

STATE OF NEVADA DEPARTMENT OF HEALTH AND HUMAN SERVICES AGING AND DISABILITY SERVICES DIVISION

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SEMI-ANNUAL PERFORMANCE REPORT COVER SHEET

1. Grant #: Award Number: 90AE0333/01 2. Project Title: **ADSSP Evidence Based Grant:** NevadaCare ADSSP 2009 Nevada Evidence-Base Grant **CarePRO** 3. Grantee Name & Address: **State Of Nevada - Aging and Disability Services Division (ADSD)** 3416 Goni Road Carson City, Nevada 89706 4. Telephone #: 702-486-3367 5. Project Period: 9/30/2009 - 9/29/2012 6. Reporting Period: 10/01/2011 - 3/31/2012Due 4/30/2012 Ending September 29th, 2012 7. Final Reporting Period: 8. Project Investigator/ Telephone Shirley Alloway, Resources Development Specialist 702-486-0852 9. Report Author Telephone #: Jeff Doucet, Management Analyst 702-486-3367 10. Date of Report: **April 30, 2012** 11. AoA Program Officer: Erin Long, Erin.Long@aoa.hhs.gov Patricia Yuen, Patricia. Yuen@alz.org 12. Grants Specialist:



Introduction:

Nevada was awarded the ADSSP Evidence-based grant called NevadaCare, funded through a cooperative agreement from the Administration on Aging, in September 2009. The purpose of this project is to translate an evidence-based caregiver intervention research program known as *Coping with Caregiving* (CWC) into a series of community-based caregiver psycho-educational group workshops and individual interventions known as CarePRO (Care Partners Reaching Out). The project is a collaboration between: the State of Nevada, Aging and Disability Services Division (ADSD); Cleveland Clinic Lou Ruvo Center for Brain Health (CCLRCBH); Arizona State University (ASU); Alzheimer's Association Northern CA / Northern NV Chapter (AA-NoNV); and the Alzheimer's Association Desert Southwest Chapter (AA-DSW).

During the first year of this project, NevadaCare partners established the required infrastructure and setup needed to implement the CarePRO demonstration which included: administration, program partner training, and process development. Funds were accepted and first-year appropriations were distributed to program partners. The required Institutional Review Board (IRB) procedures were set up and approvals were obtained from the Cleveland Clinic and Arizona State University. The NevadaCare project will continue to work with the required IRBs throughout the course of this project. Partners received training on their specific roles and how they fit into the larger role of the NevadaCare project. The first year of the project was devoted entirely to system and process development to ensure fidelity to CarePRO; no interventions were hosted during the first year of the project.

During the second year of the project (October 1, 2010-September 30, 2011), Nevada began providing the intervention into the community. A total of 71 participants completed the intervention, 41 in Northern Nevada and 30 in Southern Nevada, with six participants dropping out of the program. Nevada worked to expand the recruitment sampling in the second year and ensure community agencies had program related information to refer into the program.

This Semi-Annual report covers activities for the first six (6) months of the third year of the project and planned activities for the remainder of the project. During this reporting period (October 31, 2011 - March 31, 2012), partners continued delivering the intervention. It is anticipated that a total of 28 series or "waves" will be developed to meet the Nevada goal of serving 224 caregivers. However, follow up assessments for each participant are completed for 12 months after the last workshop to identify changes in the responses of the caregiver. This causes the project activities to extend beyond the project period. (see <u>Appendix B Nevada</u> CarePRO Participants Flow Chart).

Activities and Accomplishments

What did you accomplish during this reporting period and how did these
accomplishments help you reach your stated project goal(s) and objective(s)?
 Please note any significant project partners and their role in project activities.

During this reporting period, which represents the first half of the project's third year, a total of 61 caregivers completed the intervention (29 in Northern Nevada and 32 in Southern Nevada). The NevadaCare project continues recruiting, completing the pre and

post assessments, and delivering the CarePRO intervention. Coach calls from in-process waves and follow up assessment calls from finished waves continue. All program partners continue outreach efforts to enhance recruiting methods and expand recruitment into the program. CCLRCBH is working with its medical staff to actively refer into the program. Individuals recruited through referrals at the CCLRCBH are located all over the Las Vegas valley and will be integrated into the expanded wave structure.

A focus of the outreach plan this reporting period in Southern Nevada was to expand locations for organizations willing to host interventions and assist in specific recruiting. Six new sites were approved by the IRB in the communities of Henderson, Mesquite, Pahrump and Laughlin. A Pahrump (Nye County) intervention was held between December 2011 and February 2012 and a Henderson (Clark County) intervention was held between January 2012 and March 2012. Outreach and development continue to host and intervention in Laughlin, NV, but has been unsuccessful to date. The "promotora" concept continues to be pursued as a tool, in addition to other avenues, in rural communities to increase recruitment into CarePRO.

Nevada program partners met in Reno, NV in March to discuss strategy for the third year of the project and identify and resolve barriers to successful completion. Several key concepts were discussed including advertising, sustainability, and timeframe extensions for follow up assessments, and possibly even the intervention delivery. In addition, case specific decisions were discussed and a course of action chosen. A new interventionist is being trained at the AA-DSW with assistance from David Coon, Ph.D.

The IRB approved language continues to be utilized in flyers and other outreach activities. ADSD community partners continue to display the developed posters for use at senior facilities where populations with Alzheimer's disease are targeted. However, the most effective recruiting method for the program is through word of mouth and personal recommendations or referrals into the program. Currently, 117 individuals completed the intervention which is anticipated to increase the word of mouth referral in the various communities and through the caregiver network circles.

Outreach and Advertisement

The ADSD Health Promotion and Disease Prevention contractor continues work to secure partnerships and outreach for several discretionary grants including: Medicare Improvements for Patients and Provider's Act (MIPPA); the Chronic Disease Self Management Program (CDSMP); and ADSSP CarePRO. Currently, 22 trained volunteers attend various community events and workshops set up throughout Southern Nevada to assist in program outreach and recruitment into the program. In addition, volunteers are available at existing facilities to advocate for these programs. Activities completed during this reporting period had 18,106 attendees, which include: attending 41 Health Fairs, conducting 36 presentations, direct discussions with 35 agency directors; and the distribution of over 5200 flyers for ADSSP. The contractor and 24 volunteers promote and advocate for CarePRO and other ADSD programs beyond what a flyer can achieve, which will provide personal and passionate information to the target populations. This outreach will help promote the program and initiatives throughout the

community, even when the target population appropriate for the grant is not directly represented. Program partners are encouraged to work with the contractor as a tool to support outreach, marketing, presentations, and missions for the project.

CCLRCBH continues its outreach strategy utilizing volunteers to reach target populations. Volunteers present information at various forums in the community for several programs offered at the Clinic. CCLRCBH volunteers have completed almost 50 presentations and reached over 1,200 individuals since beginning the outreach program in June 2011. Some of the groups addressed include: Doolittle Senior Center, First Presbyterian Church Women's Group, Catholic Charities Senior Companion program, Las Vegas Rotary, Sun City Summerlin Community Association, Alpha Delta Kappa, Our Lady of Las Vegas Catholic Church and Southern Nevada Retired Teachers. CCLRCBH offers several supportive programs at its facility for both caregivers and care recipients with differing targeted populations. CCLRCBH even hosted a CDSMP workshop for caregivers at its Las Vegas facility. The resources at CCLRCBH, including the caregiver lending library, the medical staff, and the facility itself, are expected to help expand the recruitment for participants to CarePRO.

Southern Nevada Outreach Activities:

Type of Outreach	# Activities	# Contacts
Health Fairs	8	100
Contacts with Community Based Organizations	13	86
Presentations / Distribution at Education Sessions		
Direct Contact with DSW existing clients	58	168
Education Sessions/ Presentations	13	643
Earned Media (October 2011, ABC LV Channel 13 and Fox LV Channel 5;	10	90,500+
February 2012 Channel 2 TV Laughlin)		
TOTAL	202	1699

Northern Nevada Outreach Activities:

Type of Outreach	# Activities	# Contacts
Health Fairs		
Contacts with Community Based Organizations		
Presentations / Distribution at Education Sessions	43	623
Direct Contact with DSW existing clients	95	489
Education Sessions/ Presentations	43	623
Earned Media (Northern Nevada Newsletter)	2	12,000
TOTAL	202	1699

Other Activities

AA-DSW Chapter in Arizona was awarded a grant to translate CarePRO into Spanish.

Nevada is preparing to complete waves in Spanish but translation activities continue,
therefore the Spanish waves in Nevada are postponed from their initially anticipated roll
out.

AA-NoNV continues CarePRO activities and has 70 clients who have completed the intervention to date, of which 29 completed this reporting period. Activities continue to expand recruitment throughout the community. Challenges include staff time for the intervention. AA-NoNV is considering expansion to more rural areas in Nevada and is excited to conduct interventions in Spanish.

Southern Nevada - Respite was approved and provided for six participants this reporting period, for a total of 35.7 hours at a cost of \$816.

• A total of 202 coach calls, including post-wave follow-ups, were made during this reporting period, as follows:

• War	ve #1	l call/ completed	Wave #6	22 calls
• War	ve #2	3 calls/ completed	Wave #7	36 calls
• War	ve #3 2	2 calls/ completed	Wave #8	26 calls
• War	ve #4	10 calls	Wave #9	48 calls
• Way	ve #5 4	45 calls	• Wave #10	9 calls

Comments from participants during coach calls continue to be very positive overall. Mindful
breaths continue to be the favorite choice for stress reduction as stated by the majority of
participants. One participant declined to practice at home throughout the wave, stating that she
does not want to face Alzheimer's and recognizing her denial. There was limited success in
helping her overcome these barriers.

Northern Nevada - Respite was approved and provided for 13 participants during this reporting period, for a total of 196.5 hours at a cost of \$1508.00.

Action	
10 clients recruited for wave 5- began October 18th	
Coaching continued and CarePRO ended for 20 clients of Wave 1 and Wave 2	
Coaching for 10 clients in Wave 3	
Recruitment of 39 clients Waves 4, 5, 6, and 7.	
Teaching and coaching for 38 clients in Waves 4, 5, 6, and 7.	

2. What, if any, challenges did you face during this reporting period and what actions did you take to address these challenges? Please note in your response changes, if any, to your project goal(s), objective(s), or activities that were made as a result of challenges faced.

This project continuing challenges are recruitment, planning and program expansion, and communication. Many recruited individuals still come through the Alzheimer's Association care consultations and Alzheimer's Association outreach activities. However, efforts continue to expand the recruitment by all partners through specific strategies. ADSD staff are educated about program benefits and asked to refer their clients into the program. In addition, outreach activities for other projects also attempt to recruit for CarePRO when appropriate at various service provider agencies. Outreach

attempts are focused on flyers; presentations; direct referrals; visibility; and consumer interaction.

The main challenge with recruiting is to recruit the numbers of eligible and willing participants needed to meet the goals of the program. In addition, successful recruitment means getting a representative sample throughout the community of participants willing and able to complete the intervention and follow up assessments. Nevada's recruitment goal is to provide a wide base of recruitment for testing the CarePRO intervention across Chapters of the Alzheimer's Association, across Nevada, and across State borders.

Recruiting and retention difference still exist between Southern Nevada and Northern Nevada for most workshops. Recruitment in Southern Nevada is still an issue, despite the much larger population. To address the recruitment issues, Southern Nevada partners have expanded the locations for program workshops and enhanced public information on the project. The ADSD contractor also provides program information to various community entities to enhance referrals through numerous outlets, including: volunteers, health fairs, public events, community meetings, and direct consumer provider networks. A continuous action that has recently resulted in increased referrals is through medical staff at CCLRCBH. Individuals from the medical providers are actively being referred into the program.

Nevada continues having more success in recruitment in Northern Nevada with a sufficient number of participants recruited for each wave. Expansion of the recruitment beyond "low hanging fruit" is a still a continued priority throughout Nevada.

Continuing Challenges:

Recruitment- Despite significant outreach and modifying outreach paradigms,
 Nevada continues to have program recruitment challenges. An estimate of 5200
 CarePRO flyers were distributed to attendees at health fairs and other community events this reporting period. Nevada is still working to significantly expand recruitment throughout the community and hopes to improve outreach and recruitment though volunteers and program coordination with MIPPA and CDSMP.

Communication with directors of Adult Day Care facilities continue as a potential recruiting ground for the project. Many caregivers work full time and prefer to be stressed than commit two and a half hours a week for an intervention. Some prospective recruits attended the lunch and learn sessions at CCLRCBH and were content with self guided support and enhancement activities. Adult Day Care Centers are aware of the program and hopefully future eligible individuals will be interested in attending.

 Planning and Program Expansion – All program partners are actively referring into the program. The required set up for recruitment and referrals was accomplished based on the fidelity model. Efforts to expand the project to rural areas and Spanish speaking populations continue, though the results are limited. There must be sufficient eligible and willing individuals to conduct an intervention wave. Many rural activities do not elicit a response from enough participants for a wave and traveling to a more populous area where the intervention can be combined with other potential participants is often a deterrent. A wave was conducted in the rural town of Pahrump, Nevada in Nye County with six (6) entering and four (4) completing. The two participants who dropped out expressed interest in attending subsequent Pahrump workshops.

- Communication –Communication between program partners is an essential component of the intervention in coordinating available individuals for each workshop. Continuous and prompt communication is needed between partners for recruiting, screening, pre and post assessment, and the intervention, in order to conduct a successful workshop. A failure at any communication level can potential result in decreased attendance for the intervention.
- IRB Setup and Approval A continues activity is the approval of changes at the IRB. Timeframes associated with this process have been greatly reduced from the onset of this project. This psychosocial project requires specific IRB setup at both the Cleveland Clinic and Arizona State University for approval. Changes necessary for the CarePRO demonstration have been streamlined and partners work to have all needed changes submitted at one time. ASU and Cleveland

Clinic continue to communicate regularly and work closely to facilitate IRB updates. As required, all project staff have received CITI training (several hours of certified human subjects training) prior to working on the project.

- Retention Concerns Ensuring individuals attending each session complete the entire CarePRO demonstration is a continued concern but not a significant issue (11 dropped out of 128 entering to date 8.6%). To accomplish this, incentives were devised based on the experience obtained from the Arizona intervention to encourage completion for all sessions including the follow up assessment. Nevada has a high retention and follow-up rate for individuals attending the intervention. Nevada continues streamlining the process to ensure communication necessary for incentives disbursement to program participants after defined mile markers are completed.
- Projected Goals Nevada continually monitors outcomes to ensure target numbers are met. Due to the required follow up assessment and the delay in starting, Nevada is increasing efforts to ensure project goals are met. However, Nevada is attempting to accomplish in only two years what it had planned to complete in three years. In addition, a follow up assessment is required for a year after the last intervention.
- 3. How have the activities conducted during this project period helped you to achieve the measurable outcomes identified in your project proposal? Please

note in your response, information on evaluation outcome measures and systems development measures, as approved in your grant application and developed in conjunction with AoA and AoA-provided technical assistance.

All activities continue to help Nevada reach its defined goals. Modifying the outreach paradigm and continuing outreach activities is essential to informing the community about specific existing programs. Direct communication with potential participants and the developed interest in the community from completing the intervention is still a desired approach to recruitment. Utilizing the promotora outreach model strengthens the encouragement in targeted communities and helps recruitment. Volunteers provide a more lay level outreach approach which may be more accepted than previous outreach activities. Nevada does not have volunteers that have benefited from the intervention to help recruit into the program. However, due to the burdens of caregiving and other factors, program participants will probably not be the mouthpiece for recruitment for a while.

The delivery of the intervention continues with the coordination necessary to ensure the functioning of each wave, which includes: outreach; recruitment and retention; pre and post assessments and follow-up; and administrative requirements of the project. An additional essential service to support delivery of the intervention is availability of respite care service. The numbers of individuals progressing through the intervention and the follow-up assessments continues to increase. As these individuals finish the CarePRO intervention, decrease their stress levels and improve their lives, they will become much

stronger advocates for the program and perhaps eventually become promotoras in their communities.

4. What was produced during the reporting period and how have these products been disseminated? Products may include articles, issue briefs, fact sheets, newsletters, survey instruments, sponsored conferences and workshops, websites, audiovisuals, and other informational resources.

Products during this reporting period include: ADSD and Alzheimer's newsletter articles; workshops; Semi-Annual Report; and demographic data.

The newsletter is distributed to all ADSD grantees, approximately 200, in both Northern and Southern Nevada.

Appendix A CarePRO Flyers Samples (Statewide, Northern Nevada, Southern Nevada)

The flyers contain the approved wording for recruitment into CarePRO, which is approved by the Cleveland Clinic and the Arizona State University IRBs. The flyer updated and approved in May 2011.

CarePRO: Care Partners Reaching Out



Developing the Skills Needed to Care for Someone with Dementia or Memory Loss

- Are you a family caregiver residing in Nevada that helps care for someone with dementia or memory loss?
- Do you provide an average of 4 hours of care or supervision per day for that individual?
- Do you find caring for your loved one increasingly demanding of your time and energy?

If so, CarePRO may be able to help you. Through our free workshops, you will learn:

- About dementia and its impact
- > How to manage your frustration, irritation, and stress
- > How to communicate with your loved one
- How to take better care of your own health

For more information, please call: CarePRO Program to assist family caregivers

Alzheimer's Association 1-800-272-3900

- Northern Nevada Office 775-786-8061
- Southern Nevada Office 702-248-2770

Cleveland Clinic Lou Ruvo Center for Brain Health 702-483-6023 or 888-810-5687 Please see reverse for details

CarePRO:

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WHAT IS THIS PROJECT'S PURPOSE?

- To assist family members caring for a loved one by providing free dementia related education and training workshops designed to reduce caregiver stress, enhance caregiver well-being, and help caregivers manage difficult caregiving situations.
- To gather feedback from individuals about their caregiving experience to continue to improve programs for dementia caregivers.

PAYMENT:

Each participant will be given \$25 for participating in each telephone interview scheduled 3,
 6, and 9 months following the original pre-workshop interview.

WHO WILL BE INVOLVED IN THIS PROJECT?

- Approximately 224 men and women residing in Nevada, who report caregiving for a person with dementia or memory loss.
- Project staff from the local Alzheimer's Associations in Nevada, the State of Nevada Aging and Disability Services Division, Cleveland Clinic Lou Ruvo Center for Brain Health, and Arizona State University.

WHAT WILL INVOLVEMENT MEAN FOR ME?

- Attending five 2.5 hours workshops to learn strategies to help you handle difficult caregiving situations, reduce caregiver stress, improve mood, and communicate better with others, including your relative with memory problems. Respite care will be available to help caregivers attend these workshops.
- Participate in five 30-40 minute individual telephone coach calls to review material covered in the workshop and apply it to your own caregiving situation.
- Three additional 30-40 minute check-in calls 1, 2 & 6 months after the end of the workshops.
- Prior to the first workshop, you will be asked to participate in a 45 minute confidential
 telephone interview that asks you questions about your caregiving experience, including its
 impact on your stress levels, mood, and physical health. You will be asked to participate in a
 similar interview again about 3, 6 and 12 months after your first interviews to help us to
 continue to improve the program.
- You also will be encouraged to give information about this project to other caregivers of people with dementia.

HOW WILL THIS HELP MY COMMUNITY AND ME?

Many caregivers appreciate the opportunity to learn new strategies and meet other
caregivers. The feedback gathered from speaking with caregivers like you will be used to
help improve the quality of caregiving health and education programs.

WHO WILL KNOW THE INFORMATION I GIVE DURING THESE INTERVIEWS?

Every precaution will be taken to protect your privacy.
 No one will be identified individually in reports or materials developed from the project.

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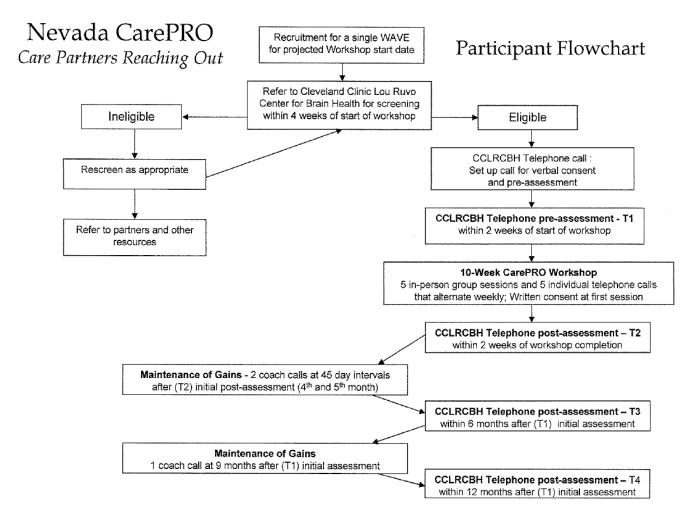
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Appendix B Nevada CarePRO Participants Flow Chart



Appendix C Nevada CarePRO Waves to Date

NEVADA CAREPRO

Southern Nevada Waves To Date

Start	End	Location	Enter	Drop	Notes
10/12/10	12/07/10	Alzheimer's Association Office	6	0	
12/15/10	02/09/11	Alzheimer's Association Office	5	1	Attended 2 workshop sessions.CR passed away. CG chose not to continue.
02/15/11	04/12/11	Alzheimer's Association Office	5	1	Attended 3 sessions. CG has health concerns. Currently unreachable.
05/03/11	06/28/11	Alzheimer's Association Office	2	0	
07/12/11	09/06/11	Alzheimer's Association Office	8	2	Attended 1 session CG dropped for personal reasons. Attended 2 sessions CR died. CG Chose not to continue.
09/13/11	11/08/11	Centennial Hills Active Adult Center	4	1	Attended 1 session. CR had med emergency, & will be placed. CG chose not to continue.
11/15/11	01/10/12	Las Vegas	8	1	Notified on 3/12/12 that SO164SCHPA dropped out after 2nd workshop.
12/14/11	02/08/12	Pahrump	6	2	SO168PARBE attended 3 sessions, wants to join next workshop in Pahrump. SO173KILDO dropped after attending 4 sessions after falling & breaking her arm. Wants to join next Pahrump workshop.
01/24/12	03/20/12	Henderson	10		
02/15/12	04/11/12	Las Vegas	4		
05/02/12	06/27/12	Las Vegas			
	Date 10/12/10 12/15/10 12/15/10 02/15/11 05/03/11 07/12/11 09/13/11 11/15/11 12/14/11 01/24/12 02/15/12	Date Date 10/12/10 12/07/10 12/15/10 02/09/11 02/15/11 04/12/11 05/03/11 06/28/11 07/12/11 09/06/11 09/13/11 11/08/11 11/15/11 01/10/12 12/14/11 02/08/12 01/24/12 03/20/12 02/15/12 04/11/12	Date Date 10/12/10 12/07/10 Alzheimer's Association Office 12/15/10 02/09/11 Alzheimer's Association Office 02/15/11 04/12/11 Alzheimer's Association Office 05/03/11 06/28/11 Alzheimer's Association Office 07/12/11 09/06/11 Alzheimer's Association Office 09/13/11 11/08/11 Centennial Hills Active Adult Center 11/15/11 01/10/12 Las Vegas 12/14/11 02/08/12 Pahrump 01/24/12 03/20/12 Henderson 02/15/12 04/11/12 Las Vegas	Date Date 10/12/10 12/07/10 Alzheimer's Association Office 6 12/15/10 02/09/11 Alzheimer's Association Office 5 02/15/11 04/12/11 Alzheimer's Association Office 5 05/03/11 06/28/11 Alzheimer's Association Office 2 07/12/11 09/06/11 Alzheimer's Association Office 8 09/13/11 11/08/11 Centennial Hills Active Adult Center 4 11/15/11 01/10/12 Las Vegas 8 12/14/11 02/08/12 Pahrump 6 01/24/12 03/20/12 Henderson 10 02/15/12 04/11/12 Las Vegas 4	Date Date 10/12/10 12/07/10 Alzheimer's Association Office 6 0 12/15/10 02/09/11 Alzheimer's Association Office 5 1 02/15/11 04/12/11 Alzheimer's Association Office 5 1 05/03/11 06/28/11 Alzheimer's Association Office 2 0 07/12/11 09/06/11 Alzheimer's Association Office 8 2 09/13/11 11/08/11 Centennial Hills Active Adult Center 4 1 11/15/11 01/10/12 Las Vegas 8 1 12/14/11 02/08/12 Pahrump 6 2 01/24/12 03/20/12 Henderson 10 02/15/12 04/11/12 Las Vegas 4

TOTALS 58 8

NEVADA CAREPRO Northern Nevada Waves To Date

Wave	Start Date	End Date	Location	Enter	Drop	Notes
1	11/30/10	2/1/11	Alzheimer's Association Office	11	0	First Wave- Dr. Coon hosted and trained staff in Northern Nevada
2	3/1/11	5/10/11	Alzheimer's Association Office	9	0	
3	5/24/11	8/2/11	Alzheimer's Association Office	11	1	CG unable to continue due to out of area hospitalization.
4	8/9/11	10/18/11	Alzheimer's Association Office	10	1	Attended 2 sessions. Unable to reach CG for reason.
5	10/18/11		Alzheimer's Association Office	11	0	
6	01/10/12	03/06/12	Alzheimer's Association Office	10	1	CG dropped after attending 2 sessions. Death in family & events cause to prefer taking wave 8 in June.
7	03/27/12	05/22/12	Alzheimer's Association Office	8		

TOTALS 70 3