported difficulty speaking with the care consultant.

Northern Nevada AA, RCI – Care Consultation delivery

For this initiative, the AA-Northern Nevada also provided care consultation services using the BRI/RCI care consultation model. The chapter reported providing services to 16 individuals during the period, spanning FY’15 through FY’17. Individual-level demographic information was not available for these care consultation services.

CONCLUSIONS AND RECOMMENDATIONS

The Alzheimer's Association annual facts and figures document (2015/ baseline) estimated a total of 41,000 people in Nevada living with dementia. Given assumptions built on national data regarding diagnosis rates and residential care status, of the 41,000 people estimated to have dementia in Nevada, we estimate 13,667 would be eligible to access community-based services (meaning they have received a diagnosis and have not transitioned into residential care community). For annual reach calculations, we use the baseline estimate of eligible program participants as a comparison/target. Thus, *given the data reported* by the program partners for the reach of all available Alzheimer's-specific care and support programs, the total reach of this initiative for each of the three years are as follows: FY'15 – 5728 (41%); FY'16 – 510 (4%); and FY'17 – 2882 (21%). In addition, 233 participants, both people living with dementia and caregivers, were reported to have received services during the 3-year period, without annual data provided. Thus the total (duplicated) number of program participants reported by program partners during the initiative is 6353. Obviously, there are very large gaps in the data that was received by the evaluator from the program partners, particularly the FY'16 and FY'17 data from the Alzheimer's Association. There are also several significant limitations in calculating the "reach" of these programs, notably: 1) the assumptions made in calculating the target population size at 13,667; 2) the potential for duplication of individuals served by multiple programs *within* each year; and 3) the inconsistency in the data received. However, these data do show that there is a very active Alzheimer's program delivery system in the state of Nevada and that the energy and emphasis on building a truly dementia capable system in the state is continuing.

The total number of providers reporting providing services to individuals living with dementia decreased from FY'16 to FY'17. Despite this decrease in the number of providers, it is estimated that 2,882 people living with dementia and/or their caregivers received community-based (non-residential) care and support services during FY’17 through some organization funded by ADSD. These providers help ensure that individuals living with dementia can remain in their community longer, delaying expensive residential care as well as increasing their overall quality of life. It is important both to increase the ability of current service providers to serve this population as well as to increase the number of providers offering help to community dwelling elders with dementia.

One of the state’s most robust service providers for individuals who have been diagnosed with Alzheimer’s disease or a related dementia, as well as their care partners, remains the Alzheimer’s Association. Data was supplied from both the Northern and Southern chapters. While data was not received from the Southern Nevada chapter, the Northern Nevada chapter reported serving approximately 2,492 individuals during FY’17 through its core services. Of specific interest, the Northern chapter indicated that approximately 50% (n = 1,240) of individuals received some form of information/referral service. An additional 34% (n = 842) received some form of general education or training regarding individuals who have been diagnosed with ADRD, with the remaining 15% (n = 369) receiving supportive services such as support groups. These services can significantly increase the ability of individuals with dementia to remain in their communities longer. Additionally, these services can help care partners deal with the increased burden associated with caring for individuals with dementia, and help them maintain their own quality of life.

Nevada Senior Services also provided caregiver support in the form of care consultations to 95 caregivers during the 3-year period. These consultations provided caregivers the opportunity to have their concerns addressed, while maintaining a single point of contact for services. This is important as it may help to reduce caregiver burden.

Recommendations from the Independent Evaluator

1) There is a need for much more robust data collection systems across all community-based provider organizations throughout Nevada. It is the evaluator's recommendation that ADSD work with SCA and other partners to identify the specific metrics to be collected by each program or service, with a standardized packet of evaluation tools made available to all providers, whether or not they are funded by ADSD. These tools should include at a minimum: 1) Unduplicated number of clients served (with both people living with dementia and caregivers distinctly reported); 2) Consistent demographic data, including severity of dementia, for all program participants; 3) Quality of life, using a consistent standardized measure across all programs administered in a pre-post fashion as appropriate to the program delivery model; and 4) Program satisfaction, using a consistent measure across all programs.
2) It is essential to increase the availability of both general and evidence-based programs and services statewide, with particular focus on reaching rural communities. The more available and accessible programs are to people living with dementia and their caregivers, the higher the reach of these programs will be in penetrating the communities and families that need them most.
3) Wide-spread awareness-raising campaigns are needed to increase the public's knowledge regarding available programs. These campaigns should target all areas of the state, but remain mindful of gaps in service in certain rural communities. In addition, these campaigns should link potential program participants with Nevada 211 for real-time, up-to-date information on program delivery in each community, with appropriate training to

211 staff to ensure accurate and meaningful information is provided.

4) It is important to increase efforts to promote early detection of Alzheimer’s to help individuals and families recognize their personal need to access the services that are made available. These early detection efforts should also include provider outreach and education to ensure that the professional-quality screening and diagnosis are available to all Nevadans, with opportunities for telemedicine diagnostics made available for rural communities.

Appendix A: Full EPIC report from Dr. David Coon

PIC: Early-stage Partners in Care
A Group Dyadic Intervention Embedded into the Community

PROJECT PARTNERS

EPIC (Early-stage Partners in Care) Project, funded by the Administration for Community Living, Administration on Aging, was a collaboration among the Aging and Disability Services Division of the Nevada Department of Health and Human Services, the Southern Nevada Regional Office of the Desert Southwest Chapter of the Alzheimer's Association, the Northern Nevada Regional Office of the Northern California/Northern Nevada Chapter of the Alzheimer's Association, and Arizona State University.

State Unit on Aging: Jeff S. Doucet, Nevada Department of Health and Human Services, Aging and Disability Services Division, served as the Project Director. ADSD was the fiscal agent for the project and responsible for its overall management, including preparing and submitting required budgetary and programmatic reports, managing project timelines, monitoring progress, documenting outcomes, and monitoring collaboration with key partners. Project management entailed the close coordination of activities between the ADSD and its partners.

Arizona State University: Dr. David W. Coon, Professor in the College of Nursing & Health Innovation Arizona State University (ASU), has extensive work developing, implementing, and evaluating both individual and group evidence-based interventions (e.g., Coping with Caregiving and REACH II), and he directs the Aging & Behavioral Health Projects lab. In the original EPIC project funded through an Innovation grant from the U.S. Administration on Aging, Dr. Coon worked closely with Dr. Carol Whitlatch of The Benjamin Rose Institute on Aging. He adapted several components of her in-home intervention with individual dyads (i.e., SHARE) and infused additional elements to create the EPIC group intervention. In the current project, Dr. Coon trained and supervised Chapter staff, worked with the Chapters in their selection of a user-friendly evaluation tool and related outcomes, and monitored EPIC's treatment fidelity across the project.

Alzheimer's Association Chapters - Southern Nevada Region of the Desert Southwest Chapter (AA-SNV) and the Northern Nevada Region of the Northern California/Northern Nevada Chapter (AA-NNV): The Chapters provide personalized guidance and support to families struggling with dementia; raise the level of knowledge and skill of family members and community professionals who provide care; offer an array of programs designed to deliver accurate and comprehensive information about the disease; and, reach out to serve more of Nevada's affected populations through an increase of consistent and equitable services and support to diverse, multicultural and rural populations. As part of the current project, the Chapters agreed to: a) promote (i.e., provide outreach and recruitment), coordinate (i.e., conduct participant screening and provide workshop logistics), and deliver the EPIC intervention under Dr. Coon's supervision; b) collaborate with Dr. Coon in the identification and implementation of user-friendly evaluation tools for EPIC; c) collect demographic data required for the project; d) provide community education on early-stage issues identified for EPIC delivery, and, e) provide culturally-appropriate and effective companion-care consultation to client families to ensure continuity of care for those families in need of additional services.

EPIC INTERVENTION RATIONALE & UNDERPINNINGS

Rationale. Recent meta-analyses and reviews of the caregiver intervention literature (Coon, et al., 2012; Coon & Evans, 2009; Gallagher-Thompson & Coon, 2007) show that psychoeducational skill-building, psychotherapy (cognitive behavioral, in particular), and multicomponent interventions that combine skill training with respite or other activities are effective in alleviating distress and improving well-being, increasing caregivers' abilities to manage stress, and reducing the risk of health decline for AD caregivers. However, these and other interventions typically address the middle to late stages of ADRD

(Alzheimer's disease and related dementias), almost halfway through the CP's caregiving career, after CPs have clearly become "caregivers."

As noted in NAPA, the *National Plan to Address Alzheimer's Disease* (U.S. Department of Health & Human Services, 2017), identifying AD in the early stages creates advantages for early-stage patients/people (EPs) and their current or future care partners (CPs). For example, pharmacological treatments for dementia-related symptoms can be provided earlier to EPs; EPs can still participate fully in legal, financial, and care decision-making; and, both informal and formal support can be mobilized for current and future concerns (Gaugler et al., 2011; Gauthier, 2002). While the emphasis on early detection and treatment is growing, there has not been a corresponding emphasis on early psychosocial intervention that would address the EP's or CP's mental health and well-being at this stage of the disease. Moreover, interventions to date have usually focused solely on EPs, ignoring CPs and the opportunity for the EPs' voices to be heard by CPs regarding future treatment decisions and care options (Whitlatch, Feinberg, & Tucke, 2005b) Finally, much of the published work has notable limitations, including few well controlled trials; limited treatment fidelity procedures; small sample sizes; and, while, the one published randomized trial that involved groups of EPs and CPs did produce some positive EP outcomes (e.g., increased quality of life and reductions in depressive symptoms), no statistically significant CP outcomes emerged (Logsdon et al., 2010).

The original EPIC project, funded by a U.S. Administration on Aging Innovation grant, adapted and enhanced a seven-session in-home intervention with individual EP-CP dyads developed by Dr. Carol Whitlatch into a group dyadic intervention for multiple participating dyads. Whitlatch's intervention (SHARE; originally named EDDI) (Whitlatch et al., 2006) was recently tested through an RCT also funded by the U.S. Administration on Aging. SHARE dyads when compared to those in a control condition more successfully constructed a balanced care plan, increased their use of services, and exhibited decreases in dyadic emotional disruptions (Orsulic-Jeras, in press; Szabo et al., 2016; Whitlatch et al., in press).

EPIC's theoretical underpinnings. EPIC is based on several complementary theoretical perspectives. First, it draws from the Stress Process Model (Aneshensel et al., 1995; Menne and Whitlatch, 2007; Pearlin et al., 1990; Zarit & Zarit, 2007), which identifies how stressors can proliferate to erode health and well-being, but also how they can be contained to offer protection from these effects. Second, the treatment draws upon community developmental prevention models (Coie et al., 1993) that take a "stress inoculation" approach, preparing people with knowledge, skills, and resources for managing problems now and in the future. Third, the treatment draws upon an extensive body of literature on treatment of relationships and families (see Zarit & Zarit, 2007, for a review). Finally, several key skill-training components and related strategies are derived from cognitive behavioral theory adapted for caregivers (Belle et al., 2006; Coon et al., 2005; Coon et al., 2003; Gallagher-Thompson et al., 2003).

Overarching approaches and proposed outcomes. These underpinnings help formulate several overarching approaches to the EPIC intervention. **Education** about dementia has been a basic component of psychosocial interventions for care partners from the beginning of interest in this area (Bourgeois, Schulz, & Burgio, 1996; Coon, Ory, & Schulz, 2003; Gallagher-Thompson & Coon, 2007). In a sense, information is a critical component of the foundation on which interventions are based. **Support** is a key component of many effective interventions, and feedback through community forums, research and clinical literature, and participant panels suggests that individuals with early stage and their care partners feel isolated and have a genuine desire to connect with others in their situation. However, evidence indicates that information and support alone is typically not enough. People need to develop skills to help them identify and effectively manage the changes and related concerns that come along with memory loss. **Skill training** solidifies the foundation of effective interventions (Coon & Evans, 2009; Coon et al., 2012; Gallagher-Thompson & Coon, 2007). For example, EPIC tailored for early-stage dyads several evidence-based behavior change strategies (e.g., relaxation skills, communication skills, pleasant-activity scheduling) shown to be effective in reducing stress and distress with later-stage caregivers and other midlife and older adults (Belle et al., 2006; Coon et al., 2005; Coon et al., 2003; Gallagher-Thompson et al., 2003; Scogin & Shah, 2012). Therefore, EPIC combines education and skill training in a supportive environment to help care partners with changes that occur across the care continuum. Finally, EPIC ties these theoretical underpinnings, treatment approaches, and intervention strategies to key proximal and distal outcomes (e.g., the reduction of distress, improvement in communication, and enhancement of quality of life indicators for both EPs and CPs). EPIC hoped to extend and enhance SHARE findings through its group dyadic mode of delivery. It was designed to enhance the dyad's current well-being and quality of life, and prevent the accumulation of caregiver burden and the downward cycle of deterioration observed among many care partners. EPIC's innovation lies in the opportunity for EPs to articulate their values and preferences for care and become active decision makers with their CPs**.** EPIC also helps CPs build an arsenal of skills to draw upon throughout their caregiving careers, becoming effective managers of care stressors, learning what types of assistance and support to look for, where to look for support, and that supports can make a difference.

Group dyadic intervention. EPIC's group format was developed based on the project partners' clinical experience, advocacy by EP-CP dyads for group activities to reduce isolation, and the potential to reduce staff time and costs associated with more intensive in-home, individualized interventions. Its group model also builds on lessons learned from other early-stage group activities in the literature (Gaugler et al., 2011; Logsdon et al., 2010; Roberts & Silverio, 2009). EPIC not only capitalizes on SHARE's protocol suggesting that dyads engaged in structured discussions about future care preferences report more positive outcomes (Whitlatch et al., 2005b; Whitlatch et al., 2006, but it also addresses the critical need voiced by EPs and CPs for group interactions to reduce isolation and connect with others facing early-stage issues.). EPIC's group format is also likely to be more cost effective than interventions that are in-home dyadic or CP-only, by reducing staffing and other costs.

EPIC INTERVENTION & ITS GOALS

EPIC consists of seven sessions that include both members of the care dyad. Dyads meet with other care dyads as a group and with their peers separately (i.e., CPs meet together, and EPs meet together). There is also one in-home session (Session 3) for each dyad that is conducted by one of the EPIC group leaders. The goals of the dyadic group intervention are to:

1. **Involve early-stage persons and their family care partners in a group dyadic intervention.** A fundamental objective is to involve both the EP and the CP in the intervention process. This is a primary innovation of the group dyadic intervention and is based on the evidence that EPs can state valid responses and express preferences for care decisions and future planning (Feinberg, & Whitlatch, 2002; Reamy, Kim, Zarit, & Whitlatch, 2011; Whitlatch, & Feinberg, 2003; Whitlatch, Feinberg, & Tucke, 2005a; Whitlatch et al., 2005b; Whitlatch et al., 2006).

2. **Increase the dyad's current knowledge and understanding about the dementia diagnosis and available services.** Dyads with more accurate knowledge about dementia can better understand the purpose and application of strategies and resources that are introduced in the sessions as well as why they may be having difficulty in communicating with each other.

3. **Improve communication skills and support between the EP and CP.** Many of the primary stressors in early- to mid-stage dementia revolve around communication difficulties that arise due to the EP's increasing difficulty in using and understanding language. By understanding these changes and utilizing strategies that minimize the impact of dementia-related deficits in communication, both can communicate more effectively in a patient and caring manner.

4. **Develop a mutually agreed long-term plan for care that balances the EP's values and preferences with the care partner's needs and ability to provide care.** Specifically, the plan needs to include options for outside help from informal and/or formal providers if the CP becomes overwhelmed with care demands. The program engages the CP and EP in a discussion of goals, care preferences, and values that leads to the development of a joint plan for future care. In this way, EPs gain a voice in planning their own care and articulating values and preferences that will guide future care decisions. Care partners will know what kind of help to seek, where to look for help and support, and get help that is consistent with their EPs' values and preferences, even into the future when their EPs become unable to engage in a rational discussion of choices and alternatives as a result of their disease progression.

5. **Build the dyad's skills and knowledge about strategies for maintaining health, leisure, and self-care. As the EP's disease progresses, health, leisure, and self-care behaviors become especially important for supporting health and well-being.** Early-stage persons may no longer initiate or sustain activities on their own, and the growing care demands may make it difficult for CPs to find time for activities. Developing a mutual plan will empower CPs to engage their EP in appropriate leisure and health-promoting activities as well as help themselves engage in better self-care behavior. This goal is a key outcome as CPs who maintain social and leisure activities will have a buffer against the buildup of care-related pressures and stress, while EPs who maintain higher activity levels may be able to function at a higher level and have fewer behavior problems

6. **Enhance self-efficacy among care partners regarding dementia-related problems and increase feelings of control among early-stage persons.** Self-efficacy may play a pivotal role in the proposed intervention by bolstering the CP's belief that there are possible solutions to dementia-related problems that they can access through a variety of strategies. Self-efficacy may be the key to preventing the care situation from unraveling, and for helping care partners avoid the cascade of negative reactions and emotions that can immobilize them, even when possible solutions are available. Empowering EPs in the planning process may also increase their feelings of control over what will happen to them.

7. **Improve the CP's and EP's well-being and quality of life.** The ultimate result of the program is not only the containment of stressors identified in the Stress Process Model, but also inoculation against future stressors that could affect the dyad's well-being. By addressing these care-related stressors, enhancing communication, providing support, and promoting well-being and quality of life, a process is initiated for maintaining health over the long-term.

The EPIC Leader manual describes each session, including the session's major goals and objectives, and the method for reaching those objectives. Leader manuals are used in conjunction with the Leader Self-evaluation/session notes, which serve as case notes for each group and their dyads. The Leader Self-Evaluation/Session notes are designed to capture any relevant information obtained during the sessions. EPs and CPs were provided their own manuals in a 3-ring binder format (each CP and each EP received a manual). However, the material for each session was provided and added to the binder at the beginning of that particular session. The basic structure of the sessions is as follows:

- Review of Last Workshop and Today's Session (Agenda)
- Relaxation Practice (Mindful Breath)
- Review of Home Practice
- Today's Session Material
- Break
- More of Today's Session Material
- Relaxation Practice
- Summary of Workshop and Review of Take Home Messages
- Home Practice Assignment

The 7 EPIC sessions are organized in two ways. **Together sessions** involve the EPIC Group leaders, all CPs, and all EPs meeting together for the entire time. **Mixed format sessions** begin and end with everyone meeting together, but include time for the EP group and CP group to each meet separately with one of the EPIC Group leaders. This format makes it possible for EPs and CPs to share information with group leaders and peers that they would be reluctant to bring up with their EP or CP partners present. Leaders often work with that person to find constructive ways of bringing that information forward at a later time. The mixed format sessions also allow each person to be more honest in expressing values and preferences, which is a key part of the intervention. In **the individual session 3**, dyads meet separately in their homes or other confidential location with one of the EPIC group leaders.

Each EPIC session is structured in a similar way, starting with the dyad together and reviewing the goals of the session (**opening phase**). During the group sessions (Sessions 1, 2, 4-7), all CPs and EPs also meet together for 20 minutes over a break to socialize with other EPIC group members; group activities afford this opportunity as well. During group and individual sessions, the **middle phase** is a time when the CP and EP continue to meet together or meet separately with the EPIC Group leader to engage in session specific material. All sessions end with the **final phase** where everyone comes together again to review material discussed in the session, answer questions, and preview the upcoming session.

THE ORIGINAL EPIC PROJECT

EPIC was the first manualized group dyadic intervention delivered with sound treatment fidelity procedures that demonstrated positive impact on proximal and distal outcomes for both EPs and CPs. It was embedded into the community from its inception and delivered by community partners, thereby helping to foster its sustainability.

Program eligibility. EPIC is designed for care dyads in the early stages of a dementing illness. Still, there are some limitations to who can benefit from the program. For example, care partners whose early stage participant resides in an institutional setting (including an assisted living setting) would not benefit as the intervention focuses on those who are both community-dwelling. In the original project, ASU screeners were responsible for determining participant eligibility. *Early-stage dyads needed to have awareness of their EP's diagnosis and/or current problems. EPIC is not designed to convince dyads that their EPs have memory loss. Those who have no awareness or who make strong, consistent denials can be counterproductive to group processes; are unlikely to benefit from the intervention; and, should not be enrolled* (Whitlatch et al., 2006; Zarit et al., 2004). The original project's telephone screen included structured and open-ended questions asked separately of the EP and the CP. Absolute concordance between EPs and CPs is not expected; rather, responses give a picture of the level of impairment, awareness and understanding of the loss, and willingness to participate. Early-stage dementia: *Three sources of information* were reviewed to help identify early-stage dementia: the dyad's awareness of AD/memory loss and related symptoms, a diagnosis of dementia, and symptoms consistent with an AD diagnosis (Coon & Whitlatch, under review; Whitlatch et al., 2006; Zarit et al., 2004). However, a diagnosis was not required for inclusion. Screening questions included basic demographics, information about if and when the diagnosis was made, and the AD8 (Galvin, Roe, Coats, & Morris, 2007; Galvin et al., 2005) where EPs needed to exhibit at least 2 of 8 AD8 changes on thinking and memory problems. As the final step in the screening process, interviewers conducted the Mini-Mental State Examination [MMSE] (Folstein, Folstein, & McHugh, 1975) at the initial in-home assessment, to determine if EPs had symptoms consistent with early-stage dementia. Care partners. Care partners needed to self-identify as the person who currently had the most hands-on responsibility and involvement with the person with dementia; or, who expected to have that responsibility in the future. CPs had to either live with the EP or have regular (weekly or more often) contact with him/her. Eligible CP-EP relationships included spouse and other family relationships and close friends.

In the original project, 9 groups enrolling 42 EP-CP dyads (84 participants) were conducted urban, suburban, and rural catchment areas. Group enrollments ranged in size from 4 to 7 dyads. Co-leaders from the Desert Southwest Chapter of the Alzheimer's Association, trained and supervised by Dr. Coon, delivered the intervention. ASU interviewers conducted pre- and post-intervention in-home assessments for the dyads with the EP assessment being interviewer-administered and CP assessments being self-administered.

Sample characteristics: The original project's 42 EP-CP dyads included 40 spouse/ partner dyads (95.2%) and 2 parent/adult child dyads (4.8%), with the vast majority living in urban or suburban settings (88.1%) and self-identifying as non-Hispanic white (94%). With regard to EPs, 95.2% were age 60 or older; 59.5% were men; and, 40.5% were veterans. In contrast, 85.7% of CPs were age 60 and older; and 38.1% were men and only 19.5% held veteran status.

Key findings: EPIC participants in the original project showed significant improvement on numerous proximal (secondary) and distal (primary) outcomes, providing initial evidence of its efficacy in terms of statistical significance (all *p's* < .05) and a range of respectable effect sizes (*d's* from .31 to .83).. Examples of *improved* *proximal outcomes* include: (1) for both EPs and CPs: care preparedness; (2) for EPs: self-esteem; positive interactions with CP and negative interactions with CP ; (3) for CPs: negative interactions with EP; knowledge of available services; knowledge of EP's daily care preferences; knowledge of EP's long-term care wishes; and problem solving self-efficacy. Examples of *improved* *distal outcomes* include: (1) for EPs: positive affect; depressive symptoms; anger/hostility; other negative affect; and overall quality of life; (2) for CPs: depressed affect; and, other negative affect. In terms of feasibility and acceptability, over 90% of EPs and CPs said EPIC improved their understanding of memory loss and its effects, increased confidence in dealing with memory problems and making key decisions reflecting values and preferences, made their lives easier, and enhanced their ability to care for each other. Well over 90% of both EPs and CPs reported the quality of material covered, the usefulness of the material covered, and the quality of the discussion in the EPIC sessions were "good" (the highest rating; ratings options are *poor, fair, good*).

THE CURRENT EPIC PROJECT

Purpose & Goals. The current project helped continue to translate into the community a successfully adapted, revised, and enhanced early-stage dyadic intervention originally delivered to individual dyads in their homes into a group based dyadic intervention offered at convenient locations in the community. In addition, the project developed a user-friendly evaluation tool for EPIC that would be acceptable to the two partnering Chapters of the Alzheimer's Association as well as to EPIC participants, both the early-stage partner (EP) and their care partner (CP).

Evaluation tool. Dr. Coon worked with Chapter staff and leadership, leading discussions and providing suggestions of empirically based evaluation tools and individual questions drawn from EPIC and other early-stage projects. Three key factors drove the Chapters' decision in the selection of an evaluation tool for EPIC participants. It needed to: 1) be user-friendly for Chapter staff and acceptable to Chapter leadership, including the National Association; 2) contain the same questions for both CPs and EPs and be acceptable to both; and, 3) be acceptable to both AA-NNV and AA-SNV (as well as the entire Desert Southwest Chapter). The Chapters ultimately selected the 4 likert-scale questions and 3 open-ended questions that were used as part of EPIC's original delivery and process evaluation. The four likert-scale questions ask CPs and EPs to separately and anonymously rate as *good, fair,* or *poor* the following at each EPIC session: 1) the quality of the material covered; 2) the usefulness of the material covered; 3) the quality of the discussion; and, 4) if the overall goals were met. The three open-ended questions asked: 1) what did you like most about the session?; 2) what suggestions do you have to improve the session?; and, 3) what additional comments or concerns do you have about this session?

Staffing. Each EPIC group requires 2 Group Co-leaders, since EPs and CPs often meet for activities in separate groups led by one of the trained facilitators. All EPIC group leaders held at least an undergraduate degree and some held a Master's degree. Experience with older adults and working with EPs and/or CPs, attention to detail combined, excellent interpersonal skills and the ability to quickly establish rapport is necessary. These interpersonal skills need to be transferable between phone work and intervention sessions. The ability to adhere to an intervention protocol while communicating naturally with participants is also required. Experience in behavior change management is highly desired. For the current EPIC project, the group leaders were drawn from AA-SNV and AA-NNV staff. Current project experience suggests that it might be best to have one of the group's co-leaders screen the group's dyads.

Training and supervision. Initial training held in Las Vegas for both AA-SNV and AA-NNV included 8 total hours of instruction and role play: 5 hours were a face-to-face meeting with Dr. Coon, and the remaining 3 hours consisted of 2 separate 1.5 hour telephone training sessions. The telephone sessions helped to reduce travel costs for staff. In addition to the initial training, Dr. Coon conducted regular telephone supervision with co-leaders as they implemented their initial EPIC group series. As part of the project's treatment fidelity procedures to foster adherence to the EPIC protocol, Dr. Coon subsequently held monthly and ad hoc supervision sessions thereafter depending upon the timing of EPIC waves in each region. EPs and CPs filled out weekly session ratings anonymously and group leaders filled out weekly evaluations monitoring their own questions, concerns, areas for improvement/input and successes. Reviewed and discussed as part of the supervision process, these forms were not shared with supervisors. Rather, they were discussed in general to help keep supervision a collaborative activity focused on staff skill-development and EPIC delivery enhancement. All of these supervision activities are critical depending upon staff members' education, training, and relevant work experience prior to EPIC. The staff in health and human services settings are often trained in case management with limited behavior change and group facilitation experiences. Their individual and group education and information and referral skills may be strong; however, implementation and facilitation of behavior change strategies in individual, dyadic, and group settings may be less developed and require both initial training as well as ongoing supervision.

Another round of formal face-to-face and telephone trainings occurred between February and June of 2017, driven by: (a) the need to train a number of new staff including two new regional directors at both Chapters; (b) the opportunity to review lessons learned from delivery of the current project; (c) the importance of reinforcing EPIC's critical elements and avoiding protocol drift; (d) the chance to gather staff feedback on modifications to EPIC intervention delivery; and, (e) the need to present differences between the current project and a forthcoming National Institute on Aging-funded randomized clinical trial designed to further investigate EPIC effectiveness as delivered by the Chapters. Ten different NNV and SNV staff attended the trainings including regional directors, family care consultants, family care associates, Latino outreach coordinators, and community resource managers. Another 3 staff completed trainings after the close of this funded project, due to scheduling conflicts. Lessons learned (highlighted at the end of this report) helped to revise EPIC group leader, EP, and CP manuals for ongoing delivery of EPIC. Finally, feedback from group leaders and other staff is consistently positive regarding EPIC's impact on EP-CP dyads. Both regions reported EPIC participants want graduation groups or some type of ongoing activity to stay connected with others going through early-stage issues.

Recruitment & Screening. A key challenge for early-stage projects is the identification and recruitment of early-stage individuals. There remains a fundamental lack of understanding of what constitutes "early-stage" as some providers and care partners refer EPs that are further along in the disease progression. In addition, many families remain isolated when health care providers rely solely on pharmacological interventions instead of recommending psychosocial interventions. Research continues to demonstrate that ethnic and racial minority families often enter the service arena and receive diagnoses much later in the disease process (Cooper, Tandy, Balamurali, & Livingston, 2011), highlighting the need for additional outreach and education in these communities to help dispel myths about ADRD and to increase access to early-stage programs to meet the needs of these populations. During the current project, EPIC was offered only in English, creating barriers for some Latino/Hispanic EPs and CPs.

All of the EPIC partners remain committed to the need for outreach to health care and human services providers to increase awareness of the needs of early-stage dyads and their families. Concerted efforts were made in developing relationships with physicians and other health providers and their organizations; this seemed to gather momentum when the National Alzheimer's Association emphasized such activities. Partners also continued to recruit through traditional venues such as presentations at local caregiver and professional education conferences, health and other community fairs, invited speaking engagements to provide overview of their programs and services, and posting EPIC information on Chapter websites. In project teleconferences, the idea of testimonials from EPIC graduates via print and/or other media emerged several times to help bolster awareness, recruitment, and enrollment. However, these and related ideas did not move forward.

Chapter staff continued to use the EPIC screen from the original project; however, there appeared to be some inconsistency in its use as staff and leaders turned over in the two regions. Key lessons learned from screening by ASU personnel in the original project did reemerge during this translation project. Some EPIC participants were screened out as inappropriate because they or their care partners were in denial about their EPs' early-stage diagnoses. While memory problems are to be expected during phone screening, Chapter screeners needed to learn to watch for memory challenges that would preclude EPIC workshop participation, such as: forgetting why he/she is doing the screen; consistent inappropriate answers to questions or refusal to answer questions; consistent confusion or responses of "I don't know" during the screen; consistently asking their care partner or someone else for the answer to questions; misdirected anger or frustration; heightened anger or anxiety during the screen; tangential or unrelated responses; inability to focus; consistent answers that dramatically diverge from their care partner's responses. The ultimate decision regarding appropriate fit was in part intuitive. While the screen includes exclusions (e.g., neither partner can be in denial about the EP's memory loss), a good deal also rests on the EPs attitude and affect during the screen and the amount of inconsistent responses from the EP including the amount of mismatches with the CP. Chapter staff began to recognize that EPs and CPs may not be in denial about the EP's memory loss but rather lack an understanding of the EP's level of impairment. As a result, some of these dyads were appropriate, while others were not, based on their level of impairment. Ultimately, the Chapter screener has to learn to make judgments (sometimes in consultation with colleagues) about whether or not the EP would benefit from the program and be a good fit in a group environment. The Desert Southwest Chapter of the Alzheimer's Association developed a Program Guide to help with these decisions and guide the overall delivery of EPIC.

Enrollment & sample characteristics. In the current project, the number of dyads enrolled were quite low per group, reflecting the difficulty the Chapters reported in recruiting dyads. The AA-SNV delivered 7 EPIC groups enrolling 21 dyads (42 participating EPs and CPs combined) with 18 dyads (36 participants) completing the series (85.7% completers). Completers attended at least 5 of 7 sessions. In terms of sociodemographic characteristics, the majority of EP participants were non-Hispanic whites (81%), and the remainder self-identified as Black/African American (5%) and Hispanic/Latino (14%). Almost all were over age 60 (90%), who did not live alone (100%); and lived in urban settings (100%). Most were spouses of CP participants (61.9%) and male (52%). CP participants described themselves as non-Hispanic white (71%), Black or African American (5%); Hispanic or Latino (5%), Asian (5%), two or more or other race (10%), and, unknown (5%). CPs were urban dwellers (100%) and mostly female (76%) and over 60 (61.9%). Military status was reported as missing for all participants.

The AA-NNV conducted 3 EPIC groups enrolling 9 dyads and 1 triad involving 2 CPs (21 participating EPs and CPs combined) with all participants completing the program. With regard to EP participants, all were non-Hispanic whites (100%), over age 60 (100%), who did not live alone (100%). The majority described themselves as spouses of CP participants (90%), lived in urban settings (90%); and were female (60%). The majority of CPs described themselves as non-Hispanic white (100%); urban (82%); female (55%); and under 60 (55%). Military status was reported as missing for all participants.

Findings. The evaluation tool (described above) gathered after each EPIC session included 4 quantitative ratings (of ***poor, fair, good***) and 3 qualitative questions/comments. In sum, ratings by both EPs and CPs were very high suggesting high levels of perceived benefit and satisfaction with the EPIC program's material, its usefulness, its goals, and the delivery of the program. While both Chapters agreed to implement the EPIC evaluation tool, the AA-NNV Region was most successful in managing the process and provided evaluation tools for each of their EPIC groups. Unfortunately, changes in leadership and the acquisition of a new database in the AA-SNV Region created challenges in tracking some of the evaluation tools that were collected across groups, and only data for 2017 was available for this report. Findings are reported for each region below, and were similar to ratings on this tool reported under *Key Findings* in the *The Original EPIC Project* section of this report.

AA-SNV Region. Evaluation ratings for both CPs and EPs were extraordinarily high. This is likely due to evaluations being limited to three small groups in 2017. Of the quantitative responses received, 100% of EPs and CPs rated all of the evaluation tool's items as "good" (the highest rating on the tool). These items included quality of material; usefulness of material; quality of the discussion; and overall goals being met. In terms of the open-ended questions, EPs and CPs reported that they most liked the group activity and interaction, as well as the opportunity to talk "about the issues and tactics the other caregivers used"; that EPIC provided the stage for the dyad to talk to one another about "expectations" and "planning for the future"; and were reminded "to make time to for nice things to do together". Overall, EPIC "created a wonderful and caring experience for everyone."

AA-NNV Region. *EP participants* in the AA-NNV region rated Session 7 the highest with 97.5% rating it as "good" (the highest) on all of the evaluation tool's parameters (quality of material; usefulness of material; quality of the discussion; and overall goals being met). Session 7's rating was followed by Session 5 (97% rated as "good") and Session 4 (94.9% as "good"). After each session, an overwhelming majority of EPs rated all items as "good": Session 1 (87.2% of EPs); Session 2 (92.3%); Session 3 (93%); and Session 6 (92.3%). Across all seven sessions, EP ratings indicated very positive views of the quality of the material covered (100% as good); usefulness of the material covered (93.8%); quality of the discussion (89%); and that the overall goals of the workshop were met (90.6%). *CP participants*, in contrast, rated Sessions 2, 6, and 7 the highest with 100% of CPs rating them as "good" on all items. In addition, the vast majority CPs rated all items as “good” after each session: Session 1 (93% of CPs); Session 3 (96%); Session 4 (95.2%); and Session 5 (98%). Item responses by CPs across sessions showed high ratings in the quality of the material covered (94.5% as good); usefulness of the material covered (97.3%); quality of the discussion (98.6%); and the overall goals of the workshop were met (100%). Only two “poor” ratings were received across all sessions. These two responses appeared in Session 4 with the care partner commenting that he/she did not see how relaxation or identifying and implementing pleasant activities would help provide care. Findings from the open-ended questions on the evaluation tool were similar to those from the AA-SNV participants: EPIC “Saved our lives”; “finding and being with others in the same boat” was so helpful; “Love the support and the members of the group”; “Very important in not feeling alone on this journey.”; “I'm enjoying sharing with others who understand & are going through the same things”; “These workshops help me plan for the future care and relieve the stress and worry that I was experiencing”; “Wonderful program - informative on a level that was easy to understand, share and discuss.”; “This has been wonderful. It occurred to me that I have a new focused strength to help me through this journey.” “I feel more confident about the future in my ability to cope”. In sum, I liked “Everything. You're the gift of life.”

Next Steps. The Desert Southwest Chapter of the Alzheimer’s Association (which includes AA-SNV) and the AA-NNV, its leadership, and staff have been so pleased with EPIC and its impact on early-stage individuals and their families that EPIC has been adopted into the early-stage programming of the Chapters. However, the development, implementation, and evaluation of a full-blown randomized clinical trial are all important next steps to provide additional evidence of EPIC’s efficacy and effectiveness. The Chapters covering all of Nevada and Arizona agreed to be partners with Dr. Coon (PI) in a recently funded grant (an R01) from the National Institute on Aging to support a randomized clinical trial (RCT) of EPIC. This RCT extends EPIC community embeddedness through our CarePRO (Care Partners Reaching Out) partnerships developed under past US Administration on Aging ADSSP endeavors in both Arizona and Nevada. The project also takes an important step forward through a community advisory board and *promotora* network in both states to reach out to the Hispanic/Latino community to enroll these families earlier in the disease progression, to provide all components of the project in both Spanish and English, and make any necessary modifications to increase EPIC’s cultural responsiveness.

CONCLUSIONS & LESSONS LEARNED

The following are the significant conclusions that can be drawn from ongoing translation of EPIC into communities in Nevada:

1) Overall, the number of dyads enrolled in this EPIC project were quite low per group, reflecting the difficulty the Chapters reported in recruiting early-stage individuals and their care partners. Recruitment is challenging for the reasons already stated; this is particularly true for ethnic minority families who come for services later in the disease progression. Key issues remain regarding misunderstandings by community service providers and families of what constitutes the early stage. Success in the original EPIC project drew from community forums and educational events focused on changes in memory and the benefits of early intervention—these types of activities are encouraged for the future, especially those conducted in collaboration with well-known and trusted community partners.

2) The project partners discussed the idea of testimonials from EPIC graduates to be produced via print, audio, or video. It would be prudent to pool funding to provide these testimonials to promote success and foster early-stage intervention for both early-stage dyads as well as individuals living alone and who are at increased risk.

3) The partners should consider a return to use of the HIPPA-compliant fax referral system that Dr. Coon developed and has used in many projects. Optimization of this approach in future community translation lies in the implementation of the fax referral with the

Chapters strongest community partners and then selling this “product” as a useful process with new partners. This process permits dyads either in person or over the phone to give their contact information to providers/community professionals for release to project partners (e.g., AA-NNV or AA-SNV and ASU), thereby enabling partners to contact potential participants directly for EPIC.

4) EPIC’s group format is also likely to be more cost effective than interventions that are in-home dyadic or CP-only, by reducing staff time and other costs. However, this benefit is greatly reduced with very small EPIC groups.

5) The Chapters agreed on an evaluation tool that was (a) user-friendly for staff and acceptable to Chapter leadership; (b) contained the same questions for both CPs and EPs; and, 3) was acceptable to both Chapters. The questions included 4 likert-scale items and 3 open-ended questions/comments that were used as part of EPIC’s original delivery and process evaluation. The four quantitative questions ask EPs and CPs for feedback after each session on: 1) the quality of the material covered; 2) the usefulness of the material covered; 3) the quality of the discussion; and, 4) if the overall goals were met. The three open-ended questions asked: 1) what did you like most about the session?; 2) what suggestions do you have to improve the session?; and, 3) what additional comments or concerns do you have about this session? Ratings were highly positive (well over 90% of participants rated almost all items as “good”), as were participant responses to the open-ended questions.

6) Combined with the quality of life outcomes from the initial pilot and the low dropout rate of 10% across the two Chapter regions in the current project, the findings from the evaluation tool support EPIC’s ongoing delivery and provide additional evidence of its positive impact and acceptability. Additional evidence of the acceptability included some EPIC groups reporting to Chapter staff that they continued to meet on their own after the end of their EPIC series and some formed teams to participate in their local Walk to End Alzheimer’s™ sponsored by the Chapter. In addition, some dyads spontaneously shared their contact information with one another to stay connected.

7) Information was also gathered anonymously during supervision sessions from Chapter staff who reported extremely high levels of satisfaction and increasing confidence in delivering the intervention. They expressed that EPIC provided them an additional skill set applicable to other job roles and responsibilities, as well as an increased sense of self-efficacy in working with EPs, in particular, since the majority of staff had much less experience with EPs than CPs or caregivers. This skill set includes not only EPIC’s content, but also its group facilitation and behavior changes activities and strategies.

8) Detailed manuals for group leaders and separate manuals for both EP and CP participants help to support EPIC’s train-the-trainer approach and foster treatment fidelity for ongoing dissemination and translation of EPIC. However, training must reoccur periodically regardless due to ongoing staff changes and/or turnover. New methods of training (including online tools) are worthy of consideration. Feedback during the booster training of staff in Spring of 2017 fostered revision of the EPIC manuals (Leader, EP, and CP manuals) improving several delivery components for the future: streamlining Sessions 2 & 3 for ease of co-leader delivery; updating Mindful Breath to match CarePRO delivery for increased consistency across Chapter programs; additional examples of ways to engage friends, family, and providers in current and future care needs; and, strategies to strengthen home practice.

9) EPIC participants want graduation groups or some type of ongoing activity to stay connected with others going through early-stage issues; and, these could serve as boosters for maintenance of gains. Similarly, longer-term follow-up is needed to help determine the preventive aspects of EPIC for future EP-CP stressors in the shorter term and future caregiver distress in the long term. The new NIH trial (see below) adds boosters, but is limited in its long-term follow-up to only one year.

10) An RCT is an important next step; particularly an RCT that includes a sizeable proportion of ethnic minorities. The Alzheimer's Association Chapters in Nevada and Arizona will participate in the new National Institute on Aging (NIH) randomized clinical trial (Coon, PI) comparing EPIC with usual care and following participants for a longer period of time. In addition, a sizeable proportion of Latinos/Hispanics will be enrolled in the trial after having received additional feedback on EPIC's utility from the Latino community through focus groups with providers and family caregivers. EPIC still needs to be evaluated for other cultural groups.

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