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# FINAL PERFORMANCE REPORT COVER SHEET

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## **Executive Summary**

The Nevada Aging and Disability Services Division's (ADSD) goal for the Innovation Grant, *To Better Serve People with Alzheimer's Disease and Related Disorders* project was to establish early intervention service delivery to Alzheimer's (dementia) patients and caregivers in rural and underserved communities of Nevada through the use of televideo and telemedicine

# **Purpose and Scope**

The Nevada Early Stage Dementia Project Telehealth Early Phase Patient and Family Support Program (TESP) involved partners throughout the state, including:: ADSD, formerly the Division for Aging Services; The Northern Nevada Northern California Alzheimer's Association; the Cleveland Clinic Lou Ruvo Center for Brain Health; and the University of Nevada Center for Cognitive Aging. Program partners provided education for care recipients and their caregivers and utilized televideo capability to reach outlying areas. Support groups in rural areas were utilized to train patients and families reducing the burden associated with long term care costs through early intervention. Participants were encouraged to bring their primary caregiver to participate and, as a result, an early stage support group for caregivers was formed.

### **Target Population**

The target population for this proposal was rural, financially compromised individuals with early phase Alzheimer's Disease, family caregivers, Spanish speaking patients and families, and Native American patients and families. A special emphasis was given to Hispanic and Native American populations spread over the 95,763 square miles in the rural and frontier areas of Nevada.

# **Results and Important Findings**

A key component of this intervention was building relationships in the targeted communities.

Relationship building takes time and continuation to maintain the trust for continued interaction. Early Stage Dementia Project Telehealth Early Phase Patient and Family Support Program (TESP) April 30, 2010 Final Report ~ Page 2

# **Products Developed**

Products from this project include the semi-annual and final reports. Other materials for this project include:

- 394 Spanish-language booklets entitled "Basics of Alzheimer's Disease-What It Is and What To Do"
- 394 Spanish-language pamphlets entitled "Signs and Symptoms of Alzheimer's Disease"
- 394 Spanish-language booklets entitled "What's Happening to Grandpa?"
- 411 English-language booklets entitled "Basics of Alzheimer's Disease-What It Is and What To Do";
   "The Ten Signs of Alzheimer's Disease,"; "Education and Support Groups in Northern Nevada,";
   "Resource List for Family Caregivers in Northern Nevada" and "Facts About Alzheimer's Disease"
- 700 Northern Nevada Newsletters.

# **Program and Policy Implementations**

The State of Nevada, Aging and Disability Services Division, continues to work with program partners and will continue to fund the agencies for respite and outreach to family caregivers which will assist the programs to continue serving individuals with Alzheimer's and other dementia and their families. In addition, ADSD continues to involve program and seek funding for Alzheimer's related projects.

## **Recommendations**

The recommendation for implementing the Televideo program is to ensure a strong coordination between all sites in terms of support, operations, and continuity. Also, the Hispanic Outreach Coordinator is constrained by time and travel budgets and would be able to reach more families for care consultations and a greater depth of education with more service hours available. **Introduction:** 

The Nevada Aging and Disability Services Division's (ADSD) goal for the 09/30/2008 – 03/31/2010 ADSSP Innovation Grant to Better Serve People with Alzheimer's Disease and Related Disorders project was to improve function and delay institutionalization of rural dementia patients through the establishment of early intervention service delivery to Alzheimer's (dementia) patients and caregivers in rural and underserved communities of Nevada utilizing "telehealth" technologies.

Project partners include the Nevada Aging and Disability Services Division, the Northern Nevada Northern California Alzheimer's Association, the University of Nevada Reno Center for Cognitive Aging and the Clevaland Clinic Lou Ruvo Center for Brain Health. The target population for this grant is financially compromised, rural individuals with early phase Alzheimer's Disease, family caregivers, Spanish speaking patients and families and Native American patients and families. The Center for Cognitive Aging Alzheimer Disease Diagnostic and Treatment Center utilized their telemedicine capacity. The Alzheimer's Association of Northern Nevada provided specialty training for persons in the early stages of Alzheimer's disease and their families through this telemedicine video. Support groups in rural areas were utilized to train patients and families, reducing the burden associated with long term care costs through early intervention. Participants were encouraged to bring their primary caregiver to participate, and an early stage support group for caregivers was formed as a result.

In February 2009, a partnership between the Lou Ruvo Brain Institute and the Cleveland Clinic was announced. The new name for the center is the Cleveland Clinic Lou Ruvo Center for Brain Health and is mostly completed and functional as of June of 2009, though construction still continues. This strategic partnership ensures Nevada is at the forefront of neurological advancement for Alzheimer's disease and related dementia diagnostics and treatment. ADSD representatives met with partners at the Cleveland Clinic's Reno location January 29, 2010 to discuss strategy, current activities and direction for the proposal, and to relate the role of the Cleveland Clinic to the projects efforts. Representatives for all partners were present. Performance measures were discussed and class schedules and data collection needs for reporting were detailed.

Nevada is a large state with its population mainly dispersed in two urban areas, Carson City/ Reno and Las Vegas. Seven of Nevada's 17 counties have fewer than two persons per square mile. Ten of Nevada's 17 counties are classified by the Census as "Frontier" because of their sparse populations. The remoteness of these areas and the sparse population complicate the service delivery options. Identifying specialists willing and able to serve these rural communities presents many challenges. The Nevada Early Stage Dementia Project Telehealth Early Phase Patient and Family Support Program (TESP) attempted to address these issues and allow access to specialists for rural patients and their caregivers through the use of technology. A special emphasis was given to Hispanic and Native American populations spread over the 95,763 square miles in the rural and frontier areas of Nevada. Sessions included; an overview of early stage dementia, medical and research updates on early stage dementia, legal and financial planning, managing change, family relationships, advocacy and planning for the future. Topics such as safety concern including three particular risks of falling and home safety were covered. Project outcomes were measured with an evaluation model and asked participants to rate their knowledge gain and confidence level. The products from this project are a final report, including validation of telemedicine use for rural and frontier areas abstracts from the project for national conferences.

# **Activities and Accomplishments**

1. What measurable outcomes did you establish for this project and what indicators did you use to measure performance? 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. To what extent did your project achieve the outcomes?

# Measurable Outcomes:

- 80% of Latino and Native American participants reported that the education/caregiving training they received increased their knowledge about Alzheimer's disease.
   (AD)/dementia and that they learned something new that applies to their situation.
- 80% of rural participants reported that the education and caregiving training they
  received increased their knowledge about Alzheimer's disease/dementia and that they
  learned something new that applies to their situation.
- 80% of participants in the telemedicine program reported that the educational information they received via this program was useful and helped them more effectively manage the care and safety of the care recipient.
- 80% of telephone support group participants reported that the group increased their knowledge about dementia and helped them more be more effective in their work as a caregiver or support group facilitator.

# Actual Outcomes:

• 100% of Hispanic participants indicated information and care consultations provided increased their knowledge about AD.

- 99% of rural participants who attended education and training indicated they learned something new that applies to their situation.
- 100% of those participating in the interactive televideo conferencing found the information very helpful in helping with the short and long-term care of their loved one with AD.

## **Evaluation outcome measures and systems development measures**

Staff from the Aging and Disability Services Division stayed in continuous contact with program partners and routinely visited partners as needed.

The Nevada project achieved and surpassed these outcomes. The program was positive and beneficial for participates and their caregivers.

# To recruit Spanish-speaking and Native American dyads impacted by early-stage dementia through Indian Health Services and Nevada Hispanic Services

Between April 2009 and September 30, 2009, the staff of the Alzheimer's Association in Northern Nevada participated in three health fairs sponsored by and for Native American populations in Northern Nevada. These health fairs included one in May 2009 and two in July 2009 and were held in Washoe and Churchill Counties. At these health fairs, the Alzheimer's Association distributed basic information about Alzheimer's disease. A total of 115 Native Americans received basic informational pamphlets and booklets about Alzheimer's disease at these health fairs.

Between April 2009 and September 30, 2009, the Hispanic Outreach Coordinator of the Alzheimer's Association in Northern Nevada worked hand-in-hand with one of the staff of Nevada Hispanic

Services to provide information about Alzheimer's disease to the Hispanic Community in Rural Nevada. The Hispanic Outreach Coordinator made 13 trips to Dayton, Incline Village, Cold Springs, Carson Valley, and Wellington and disseminated basic information about AD at Spanish restaurants, video stores, and Mexican markets. She also distributed information about AD at the annual Cinco de Mayo event in Sparks, Nevada, where both urban and rural Hispanics gather annually to celebrate Mexican Independence Day. As a result of these outreach efforts, 394 Spanish-speaking individuals were provided with basic information about Alzheimer's disease and, nine Spanish-speaking families were provided with care consultations and continue to be provided with follow-up so they can make short and long-term plans for their loved one with Alzheimer's disease.

# <u>To provide workshop classes onsite conducted by the Alzheimer's Association's Rural Outreach</u> <u>Coordinator</u>

The following nine workshop classes were held in rural communities by the Alzheimer's Association between April and September 30, 2009 and served 138 individuals:

## April 2009:

Maintain Your Brain: Carson City, Nevada (held twice) Understanding Memory Loss: Gardnerville, Nevada Compassionate Communication and Challenging Behaviors: Carson City, Nevada

#### May 2009:

Alzheimer's Association's Annual Education Conference: Reno, Nevada (43 professionals and family members from rural communities attended this all day conference)

#### July 2009:

Understanding Memory Loss: Carson City, Nevada

Compassionate Communication and Challenging Behaviors: Gardnerville, Nevada

## August 2009:

10 Warning Signs: Winnemucca, Nevada

# September 2009:

10 Signs: Fallon, Nevada

Introduction to Alzheimer's Disease: Gardnerville, Nevada

• To provide telephone, interactive video, and face to face behavioral and counseling consultations for Spanish-speaking and English-speaking caregivers and patients on an ongoing, as needed bases

The Hispanic Outreach Coordinator provided nine Spanish-speaking families with care consultations during this time period. The initial care consultations were provided in person, and 34 telephone follow-ups were provided via telephone. Fifty-seven English-speaking families residing in the rural communities participated in care consultations during this time period.

# • To provide interactive video question and answer sessions for families

Two tele-health interactive video-teleconference sessions were held during the period (one in June and one in July). 38 family members attended these sessions.

The Cleveland Clinic Lou Ruvo Center for Brain Health, held the following presentations:

- October 8 Presentation to seven neurologists in Carson City on the latest trends in Alzheimer' Disease ~ Dr. Charles Bernick
- November 5 Presentation to 15 staff at Highland Manor and grand rounds to Northeastern Nevada Hospital with 20 participants, both located in Elko ~ Dr. Charles Bernick
- March 4 Presentation to five neurologists in Reno ~ Dr. Charles Bernick
- April 6 Grand rounds at Northeastern Nevada Hospital in Elko with 20 participants ~
   Dr. Charles Bernick
- October 15 Presentation to 100 individuals from the 2009 TRIAD Senior Education Seminar in Gardnerville on Alzheimer's disease including an update on research and the importance of early diagnosis.
- 2. How has your project met the 50% direct service requirement? Has the project limited administrative costs to 10% of federal funds? In your response, include the following, completed statements:
  - The funded project has spent \$110,857 (i.e., 100 percent) of federal funds on direct services.
  - The funded project has spent \$0 (i.e., 0 percent) of federal funds on administrative costs."

The Nevada project shifted \$11,054 from personnel to program partners to use on direct services. In the October 2009 report, it was estimated that \$7,390 was spent on administrative cost. ADSD felt it was a more prudent use of funds to allocate money to

program partners for direct service activities and moved \$11,054 from personnel to program partners. All other ADSD allocations were utilized for direct services.

# 3. What, if any, challenges did you face during the project and what actions did you take to address these challenges?

Nevada faced many challenges during this project, including budgetary. Challenges faced during this reporting period include procedural issues, legal issues, and economical issues. The procedural issues involve the acceptance of funds into the state system and the distribution of funds and agreements to program partners.

The legal issues involved in this project involved the incorporation of the Cleveland Clinic Lou Ruvo Center for Brain Health. The Lou Ruvo Center for Brain Health merged with the Cleveland Clinic Center for Brain Health. After the merger, the University of Nevada Center for Cognitive Aging released control of grant initiatives to the Cleveland Clinic Lou Ruvo Center for Brain Health. The Cleveland Clinic Lou Ruvo Center for Brain Health continued activities from the Center for Cognitive Aging and involved the integration of several key individuals into the Cleveland Clinic family.

The economic issues involved the tightening of the state budget and limitations imposed on state personnel including furloughs, travel restrictions, and limitation of funding. ADSD continued to provide project oversight and communicated more often with partners through email and phone conversations. Site visits were limited as travel restrictions were increased, mainly in 2010. These issues continue to inhibit state processes and have limited allowable travel, even grant funded travel. ADSD will continue to work within our defined structure to accomplish our given directives.

The project implementation leadership was change with the loss of the Nurse practitioner. The Cleveland Clinic Lou Ruvo Center for Brain Health provided two Neurologists to rotate time at the Reno clinic to continue project activates after the loss of the nurse practitioner position. The nurse practitioner position was filled in March, 2010 and provides services five days a week. Currently, the neurologists provide services at the Reno clinic every other Friday on a rotational schedule. In the near future, a third neurologist will be included in the rotation for a weekly presence.

The Hispanic Outreach Coordinator would be able to reach more families for care consultations and a greater depth of education, but she is constrained by time and travel budget restrictions. The relationships built by the outreach coordinator to develop in roads to the various communities involved time and patience. She relied on the established relationship of the Alzheimer's Association and also established trust to solidify further relationships into diverse cultural communities.

# 4. What impact do you think this project has had to date? What are the lessons you learned from undertaking this project?

The project has received significant praise from program participants, who value the relationships and the information provided. Without these resources, many participants would be without experienced assistance and guidance related to Alzheimer's disease and related dementia.

5. What will happen to the project after this grant has ended? Will project activities be sustained? Will project activities be replicated? If the project will be sustained/replicated what other funding sources will allow this to occur? Please note your significant partners in this project and if/how you will continue to work on this activity. Program partners are passionate about the services they provide and continue to seek funding opportunities to enhance these services from independent sources as well as from the State of Nevada, Aging and Disability Services Division through Federal and State funds. ADSD continues to seek and fund partners to sustain successful activities.

As a start to the continuation of the project, the Cleveland Clinic provided training to Northeastern Nevada Hospital in Elko to 20 participants on April 6<sup>th</sup> and continues their outreach efforts. In addition, ADSD maintains close relationships with community partners to assist with activities in support of older Nevadans. These relationships help to ensure the resources to support individuals affected by Alzheimer's disease, and their care partners continue to exist throughout Nevada and are continually developed and strengthened.

6. Over the entire project period, what were the key publications and communications activities? How were they disseminated or communicated? Products and communications activities may include articles, issue briefs, fact sheets, newsletters, survey instruments, sponsored conferences and workshops, websites, audiovisuals, and other informational resources.

The products from this project are the semi-annual and final reports including validation of telemedicine use for rural and frontier areas abstracts from the project for national conferences.

In addition, the Alzheimer's Association developed the following materials:

 394 Spanish-language booklets entitled "Basics of Alzheimer's Disease—What It Is and What To Do" were disseminated by Spanish-speaking staff into stores/bars/ and one health care facility working with Hispanics in the rurals.

- 394 Spanish-language pamphlets entitled "Signs and Symptoms of Alzheimer's Disease" were provided by Spanish-speaking staff directly to Spanish-speaking families in the rurals.
- 394 Spanish-language booklets entitled *What's Happening to Grandpa* were given to Spanish-speaking families by Spanish-speaking staff in the rurals.
- 411 English-language booklets entitled "Basics of Alzheimer's Disease—What It Is and What To Do," "The Ten Signs of Alzheimer's Disease," "Education and Support Groups in Northern Nevada," "Resource List for Family Caregivers in Northern Nevada " and "Facts About Alzheimer's Disease" were mailed to clients from rural Nevada who called and requested information and referral.
- 700 Northern Nevada Newsletters were mailed to families in rural Northern Nevada September 2009.

# Conclusions

This project utilized technology resources to ensure access and support for financially compromised individuals with early phase Alzheimer's Disease, family caregivers, Spanish speaking patients and families, and Native American patients and families individuals in rural communities. These individuals really valued the services and training provided in their communities.

To ensure continued success, community relationships must be developed and maintained. Advertisements in public media are not as effective as the personalized stories, with which people can identify. Sharing stories in available media is more effective than advertisement, as individuals connect to the personal stories and identify status of support to their specific situations. Outreach activities must be personal and not just an advertisement about support or training. A key component of this intervention was building relationships in the targeted communities. Relationship building takes time and must be ongoing to maintain the trust for continued interaction. To implement the Televideo program it is essential to ensure a strong coordination between the all sites in terms of support, operations and continuity. Also, outreach and relationship, including activities must be maintained and supported.

# Appendix

## See Attachments

- A. NV ADSSP Semi Annual Report March 2009
- B. NV ADSSP Semi Annual Report October 2009
- C. Elko Satisfaction Survey
- D. Reno Satisfaction Survey
- E. Rural Dementia Telemedicine Initiative Evaluation Forms
- F. Email Response to Questions, Additional Information on Structure

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